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Original Paper

# Use of a Paid Digital Marketing Campaign to Promote a Mobile Health App to Encourage Parent-Engaged Developmental Monitoring: Implementation Study

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## Abstract

**Background:** The internet has become an increasingly popular medium for parents to obtain health information. More studies investigating the impact of paid digital marketing campaigns for parents on promoting children's healthy development are needed.

**Objective:** This study aims to explore the outcomes of a paid digital marketing campaign, which occurred from 2018 to 2020, to promote messages about parent-engaged developmental monitoring and ultimately direct parents to the Centers for Disease Control and Prevention's (CDC's) *Milestone Tracker* app, a mobile health (mHealth) app developed by the CDC.

**Methods:** The paid digital marketing campaign occurred in 3 phases from 2018 to 2020. In each phase, 24 to 36 marketing messages, in English and Spanish, were created and disseminated using Google's Universal App Campaigns and Facebook Ads Manager. Outcomes were measured using impressions, clicks, and install data. Return on investment was measured using click-through rate (CTR), cost per click, and cost per install metrics.

**Results:** The Google-driven marketing messages garnered a total of 4,879,722 impressions (n=1,991,250, 40.81% for English and n=2,888,472, 59.19% for Spanish). The messages resulted in a total of 73,956 clicks (n=44,328, 59.94% for English and n=29,628, 40.06% for Spanish), with a total average CTR of 1.52% (2.22% for English and 1.03% for Spanish). From these clicks, there were 13,707 installs (n=9765, 71.24% for English and n=3942, 28.76% for Spanish) of the CDC's *Milestone Tracker* app on Google Play Store. The total average cost per install was US \$0.93 across all phases. The phase 3 headline "Track your child's development" generated the highest CTR of 3.23% for both English and Spanish audiences. The Facebook-driven marketing messages garnered 2,434,320 impressions (n=1,612,934, 66.26% for English and n=821,386, 33.74% for Spanish). The messages resulted in 44,698 clicks (n=33,353, 74.62% for English and n=11,345, 25.38% for Spanish), with an average CTR of 1.84% (2.07% for English and 1.38% for Spanish). In all 3 phases, animated graphics generated the greatest number of clicks among both English and Spanish audiences on Facebook when compared with other types of images.

**Conclusions:** These paid digital marketing campaigns can increase targeted message exposure about parent-engaged developmental monitoring and direct a parent audience to an mHealth app. Digital marketing platforms provide helpful metrics that can be used to assess the reach, engagement, and cost-effectiveness of this effort. The results from this study suggest that paid digital marketing can be an effective strategy and can inform future digital marketing activities to promote mHealth apps targeting parents of young children.

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**KEYWORDS**

health communication; health promotion; internet; social media; child development; mobile health; pediatrics; parenting; early child development; developmental disability; mobile phone

## Introduction

### Background

An estimated 1 in 6 children in the United States has a diagnosed developmental disability [1]. Developmental disabilities are conditions because of impairments in physical, learning, language, and behavioral domains. Early intervention of children with developmental disabilities can have a positive impact on their lives [2]. As a response, the Centers for Disease Control and Prevention (CDC) developed the *Learn the Signs. Act Early.* program, which aims to improve early identification of developmental delays and disabilities by facilitating parent-engaged developmental monitoring using developmental milestone checklists from birth through the age of 5 years. For many years, the CDC's milestone checklists were offered as printed handouts and booklets. A Pew Research Center study [3] found that 85% of Americans owned a smartphone in 2021, which has increased from just 35% in 2011. The groups most dependent on smartphones include lower income Americans and those with a high school education or less. In addition, approximately half of parents with cell phones download apps on their mobile phones compared with one-third of nonparents [4]. Owing to the increasing smartphone use in America and the interest in mobile apps among parents, *Learn the Signs. Act Early.* developed the CDC's *Milestone Tracker* mobile app, a mobile-friendly version of the milestone checklists. The app helps parents actively monitor their children's developmental progress, sends notifications to parents about their child's progress, and encourages parents to share any potential concerns with their child's physician, a critical step toward early identification and connection with intervention services and supports.

Although traditional promotion using brochures and flyers have supported the promotion of the CDC's *Milestone Tracker* app for a few years, there is mounting evidence that parents of young children learn about parenting and health information and resources through the internet and social media [5]. In a study conducted by Plantin and Daneback [6], first-time mothers aged 30 to 35 years were found to actively use the internet for health and parenting information and resources as well as social support. In addition, Facebook was reported as the most frequently used social media platform among parents seeking social support and health information on infant and child health [7].

The internet offers ample opportunities for promoting public health messages for many audiences, including parents of young children. There are easy-to-use digital marketing platforms such as Facebook and Google. Both platforms offer unpaid and paid placement options. However, the paid options increase the visibility of content, whereas the unpaid options do not, thereby increasing the likelihood of message exposure.

In 2014, Facebook announced that the mass production of content on their platform made it highly competitive for

marketers. In their efforts to only serve the most valuable content to each user, most businesses and organizations saw a decline in their organic reach [8]. Ogilvy, a public relations firm, analyzed Facebook brand pages to assess the extent of the decline of organic (unpaid) reach [9]. Organic reach was defined as the number of people who saw the page's post through their news feed or the page's timeline or, in other words, anyone who saw content that was not a consequence of paid advertising. They selected 106 brand pages representing various industries, markets, countries, and sizes to obtain a comprehensive sample. The total audience reach for the sample was 48 million. In October 2013, the organic content from brand pages reached 12.05% of the total audience. By February 2014, there was a 49% drop, resulting in only 6.15% of the total audience being reached. In 2018, Facebook also announced that an update to their news feed algorithm would likely result in further decreases in organic reach [10]. This demonstrates the limits of organic reach, thus making the argument for methods such as paid digital marketing to increase the exposure to a message.

On Google, Yang and Ghose [11] found higher click-through rates (CTRs), which are the total clicks on a message divided by the total impressions, when paid content was available on Google search engines in addition to organic (unpaid) content, instead of organic content alone. As paid digital marketing plays an increasingly important role in reaching large audiences on the web, the need for more studies examining the effectiveness of such strategies in promoting health information and resources is warranted.

### Study Objective

This study assesses the outcomes of a paid digital marketing campaign that was conducted in 3 phases using both Google's Universal App Campaigns (UAC) and Facebook Ads Manager to promote the CDC's *Milestone Tracker* app among parents of young children.

## Methods

### Google's UAC

Google's UAC is a paid service to promote mobile apps. UAC distributes marketing messages across several Google formats and networks, such as the first page of relevant Google search results and small banner advertisements appearing on relevant YouTube channels. Google's UAC also offers placement across the Google Display Network, which includes small banners next to videos on webpages and within apps in the Google Play Store, Gmail, and more [12]. This platform optimizes message performance by disseminating messages during certain times and in placements that the desired audience engages with the most.

### Facebook Ads Manager

Facebook Ads Manager is a paid advertising management service used to oversee paid digital marketing campaigns across the Facebook platform. Paid content is displayed within the

Facebook news feeds as well as in between videos and news articles that appear when the user is scrolling [13]. The *Campaign Budget Optimization* feature within this service helps campaigns more efficiently spend the allocated budget by finding active opportunities that can help them achieve their desired results (eg, allocating more money toward top-performing messages and posting messages at times when audience engagement is high). Options to target parents who were already consuming and engaging with content related to young children were available and used as well.

### Campaign Design

The campaign occurred in 3 phases, each lasting 6 to 8 weeks. It began on June 6, 2018, and ended on June 14, 2020 (phase 1: June 6 to July 28, 2018; phase 2: March 27 to May 21, 2019; and phase 3: May 4 to June 14, 2020). The total campaign budget for the 3 phases, across both the Google and Facebook platforms, was US \$24,500. The time frame and the allocated budget for each phase varied based on the availability of funding for each fiscal year. The first phase targeted only English-speaking audiences as only the English version of the CDC's *Milestone Tracker* app was available at the time. In October 2018, the Spanish version of the app, *Sigamos el Desarrollo*, became available; thus, phases 2 and 3 targeted the promotion of the mobile health app to both English- and Spanish-speaking audiences. The paid digital marketing campaign on both Google and Facebook was managed by an Atlanta-based public relations firm, Porter Novelli (PN). After each phase, the CDC and PN reviewed the results and fielded the top-performing marketing messages in the next phase.

The CDC Plain Language framework [14] and CDC Health Equity Guiding Principles for Inclusive Communication framework [15] were used to ensure that the marketing messages were designed in a clear, accessible, and audience-specific manner. In total, 24 to 36 marketing messages were produced and implemented across each phase on each platform. Each

message included 1 graphic (series of 2-3 rotating images [carousel], animated graphics interchange format [GIF], or static image) and 1 copy (text) combination. The graphics depicted young children from varying racial backgrounds aged <5 years, and the text included short, parent-friendly calls to action about tracking their children's milestones and installing the CDC's *Milestone Tracker* app.

For Google, phase 1 included 24 English marketing messages, including 3 sets of copies. Both phases 2 and 3 included 36 English and Spanish marketing messages each, including 5 sets of copies. Either previews of the app or the app logo accompanied the copy. Owing to the platforms' automated optimization features, only the highest performing marketing messages were used in each phase. For Facebook, phase 1 included 25 English marketing messages, including 5 sets of copies and 5 graphics (n=1, 20% carousel; n=1, 20% animated GIF; and n=3, 60% static images). Phase 2 included the same number of English marketing messages but also included 25 Spanish versions, including 5 sets of copies and 5 graphics (n=1, 20% carousel; n=2, 40% animated GIFs; and n=2, 40% static images). Phase 3 included 30 English marketing messages, including 5 sets of copies and 6 graphics (n=1, 17% carousel; n=2, 33% animated GIFs; and n=3, 50% static images), as well as 35 Spanish versions, including 5 sets of copies and 7 graphics (n=1, 14% carousel; n=1, 14% animated GIF; and n=5, 71% static images). All the marketing messages remained the same throughout the phases, except for 2 English graphics and 3 Spanish graphics from phase 2 to 3 and minor text updates. These updates were made to replace low-performing messages in the previous phases. All content was developed and reviewed by communications specialists at CDC and PN. [Figure 1](#) includes just a sampling of the assets developed for this campaign. It demonstrates the racial and age diversity of the families and children depicted in the photos, as well as the various graphics used for optimization purposes. Each graphic was adapted for Spanish-speaking audiences as well.

**Figure 1.** Screenshots of paid digital marketing posts on Facebook used in phases 1 to 3. GIF: graphics interchange format.



**Audience Parameters**

For Google-driven marketing messages, UAC uses machine learning to target users who are likely to install and use the CDC’s *Milestone Tracker* app: parents of young children. Google’s automated targeting strategy is based on user data collected by its platforms and properties, similar digital marketing campaigns, and current reach and engagement trends [10]. For instance, the marketing messages were served to users who searched keywords on children’s development.

In addition, Google and Apple do not share data between their respective platforms and properties; thus, Google-driven traffic to Apple’s App Store was not collected. Google-driven marketing messages were only served on Android devices using English and Android devices using Spanish, which is a limitation of the study.

On Facebook, the audience parameters for marketing messages were set for parents in the United States aged 18 to 45 years with young children aged <5 years. This included the following Facebook audience categories: parents of newborn babies, new

parents (0-12 months), parents with toddlers (1-2 years), and parents with preschoolers (3-5 years). Separate sets were created for English- and Spanish-speaking parents. Marketing messages were distributed to four types of devices: Android devices using English, Android devices using Spanish, iOS devices using English, and iOS devices using Spanish. Therefore, when a user clicked on a marketing message, they were directed to either

the Google Play Store or Apple's App Store, depending on their device type.

### Data Collection

When users receive a Google- or Facebook-driven marketing message, they may click on the message. They will be directed to the App Store or Google Play Store, where they can install the CDC's *Milestone Tracker* app. These steps are measured by the following metrics in [Textbox 1](#).

**Textbox 1.** Definitions of digital marketing metrics.

| Metric and definition  |
|--|
| <ul style="list-style-type: none"> <li>• Impressions               <ul style="list-style-type: none"> <li>• Number of times a paid digital marketing message is served to a user (includes repeat exposures)</li> </ul> </li> <li>• Click               <ul style="list-style-type: none"> <li>• Action taken by a user upon seeing a paid digital marketing message to visit the App Store or Google Play Store to learn more about the Centers for Disease Control and Prevention's (CDC's) <i>Milestone Tracker</i> app</li> </ul> </li> <li>• Click-through rate               <ul style="list-style-type: none"> <li>• Total number of clicks on the paid digital marketing message divided by the total number of impressions</li> </ul> </li> <li>• Cost per click               <ul style="list-style-type: none"> <li>• Total cost of the paid digital marketing campaign divided by the number of clicks on a paid digital marketing message</li> </ul> </li> <li>• Install               <ul style="list-style-type: none"> <li>• Downloads of the CDC's <i>Milestone Tracker</i> app</li> </ul> </li> <li>• Install rate               <ul style="list-style-type: none"> <li>• Total number of installations of the CDC's <i>Milestone Tracker</i> app divided by the total number of clicks on the paid digital marketing message</li> </ul> </li> <li>• Cost per install               <ul style="list-style-type: none"> <li>• Total cost of the paid digital marketing campaign divided by the number of installations of the CDC's <i>Milestone Tracker</i> app</li> </ul> </li> </ul> |

As Google shares information between platforms, including Google Display Network, YouTube, and Google Play Store, UAC could capture the number of Google-driven impressions, clicks, and installs on Android devices.

Facebook-driven marketing messages were served on both Apple and Android devices in both English and Spanish. However, install data were not available. To obtain install data from Facebook, the CDC's *Milestone Tracker* app would need to be registered with Facebook, which includes the implementation of the Facebook Software Development Kit—a functionality that integrates Facebook into the app. As the CDC's *Milestone Tracker* app must adhere to federal guidelines, this capability was restricted and thus served as a limitation in terms of data collection.

### Ethical Considerations

Institutional review board approval was not required for this project as no human participants were involved in the study,

and the analyzed data were limited to publicly available digital metrics collected in aggregate.

## Results

### Impressions

Across all 3 phases, Google-driven marketing messages generated a total of 4,879,722 impressions, and Facebook-driven marketing messages generated 2,434,320 impressions. In phase 3, the CDC manually allocated more of the Facebook budget toward Spanish-speaking audiences as the *Campaign Budget Optimization* feature was allocating more funds toward and generating more impressions for English-speaking audiences in phase 2. For this reason, the number of Facebook-driven Spanish impressions was larger than English impressions in phase 3 ([Table 1](#)).

**Table 1.** Impressions from Google- (N=4,879,722) and Facebook-driven (N=2,434,320) marketing messages.

| Campaign phases           | Impressions, n (%) |
|---------------------------|--------------------|
| <b>Phase 1 (2018)</b>     |                    |
| <b>Google<sup>a</sup></b> |                    |
| English                   | 982,568 (20.14)    |
| <b>Facebook</b>           |                    |
| English                   | 626,382 (25.73)    |
| <b>Phase 2 (2019)</b>     |                    |
| <b>Google<sup>a</sup></b> |                    |
| English                   | 676,628 (13.87)    |
| Spanish                   | 1,009,547 (20.68)  |
| Total                     | 1,686,175 (34.55)  |
| <b>Facebook</b>           |                    |
| English                   | 444,658 (18.27)    |
| Spanish                   | 217,465 (8.93)     |
| Total                     | 662,123 (27.2)     |
| <b>Phase 3 (2020)</b>     |                    |
| <b>Google<sup>a</sup></b> |                    |
| English                   | 332,054 (6.8)      |
| Spanish                   | 1,878,925 (38.5)   |
| Total                     | 2,210,979 (45.31)  |
| <b>Facebook</b>           |                    |
| English                   | 541,894 (22.26)    |
| Spanish                   | 603,921 (24.81)    |
| Total                     | 1,145,815 (47.07)  |

<sup>a</sup>For Google, the messages were only served on Android devices, not Apple devices, because of a tracking pixel needed to share data between Google and Apple.

### Clicks and CTR

During the campaign, the Google-driven marketing messages were clicked a total of 73,956 times (CTR 1.52%; [Table 2](#)). Although they were displayed across Google Search, Google

Display Network, and YouTube properties, most of the impressions, clicks, and installs were driven by Google Display Network in all 3 phases ([Table 3](#)). In all 3 phases, the English messages had a higher CTR than the Spanish messages.

**Table 2.** Clicks, CTR<sup>a,b</sup>, and CPC<sup>c,d</sup> metrics from Google- (N=73,956) and Facebook-driven (N=44,698) marketing messages.

| Campaign phases           | Clicks, n (%)  | CTR (%) | CPC (US \$) |
|---------------------------|----------------|---------|-------------|
| <b>Phase 1 (2018)</b>     |                |         |             |
| <b>Google<sup>e</sup></b> |                |         |             |
| English                   | 19,782 (26.75) | 2.01    | 0.20        |
| <b>Facebook</b>           |                |         |             |
| English                   | 11,822 (26.45) | 1.89    | 0.30        |
| <b>Phase 2 (2019)</b>     |                |         |             |
| <b>Google<sup>e</sup></b> |                |         |             |
| English                   | 16,284 (22.02) | 2.41    | 0.18        |
| Spanish                   | 18,138 (24.53) | 1.80    | 0.12        |
| Total                     | 34,422 (46.54) | 2.04    | 0.15        |
| <b>Facebook</b>           |                |         |             |
| English                   | 9711 (21.73)   | 2.18    | 0.34        |
| Spanish                   | 3595 (8.04)    | 1.65    | 0.34        |
| Total                     | 13,306 (29.77) | 2.01    | 0.34        |
| <b>Phase 3 (2020)</b>     |                |         |             |
| <b>Google<sup>e</sup></b> |                |         |             |
| English                   | 8262 (11.17)   | 2.49    | 0.23        |
| Spanish                   | 11,490 (15.54) | 0.61    | 0.16        |
| Total                     | 19,752 (26.71) | 0.89    | 0.19        |
| <b>Facebook</b>           |                |         |             |
| English                   | 11,820 (26.44) | 2.18    | 0.14        |
| Spanish                   | 7750 (17.34)   | 1.28    | 0.15        |
| Total                     | 19,750 (44.19) | 1.71    | 0.19        |

<sup>a</sup>CTR: click-through rate.

<sup>b</sup>Total number of clicks on the paid digital marketing message divided by the total number of impressions.

<sup>c</sup>CPC: cost per click.

<sup>d</sup>Total cost of the paid digital marketing campaign divided by the number of clicks on a marketing message.

<sup>e</sup>For Google, the messages were only served on Android devices, not Apple devices, because of a tracking pixel needed to share data between Google and Apple.



**Table 3.** Metrics<sup>a</sup> for Google-driven marketing messages by Google platform placement.

| Placements             | Impressions (N=4,879,722), n (%) | Clicks (N=73,956), n (%) | CTR <sup>b</sup> (%) | Installs (N=13,707), n (%) |
|------------------------|----------------------------------|--------------------------|----------------------|----------------------------|
| <b>Phase 1 (2018)</b>  |                                  |                          |                      |                            |
| Google Search          | 20,236 (0.41)                    | 1542 (2.09)              | 7.62                 | 671 (4.9)                  |
| Google Display Network | 962,257 (19.72)                  | 18,226 (24.64)           | 1.89                 | 2669 (19.47)               |
| YouTube                | 75 (0)                           | 14 (0.01)                | 18.67                | 0 (0)                      |
| Total                  | 982,568 (20.14)                  | 19,782 (26.75)           | 2.01                 | 3340 (24.37)               |
| <b>Phase 2 (2019)</b>  |                                  |                          |                      |                            |
| Google Search          | 12,506 (0.26)                    | 1027 (1.39)              | 8.21                 | 442 (3.22)                 |
| Google Display Network | 1,672,818 (34.28)                | 33,376 (45.13)           | 2.00                 | 4218 (30.77)               |
| YouTube                | 851 (0.02)                       | 19 (0.03)                | 2.23                 | 2 (0.01)                   |
| Total                  | 1,686,175 (34.55)                | 34,422 (46.54)           | 2.04                 | 4662 (34.01)               |
| <b>Phase 3 (2020)</b>  |                                  |                          |                      |                            |
| Google Search          | 18,828 (0.39)                    | 1389 (1.88)              | 7.38                 | 613 (4.47)                 |
| Google Display Network | 2,191,913 (44.92)                | 18,357 (24.82)           | 0.84                 | 5091 (37.14)               |
| YouTube                | 238 (0)                          | 6 (0.01)                 | 2.52                 | 1 (0.01)                   |
| Total                  | 2,210,979 (45.31)                | 19,752 (26.71)           | 0.89                 | 5705 (41.62)               |

<sup>a</sup>Cost per click and cost per install metrics were not included. Google's optimization features allocated varying amounts of the budget to each placement. Thus, individualized cost metrics could not be calculated.

<sup>b</sup>CTR: click-through rate.

Of the 73,956 clicks, during phase 1, the top-performing Google copy was "Track Milestones Today," with 9288 (12.56%) clicks (CTR 2.97%); however, in phase 2, this headline was the second-best, with 3458 (4.68%) clicks (CTR 2.86%), whereas "Track Child Development" was the top-performing headline, with 4802 (6.49%) clicks (CTR 2.78%). In phase 3, the adapted phase 2 headline "Track your child's development" generated the best CTR (3.23%).

The Facebook-driven marketing messages were clicked a total of 44,698 times (CTR 1.84%). In all 3 phases, the animated GIFs in both English and Spanish generated the greatest number of clicks when compared with other types of graphics, suggesting that the marketing messages formatted as animated GIFs may result in higher engagement than standalone static images. Of the 44,698 clicks, an image of 2 boys aged 1 year hugging from phase 3 received 8330 (18.64%) clicks (CTR 4.75%) singlehandedly, which made it the top-performing image

among English marketing messages; images of babies aged 9 months resonated with both English and Spanish audiences, resulting in a total of 1797 (4.02%) clicks (CTR 0.91%) and 4175 (9.34%) clicks (CTR 1.19%) during phase 3, respectively.

### Cost per Click

For all 3 phases, the Google-driven marketing messages, on average, cost a total of US \$0.17 per click (cost per click [CPC]). Specifically, it cost US \$4000 to receive 19,782 clicks (CPC US \$0.20) in phase 1, US \$5000 to receive 34,422 clicks (CPC US \$0.15) in phase 2, and US \$3750 to receive 19,752 clicks (CPC US \$0.19) in phase 3 (Tables 2 and 4).

Overall, the average Facebook-driven marketing messages cost a total of US \$0.26 per click (CPC). They improved in efficiency from phase 2 to 3. In phase 2, it cost US \$4500 to receive 13,306 clicks (CPC US \$0.34), whereas in phase 3, it cost US \$3750 to receive 19,572 clicks (CPC US \$0.19). In phase 1, it cost US \$3500 to receive 11,822 clicks (CPC US \$0.30).

**Table 4.** Campaign budget breakdown.

| Phases                             | Google (US \$) | Facebook (US \$) |
|------------------------------------|----------------|------------------|
| Phase 1 (June 6 to July 28, 2018)  | 4000           | 3500             |
| Phase 2 (March 27 to May 21, 2019) | 5000           | 4500             |
| Phase 3 (May 4 to June 14, 2020)   | 3750           | 3750             |

### Installs and Cost per Install

During the 7-week period of phase 1, there were 34,431 app installs, an 84% increase compared with 7 weeks before the paid digital marketing campaign began. After 7 weeks from the phase 1 end, there were only 19,391 app installs, a 44% decrease

compared with when the paid digital marketing messages were running in phase 1 (Table 5). The Google-driven marketing messages contributed to 3340 app installs at a cost per install (CPI) of US \$1.19 (Table 6). During the 8-week period of phase 2, there were 39,443 app installs, a 14% increase compared with

8 weeks before the paid digital marketing messages ran. After 8 weeks from phase 2, there were only 23,725 app installs, a 40% decrease compared with when the paid digital marketing messages were running in phase 2 (Table 5). The Google-driven marketing messages contributed to 4662 app installs at a CPI of US \$1.07 (Table 6).

During the 6-week period of phase 3, there were 42,239 app installs. No major differences in app installs were found between phase 3 and the 6-week periods before and after the phase. The Google-driven marketing messages contributed to 5705 app installs at a CPI of US \$0.66 (Table 6). For all 3 phases, the average CPI for Facebook could not be calculated because of the limitation of collecting Facebook-driven installs. The average CPI for Google across all 3 phases was US \$0.93.

**Table 5.** Total CDC<sup>a</sup>*Milestone Tracker* app install data.

| Time point and period  | Installs, n |
|------------------------|-------------|
| <b>Before campaign</b> |             |
| 7 weeks before         | 18,755      |
| 8 weeks before         | 34,730      |
| 6 weeks before         | 41,255      |
| <b>During campaign</b> |             |
| Phase 1 <sup>b</sup>   | 34,431      |
| Phase 2 <sup>c</sup>   | 39,443      |
| Phase 3 <sup>d</sup>   | 42,239      |
| <b>After campaign</b>  |             |
| 7 weeks after          | 19,391      |
| 8 weeks after          | 23,725      |
| 6 weeks after          | 43,196      |

<sup>a</sup>CDC: Centers for Disease Control and Prevention.

<sup>b</sup>Phase 1 occurred from June 6 to July 28, 2018, a 7-week period.

<sup>c</sup>Phase 2 occurred from March 27 to May 21, 2019, an 8-week period.

<sup>d</sup>Phase 3 occurred from May 4 to July 14, 2020, a 6-week period.



**Table 6.** Installs, install rate, and CPI<sup>a,b</sup> metrics from Google- (N=13,707) and Facebook-driven marketing messages.

| Campaign phases           | Installs <sup>c</sup> , n (%) | Install rate (%) | CPI (US \$) |
|---------------------------|-------------------------------|------------------|-------------|
| <b>Phase 1 (2018)</b>     |                               |                  |             |
| <b>Google<sup>d</sup></b> |                               |                  |             |
| English                   | 3340 (24.37)                  | 16.89            | 1.19        |
| <b>Facebook</b>           |                               |                  |             |
| English                   | — <sup>d</sup>                | —                | —           |
| <b>Phase 2 (2019)</b>     |                               |                  |             |
| <b>Google<sup>d</sup></b> |                               |                  |             |
| English                   | 3308 (24.13)                  | 20.31            | 0.88        |
| Spanish                   | 1354 (9.88)                   | 7.46             | 1.62        |
| Total                     | 4662 (34.01)                  | 13.54            | 1.07        |
| <b>Facebook</b>           |                               |                  |             |
| English                   | —                             | —                | —           |
| Spanish                   | —                             | —                | —           |
| Total                     | —                             | —                | —           |
| <b>Phase 3 (2020)</b>     |                               |                  |             |
| <b>Google<sup>e</sup></b> |                               |                  |             |
| English                   | 3117 (22.74)                  | 37.73            | 0.60        |
| Spanish                   | 2588 (18.88)                  | 22.52            | 0.73        |
| Total                     | 5705 (41.62)                  | 28.88            | 0.66        |
| <b>Facebook</b>           |                               |                  |             |
| English                   | —                             | —                | —           |
| Spanish                   | —                             | —                | —           |
| Total                     | —                             | —                | —           |

<sup>a</sup>CPI: cost per install.

<sup>b</sup>Total cost of the paid digital marketing campaign divided by the number of installs of the Centers for Disease Control and Prevention's *Milestone Tracker* app.

<sup>c</sup>For Facebook, install data were not available because of federal guidelines against the integration of Facebook Software Development Kit into a mobile app.

<sup>d</sup>Data not available.

<sup>e</sup>For Google, the messages were only served on Android devices, not Apple devices, because of a tracking pixel needed to share data between Google and Apple.

## Discussion

### Principal Findings

This study investigated the outcomes of a paid digital marketing campaign for promoting Google- and Facebook-driven marketing messages about parent-engaged developmental monitoring and direct parents with children aged <5 years to the CDC's *Milestone Tracker* app. Overall, the Google-driven marketing messages garnered a total of 4,879,722 impressions (n=1,991,250, 40.81% for English and n=2,888,472, 59.19% for Spanish). The messages resulted in a total of 73,956 clicks (n=44,328, 59.94% for English and n=29,628, 40.06% for Spanish), with a total average CTR of 1.52% (2.22% for English and 1.03% for Spanish). From these clicks, there were 13,707

installs (n=9765, 71.24% for English and n=3942, 28.76% for Spanish) of the CDC's *Milestone Tracker* app on Google Play Store. The total average CPI was US \$0.93 across all phases. The phase 3 headline, "Track your child's development," generated the highest CTR of 3.23% for both English and Spanish audiences. The Facebook-driven marketing messages garnered 2,434,320 impressions (n=1,612,934, 66.26% for English and n=821,386, 33.74% for Spanish). The messages resulted in 44,698 clicks (n=33,353, 74.62% for English and n=11,345, 25.38% for Spanish), with an average CTR of 1.84% (2.07% for English and 1.38% for Spanish). In all 3 phases, animated graphics generated the greatest number of clicks among both English and Spanish audiences on Facebook when compared with other types of images.

## Marketing Messages

Among the Facebook- and Google-driven marketing messages fielded through this campaign, the marketing messages with animated GIFs and images with younger children (eg, 2 boys aged 1 year hugging and a baby aged 9 months) performed higher than messages without GIFs and images of older children. The marketing messages with simple and direct calls to action, such as the “Track your child’s development” copy, generated high CTRs. Future public health campaigns targeting parents of young children can consider these findings when designing marketing messages for Facebook and Google.

## Return on Investment

The return on investment was measured by the increase in app installs during the paid digital marketing campaign compared with the periods before and after the campaign, when no paid digital marketing efforts were active. As no benchmarks for CPI for similar populations or studies were found for comparison, CTR and CPC were also analyzed. CTR provides additional information on the returns of the study, whereas CPC provides additional information on the cost-effectiveness of the investment. According to [Table 5](#), the app installs during phases 1 and 2 were higher than the periods both before (84% and 14% higher, respectively) and after the campaign (44% and 40% higher, respectively). This demonstrates the effectiveness that the paid digital marketing campaign had on increasing app installs. The app installs during phase 3 remained consistent with the periods before and after the campaign, likely because of the competing health information on the web during the COVID-19 pandemic.

In total, the campaign generated 13,707 Google-driven installs, which excludes the app installs from Facebook. With a US \$12,750 Google budget, the Google-driven marketing messages resulted in 13,707 users installing the CDC’s *Milestone Tracker* app.

The CTR depicted the effectiveness of a marketing message, particularly whether it could persuade the parents to click on the impression to learn more. The CPC depicted how cost-effective the campaign was in terms of clicks, particularly whether the campaign could receive a high number of clicks for a low cost. According to a study on industry-specific Google benchmarks, the benchmarks for the health and medical field were a CTR of 3.27% and CPC of US \$2.62 for Google Search, as well as a CTR of 0.59% and a CPC of US \$0.63 for the Google Display Network [16]. In a similar study on industry-specific Facebook benchmarks, the health care field showed a CTR of 0.83% and a CPC of US \$1.32 [17]. For CTR, all Google-driven marketing messages, including Google Search and Google Display, outperformed industry standards ([Table 3](#)). Although CPC could not be calculated for Google Search and Google Display Network individually, the Google- and Facebook-driven marketing messages, in total, had significantly lower CPCs than those of industry standards ([Table 2](#)).

However, it is important to note that comparing CTR and CPC with industry-specific benchmarks for the whole health and medical field should not be the only method of evaluating effectiveness, as those benchmarks may be too broad. In

addition, the focus of our campaign was not to sell a medical product but rather to promote public health messages to parents with young children. The *Campaign Budget Optimization* feature’s tendency to increase the efficiency of budget spending by disregarding lower performing devices and increasing delivery of impressions to higher performing devices is not ideal for public health purposes. It is crucial that messages about the CDC’s *Milestone Tracker* app are equitably promoted to all populations, which includes all device types regardless of performance. Thus, comparing CTR and CPC with marketing campaigns with similar populations, public health topics, and campaign goals may provide a more useful reference point than solely industry benchmarks.

For instance, Graham et al [18] conducted a similarly structured 3-phased paid digital marketing campaign using both Google- and Facebook-driven messages on healthy weight gain with expecting parents and parents of young children up to the age of 6 years in Alberta, Canada. Although their study differed in audience size, public health topic, and budget spending, their CTR and CPC could be used as reference points for evaluating the effectiveness of our campaign in terms of reaching similar audience demographics. On average, their Facebook-driven messages resulted in a CTR of 1.88% and a CPC of CAD \$0.35 (US \$0.26). Their Google-driven messages resulted in a CTR of 5.8% and CPC of CAD \$0.76 (US \$0.56). In comparison, our total average CTR for Facebook was 1.84%, and CPC was US \$0.26, whereas for Google, the CTR was 1.52%, and CPC was US \$0.17. A contributing reason for our Google CTR (1.52%) being much lower than their Google CTR (5.8%) was our study’s efforts to message Spanish-speaking audiences, a group that had lower Google CTRs (phase 2: 1.80%; phase 3: 1.65%) than the Google CTRs for English-speaking audiences (phase 2: 2.41%; phase 3: 2.49%; [Table 2](#)). Nevertheless, this paid digital marketing campaign was shown to be on par with industry benchmarks as well as a campaign with a similar public health approach. In addition, the metrics from this study can serve as a reference point for future digital marketing campaigns that target parents with children aged <5 years around topics related to parent-engaged developmental monitoring.

## Other Influences

In addition, it is important to note that the time frame for phase 3 overlapped with the beginning of the COVID-19 pandemic during a time when many consumers were searching for health-related apps but were also inundated with competing health information on the web.

## Limitations

There were multiple limitations to this study. First, only aggregate data were collected for this study. Therefore, it is not possible to know information about the users who installed the app. It cannot be confirmed that the app installs came from parents of young children. However, as Facebook- and Google-driven marketing messages only targeted parents of young children, they are the most likely audience to have installed the app because of the campaign. Second, the number of installs because of the Facebook-driven marketing messages could not be tracked. Thus, alternative measures, including CTR

and CPC, were used as proxies. Third, mobile app use could not be tracked through this study.

### Conclusions

This study contributes to the literature by reporting on the outcomes and providing a cost analysis of using paid digital

marketing campaigns on Google and Facebook to promote public health messages to parents of young children. As the internet and social media have become an increasingly popular medium of accessing health information, public health organizations should consider paid digital marketing as a tactic for reaching target audiences on the web.

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### Conflicts of Interest

None declared.

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**Abbreviations**

**CDC:** Centers for Disease Control and Prevention  
**CPC:** cost per click  
**CPI:** cost per install  
**CTR:** click-through rate  
**GIF:** graphics interchange format  
**PN:** Porter Novelli  
**UAC:** Universal App Campaigns

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Original Paper

# Online Health Information Seeking for Self and Child: An Experimental Study of Parental Symptom Search

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## Abstract

**Background:** Parents often search the web for health-related information for themselves or on behalf of their children, which may impact their health-related decision-making and behaviors. In particular, searching for somatic symptoms such as headaches, fever, or fatigue is common. However, little is known about how psychological and relational factors relate to the characteristics of successful symptom-related internet searches. To date, few studies have used experimental designs that connect participant subjective search evaluation with objective search behavior metrics.

**Objective:** This study aimed to examine the features of web-based health-related search behaviors based on video-coded observational data, to investigate which psychological and relational factors are related to successful symptom search appraisal, and to examine the differences in search-related outcomes among self-seekers and by-proxy seekers.

**Methods:** In a laboratory setting, parents living in Austria (N=46) with a child aged between 0 and 6 years were randomized to search their own (n=23, 50%) or their child's (n=23, 50%) most recent somatic symptom on the web. Web-based activity was recorded and transcribed. Health anxiety, eHealth literacy, attitude toward web-based health information, relational variables, state of stress, participants' search appraisals, and quantitative properties of the search session were assessed. Differences in search appraisals and search characteristics among parents who searched for themselves or their children were examined.

**Results:** Across both groups, searches were carried out for 17 different symptom clusters. Almost all parents started with Google (44/46, 96%), and a majority used initial elaborated key phrases with >1 search keyword (38/45, 84%) and performed on average 2.95 (SD 1.83) search queries per session. Search success was negatively associated with health anxiety ( $r_s = -0.39, P = .01$ ), stress after the search ( $r_s = -0.33, P = .02$ ), and the number of search queries ( $r_s = -0.29, P = .04$ ) but was not significantly associated with eHealth literacy ( $r_s = 0.22, P = .13$ ). Of note, eHealth literacy was strongly and positively correlated with satisfaction during the search ( $r_s = 0.50, P < .001$ ) but did not significantly correlate with search characteristics as measured by search duration ( $r_s = 0.08, P = .56$ ), number of performed search queries ( $r_s = 0.20, P = .17$ ), or total clicks ( $r_s = 0.14, P = .32$ ). No differences were found between parents searching for their own symptoms and parents searching for their child's symptoms.

**Conclusions:** This study provides exploratory findings regarding relevant dimensions of appraisals for symptom-based information seeking on the web. Consistent with previous literature, health anxiety was found to be associated with poorer search evaluation. Contrary to expectations, eHealth literacy was related neither to search success nor to search characteristics. Interestingly, we did not find significant differences between self-seekers and by-proxy seekers, suggesting similar search and evaluation patterns in our sample. Further research with larger samples is needed to identify and evaluate guidelines for enhanced web-based health information seeking among parents and the general public.

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**KEYWORDS**

online health information seeking; digital health; parents; parent-child; eHealth literacy; human computer interaction; mobile phone

## Introduction

### Background

The entry into the digital age has fundamentally altered information behavior, particularly information retrieval and information seeking [1,2]. Internet users commonly use search engines to obtain references related to all facets of everyday life [3,4]. More than 5 billion search queries are performed daily via Google [5], indicating enormous informational needs on a global level. Information retrieved from the web influences consumer behavior and decision-making in various contexts, both on the web and offline [1,6,7]. Understanding how information is sought and used has important implications for decision-making processes across a wide array of research fields in business, education, medicine, or public health [1,6,8,9].

Most notably, online health information seeking (OHIS) is a very common information behavior among all age groups and countries. In 2020, a total of 55% of European citizens aged between 16 and 74 years searched on the web about health-related topics such as disease, injury, or nutrition at least once in the past 3 months [10]. Emerging trends of individuals looking for information on health and illness can be observed around the globe [10-12]. OHIS has a crucial impact on health decision-making [13-15] and the nature of the physician-patient relationship [16]. It also provides significant opportunities for receiving social and emotional support in health affairs [17].

Large-scale studies from Europe [18] and the United States [19] imply that between 35% and 61% of web-based information seekers conducted health-related searches not only for themselves but also on behalf of others, such as for their children, friends, or relatives. In particular, parents of young children play a special mediating role, as they decide on the extent and timing of health measures for their offspring. In a recent review by Kubb and Foran [20], the prevalence rates for parental OHIS were considerably higher than those in the general population, suggesting that parents are heavy users of web-based health information. However, seeking by proxy can threaten children's health status if the search leads to detrimental self-treatments or a delay in seeking professional health services. In particular, misleading information and medical fake news on the internet can impede decision-making and thus are a potential threat for self-health, children's health, and public health [21-24].

Searching for somatic symptoms is common among internet users. Approximately 1% of all Google searches are symptom-related [25], with search queries on persistent or acute symptoms, such as chest pain, headache, fever, or diarrhea [26]. According to Cartright et al [27], two phases of exploratory diagnostic search are supposed: either to investigate the relevance of symptoms (evidence-directed) or to inform about certain diseases (hypothesis-directed). In this context, parents use the web to determine whether their child needs medical consultation [28-30]. However, the quality of health websites

varies greatly [31,32] and is often lacking in terms of relevant information whether a symptom requires treatment [26]. More dedicated research on parental symptom search and the underlying factors for a successful search could therefore contribute significantly to better health-related decision-making by parents.

In the past, various traits and concepts were introduced for being pivotal in the context of health-related web-based searches. A growing body of literature has examined the relation between health anxiety and OHIS [33]. Broadly defined, health anxiety encompasses illness worries and excessive fears about developing or having a serious disease [34]. A meta-analysis by McMullan et al [35] found health anxiety being moderately positively correlated with OHIS across 10 studies. Further studies examined the reciprocal relationship between health anxiety and OHIS [36] or the effect on health care use [37]. Trait health anxiety is associated with poorer outcomes during as well as after a health-related web-based search, including negative emotions [38], worsening anxiety [39], and an increased number of physician visits [33,37]. A promising construct for diminishing adverse outcomes of OHIS is eHealth literacy, introduced by Norman and Skinner [40]. The term describes the ability to search, find, understand, evaluate, and ultimately use health-relevant information on the web. Previous studies suggested that higher eHealth literacy is associated with less frustration during the information search [41], gain in empowerment [42], and better evaluating skills of web-based health information [43]. In the future, targeting eHealth literacy could become a key element for enhancing OHIS skills and related outcomes [44,45].

The assessment of appraisals during or after information-seeking behavior offers opportunities for identifying the kind of information that users find helpful. In this context, search success and search satisfaction are two central concepts within users' information evaluation processes [46-48]. Search success refers to finding an answer to a predefined question or information regarding the search topic [49,50]. In comparison, search satisfaction relates to the emotional fulfillment during the search [48,51]. Although both concepts are strongly connected, satisfaction during the search does not guarantee a successful search or vice versa [46]. To date, neither the prerequisites nor the properties of a successful and satisfactory web-based health search have been well understood. Consequently, evidence-based recommendations for parental OHIS on effective and successful OHIS are yet missing [20].

Some methodological approaches have been applied to investigate the process of OHIS sessions in depth, including video recording, think-aloud protocols, or interviews [52-58]. Unfortunately, solely the study by Benedicta et al [56] was conducted in a sample of parents, and only two studies [55,57] focused on symptom-driven queries. In addition, previous studies may no longer reflect current search behavior, as the nature of information seeking has changed significantly in recent

years. New opportunities, among others, were given with web-based symptom checkers [59], highly specialized communities on specific rare diseases [60], YouTube videos [61], or smartphone health apps [62]. Therefore, there is an urgent need for more experimental research on the health-related search process on the web itself, including the assessment of long-term traits, short-term emotional states, appraisals during and after the search, and their impact on health behavior in real life.

## Objective

The aims of this study are 3-fold: (1) to categorize and analyze the performed search queries; (2) to investigate the associations of health anxiety, eHealth literacy, and eHealth attitudes with log file data and self-reported appraisals of recorded symptom-driven search sessions; and (3) to examine differences between self-seekers and by-proxy seekers in terms of log file data and self-reported appraisals. We hypothesize that health anxiety is positively correlated with poorer outcomes (ie, unmet information needs, information overload, and need to talk to a physician), whereas eHealth literacy and favorable attitudes toward web-based health information will be positively associated with beneficial search appraisals (ie, success, satisfaction, and empowerment). In addition, we presume that OHIS by proxy is accompanied with poorer search outcomes than seeking for one's own health (eg, higher unmet information needs, more information overload, higher need to talk to a physician, lower search appraisal, more dissatisfaction, and lower levels of empowerment).

## Methods

### Inclusion and Exclusion Criteria

Participants were required to be aged  $\geq 18$  years, be a parent of a child aged between 0 and 6 years, and have used the internet at least sometimes for health-related information seeking. We began recruitment with child age range between 0 and 3 years and extended the recruitment to kindergartens, which included children aged  $\leq 6$  years. Parents or children with chronic illnesses were excluded from participation. A maximum of 1 parent per household could participate. In cases where both parents participated, one was chosen at random to maintain a sample without dependent data at the couple level.

To measure ecological validity, participants were asked at the end of the experiment how similar the expressed search behavior was to the normal at home on a 6-point Likert scale (0 *not similar at all*; 5 *exactly what I would do at home*). Participants with a score of  $\leq 3$  were excluded from the analysis ( $n=6$ ).

### Recruitment

Participants were recruited predominantly with leaflets in kindergartens, pediatrician waiting rooms, playgroups, and parent-child facilities. The local media also published our call for participation. In addition, we ran local advertising on *Instagram* and *Facebook*. Participants contacted us by phone or email to set up an appointment at the university laboratory. The experiment was advertised with an estimated duration of 1 hour. As an incentive, each participant received an expense allowance of €10 (US \$11) for completing the study. The chance to win a €100 voucher was raffled among all participants. Recruitment lasted from November 2019 to March 2020 and was stopped prematurely by governmental measures to contain the spreading of SARS-CoV-2 that began in March in Austria. At the point in which recruitment stopped, there were almost no cases of SARS-CoV-2 in Carinthia.

### Participants

A total of 59 individuals participated in the experiment. Of these 59 participants, 6 (10%) were excluded because they stated that their health-related web-based search was not similar to that at home. Furthermore, 12 other participants were members of a couple, and one member of each dyad was excluded at random. Unfortunately, of the 59 participants, 1 (2%) was affected by technical issues with the recording program. This resulted in a final sample of  $N=46$ , equally balanced for both experimental groups.

Participants were mainly mothers (40/46, 87%) and had Austrian citizenship (40/46, 87%). Parents were aged between 25 and 46 years (mean 33.72, SD 4.11 years). The youngest child was on average aged 28.93 (SD 17.73) months, with the youngest being aged 2 months and the oldest being aged 6 years. Of the 46 parents, 9 (20%) had a small child with them during the experiment. In addition, of the 46 parents, 44 (96%) reported being in a relationship, ranging from 1 to 20 years (mean 9.86, SD 4.5 years). The demographic characteristics of participants are reported in [Table 1](#).

**Table 1.** Sociodemographic characteristics of participants (N=46)<sup>a</sup>.

|                            | Full sample, n (%) |
|----------------------------|--------------------|
| <b>Sex</b>                 |                    |
| Female                     | 40 (87)            |
| Male                       | 6 (13)             |
| <b>Nationality</b>         |                    |
| Austria                    | 40 (87)            |
| Germany                    | 3 (7)              |
| Other                      | 3 (7)              |
| <b>Marital status</b>      |                    |
| Unmarried                  | 15 (33)            |
| Married                    | 30 (65)            |
| Divorced                   | 1 (2)              |
| <b>Relationship status</b> |                    |
| Single                     | 2 (4)              |
| In a relationship          | 44 (96)            |
| <b>Number of children</b>  |                    |
| 1                          | 17 (37)            |
| 2                          | 25 (54)            |
| 3                          | 4 (9)              |
| <b>Educational level</b>   |                    |
| Prefer not to say          | 2 (4)              |
| Lower secondary            | 1 (2)              |
| Apprenticeship             | 8 (17)             |
| High school                | 5 (11)             |
| Tertiary education         | 30 (65)            |

<sup>a</sup>Participants were on average aged 33.72 (SD 4.11) years.

## Experimental Procedure

Our experimental setup was developed based on the approach of Singh and Brown [55]. Written informed consent was obtained from all participants before the study. Subsequently, participants were asked to fill out the initial test inventory on paper. A smartwatch was worn during the experiment to measure physiological responses; however, these data are not included in this study. Participants were asked to search the web for current or recent somatic health issues related to self-symptoms or child symptoms. A between-subject design with block randomization was applied to assign parents to either the self-seeking or by-proxy seeking group. The Patient Health Questionnaire-15 (PHQ-15) was used to identify recent symptoms for the participants' search task. An adapted version

to appropriate symptoms in children was presented to parents in the respective group. Participants rated on a 6-point Likert scale the likelihood that each experienced symptom will recur (0 *not likely at all* to 5 *extremely likely*) and the fear that it will recur (0 *not worried at all* to 5 *extremely worried*). The symptom with the highest sum score was selected as the topic for the task. We framed the participants with an approximate maximum search time of 15 minutes. No further guidance or instructions on what or how to search were provided. The exact task text can be found in [Textbox 1](#). Desktop activity was recorded using Open Broadcaster Software [63]. After the task, the participants received another questionnaire regarding their search, including items on ecological validity, search appraisal, and their stress level.

### Textbox 1. Task description.

Imagine that the symptom \_\_\_\_\_ is acute or recently in the past. You now have a maximum of 15 minutes to search for information on the internet. Search like you would at home. There is no right or wrong approach in doing this. When you think you are done, report to the experimenter.



## Ethics Approval

Ethical approval for this study was obtained from the institutional review board of the University of Klagenfurt on April 2, 2019 (2018-116).

## Transcribing of Video Data

The software application ELAN [64] was used to determine the time spans and number of clicks for each recorded search session (ie, search duration, total clicks, unique resources, search queries, and page views). In addition, 3 undergraduate psychology students independently transcribed the videos. Intraclass correlation coefficients (ICCs;  $k=3$ , absolute-agreement, 2-way mixed-effects model) were excellent for total clicks (ICC=0.99), unique resources (ICC=0.99), search queries (ICC=0.99), page views (ICC=0.99) and search duration (ICC=1.00). If there was complete agreement among all 3 raters, the respective value was used. In case of agreement between at least two raters, this value was used. For discordance in all 3 raters, the median was used.

## Measures

### Demographics and General Questions on OHIS

Data on age, gender, citizenship, occupation, education, and civil status were collected as part of the sociodemographic characteristics. Moreover, we assessed relationship status, the length of the relationship in years, the age of the youngest child in months, and the total number of children in the household. Items on OHIS behavior, in particular, included the weekly time spent, the number of days during the week, the average time spent for an individual search session, the used device, and for whom the searches are (ie, self, child, partner, relative, friends, and others).

### eHealth Impact Questionnaire

The eHealth Impact Questionnaire (Part 1) by Kelly et al [65] is an 11-item scale for measuring the attitude to use the web for health-related purposes. The scale is divided into two subscales with 5 items on attitudes toward web-based health information and 6 items regarding attitudes toward sharing health experiences on the web. Part 2 of this scale was not included because that measure is for the evaluation of single websites that do not match with this study design. Each item is scored on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Scores were calculated by transforming the raw scores into a metric ranging from 0 to 100. The internal consistency in this sample was Cronbach  $\alpha=.67$  for the first subscale and Cronbach  $\alpha=.71$  for the second subscale.

### German eHealth Literacy Scale

The German eHealth Literacy Scale by Soellner et al [66] is the translated version of the eHealth Literacy Scale by Norman and Skinner [67] for assessing self-perceived health problem-solving skills in electronic environments. The scale consists of 8 items rated on a 5-point Likert scale. In our sample, the German eHealth Literacy Scale demonstrated acceptable internal consistency, with Cronbach  $\alpha=.78$ .

## PHQ-15 Measures

The PHQ-15 by Kroenke et al [68] is an instrument for the screening of somatic symptoms and the severity of somatization. The inventory contains 15 items on different somatic symptom groups, which cover more than 90% of the presented symptoms in primary care. In contrast to the original version, we asked only in a binary response format (yes or no) about the occurrence within the last 2 weeks to keep the scenario topic as current as possible. The following symptoms were removed for the by-proxy group because they were not appropriate for young children or commonly reported health symptoms: menstrual cramps, pain or problem during sexual intercourse, chest pain, dizziness, and having low energy. We replaced them with skin rash, fever, earache, vomiting, cough, sore throat, and uncontrollable crying. For both groups, an option was provided to write in symptoms not listed.

## Modified Short Health Anxiety Inventory

The Modified Short Health Anxiety Inventory (mSHAI) by Bailer et al [69] is a 14-item scale for assessing health anxiety. Initially published by Salkovskis et al [70] as the Short Health Anxiety Inventory, the mSHAI has, in contrast, an abridged response format and is proposed as unidimensional. On the basis of the previous 6 months, participants rate their fear of illness on a 5-point Likert scale, with higher values indicating greater fear of illness. Total scores range between 0 and 56. The health anxiety inventory was highly reliable in this sample, with a Cronbach  $\alpha$  of .91.

### mSHAI-Child

The mSHAI-Child is an adaption of the mSHAI by Bailer et al [69] for the self-report measurement of health anxiety by proxy toward the child. A similar approach was conducted with health anxiety by proxy in pregnant mothers [71]. Parents rate their health-related anxiety regarding their youngest child on a scale of 0 (strong disagreement) to 4 (strong agreement) on each of the 14 items, with a total score range of 0 to 56. In this study, the Cronbach  $\alpha$  was good ( $\alpha=.89$ ).

### State Anxiety

The Short State Anxiety Inventory by Grimm [72] is a 10-item scale to measure current emotional stress and anxiety. The German translation was published by Laux et al [73] and is originally based on the State-Trait Anxiety Inventory [74]. Participants rate on an 8-point Likert scale their tension, nervousness, and apprehension. The higher the total score, the higher the level of state anxiety and stress. Participants completed the questionnaire twice, immediately before and after the search task. In this study, the internal consistencies were Cronbach  $\alpha=.66$  at the preassessment stage and Cronbach  $\alpha=.74$  at the postassessment stage.

### Couple Satisfaction Index

The Couple Satisfaction Inventory-32 by Funk and Rogge [75] is a global self-report measurement of satisfaction in a relationship. The 32-item version of the Couple Satisfaction Inventory is psychometrically sound and precise for detecting differences in the level of relationship satisfaction. Total scores can range between 0 and 161, with higher scores indicating

better couple satisfaction. Funk and Rogge [75] recommended a distress cut-off of 104.5 to identify distressed relationships. In this study, the Cronbach  $\alpha$  was excellent ( $\alpha=.96$ ).

### **Parenting Stress Scale**

The Parental Stress Scale by Berry and Jones [76] is an 18-item measure for quantifying stress that results from the parent-child relationship. The scale covers different components of stress during parenthood, including parental rewards, parental stressors, parental satisfaction, and lack of control. Total scores range from 18 to 90, with higher scores indicating greater parental stress. The Parental Stress Scale showed acceptable internal consistency in our sample (Cronbach  $\alpha=.73$ ).

### **Subjective Search Evaluation**

We developed 6 items for the evaluation of search appraisal and the impact of participants' web-based search on their behavior based on a review of previous literature and pilot testing [20]. Scoring ranged from 0 (strong disagreement) to 4 (strong agreement) for each item. This included (1) search satisfaction with the progress of the search ("I am satisfied with the way my search has gone"), (2) search success of the final result of the search ("I am satisfied with the result of my search"), (3) self-empowerment that originates from the search ("The search makes me feel more self-empowered than before"), (4) the presence of an information overload during the task ("There was a point during the search when I felt overwhelmed by the amount of information"), (5) the need to contact a physician and discuss the information with him or her ("I will discuss the information found with my doctor"), and (6) the presence of unmet information needs ("I now have more open questions than before").

### **Objective Search Characteristics**

Quantitative search characteristics were extracted from the recorded desktop activity. These included the duration of the search, from the start of the first keystroke to the last significant mouse movement (*search duration*); the sum of all clicks that lead to visible actions (*total clicks*); the number of performed search queries (*search queries*); the number of unique accessed webpages, including search engine result pages, websites, and their subpages (*page impressions*); and the number of resources used during the search (*unique resources*).

## **Results**

### **General OHIS Behavior**

Parents report seeking on the web for health information for their child (44/46, 96%) rather than for themselves (37/46, 80%),

followed by searching for their intimate partner (19/46, 41%), relatives (10/46, 22%), and friends (7/46, 15%). Most parents spend up to 1 hour weekly on OHIS (32/46, 70%). The average time for search session at home varied greatly in the sample: 1 to 5 minutes (11/46, 24%), 5 to 10 minutes (13/46, 28%), 10 to 20 minutes (12/46, 26%), 20 to 40 minutes (5/46, 11%), 40 to 60 minutes (4/46, 9%), and no answer (1/46, 2%).

### **Topic of the Search Task**

Across groups, searches were carried out for 17 different symptoms. The most common scenario in the self-seeker group was back pain (5/23, 22%), whereas the most common topic in the by-proxy group was cough (8/23, 35%). A total of 2 participants searched for own suggested topic (ie, eye inflammation and common cold). A minority had already searched the internet for the respective symptom in the past 4 weeks (10/46, 22%). Less than half of the sample (20/46, 43%) had already seen their physician about the symptom. All topics of the search task are listed in Table 2.

### **Analysis of Search Queries**

Parents performed on average 2.95 search queries (SD 1.83) during their search. On the basis of the first search query, most parents started the search on symptoms (40/46, 87%); however, a small number of participants initially looked for treatments (4/46, 9%) or specific diseases (2/46, 4%). Of the 46 parents, 44 (96%) used Google as the search engine. In addition, of the 46 parents, only 1 (2%) started with an alternate search engine, whereas 1 (2%) began to seek in Facebook groups. A minority began with a single keyword search (7/45, 16%), whereas most participants used key phrases of >1 keyword (38/45, 84%). The 22 parents who searched for their child (mean 3.77, SD 1.75) compared with the 23 participants who searched for themselves (mean 2.43, SD 1.27) used significantly more words in their initial search term ( $t_{43}=-2.86$ ,  $P=.01$ ). Many parents in the by-proxy group specified their search terms with the child's age to find more suitable results. In the overall sample, the average position of the organic search result clicked first was 2.40 (SD 3.19), suggesting high attention on the top search results. Nearly all parents (40/46, 87%) stayed on the first page of the search engine results and never clicked on page 2 or further. During the search sessions, only 4% (2/46) of the parents clicked on an advertisement within the Google search results.

**Table 2.** Scenario topic.

| Group and scenario                  | Times searched, n |
|-------------------------------------|-------------------|
| <b>Self-seeker group (n=23)</b>     |                   |
| Back pain                           | 5                 |
| Headaches                           | 4                 |
| Feeling tired or lack of energy     | 3                 |
| Vertigo                             | 3                 |
| Diarrhea                            | 2                 |
| Elbow pain                          | 1                 |
| Stomachache                         | 1                 |
| Trouble sleeping                    | 1                 |
| Menstrual pain                      | 1                 |
| Tachycardia                         | 1                 |
| Eye inflammation                    | 1                 |
| <b>By-proxy-seeker group (n=23)</b> |                   |
| Cough                               | 8                 |
| Stomachache                         | 3                 |
| Diarrhea                            | 3                 |
| Headaches                           | 2                 |
| Fever                               | 2                 |
| Skin rash                           | 2                 |
| Sore throat                         | 1                 |
| Nausea                              | 1                 |
| Common cold                         | 1                 |

## Correlations Among Study Variables

[Multimedia Appendix 1](#) shows the correlations among all study variables. Health anxiety was moderately negatively associated with search satisfaction ( $r_s=-0.34$ ,  $P=.02$ ) and search success ( $r_s=-0.39$ ,  $P=.01$ ) and moderately positively associated with the need to talk to a physician after the search ( $r_s=0.31$ ,  $P=.03$ ) and unmet information needs ( $r_s=0.30$ ,  $P=.04$ ). eHealth literacy was positively correlated with the attitude toward web-based health information ( $r_s=0.35$ ,  $P=.01$ ) and search satisfaction ( $r_s=0.50$ ,  $P<.001$ ), whereas a moderate negative correlation was observed with unmet information needs ( $r_s=-0.32$ ,  $P=.02$ ) and information overload ( $r_s=-0.30$ ,  $P=.04$ ). No associations were found between relational variables (ie, couple satisfaction and parental stress) and any search-related variables. Perceived stress after the search was negatively correlated with search success ( $r_s=-0.33$ ,  $P=.02$ ) and positively correlated with the need to talk to a physician ( $r_s=0.31$ ,  $P=.03$ ); however, this was not the case for other evaluation items or characteristics of the

search. In general, our analysis showed few associations between the chosen inventories (ie, health anxiety, eHealth literacy, attitudes toward web-based information, and stress) and objective search characteristics. Similarly, there was only 1 significant association between the items on search evaluation and objective search characteristics, suggesting the absence of a clear relationship between appraisals and the manner of searching the web for symptoms.

## Comparison of Self-seeker and By-proxy Seeker

A series of independent sample 2-tailed  $t$  tests were conducted between both experimental conditions ([Table 3](#)). As expected, due to the randomization, no significant differences were found for in baseline variables. There were also no significant differences in any of the 6 items on the evaluation of the health-related search. Parents who searched for their child reported a greater need to communicate with a physician than those who searched for themselves, but this difference was not statistically significant with the current sample ( $U=187.5$ ,  $z=-1.78$ ,  $P=.07$ ), although the effect size was moderate (Cohen  $d=.58$ ).

**Table 3.** Descriptive statistics and 2-tailed *t* tests or Mann-Whitney U tests for the comparison of self-seeker and by-proxy seeker<sup>a</sup>.

| Measure                                  | Self-seeker, mean (SD) | By-proxy seeker, mean (SD) | 2-tailed <i>t</i> test ( <i>df</i> ) | <i>Z</i>         | <i>P</i> value |
|--|------------------------|----------------------------|--------------------------------------|------------------|----------------|
| mSHAI <sup>b</sup>                       | 11.60 (8.70)           | 12.65 (10.25)              | -0.37 (44)                           | N/A <sup>c</sup> | .71            |
| mSHAI-Child <sup>d</sup>                 | 14.82 (9.48)           | 16.04 (9.37)               | -0.43 (44)                           | N/A              | .66            |
| G-eHEALS <sup>e</sup>                    | 30.21 (3.84)           | 30.86 (3.74)               | -0.58 (44)                           | N/A              | .56            |
| eHIQ-Ohis <sup>f</sup>                   | 55.86 (18.80)          | 62.39 (17.76)              | -1.20 (44)                           | N/A              | .23            |
| eHIQ-Share <sup>g</sup>                  | 70.65 (16.20)          | 69.56 (13.90)              | 0.24 (44)                            | N/A              | .80            |
| CSI-32 <sup>h</sup>                      | 134.70 (15.84)         | 130.68 (24.19)             | 0.61 (37)                            | N/A              | .54            |
| PSS <sup>i</sup>                         | 34.68 (7.27)           | 35.69 (6.10)               | -0.50 (43)                           | N/A              | .61            |
| Stress before the task <sup>j</sup>      | 24.43 (7.56)           | 27.30 (10.26)              | -1.07 (44)                           | N/A              | .28            |
| Stress after the task <sup>k</sup>       | 23.60 (10.27)          | 28.00 (9.56)               | -1.50 (44)                           | N/A              | .14            |
| <b>Objective search characteristics</b>  |                        |                            |                                      |                  |                |
| Search duration <sup>l</sup>             | 562.95 (338.22)        | 525.08 (302.90)            | 0.40 (44)                            | N/A              | .69            |
| Total clicks <sup>m</sup>                | 27.56 (25.61)          | 21.26 (14.60)              | 1.02 (44)                            | N/A              | .31            |
| Page impressions <sup>n</sup>            | 9.56 (5.46)            | 9.82 (5.79)                | -0.15 (44)                           | N/A              | .87            |
| Unique resources <sup>o</sup>            | 5.17 (4.27)            | 4.69 (2.77)                | 0.45 (44)                            | N/A              | .65            |
| Search queries <sup>p</sup>              | 2.60 (1.55)            | 3.30 (2.05)                | -1.29 (44)                           | N/A              | .20            |
| <b>Subjective search evaluation</b>      |                        |                            |                                      |                  |                |
| Search satisfaction <sup>q</sup>         | 2.96 (0.82)            | 3.30 (0.63)                | N/A                                  | -1.45            | .14            |
| Search success <sup>r</sup>              | 3.30 (0.87)            | 3.48 (0.73)                | N/A                                  | -0.60            | .54            |
| Self-empowerment <sup>s</sup>            | 1.83 (1.11)            | 2.22 (1.08)                | N/A                                  | -1.17            | .23            |
| Information overload <sup>t</sup>        | 1.22 (1.31)            | 0.91 (0.99)                | N/A                                  | -0.53            | .59            |
| Need to talk to a physician <sup>u</sup> | 0.83 (1.02)            | 1.52 (1.31)                | N/A                                  | -1.78            | .07            |
| Unmet seeking needs <sup>v</sup>         | 0.74 (0.86)            | 0.83 (0.83)                | N/A                                  | -0.49            | .62            |

<sup>a</sup>Independent sample 2-tailed *t* tests for inventories and objective search characteristics. Mann-Whitney *U*-test for subjective search evaluation.

<sup>b</sup>mSHAI: Modified Short Health Anxiety Inventory.

<sup>c</sup>N/A: not applicable.

<sup>d</sup>mSHAI-Child: Modified Short Health Anxiety Inventory (by proxy related to own child).

<sup>e</sup>G-eHEALS: German eHealth Literacy Scale.

<sup>f</sup>eHIQ-Ohis: eHealth Impact Questionnaire, attitudes toward web-based health information.

<sup>g</sup>eHIQ-Share: eHealth Impact Questionnaire, attitudes toward sharing health experiences.

<sup>h</sup>CSI-32: Couple Satisfaction Index-32.

<sup>i</sup>PSS: Parental Stress Scale.

<sup>j</sup>Stress before the task: measured with the Short State Anxiety Inventory.

<sup>k</sup>Stress after the task: measured with the Short State Anxiety Inventory.

<sup>l</sup>Search duration: length of the search session (in seconds).

<sup>m</sup>Total clicks: the sum of all clicks during the search session that lead to visible actions.

<sup>n</sup>Page impressions: number of unique accessed webpages during the search session.

<sup>o</sup>Unique resources: number of resources used during the search session.

<sup>p</sup>Search queries: number of performed search queries.

<sup>q</sup>Search satisfaction: "I am satisfied with the way my search has gone."

<sup>r</sup>Search success: "I am satisfied with the result of my search."

<sup>s</sup>Self-empowerment: "The search makes me feel more self-empowered than before."



<sup>†</sup>Information overload: "There was a point during the search when I felt overwhelmed by the amount of information."

<sup>‡</sup>Need to talk to a physician: "I will discuss the information found with my doctor."

<sup>§</sup>Unmet seeking needs: "I now have more open questions than before."

For self-seekers, the results from the pretest (mean 24.43, SD 7.56) and posttest (mean 23.60, SD 10.27) stress indicate that the search task did not result in an increase of stress (paired  $t_{44}=0.43$ ,  $P=.66$ ). There was also no significant increase for the by-proxy seeker group in stress before the search task (mean 27.30, SD 10.26) compared with that after the search task (mean 28.00, SD 9.56; paired  $t_{44}=-0.34$ ,  $P=.73$ ). Moreover, no differences were found for total clicks, page impressions, number of unique resources, and search queries ( $P>.05$ ).

## Discussion

### Principal Findings

This study investigated the relationship between health anxiety, eHealth literacy, search appraisals, and quantitative search characteristics in the context of a symptom-driven web search. Few differences between self-seekers and proxy-seekers were found, but there was trend for parents searching for their young child to report a higher need to communicate with a physician than those searching for themselves. Consistent with previous experimental studies, this study contributes further evidence to the importance of trait health anxiety. In contrast to Singh and Brown [55] or Jungmann et al [57], we focused on the comparison of self-seekers and proxy seekers as well as the connection with search appraisals, thus expanding the contemporary understanding of OHIS processes and their evaluation by consumers. Contrary to expectations based on the literature, eHealth literacy was related neither to search success nor to a more efficient search.

### Comparison With Previous Work

Not surprisingly, almost all parents used the Google search engine as the first entry point, which is in full agreement with other studies [20,56]. We observed that the entire symptom search experience primarily occurred on the first search result page within the top rankings. Similarly, Beus [77] has also found a click rate of more than 50% for the first 3 organic search results in mobile searches. Google's ranking algorithm is important in influencing how fast consumers find health information. In our experiment, parents specified their search query term rather than searching more in depth when results were not perceived as useful. In general, the search queries parents used on behalf of their children tended to be more elaborate, for example, with precise age information. This observation has implications for providers of pediatric health content on the web. For pediatric health information, age-specific information in combination with specific symptoms may be most helpful in meeting parents' needs. Given the fact that uncertainty is a potential difficulty during OHIS [78,79] and symptoms have different health implications based on developmental age, this approach could support parents' connection to information that is more developmentally appropriate for their child.

Furthermore, advertisements both in Google search results and on further websites received little to no attention. This could be due to a general blindness for web-based advertisements [80] as well as the mistrust that consumers attribute to advertisements on the internet [81-83]. This is an important finding for possible future interventions as it suggests that target group-oriented advertising may not work in symptom-related searches, for example, to address stressed parents with relevant information directly during their search. Previous research has also shown that health websites with advertisements are perceived as less trustworthy [84]. Therefore, it could be more promising to provide parents with relevant eHealth knowledge via social media influencers, as there may be a pre-existing higher level of trust [85] that is lacking in conventional text advertising.

Similar to previous findings, we found a relationship between trait health anxiety and the need to talk to a physician after the search [37,57] and poorer search outcomes [38]. The relationship between pretask stress and health anxiety was also significant but not that between health anxiety and change in stress after the task. The experimental setting may have increased the baseline levels of pretask stress. Although not reported in this study, physiological data were also collected and showed a downward trend of electrodermal activity in many participants, which may have made detecting individual differences in change in stress after the task more difficult.

There was no association of eHealth literacy with search success, self-empowerment, need to talk to a physician, search duration, number of search queries, and stress after the search. We hypothesized that parents with higher eHealth literacy would search the web faster, use fewer resources, need fewer search queries, and thus search more efficiently. In theory, individuals with higher eHealth literacy should be better at finding, selecting, and using health information on the web than individuals with lower eHealth literacy. The nonsignificant results may raise concerns about the general difficulty of valid assessment of eHealth literacy using previous methods. The validity problems of the eHealth Literacy Scale have been described in the literature [86,87] and are generally attributable to the self-assessment character of the scale [87,88]. Parents with low eHealth literacy may not be aware of their lack of competence, whereas parents with high eHealth literacy may underestimate their skills [89,90]. In a study by Meppelink et al [91] on vaccination information seeking on the web, confirmation bias was more prevalent in parents with high health literacy. Prospectively, the dissemination on pitfalls and common cognitive biases of OHIS [92] could be valuable for enhancing eHealth literacy and mitigating the ramifications of maladaptive OHIS. A review by Karnoe and Kayser [93] found that although there are alternative methods of measuring eHealth literacy, these need further testing for use in research.

Contrary to expectations, we found no statistically differences between parents who searched for themselves and those who searched for their child, although these results should be interpreted tentatively due to the small sample size. We did find

a trend that parents who searched for their child reported a higher need to talk to a physician after the search than among parents who searched for themselves ( $P=.07$ , Cohen  $d=.58$ ). This finding should be explored further in a large and more diverse sample of parents. Regarding other differences, we had hypothesized that a higher level of self-perceived responsibility and uncertainty during managing children's symptoms in by-proxy seekers would lead to poorer outcomes in various dimensions (ie, search appraisals, longer search time, and higher stress). Although previous research has shown substantial differences between the characteristics of self-seekers and by-proxy seekers [18,94-96], these studies did focus neither on intraindividual differences on web users who usually act in both roles (ie, parents) nor on search appraisals. Nevertheless, we have several explanations for these unexpected results. First, there is the absence of considerable differences in most of the dimensions examined between self-seekers and by-proxy seekers exclusively in parents. In contrast to previous studies [18,94-96], our sample consisted only of parents. Within the general research on OHIS by proxy, the parent-child relationship may differ from OHIS on behalf of intimate partners, elderly relatives, informal caregivers, or friends. Parents are responsible for their children's health, whereas in most other by-proxy search relationships, there is still a certain degree of personal responsibility. Reifegerste and Bachl [97] found that relationship closeness was a relevant factor for OHIS by proxy, and that motives can differ across various by-proxy search types (ie, between parent-child and parent-partner). Thus, parents' OHIS for themselves could be very similar to OHIS by proxy for their children but may differ considerably for other relationships. Second, although the symptoms were derived from the recent past, they may no longer be relevant at the time when participants processed the task in the laboratory. Acuteness, perceived information need, and risk perception are important catalysts for OHIS [98-100]. Additional findings from Rains and Tukachinsky [101] suggest the association between information seeking depth on the web (ie, number of webpages) and the uncertainty appraisal intensity. Future research in larger samples and natural settings is essential, for example, with the support of smartphone apps that record health-related symptom searches just in time.

Finally, a recent scoping review revealed a wide variety of information needs among internet users [102], suggesting the requirement for better-tailored web-based health resources at the individual level. In addition to frequently examined relating factors on search success, such as credibility, trust, or information quality [103,104], other factors should also

increasingly be included in theoretical considerations and tested experimentally, for example, contemporary features of social media and their effectiveness on knowledge transfer [105,106]. Likewise, the use of artificial intelligence-based chatbots could be very promising for addressing the individual needs of consumers during OHIS [107-109]. Although in our experiment we only assessed subjective search success and search satisfaction, future studies could evaluate the respective website elements of a health-related website more precisely in terms of their contribution to search success. Approaches that consider perceived user trust and enhance interactivity may significantly improve users' experience with health websites [110].

### Limitations

Our work has some limitations. The experiment was based on a small sample size and did not allow any conclusions about the search behavior of the public. The sample consisted mainly of mothers with a high level of education and therefore underrepresented both fathers and parents with lower educational attainments. Neither the medical knowledge nor the possible work in a medical profession was assessed. Previous expertise could have had a substantial impact on the search and its evaluation. Furthermore, we applied an experimental approach in a laboratory setting; thus, the findings might not be generalized to real search behavior at home, although parents reported that their search behaviors were similar to those at home. In addition, we used single items for evaluating the subjective search outcomes and thus may have overlooked important dimensions. Future studies should apply more sophisticated assessment approaches in this context. Finally, the lack of association between eHealth literacy and search characteristics in our study may be related to the type and complexity of the search task. Further studies should examine the relationship between eHealth literacy and search characteristics based on the perceived task difficulty.

### Conclusions

The results of this study indicate that parents' symptom search evaluation is considerably associated with health anxiety, less with eHealth literacy, and not significantly with attitudes toward OHIS. These findings contribute additional evidence to a growing body of literature on the role of health anxiety during OHIS for oneself and others. Given the prevalence of web-based health information use among parents, further research is urgently needed to provide evidence-based recommendations on how to search the web most effectively and how this connects with subsequent health behaviors.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Spearman correlations for inventories, search evaluation items, and search characteristics.

[[PDF File \(Adobe PDF File\), 194 KB - pediatrics\\_v5i2e29618\\_app1.pdf](#)]

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## Abbreviations

- ICC:** intraclass correlation coefficient
  - mSHAI:** Modified Short Health Anxiety Inventory
  - OHIS:** online health information seeking
  - PHQ-15:** Patient Health Questionnaire-15
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Original Paper

# Parental Knowledge, Self-confidence, and Usability Evaluation of a Web-Based Infographic for Pediatric Concussion: Multimethod Study

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## Abstract

**Background:** Concussions, which are known as mild traumatic brain injuries, are complex injuries caused by direct or indirect blows to the head and are increasingly being recognized as a significant public health concern for children and their families. Previous research has identified few studies examining the efficacy of educational interventions on parental concussion knowledge. The aim of this research was to actively work together with children who have experienced a concussion and their parents to develop, refine, and evaluate the usability of a web-based infographic for pediatric concussion.

**Objective:** The objective of this study was to report on the usability of the infographic, parental knowledge, and self-confidence in pediatric concussion knowledge before and after exposure to the infographic.

**Methods:** A multiphase, multimethod research design using patient engagement techniques was used to develop a web-based infographic. For this phase of the research (usability, knowledge, and confidence evaluation), parents who could communicate in English were recruited via social media platforms and invited to complete web-based questionnaires. Electronic preintervention and postintervention questionnaires were administered to parents to assess changes to concussion knowledge and confidence after viewing the infographic. A usability questionnaire with 11 items was also completed.

**Results:** A web-based, infographic was developed. The infographic is intended for parents and children and incorporates information that parents and children identified as both wants and needs about concussion alongside the best available research evidence on pediatric concussion. A total of 31 surveys were completed by parents. The mean scores for each item on the usability surveys ranged from 8.03 (SD 1.70) to 9.26 (SD 1.09) on a 10-point Likert scale, indicating that the usability components of the infographic were largely positive. There was no statistically significant difference between preintervention and postintervention knowledge scores ( $Z=-0.593$ ;  $P=.55$ ; both preintervention and postintervention knowledge scores had a median of 9 out of 10). In contrast, there was a statistically significant difference between preintervention (mean 3.9/5, SD 0.56) and postintervention (mean 4.4/5, SD 0.44) confidence in knowledge scores ( $t_{30}=-5.083$ ;  $P<.001$ ).

**Conclusions:** Our results demonstrate that parents positively rated a web-based, infographic for pediatric concussion. In addition, although there was no statistically significant difference overall in parents' knowledge scores before and after viewing the infographic, their confidence in their knowledge did significantly increase. These results suggest that using a web-based infographic as a knowledge translation intervention may be useful in increasing parents' confidence in managing their child's concussion.

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**KEYWORDS**

concussion; mTBI; usability evaluation; knowledge assessment; knowledge translation; parent knowledge; parent confidence; patient engagement; educational tool

## Introduction

### Background

Concussions, which are known as mild traumatic brain injuries, are complex injuries caused by direct or indirect blows to the head [1]. An estimated 125,000 youths in Canada and 750,000 in the United States will sustain concussions annually [2,3]. Typical signs and symptoms of a concussion include headaches, nausea, dizziness (or fogginess), and sensitivity to light or noise [4]. For most children, recovery occurs within 1 to 4 weeks after the injury [5]. An estimated one-third of children and youths will have persistent symptoms that occur beyond 28 days. Persistent symptoms may include headaches, sleep problems, and emotional distress [2,3].

Rapid increases in the amount of health research, particularly in pediatric concussion, and the increased accessibility to research offered through the internet, suggest a demand for reliable, evidence-based health information that is relevant and easy to understand for patients and families [6]. Innovative media have been shown to be superior to traditional methods (ie, handouts) for transferring health information to consumers [7]. Our research team conducted an environmental scan of pediatric concussion resources found on the internet and in app stores. Despite innovative media being superior to traditional methods for transferring health information, our scan revealed that most pediatric concussion resources are PDF documents, suggesting that organizations struggle to optimize the use of innovative media (eg, infographics, videos, and narratives) when sharing health information. Our environmental scan also revealed that many resources are not developed in collaboration with health consumers. Using patient engagement approaches to involve end users (eg, parents and children) in the development of educational resources is key to effective knowledge translation (KT) [8].

A systematic review [9] evaluating the effectiveness of concussion education programs for coaches and parents of youth athletes found a limited number of studies examining the efficacy of educational interventions on parental knowledge of concussion and a lack of interventions designed specifically for parents. This suggests that additional research is necessary to investigate changes in parental knowledge following educational interventions and a need for more interventions specifically intended for parents and families. Furthermore, although studies have assessed parental knowledge of concussion, most have focused on sport-related concussions [9-14]. Few studies have evaluated changes in concussion knowledge after exposure to an educational intervention [13], and no known studies have assessed changes in self-confidence. Confidence is an important construct for behavior change. Higher levels of confidence increase the likelihood that an individual will change a health behavior when faced with obstacles [15]. Understanding how confident parents are in their knowledge and abilities to parent is an essential component of the quality and sustainability of

parenting behaviors [16]. In the context of our research, understanding how confident parents are in their knowledge of concussion and if an increase in confidence before and after an intervention is observed may provide critical insight into their health decision-making for their child, such as when to seek emergency care and at-home recovery.

To date, KT efforts have largely focused on ensuring that health care professionals use the latest research to inform their practice; however, emerging evidence suggests that efforts that target health consumers (eg, patients and families) can inform their decision-making and shape their treatment expectations (eg, what to expect in the emergency department) [17-20]. Although research is beginning to demonstrate that strategies targeting parents for KT can reduce health care use and improve outcomes, more research is required to fully understand the power and impact of these efforts on both children and families [21-23].

### Objectives

Developing innovative KT tools that present research-based information in user-friendly languages and formats provides consumers with accurate recommendations while addressing knowledge or information needs. In addition, these tools may foster and empower consumers to make informed decisions about health care for themselves and their families. To date, limited research has explored the usefulness and effectiveness of web-based infographics as an innovative way to share health information with patients and families. The purpose of this research was to actively work together with children who have experienced a concussion and their parents to develop, refine, and evaluate the usability of a web-based infographic for pediatric concussion. We also aimed to assess parental self-confidence and knowledge of pediatric concussion before and after exposure to the infographic. This paper provides an overview of the development of the infographic prototype and reports on the results of parental usability, knowledge, and confidence testing.

## Methods

### Overview

A multiphase, multimethod study using patient engagement techniques was used to develop, refine, and evaluate the usability of a web-based infographic for pediatric concussion to promote KT. Details of phases 1 and 2 of this work are reported by Campbell et al [24]. Changes in concussion knowledge and confidence in responses were also evaluated through preintervention and postintervention tests.

### Ethics Approval

Ethics approval was obtained from the University of Alberta Health Research Ethics Board (Pro0096202).

## Exploring Gaps in Current Concussion Tools (Intervention Development, Phase 1)

An environmental scan was conducted (May 2021) by the first author (AC) to identify publicly available Canadian developed resources providing information on pediatric concussion found on the internet and in apps. Information gaps in these resources were extracted (eg, resource format, target audience, and information) and used to inform the subsequent phases of this research, including the target audience for semistructured interviews (phase 2) and elements of the infographic, including target audience, content, and format (phase 3). The full results of this environmental scan are reported by Campbell et al [24].

## Compilation of Child and Parent Narratives (Intervention Development, Phase 2)

Phase 2 of this multiphase study was a qualitative description [25,26]. The first author (AC; trained in qualitative methods and supervised by the senior author and principal investigator (SDS) conducted semistructured interviews with a convenience sample of children who have experienced a concussion and their parents. Children and parents were recruited on the web through our research group's (Evidence in Child Health to Enhance Outcomes [ECHO] KT) social media platforms (Twitter @echoktresearch, Facebook ECHO Research, and Instagram @echoktofficial) and website [27]. The overarching purpose of these interviews was to explore the concussion experience of children and parents to understand their information needs and preferences regarding concussion. For children, questions focused on the concussion experience from the child's perspective, and for parents, questions focused on the experience of caring for a child with concussion. Interview topics included mechanism of injury, symptom experience, experience with the health care team, recovery and follow-up, and concussion information needs and preferences. The interviews were recorded and transcribed verbatim. The findings from these interviews informed the content and format of the web-based infographic. The sample demographics and full results of this qualitative study are reported by Campbell et al [28].

## Prototype Development (Phase 3)

The development of the infographic prototype involved first creating a composite infographic *skeleton*, which integrated the information needs and preferences of parents and children (as reported in the qualitative interviews) with the best available research on pediatric concussion management [28-30]. This integration determined the content for the infographic. The author AC led the development of the infographic with ongoing input and feedback from all authors. We then worked with a graphic design team that assisted in developing the accompanying artwork that would coincide with the content for the infographic.

## Parent, Youth, and Expert Feedback and Prototype Refinement

Upon completion of the infographic prototype, it was thoroughly reviewed and vetted for content accuracy by the author VP (content expert). The author VP is ideally suited for this assessment as she is well abreast of the best available research evidence in this specialized field. All authors provided extensive

input and feedback on each iteration of the prototype until a finalized version was agreed upon to be disseminated for user feedback and evaluation. The prototype was then shared with a group of parents from the Pediatric Parent Advisory Group. The Pediatric Parent Advisory Group is a group of parents, legal guardians, and grandparents who serve as advisers to the ECHO Research and Alberta Research Centre for Health Evidence programs (the authors SDS and LH's research programs) by providing advice and feedback on research aimed at improving child health outcomes [31]. Finally, the prototype was informally shared with a diverse group of youth for further advice and feedback. On the basis of the recommendations and feedback from content experts, parents, and youth, changes were made to the infographic (eg, changes to colors, images, word choice, and order of information).

## Prototype Usability Evaluation and Knowledge Change

We collected a convenience sample of participants to complete our web-based surveys. Collaborating clinicians from across Canada emailed potential participants with links to the infographic, usability test, and preintervention and postintervention knowledge and confidence tests. Potential participants included any parent, legal guardian, or grandparent. Participants were required to read and understand English. We asked for assistance from clinicians with known connections to concussion clinics, as potential participants from these clinics would be best suited to assess the relevance of the infographic and are more likely to seek out similar resources. Parent participants who previously participated in the qualitative interview portion of this research were also contacted via email with links to the infographic and surveys. In addition, we recruited participants via advertisements on our research group's social media platforms (Twitter, Facebook, and Instagram) with a link to the surveys.

A link to the infographic, usability test, and preintervention and postintervention knowledge and confidence tests was made available to all potential participants. The study description, including potential risks and benefits, was made available before beginning the survey. Consent was implied if the web-based survey was completed and submitted. Completion of the survey was completely voluntary. Participants were asked to complete a web-based survey that assessed their perceptions of the infographic using an adapted version of the validated User Experience Questionnaire (UEQ) [32,33]. We adapted the UEQ by reducing the number of items from 26 to 11 based on relevance to our infographic. The adapted UEQ contained 11 items, rated on a 10-point Likert scale ranging from 1 (least favorable answer) to 10 (most favorable answer). Participants had the opportunity to provide free-text feedback on areas that required revisions or more information.

To evaluate the knowledge of pediatric concussion, participants were asked to answer 10 true or false questions reflecting the most common misunderstandings about concussion. The true or false questions were adopted from a questionnaire developed by McKinlay et al [34]. Participants rated their level of confidence in their response to each question using a 5-point Likert scale (very sure to very unsure). After completing the baseline knowledge test, participants were to read the

infographic, and knowledge questions were answered again to assess short-term knowledge changes. Participants were again asked to rate their confidence. The UEQ was also completed following postintervention knowledge and confidence testing.

Survey data were collected from May 6, 2021, to June 14, 2021, through the Canadian web-based electronic platform SimpleSurvey. SimpleSurvey is secure, protected by several firewalls and layers of security, in alignment with Canadian privacy laws. The data collected through SimpleSurvey are completely anonymous and cannot be traced back to any individual. We followed the Checklist for Reporting the Results of Internet E-Surveys.

### Data Analysis

Data were entered into SPSS (version 26; IBM Corporation) [35], and descriptive statistics (eg, frequencies), measures of central tendency, and tests of statistical significance were completed. We conducted sample size calculations based on change in overall knowledge score to achieve a power of 80% and a level of significance of 5% (2-sided) with a 1-point difference (on a 10-point scale) between preintervention and postintervention knowledge scores (correlation estimate 0.6). A total sample size of 28 participants was required.

To assess knowledge change, we statistically compared preintervention and postintervention knowledge scores overall, as well as pretest and posttest scores for each topic. To assess knowledge change in each topic, items on the knowledge questionnaire were scored as 1 for correct and 0 for incorrect. The percentage of correct answers for each item and overall was then calculated. Owing to the nonnormality of knowledge scores, the median knowledge scores for both preintervention- and postintervention questionnaires were compared using Wilcoxon signed-rank tests.

To assess change in confidence, we statistically compared preintervention and postintervention confidence scores overall, as well as pretest and posttest scores for each topic. Likert scale scores were averaged, and differences in pre- and posttest scores were compared using paired 2-tailed *t* tests. Free-text data were analyzed using content analysis [25].

## Results

### The Tool (Web-Based Interactive Infographic)

In collaboration with a creative design team, we developed a web-based infographic based on 14 interviews with children and parents who have had experiences with concussion. The infographic targets parents and children and was designed to incorporate information parents and children identified as both wants and needs about concussion, including symptoms, when to go to the emergency department, return to play and learn guidance, and recovery tips. Interactive elements of the infographic include an animated GIF depicting what happens to the brain inside the skull after a direct or indirect blow to the head, drop-down lists, horizontal scrolling, audio clips of children telling their story and experience with concussion, and downloadable PDF information sheets targeting teachers, coaches, and family or friends that can be shared (Figures 1-4). Modifications to the infographic were also made in careful consideration of those experiencing concussions. For example, we opted to make the font size larger than average and ensured the colors used throughout the infographic were *less bright* (softer or *dull*) to accommodate the visual disturbances and sensitivity to light often experienced with concussions [36,37]. We ensured that the characters used throughout the infographic were representative of a diverse population. On average, the infographic takes approximately 5 to 10 minutes to read and review from beginning to end.



Figure 1. Infographic sample 1.



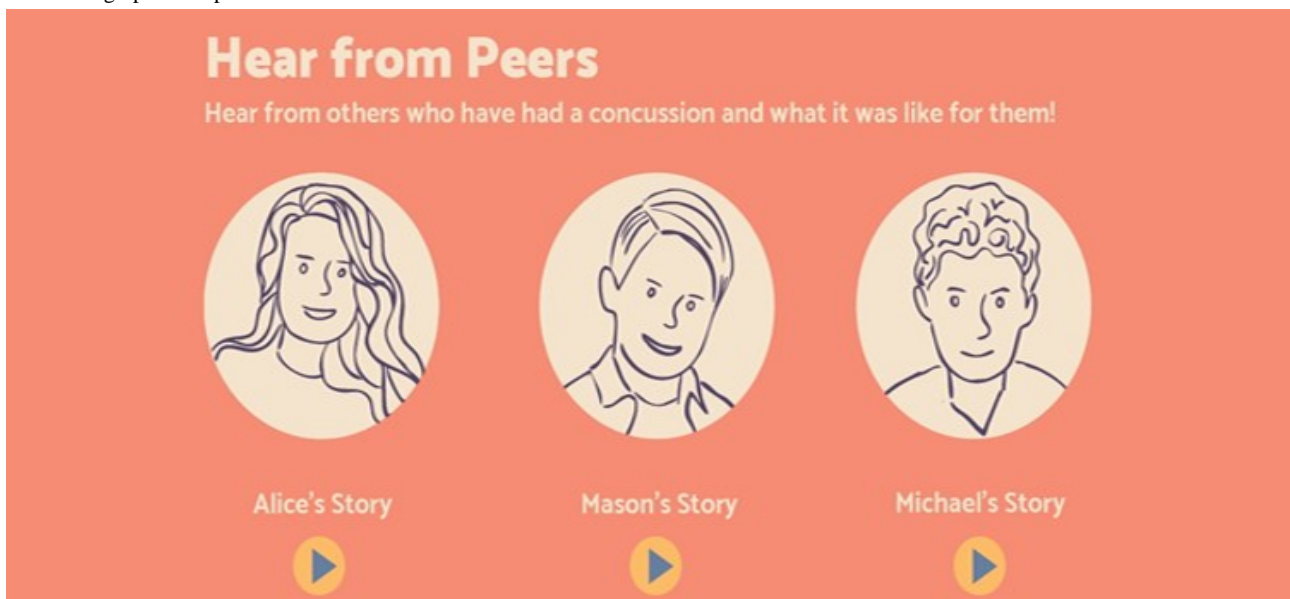
Figure 2. Infographic sample 2.



Figure 3. Infographic sample 3.



Figure 4. Infographic sample 4.



### Usability Testing Results

In total, 43 surveys were started, of which 31 (72%) were completed. Table 1 shows the demographic characteristics of the study population.

**Table 1.** Demographic characteristics (N=31).

| Variable  | Value, n (%) |
|---|--------------|
| <b>Sex</b>                                      |              |
| Female  | 28 (90)      |
| Male  | 3 (10)       |
| <b>Age (years)</b>                              |              |
| 20-29   | 7 (23)       |
| 30-39   | 10 (32)      |
| 40-49   | 5 (16)       |
| 50-59   | 6 (19)       |
| ≥60   | 3 (10)       |
| <b>Marital status</b>                           |              |
| Married, partnered, or common law               | 28 (90)      |
| Single, separated, divorced, or widowed         | 2 (7)        |
| Prefer not to answer                            | 1 (3)        |
| <b>Education</b>                                |              |
| Postsecondary certificate or diploma            | 6 (19)       |
| Postsecondary degree                            | 9 (29)       |
| Graduate degree                                 | 15 (48)      |
| Other   | 1 (3)        |
| Prefer not to answer                            | 1 (3)        |
| <b>Annual household income (CAD \$ [US \$])</b> |              |
| 40,000-59,000 (31,318-46,194)                   | 1 (3)        |
| 60,000-79,000 (46,977-61,853)                   | 1 (3)        |
| 80,000-99,000 (62,636-77,512)                   | 4 (13)       |
| ≥100,000 (78,295)                               | 22 (71)      |
| Prefer not to answer                            | 3 (10)       |
| <b>Number of children</b>                       |              |
| 0   | 2 (7)        |
| 1   | 12 (39)      |
| 2   | 15 (48)      |
| 3   | 1 (3)        |
| 4   | 1 (3)        |
| <b>Age of children (years)</b>                  |              |
| <1  | 4 (13)       |
| 1-5   | 14 (45)      |
| 6-10  | 2 (7)        |
| 11-15   | 6 (19)       |
| 16-20   | 11 (36)      |
| 21-25   | 3 (10)       |
| >25   | 9 (29)       |
| N/A <sup>a</sup>                                | 2 (7)        |
| <b>Has your child ever had a concussion?</b>    |              |
| Yes   | 14 (45)      |

| Variable | Value, n (%) |
|----------|--------------|
| No       | 17 (55)      |

<sup>a</sup>N/A: not applicable.

In general, parental reaction to the infographic was positive. The mean scores for each item of the usability scale ranged from 8.03 (SD 1.70) to 9.26 (SD 1.09) out of 10 (Figure 5). Only 1 parent indicated that the infographic did not meet their expectations and 1 parent commented that they would not recommend this tool to other families managing a child’s concussion. Common comments on the usability survey indicated parents felt the infographic was “simple and easy to follow,” “user friendly,” and “concise.” Other comments on the most positive aspects of the infographic included the following:

*Good layout and flow to answer questions, easy to navigate, and flow chart easy to follow on next steps.* [Participant 14]

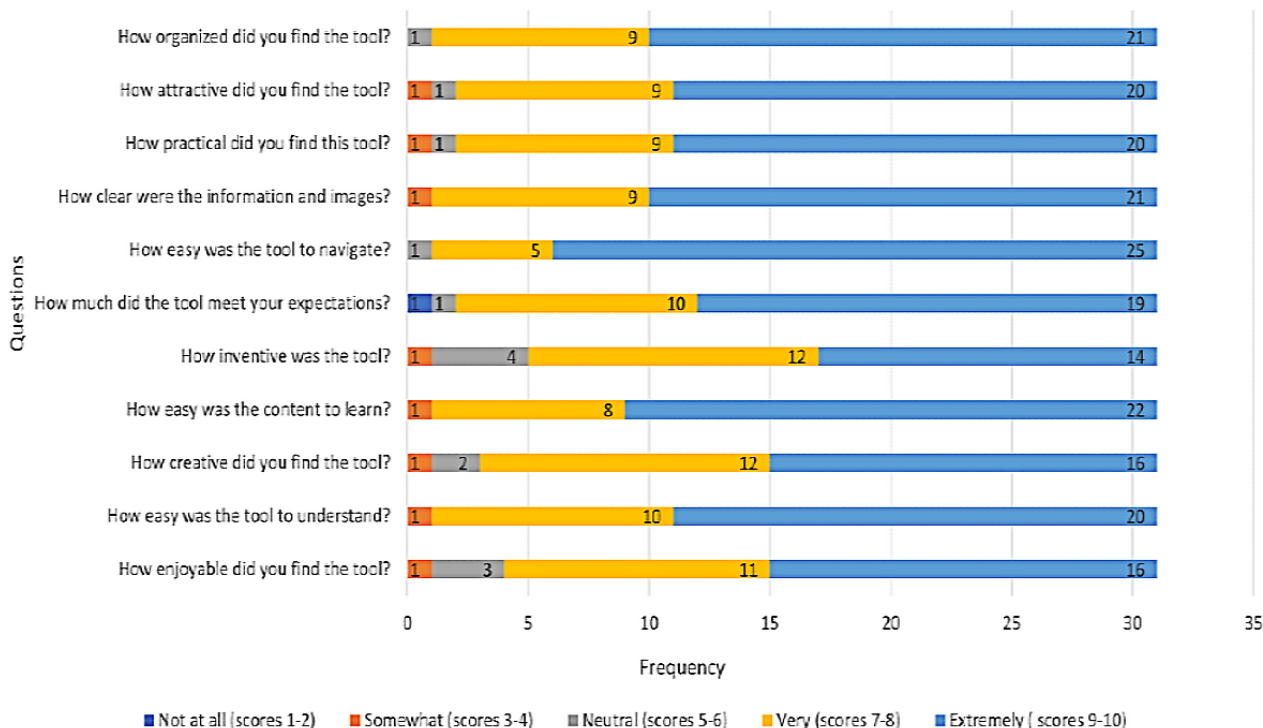
*The points were well highlighted. Easy to follow. Informative, quick to look at for what to do or watch for. Not too overwhelming. Touched the most important information.* [Participant 23]

*It did not overwhelm with information.* [Participant 8]

Some parents felt that the infographic colors were “dull” and “sometimes hard to view” (ie, Participants 26 and 29). For instance, a parent said:

*Mostly blocks of words, not unlike a pamphlet. Colours somewhat dull and lacking contrast between text and background. May be difficult for people with low vision or differences in colour perception.* [Participant 11]

Figure 5. Usability testing results.



### Knowledge Evaluation and Confidence in Response

The median preintervention knowledge score across the 10 knowledge topics was 9 (IQR 9-10), and the median postintervention knowledge score was 9 (IQR 9-10). A Wilcoxon signed-rank test showed no statistically significant difference in median knowledge scores before and after viewing the infographic ( $Z=-0.593$ ;  $P=.53$ ). Individually, an overall knowledge gain (although minor) was observed for topics 2, 7, and 10, and an overall knowledge loss was observed for topics 1, 6, 8, and 9, but Wilcoxon signed-rank tests showed no statistically significant changes before and after the intervention (Table 2). In the remaining 3 topics (topics 3, 4, and 5), 100%

(31/31) of the parents successfully identified the correct response before viewing the infographic, and this was retained after.

The mean preintervention confidence score across the 10 knowledge topics was 3.9 (SD 0.56; 3.9/5, 78%) and the mean postintervention confidence score was 4.4 (SD 0.44; 4.4/5, 88%). A paired 2-tailed  $t$  test showed a statistically significant difference in average confidence scores before and after viewing the infographic ( $t_{30}=-5.083$ ;  $P<.001$ ). Across each knowledge topic, paired 2-tailed  $t$  tests showed a statistically significant difference in confidence in answering the true or false questions for 70% (7/10) of the topics (topics 2, 3, 5, 6, 7, 9, and 10; Table 3).

**Table 2.** Changes in knowledge before and after exposure to the intervention.

| Question (correct answer) and answer combination  | Scenario        |                | Frequency, n (%) | Before exposure, % correct | After exposure, % correct | P value |
|---|-----------------|----------------|------------------|----------------------------|---------------------------|---------|
|   | Before exposure | After exposure |                  |                            |                           |         |
| <b>A concussion only occurs when there is loss of consciousness (F<sup>a</sup>)</b>           |                 |                |                  | 100                        | 97                        | .32     |
| Combination 1   | T <sup>b</sup>  | F              | 0 (0)            |                            |                           |         |
| Combination 2   | F               | T              | 1 (3)            |                            |                           |         |
| Combination 3   | T               | T              | 0 (0)            |                            |                           |         |
| Combination 4   | F               | F              | 30 (97)          |                            |                           |         |
| <b>A concussion only occurs after a blow directly to the head (F)</b>                         |                 |                |                  | 87                         | 97                        | .32     |
| Combination 1   | T               | F              | 4 (13)           |                            |                           |         |
| Combination 2   | F               | T              | 1 (3)            |                            |                           |         |
| Combination 3   | T               | T              | 0 (0)            |                            |                           |         |
| Combination 4   | F               | F              | 26 (84)          |                            |                           |         |
| <b>Confusion is not a sign of concussion if it clears within 5 minutes (F)</b>                |                 |                |                  | 100                        | 100                       | >.99    |
| Combination 1   | T               | F              | 0 (0)            |                            |                           |         |
| Combination 2   | F               | T              | 0 (0)            |                            |                           |         |
| Combination 3   | T               | T              | 0 (0)            |                            |                           |         |
| Combination 4   | F               | F              | 31 (100)         |                            |                           |         |
| <b>It is safe to return to playing sports as soon as the child is no longer confused (F)</b>  |                 |                |                  | 100                        | 100                       | >.99    |
| Combination 1   | T               | F              | 0 (0)            |                            |                           |         |
| Combination 2   | F               | T              | 0 (0)            |                            |                           |         |
| Combination 3   | T               | T              | 0 (0)            |                            |                           |         |
| Combination 4   | F               | F              | 31 (100)         |                            |                           |         |
| <b>Concussion symptoms are only apparent at the time of injury (F)</b>                        |                 |                |                  | 100                        | 100                       | >.99    |
| Combination 1   | T               | F              | 0 (0)            |                            |                           |         |
| Combination 2   | F               | T              | 0 (0)            |                            |                           |         |
| Combination 3   | T               | T              | 0 (0)            |                            |                           |         |
| Combination 4   | F               | F              | 31 (100)         |                            |                           |         |
| <b>Being knocked out is not the same as a concussion (T)</b>                                  |                 |                |                  | 77                         | 65                        | .16     |
| Combination 1   | T               | F              | 6 (19)           |                            |                           |         |
| Combination 2   | F               | T              | 2 (7)            |                            |                           |         |
| Combination 3   | T               | T              | 18 (58)          |                            |                           |         |
| Combination 4   | F               | F              | 5 (16)           |                            |                           |         |
| <b>Someone with a concussion should be kept awake for the first 24 hours after injury (F)</b> |                 |                |                  | 90                         | 94                        | .32     |
| Combination 1   | T               | F              | 1 (3)            |                            |                           |         |
| Combination 2   | F               | T              | 0 (0)            |                            |                           |         |
| Combination 3   | T               | T              | 2 (7)            |                            |                           |         |
| Combination 4   | F               | F              | 28 (90)          |                            |                           |         |
| <b>A concussion does not have longer-term effects (F)</b>                                     |                 |                |                  | 97                         | 94                        | .32     |
| Combination 1   | T               | F              | 0 (0)            |                            |                           |         |
| Combination 2   | F               | T              | 1 (3)            |                            |                           |         |
| Combination 3   | T               | T              | 1 (3)            |                            |                           |         |
| Combination 4   | F               | F              | 29 (94)          |                            |                           |         |



| Question (correct answer) and answer combination                            | Scenario        |                | Frequency, n (%) | Before exposure, % correct | After exposure, % correct | P value |
|---|-----------------|----------------|------------------|----------------------------|---------------------------|---------|
|   | Before exposure | After exposure |                  |                            |                           |         |
| <b>Children will recover better from a concussion than adults (F)</b>       |                 |                |                  | 61                         | 58                        | .56     |
| Combination 1   | T               | F              | 1 (3)            |                            |                           |         |
| Combination 2   | F               | T              | 2 (7)            |                            |                           |         |
| Combination 3   | T               | T              | 11 (36)          |                            |                           |         |
| Combination 4   | F               | F              | 17 (55)          |                            |                           |         |
| <b>Sometimes, concussion symptoms can take hours or days to show up (T)</b> |                 |                |                  | 90                         | 97                        | .32     |
| Combination 1   | T               | F              | 1 (3)            |                            |                           |         |
| Combination 2   | F               | T              | 3 (10)           |                            |                           |         |
| Combination 3   | T               | T              | 27 (87)          |                            |                           |         |
| Combination 4   | F               | F              | 0 (90)           |                            |                           |         |

<sup>a</sup>F: false.

<sup>b</sup>T: true.

**Table 3.** Confidence in knowledge responses (N=31).

| Question (correct answer and pre- or posttest)   | Confidence, n (%)    |                    |   |                |                     | Score, mean (SD) | P value            |
|--|----------------------|--------------------|---|----------------|---------------------|------------------|--------------------|
|  | Not at all confident | Somewhat confident | More than somewhat but not very confident | Very confident | Extremely confident |                  |                    |
| <b>A concussion only occurs when there is loss of consciousness (false)</b>                      |                      |                    |   |                |                     |                  | .06                |
| Pretest  | 0 (0)                | 0 (0)              | 2 (7)                                     | 9 (29)         | 20 (65)             | 4.58 (0.62)      |                    |
| Posttest   | 0 (0)                | 0 (0)              | 1 (3)                                     | 6 (19)         | 24 (77)             | 4.74 (0.51)      |                    |
| <b>A concussion only occurs after a blow directly to the head (false)</b>                        |                      |                    |   |                |                     |                  | .02 <sup>a</sup>   |
| Pretest  | 1 (3)                | 1 (3)              | 5 (16)                                    | 9 (29)         | 15 (48)             | 4.16 (1.04)      |                    |
| Posttest   | 0 (0)                | 0 (0)              | 2 (7)                                     | 7 (23)         | 22 (71)             | 4.65 (0.61)      |                    |
| <b>Confusion is not a sign of concussion if it clears within 5 minutes (false)</b>               |                      |                    |   |                |                     |                  | .004 <sup>a</sup>  |
| Pretest  | 0 (0)                | 1 (3)              | 12 (39)                                   | 10 (32)        | 8 (26)              | 3.81 (0.87)      |                    |
| Posttest   | 0 (0)                | 1 (3)              | 3 (10)                                    | 8 (26)         | 19 (61)             | 4.45 (0.81)      |                    |
| <b>It is safe to return to playing sports as soon as the child is no longer confused (false)</b> |                      |                    |   |                |                     |                  | .06                |
| Pretest  | 0 (0)                | 10 (32)            | 5 (16)                                    | 0 (0)          | 16 (52)             | 4.35 (0.76)      |                    |
| Posttest   | 0 (0)                | 1 (3)              | 0 (0)                                     | 8 (29)         | 22 (71)             | 4.65 (0.66)      |                    |
| <b>Concussion symptoms are only apparent at the time of injury (false)</b>                       |                      |                    |   |                |                     |                  | .03 <sup>a</sup>   |
| Pretest  | 0 (0)                | 0 (0)              | 4 (13)                                    | 11 (36)        | 16 (52)             | 4.39 (0.72)      |                    |
| Posttest   | 0 (0)                | 0 (0)              | 1 (3)                                     | 7 (23)         | 23 (74)             | 4.71 (0.53)      |                    |
| <b>Being knocked out is not the same as a concussion (true)</b>                                  |                      |                    |   |                |                     |                  | .008 <sup>a</sup>  |
| Pretest  | 0 (0)                | 2 (7)              | 14 (45)                                   | 10 (32)        | 5 (16)              | 3.58 (0.85)      |                    |
| Posttest   | 0 (0)                | 2 (7)              | 6 (19)                                    | 12 (39)        | 11 (36)             | 4.03 (0.91)      |                    |
| <b>Someone with a concussion should be kept awake for the first 24 hour after injury (false)</b> |                      |                    |   |                |                     |                  | .001 <sup>a</sup>  |
| Pretest  | 1 (3)                | 4 (13)             | 10 (32)                                   | 10 (32)        | 6 (19)              | 3.52 (1.06)      |                    |
| Posttest   | 1 (3)                | 1 (3)              | 3 (10)                                    | 9 (29)         | 17 (55)             | 4.29 (1.01)      |                    |
| <b>A concussion does not have longer-term effects (false)</b>                                    |                      |                    |   |                |                     |                  | .07                |
| Pretest  | 0 (0)                | 0 (0)              | 5 (16)                                    | 14 (45)        | 12 (39)             | 4.23 (0.72)      |                    |
| Posttest   | 0 (0)                | 0 (0)              | 3 (10)                                    | 9 (29)         | 19 (61)             | 4.52 (0.68)      |                    |
| <b>Children will recover better from a concussion than adults (false)</b>                        |                      |                    |   |                |                     |                  | .004 <sup>a</sup>  |
| Pretest  | 3 (10)               | 6 (19)             | 14 (45)                                   | 5 (16)         | 3 (10)              | 2.97 (1.08)      |                    |
| Posttest   | 2 (7)                | 1 (3)              | 11 (36)                                   | 12 (39)        | 5 (16)              | 3.55 (1.03)      |                    |
| <b>Sometimes, concussion symptoms can take hours or days to show up (true)</b>                   |                      |                    |   |                |                     |                  | <.001 <sup>a</sup> |
| Pretest  | 2 (7)                | 1 (3)              | 8 (26)                                    | 12 (39)        | 8 (26)              | 3.74 (1.09)      |                    |
| Posttest   | 0 (0)                | 0 (0)              | 3 (10)                                    | 11 (36)        | 17 (55)             | 4.45 (0.68)      |                    |

<sup>a</sup>Statistically significant at  $P < .05$ .

## Discussion

### Principal Findings

This study evaluated the usability of a novel, web-based infographic for parents who have experiences managing a child with a concussion, in addition to parental knowledge about pediatric concussion and confidence in their responses. Previous research has explored student and parent knowledge and

perceived confidence about brain injury and concussion but has not assessed changes in knowledge or confidence before and after exposure to an educational intervention [38]. Our study is the first to examine how web-based and arts-based media impact parental knowledge and confidence about pediatric concussions.

Parental concussion education is critically important, as many concussion signs and symptoms may not appear until hours or even days after the incident. As such, the onus falls on parents to identify signs and symptoms to ensure prompt and proper

diagnosis, treatment, management, and safe return to play or school [9]. Previous studies on parental concussion knowledge have found that parents are generally knowledgeable about concussion signs, symptoms, and recovery time even before exposure to an educational intervention, with small improvements in knowledge following exposure [9,13]. Parents in our study were also found to be generally knowledgeable about concussion before exposure to our infographic. Overall, the results of this study showed no significant overall increase in concussion knowledge. This may be because most parents in our study had previous experience with concussion and possessed high levels of concussion knowledge at baseline. A more diverse sample (particularly those without previous concussion experience) and more pronounced knowledge deficits at baseline may have yielded more significant knowledge changes.

Unique to our study was the evaluation of not only parental knowledge changes but also changes in confidence in their responses. After exposure to the infographic, parents' confidence in their responses significantly increased in 70% (7/10) of the content areas. This suggests that our infographic was effective in helping parents feel more confident about their knowledge of pediatric concussions. Increasing parental confidence in knowledge of their child's illness or injury may positively influence their child health care decision-making (eg, when seeking medical attention, home care, and recovery), ultimately improving child health outcomes [15]. This phenomenon was observed in a previous study conducted by our research team in the area of pediatric chronic pain [22].

Overall, the results on the usability of the infographic were positive, with most parents rating each aspect of the tool as very favorable or extremely favorable. Our study and others have demonstrated that innovative media, using narrative and artistic elements, is a promising approach for communicating complex health information to parents and families [18,19,22]. Although time and resource strain often determine how resources are developed, more innovative media may be beneficial in evoking relevance, timely accessibility, and engagement. In fact, more innovative media such as cartoons and videos have been found to be superior to standard medical sheets in transferring information to consumers [7]. Our chronic pain study yielded results similar to those in this study, suggesting that innovative, web-based, and arts-based interventions (eg, e-books and infographics) are viewed positively by parents and may increase parental confidence in their knowledge of pediatric conditions [22].

The systematic review by Feiss et al [9] found only 3 concussion education programs to be evaluated in the literature. Furthermore, although these programs include written content directed toward parents, there are no programs specifically designed for parents. Our infographic is unique in that it was designed specifically for parents based on their information needs and preferences, and parents were involved throughout the tool development process. Furthermore, our infographic was designed to be *safe* or *comfortable* for youth with concussions to view, as we carefully considered elements such as font size and colors that would not cause eye strain and potentially exacerbate concussion symptoms. Although the

rapidly developing evidence base in pediatric concussion places increased demands on updating information that is included in educational interventions to ensure they are timely and relevant, researchers have an opportunity to expand on the evidence being shared by taking a more participatory approach, involving end users in the development of these interventions.

The finalized version of this infographic (finalized February 2022) is now being disseminated through established social media platforms, including ECHO Research's Instagram, Twitter, Facebook, and website [27] and Translating Emergency Knowledge For Kids [39], which is a national network of health professionals and parents whose goals are to improve emergency care for children.

### Limitations

We relied on parent self-report data. The parents in our study consistently possessed high levels of education, and our findings cannot be extrapolated to all parents, including those with more pronounced information deficits or poor health literacy. Recruitment and data collection for this study occurred during the COVID-19 pandemic; thus, in adherence to government guidelines, recruitment occurred on the web through convenience sampling, which may not have provided the most information-rich sources. We acknowledge the approximately 25% (31/43) dropout attrition in our surveys. The reasons for dropout attrition in our study are unknown, although they are common in web-based surveys. However, careful review of the survey is warranted to potentially diminish dropout attrition in the future. Our study evaluated short-term changes in knowledge and confidence. Future research should examine changes in knowledge and confidence over time, as well as whether this change affects decisions made regarding the care and outcomes of the child. In addition, approximately half of the parents in our study had previous experience with concussions and may have received information about concussions via other sources. This may confound our results in terms of the effectiveness of the infographic on knowledge and confidence. Furthermore, the baseline knowledge score was very high, leaving little room to see an effect in terms of knowledge change. Our study did not ask about previous education sources, training, or exposure to pediatric concussions. A better understanding of the impact of various forms of education on knowledge and confidence, including participants with lower socioeconomic backgrounds, will help improve the design and format of future educational interventions.

### Conclusions

Our results demonstrated that parents positively rated a web-based infographic about pediatric concussion, and this infographic increased their confidence in knowledge of pediatric concussion. These findings hold promise for future development, application, and effectiveness testing of web-based, arts-based KT interventions for transferring complex health information to parents. Future research using innovative digital media for knowledge transfer with different clinical conditions and participant demographics (ie, children and different parents) should be explored as well as the effectiveness of different formats (eg, videos, e-books, and standard information sheets).

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## Conflicts of Interest

None declared.

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**Abbreviations**

**ECHO:** Evidence in Child Health to Enhance Outcomes

**KT:** knowledge translation

**UEQ:** User Experience Questionnaire

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Original Paper

# Exploring the Use of a Facebook-Based Support Group for Caregivers of Children and Youth With Complex Care Needs: Qualitative Descriptive Study

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## Abstract

**Background:** Caregivers of children and youth with complex care needs (CCN) require substantial support to ensure the well-being of their families. Web-based peer-to-peer (P2P) support groups present an opportunity for caregivers to seek and provide timely informational and emotional support. Despite the widespread use of social media for health-related support across diverse patient and caregiver populations, it is unclear how caregivers of children and youth with CCN use and potentially benefit from these groups.

**Objective:** The aim of this study is to explore the use of a web-based P2P support group for caregivers of children and youth with CCN in New Brunswick, Canada, and investigate factors related to its use by members.

**Methods:** The study sample consisted of individuals who joined a closed Facebook group and an analysis of content published to the group. In phase 1, a Facebook group was developed in consultation with a patient and family advisory council, and members were recruited to the group. Phase 2 of this study consisted of an observation period during which posts and related interactions (ie, likes, loves, and comments) by members were collected. In phase 3, a web-based survey was distributed, and semistructured interviews were conducted with a subsample of group members. Survey and interview data were analyzed using thematic analysis.

**Results:** A total of 108 caregivers joined the Facebook group between October 2020 and March 2021. There were 93 posts with 405 comments and 542 associated interactions (448/542, 82.7% likes and 94/542, 17.3% loves). Of these 93 posts, 37 (40%) were made by group members, and 56 (60%) were made by moderators. Of the 108 members, a subsample of 39 (36.1%) completed a web-based survey, and 14 (13%) participated in the interviews. Content analyses of posts by members revealed that inquiry (17/37, 46%), informational (15/37, 41%), and emotional posts (4/37, 11%) were the most common. Emotional posts received the highest number of interactions (median 24.5). In total, 5 themes emerged from the interviews related to the use of the group and mediating factors of interactions between group members: resource for information, altruistic contribution, varying level of engagement, perceived barriers to and facilitators of group activity, and moderators as contributing members.

**Conclusions:** These findings demonstrate that caregivers of children and youth with CCN seek geography-specific P2P support groups to meet informational and social support needs. This study contributes to the knowledge on how caregivers use Facebook groups to meet their support needs through moderate and passive engagement.

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**KEYWORDS**

peer-to-peer support; children; youth; complex care needs; social media; social support

## Introduction

### Background

Children and youth with complex care needs (CCN) are those with multidimensional health and social care needs who may or may not possess a diagnosis of a recognized condition [1]. Children and youth with CCN are present across diverse settings, requiring services from multiple care providers, which can result in significant physical, mental, and emotional pressures on their caregivers. The exact incidence and prevalence rate of children and youth with CCN is not well understood, in part because of ambiguity in the terms used to define this population [2], such as *medical complexities* [3], *special needs* [4], and *medical fragility* [5].

Caregivers of children and youth with CCN face many unique challenges owing to their complicated and multifaceted care needs. Barriers related to financial resources, continuity of care, and service navigation make accessing timely support challenging for these caregivers [6-8]. However, these caregivers possess invaluable experiential knowledge related to the available services and programs, access to resources, and effective professional support. Connecting these caregivers with each other through web-based peer-to-peer (P2P) support is one way to meet their informational and emotional support needs. Social media websites in particular provide an accessible and inexpensive space for the exchange of support between individuals with similar lived experiences.

Web-based P2P support has been shown to provide users with valuable informational, social, and emotional support [9] and allows users to communicate with peers and receive timely support without leaving their homes [10]. Internet-based P2P support allows for connections with peers on the caregivers' own time [11,12] and improves access despite geographical isolation [13]. P2P support groups present an opportunity for caregivers of children and youth with CCN to learn about and make sense of the maze of services, programs, and treatments available to them as well as the overwhelming amount of information provided to them by various sources [14]. Finally, web-based support allows those facing rare or stigmatized conditions to benefit from web-based discussions with peers [15].

Concerns related to lack of confidentiality and privacy have been identified as barriers to web-based health-related P2P support [16-19]. However, the opportunity to share experiences and connect with peers in similar situations has been reported to outweigh risks related to privacy as well as concerns about web-based negativity and potentially low-quality information [20]. Reaching out to others on the web requires a certain level of candidness and honesty that can sometimes prompt negative support; messages perceived by the receiver as negative or unsupportive are known to lead to poorer overall mental health [21]. Despite the risks associated with sharing personal stories and issues on the web, parents of children and youth with CCN

have reported fewer instances of judgment within Facebook support groups than in offline interactions [22].

Many social media websites and applications exist for use by the general public to connect and share content. Facebook in particular has been noted for its use in health-related communication among diverse types of patient and caregiver populations [23-27]. Facebook is among the most popular social networking websites worldwide [28], particularly in Canada [29], where 19.6 million users registered on the website in 2018 [30]. Previous research has demonstrated the prevalence and use of Facebook for health-related P2P support [31], including by parents of children with CCN [22]; however, it is unclear how caregivers of children and youth with CCN use these groups. Moreover, the factors that facilitate the success of these support groups have not been investigated in this population. Understanding the content and interactions between caregivers of children and youth with CCN can inform our understanding of these groups and how they may be leveraged to better support this population.

### Purpose of Research

This research aimed to explore the use of a Facebook-based P2P support group by caregivers of children and youth with CCN in the semirural Canadian province of New Brunswick (NB). Despite previous research demonstrating the use of Facebook groups by caregivers of children and youth with CCN [22], the way in which caregivers use these groups is unclear. Moreover, previous literature has not assessed the factors that contribute to the use of these groups by caregivers. In a preceding environmental scan of Facebook groups for caregivers of children and youth with CCN [32], we determined that there were no province-wide support groups for this population in NB. Therefore, this study aimed to implement and examine the use of a Facebook-based P2P support group for caregivers of children and youth with CCN in NB developed for the purposes of this research.

This research consisted of three phases: (1) developing a Facebook P2P support group for caregivers of children and youth with CCN in NB, (2) assessing its use by caregivers through analysis of posts and interactions (ie, likes, loves, and comments), and (3) exploring the factors that contribute to the group's activity levels and perceived success or failure by members. The following research questions guided this study: (1) How is the Facebook-based P2P support group used by NB caregivers of children and youth with CCN? (2) What factors affect the activity levels (ie, interactions between members) and perceived success or failure of the Facebook-based support group by caregivers of children and youth with CCN in NB?

## Methods

### Design and Sample

A qualitative descriptive design was used to explore how caregivers of children and youth with CCN used a Facebook-based P2P support group to communicate and to

examine factors related to ongoing activity levels within the group. Our sample consisted of caregivers of children and youth with CCN in NB who joined and interacted with the Facebook group and of a subsample of these participants who agreed to take part in the survey and interviews.

### ***Phase 1: Development and Implementation of the Facebook Group***

A bilingual (English and French) Facebook P2P support group was developed in consultation with NaviCare/SoinsNavi, a patient navigation center for children and youth with CCN in NB. Focus groups and meetings were held with members of the NaviCare/SoinsNavi Patient and Family Advisory Council (PFAC) to delineate an implementation strategy and determine the appropriate content for the group. The PFAC consists of 6 parents or guardians who have children and youth with CCN and 1 young adult who grew up with CCN in NB. Investigators met with the PFAC 3 times during the development of the group and then monthly after its implementation until the conclusion of the study. Specifically, the PFAC informed our team on the development of group characteristics (eg, title, description, membership screening, and rules), plans for discussion moderation and recruitment, and evaluation.

The Facebook group, created for the purpose of this research, was designed to facilitate the exchange of support between caregivers of children and youth with CCN. The group is closed to members, meaning that the member list and information posted within the group are not visible to nonmembers; this was to protect the confidentiality of those within the group and to create a space conducive to the exchange of support. Elements of the group that were visible to nonmembers included the group title, description, and moderators. All prospective members underwent a screening process before gaining approval from the group moderators to join the private group, which included providing informed consent to participate in this research. All members were made aware of the research focus upon joining the group during the study period and were informed when the research observation period ended. Specifically, information about the research was detailed in the group description, screening process of prospective members, and link to a letter of information detailing the research.

The group was moderated by a member of the NaviCare/SoinsNavi PFAC and the NaviCare/SoinsNavi patient navigator. These moderators monitored the discussion page to respond to unanswered posts, ensure the validity of the information, and enforce group rules. Although the patient navigator represented a unique contribution to the support group as a health professional, this individual's role within the group was simply to offer one perspective in addition to those of the caregivers within the group. The patient navigator's role was to ensure that the posts received a timely response (ie, respond to posts that did not receive a prompt reply from peers).

The Facebook support group was launched on October 5, 2020. Members were recruited to the group using four strategies: (1) email blast to past and present NaviCare/SoinsNavi clients, (2) media release sent to 35 community organizations that support families of children and youth with CCN in NB, (3) messages sent to moderators of Facebook groups and pages used by

caregivers in NB (eg, general parent support groups), and (4) media releases on other social media platforms and websites.

Upon the implementation of the Facebook group, the moderators created a social media plan for ensuring that the group remained active and relevant while it began to grow. The social media plan involved a weekly structure of planned posts that included a welcome post each Friday (tagging all new members that week), a discussion post that prompted members to answer a question or share their experience, and ongoing interaction with posts made by members to ensure that content was not left unacknowledged.

### ***Phase 2: Observation of the Facebook Group***

Phase 2 of the study consisted of an observation period during which the participants joined and began to use the group; this phase took place over 6 months (October 2020 to March 2021). Content published within the group (ie, posts, comments, likes, and loves) was collected and organized in Microsoft Excel to examine how members and moderators used the group. Additional factors observed to potentially influence ongoing activity levels within the group (eg, time and date of posts) were also noted throughout the research period.

### ***Analysis Strategy: Group Posts and Interactions***

A qualitative descriptive design was used to investigate the use of the group by members and the factors related to the success or failure of the Facebook-based P2P support group. Specifically, deductive qualitative content analyses were used to analyze the posts published to the group. Content analysis is a qualitative and systematic approach to coding and categorizing text [33] that aims to describe a phenomenon [34]. Posts were categorized according to one of 6 labels based on their content: informational, emotional, inquiry, advertising, fundraising, and other [23,35]. Posts categorized as informational were those containing information of relevance (eg, shared articles or details on a program). These differed from inquiry-based posts, which were centered on a question. Emotional posts described experiences, stories, or narratives. Advertising posts comprised the promotion or sale of a product or service, and posts labeled as *other* were those that did not fit the previous categories. The total numerical count of these posts was recorded along with the total number of associated interactions (eg, likes and comments).

Observed numerical data related to the factors of membership activity (eg, number of interactions) were analyzed using Microsoft Excel. Specifically, descriptive statistics and comparisons related to the frequency of post types (eg, informational, emotional, and inquiry), interactions (eg, likes, loves, and comments), time and date of publication, and source (ie, moderator or group member) were conducted to explore possible associations.

### ***Phase 3: Web-Based Survey and Interviews***

In phase 3 of the study, a web-based survey was distributed to members within the group, and interviews were conducted. The following section describes the process for data collection and analysis for the survey followed by the process for the interviews.



### Web-Based Survey: Data Collection and Analysis

The web-based survey was developed using Qualtrics XM (Qualtrics International Inc) and consisted of 16 closed-ended questions and 3 open-ended questions related to the participants' use of the group and perception of its success or failure. A group administrator posted the survey, available in both English and French, as a link in the Facebook group. The survey questions were developed in consultation with the PFAC and were specific to this research.

Survey results from the closed-ended questions were collated in Qualtrics XM and exported to Microsoft Excel for analysis.

### Semistructured Interviews: Data Collection and Analysis

The semistructured interviews consisted of 15 open-ended questions based on the participants' use of the P2P support group, experience as caregivers of a child or youth with CCN, and barriers to and facilitators of using the group to exchange or receive support. Participants were recruited from the closed Facebook group through posts made by moderators. The interviews were conducted in both English and French and were approximately 20 to 25 minutes in length. The interviews took place using Zoom (Zoom Video Communications) videoconferencing software because of its ease of qualitative data collection, data management features, and security options [36]. All the interview participants received an Amazon gift card as remuneration.

The interviews were audio-recorded using Zoom and then transcribed verbatim into Microsoft Word by the lead author (KJK). The interview transcripts and open-ended survey questions were analyzed using thematic analysis [37]. Specifically, the lead author read through the transcripts and assigned initial codes to the content. Codes and associated quotes were collected in Microsoft Excel to produce a summary table [38] and grouped into broader themes using an iterative process to ensure that the original context of the quotes was preserved. Thematic analysis differs from content analysis, which was used to analyze posts from the Facebook group, as thematic analysis aims to provide a comprehensive summary of a phenomenon in the everyday language of those events by remaining close to the *surface* of the words used by the participants themselves rather than attempting to interpret meaning [39]. Previous investigations of web-based P2P support groups that have used content analyses often focus on received support rather than perceived support [40], and the addition of interview data provides an opportunity to better understand and contextualize findings from content analyses [41].

### Ethics Approval

This research was approved by the University of New Brunswick Research Ethics Board (040-2019). A protocol for this research, including the development of the Facebook group, has been published previously [42].

## Results

### Overview

A total of 108 caregivers of children and youth with CCN joined the Facebook group during the study period. Between October

5, 2020, and March 26, 2021, there were 93 posts with 405 comments, 255 likes (ie, thumbs-up emoji), and 81 loves (ie, heart emoji) from the participants and moderators on the Facebook P2P support group. Of these 93 posts, 37 (40%) were made by group members (ie, caregivers of children and youth with CCN), and 56 (60%) were made by moderators. The date of post publication indicated an increase in the total number of posts each month throughout the data collection period (Figure 1). A breakdown of interactions on posts revealed that most comments, likes, and loves came from group members (537/741, 72.5%) rather than moderators (204/741, 27.5%); specifically, group members made 78.5% (318/405) of the comments, 61.2% (156/255) of the likes, and 78% (63/81) of the loves on posts.

In total, 14 interviews (13/14, 93% in English and 1/14, 7% in French) were completed with members of the Facebook support group. Just over half of the interview participants (8/14, 57%) reported caring for children aged <5 years.

Of the 108 members of the Facebook group, a subsample of 39 (36.1%) completed the web-based survey (all in English). Most of the survey participants were women (29/39, 74%), and the remaining 26% (10/39) preferred not to answer. The survey participants were primarily between the ages of 25 and 34 years (16/39, 41%) and 35 and 44 years (9/39, 23%). Only 10% (4/39) of the participants were aged between 45 and 54 years, and 3% (1/39) were aged >55 years. The remaining participants (9/39, 23%) preferred not to respond. The participants represented a wide geographical range across the province of NB, with nearly one-third (11/39, 28%) reporting the province's capital (Fredericton) as their place of residence.

More than half of the survey participants (22/39, 56%) reported belonging to the group as members for >3 months. In total, 13% (5/39) of the participants reported a length in membership between 2 and 3 months, and 18% (7/39) reported a length in membership between 1 and 2 months. A total of 13% (5/39) of the participants reported belonging to the group for <1 month.

Most participants reported seeing content from the Facebook group appear on their main timeline a few times per month (12/39, 31%), once a week (8/39, 21%), or once a month (7/39, 18%). Only 5% (2/39) of the participants reported that they had never seen content from the group appear on their main timeline. Most survey participants (29/39, 74%) reported logging in to Facebook daily.

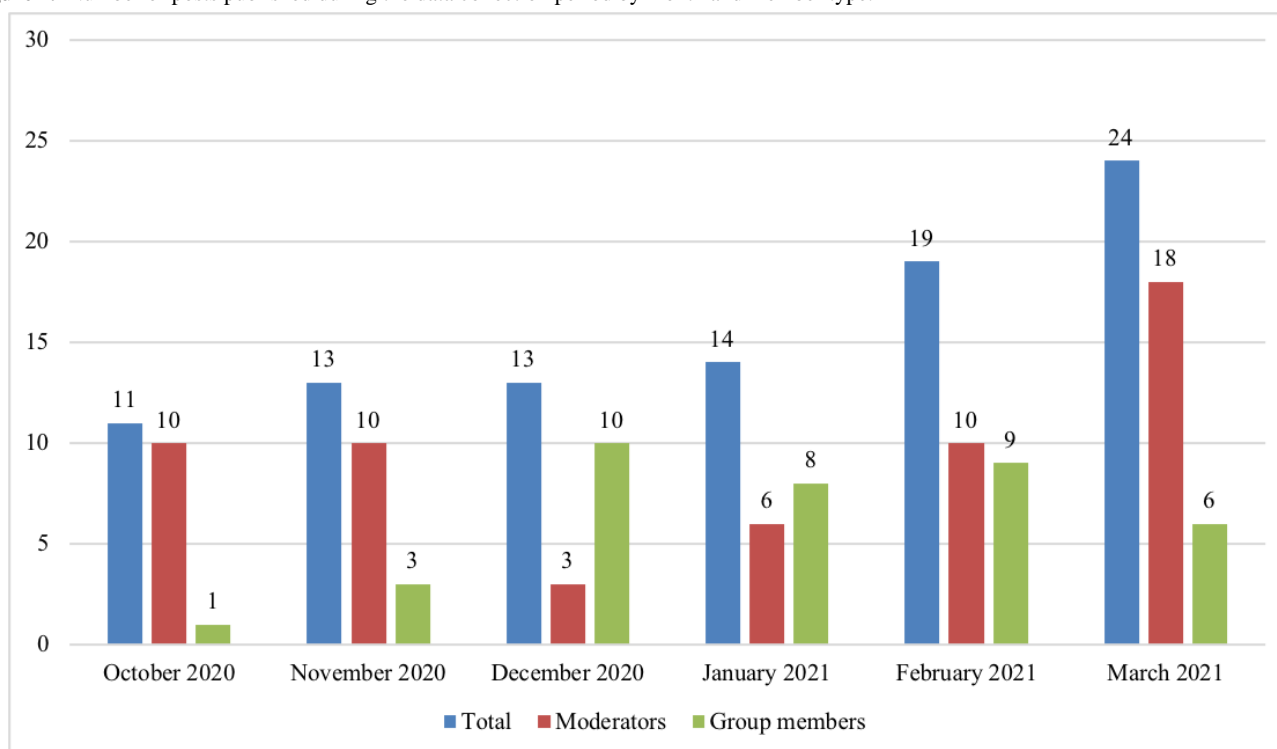
Of the 39 survey respondents, 23 (59%) indicated that they had never published a post within the group; however, when asked about their approximate number of interactions on posts within the group, most participants indicated that they had had 1 to 2 interactions (15/39, 38%) or 3 to 5 interactions (8/39, 21%) with posts. Only 13% (5/39) of the participants indicated that they had never interacted with a post within the group (Table 1). When asked about their perceived comfort with posting in the group, 64% (25/39) of the participants indicated that they felt "comfortable" posting or commenting in the group; those who reported that they did not feel comfortable indicated that their hesitation was due to the research focus of the group (2/39, 5%) and concern that information would become available to personal connections (1/39, 3%).



Nearly two-thirds of the survey respondents (23/39, 59%) reported belonging to at least one other Facebook-based P2P support group related to their role as caregivers of a child or youth with CCN. Most of these participants (14/23, 61%)

reported belonging to 3 or more other Facebook support groups. Many survey participants (18/39, 46%) reported using Facebook support groups when they had questions or support needs related to the care of their child.

**Figure 1.** Number of posts published during the data collection period by month and member type.



**Table 1.** Reported number of interactions on group posts by survey participants (N=39).

| Interaction frequency | Participants, n (%) |
|-----------------------|---------------------|
| Never                 | 5 (13)              |
| 1 to 2 times          | 20 (51)             |
| 3 to 5 times          | 10 (26)             |
| 6 to 9 times          | 2 (6)               |
| ≥10 times             | 2 (6)               |

### Content Analysis of Posts

Posts published to the Facebook group's wall represented 5 of the 6 categories of post types (informational, emotional, inquiry, fundraising, and other); no advertising posts were observed during the data collection period. Combining posts made by both moderators and administrators and group members, inquiry posts were the most commonly observed (38/93, 41%), followed by other posts (28/93, 30%) and informational posts (23/93, 25%). In group members alone, inquiry posts were the most common (17/37, 46%), followed by informational posts (15/37, 41%) and emotional posts (4/37, 11%). Fundraising (1/37, 3%) posts were the least commonly observed type of post (Figure 2).

Posts in the *other* category were published exclusively by moderators and administrators (28/56, 50%). This category consisted of posts welcoming new members (14/28, 50%), invitations for members to introduce themselves or share photos

(8/28, 29%), and research-gathering posts (6/28, 21%). The remaining post consisted of an update made to the group description during the data collection period.

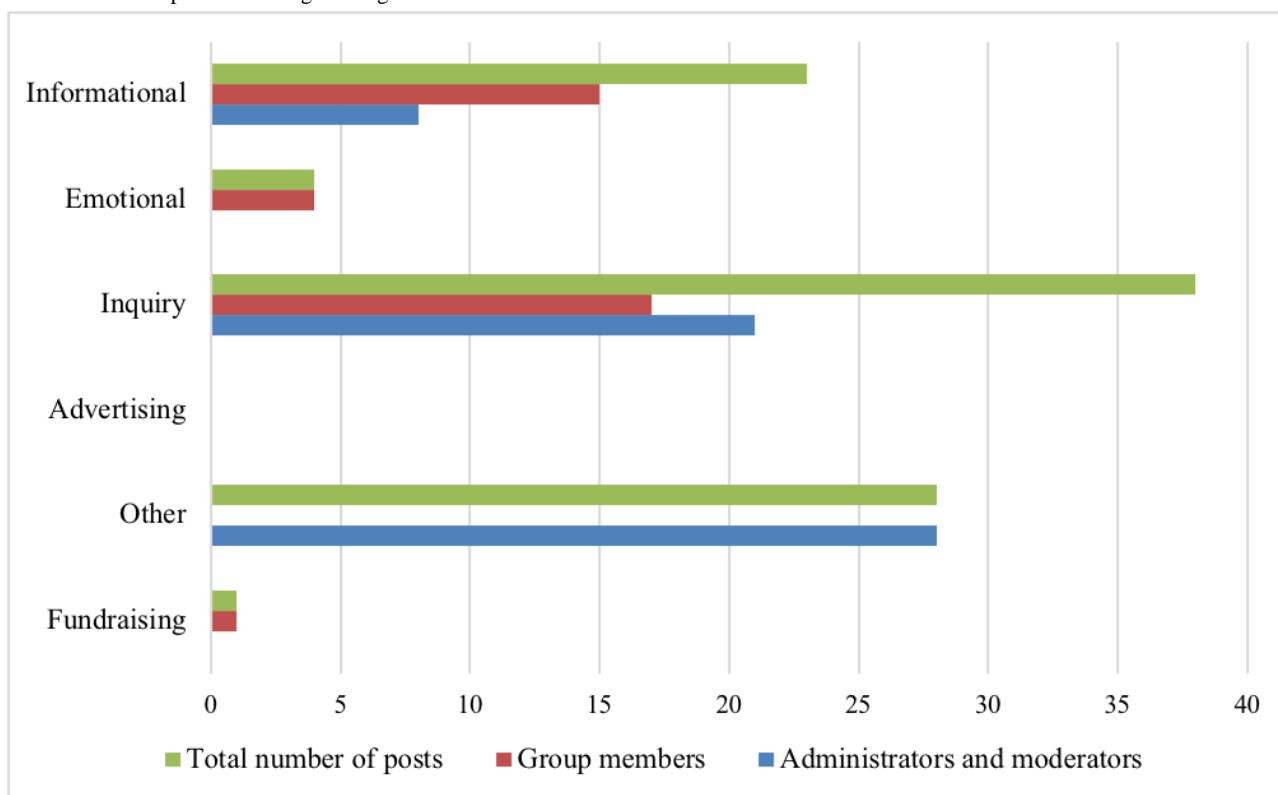
Emotional posts received the greatest number of interactions, including comments, likes, and loves (median 24.5, range 18-35), followed by other (median 9.0, range 2-20), inquiry (median 7.2, range 0-29), and informational (median 5.1, range 0-33) posts. Fundraising and advertising received no interactions.

The type of interactions elicited by each type of post varied, with emotional posts (4/37, 11%) receiving the greatest number of comments (median 10), followed by inquiry posts (median 5.5) and other posts (median 4.0). Emotional posts (4/37, 11%) also received the greatest number of likes (n=5) and loves (n=10), followed by other posts (likes: median 4.1; loves: median 1.0) and informational posts (likes: median 2.7; loves: median 0.4).

The time at which posts were made to the group and the number of corresponding interactions indicated a positive but weak correlation between the 2 variables ( $r_{97}=0.20$ , not significant).

No correlation was observed between the number of views that a post received and the corresponding interactions ( $r_{97}=0.02$ , not significant).

**Figure 2.** Number of posts according to categorization.



### Thematic Analysis of Interviews

#### Overview

The use of the Facebook-based P2P support group and factors that affect its perceived success or failure were further explored through a thematic analysis of interviews with group members (ie, caregivers of children and youth with CCN). Five themes emerged from these interviews: (1) resource for information, (2) altruistic contribution, (3) varying level of engagement, (4) perceived barriers to and facilitators of group activity, and (5) moderators as contributing members. Each of these themes is described in further detail in the following sections.

#### Theme 1: Resource for Information

The interview participants reported using the group as a resource for informational support. The participants described other caregivers within the group as a knowledgeable source of information that could assist them in the care of their child or children by providing information gained through lived experience:

*And the fact that there is a Facebook group...cause at my age, that's what they use for information, right? To know that it is from a source that is knowledgeable, and they've done their homework and those things, or that they'll point you in the right direction helps.*

Some participants described joining the group in anticipation of support that they would need as their child or children

transitioned to new stages, thus using it as a resource for future informational support needs:

*I find, for myself, I read comments a lot or I read the post, and then I get a lot of information out of what people are commenting back. I find that is extremely helpful because even if I don't, if it's not directly related to me yet, it might be something I encounter later on. So it's helpful to have, like, "oh, I can go back to this and read it."*

Many participants identified the geography-specific aspect of the group as an important resource for navigational support. Most interview participants indicated that they were members of other Facebook-based support groups that were not specific to NB that aided in their role as caregivers of a child or youth with CCN. These participants described using the NB group to complement support received from their other Facebook support groups; specifically, the NB support group was used for local informational and navigational support needs, whereas many described using condition-specific groups for support related to their child or children's medical care:

*The other [condition-specific] groups, I tend to go more for, like, medical things. So for instance, like on my [condition] group, I'll post like, you know, "what medications are you guys being given for seizures and sleep, because we're struggling right now." And then I can get the support from that. So the other groups, I tend to use more of like a medical*

*piece. But this one here, I see more as like a resource piece, looking for resources and things like that.*

Some participants discussed the impact of the COVID-19 pandemic on their role as caregivers of a child or youth with CCN and specifically how it affected their use of Facebook support groups. The participants noted an increase in their use of Facebook for informational support because of additional pressures faced by having a child or youth who was immunocompromised. Moreover, the participants described experiencing barriers related to the pandemic and using the support group to fill the gaps left in their information resources:

*I'm so new here and because of the pandemic, it hasn't really allowed me to go out and explore and find these things for [my daughter]. And all these questions that I've asked, everyone's been very helpful and very kind, and yeah.*

### **Theme 2: Altruistic Contribution**

Many participants described using the group to share the knowledge that they had gained through lived experience as caregivers of a child or youth with CCN. The participants described a desire to help other individuals going through similar situations by sharing the knowledge that they had obtained:

*So like, now I don't feel like I'm an expert at all, but I have so many, like, things in my backpack, like that I can reach out to and go to. I wish that I could give that backpack to me eight years ago. Like, other people that I know now that are starting to go through it. And that's why it's really awesome that this Facebook group happened, because it's a way for other people to share with me what's in their backpack and for me to share with those people.*

### **Theme 3: Varying Level of Engagement**

The interview participants described a range of engagement with the Facebook group. Although many participants described themselves as *lurkers* and *stalkers* within the group, many still felt that they benefited from participation:

*I'm a Facebook stalker, I'm a group stalker, so I just wait for other people to [laughs] post stuff and people have posted exactly what's on my mind all of the time so I don't even have to post, which is really nice. Just being on the group.*

The participants who reported making contributions to the group through posts and related interactions described using the group infrequently or inconsistently:

*I'm not on Facebook a ton. Um, um, so I "like" things and sometimes I'll share things that I think are relevant to the group. Um, and I have made a post, a post or two and commented on a post.*

The participants who reported feeling comfortable posting in the group when they had a question or concern attributed it to the geography-specific nature of the group and observing other members model interactions with content:

*I think just personally I still have a hard time putting myself out there. Like, to ask a question. But when I*

*see someone else, like I feel comfortable commenting on someone else, or like, liking and things like that.*

### **Theme 4: Perceived Barriers to and Facilitators of Group Activity**

Several factors were described by the participants as affecting their use of the group and perception of overall group activity. These perceived barriers to and facilitators of group activity were divided into 4 subthemes: target conditions or diagnoses, research emphasis, privacy of content, and group duration (time since implementation).

#### **Targeted Conditions or Diagnoses**

Some participants described a lack or low incidence of activity within the Facebook group compared with other Facebook support groups of which they were members. These participants felt that part of the reason for this lack of activity may be the diversity in conditions experienced by caregivers and their children within the group:

*Her condition is so rare. I only know of one other family here whose son has [it], like I said so I don't expect, yeah, I don't expect to learn too much more about her condition and a lot of the times, her condition isn't black and white either.*

Despite the diversity in conditions, the participants felt that the similarities between the journeys of individual caregivers, owing to the geography-specific nature of the group, may promote the long-term success of the group:

*Having [a group based] in New Brunswick has been very helpful, just to know that we can connect to people who are close by. And even just knowing someone is, even if they're in Moncton, or they're anywhere else, like just knowing they're in New Brunswick is helpful, and they're kind of on a similar journey.*

#### **Research Emphasis**

Some participants identified the research focus of the group as a potential reason for a lack of activity, although these individuals did not feel uncomfortable posting or interacting with posts themselves. The participants who identified the research focus as a potential barrier described it as a unique factor to the group, as an avenue to advocate for gaps in support availability:

*I mean I don't have a problem with it, some people maybe are worried to share things because there's administrators or moderators in there, you know what I mean? I wouldn't, but maybe some people wouldn't complain about services in New Brunswick if they're worried it would get back to the service provider, I don't know. I personally don't think that it makes a difference, knowledge is power, and I think that if people hear what we go through or what our struggles are or what's lacking or where it's lacking, that it's going to help our kids in the long run.*

### Privacy of Content

The private nature of the group and restricting content to members were considered facilitators of activity within the group:

*I think that it being, like, a private, like New Brunswick group, um, makes it feel more comfortable.*

However, a lack of clarity in exactly what content is visible to nonmembers was identified as a barrier to participation by a participant:

*Overall, uh, we haven't really used it a lot. That's more because, uh, there's not the comfort level there, knowing who's in it and who's in charge of it, and who can be looking in.*

### Group Duration: Time Since Implementation

There was a sense that the community within the Facebook group was growing. Many participants described referring prospective members to the group as a means to continue building the web-based community. The participants reported feeling that a larger community would lead to increases in group activity, such as more posts and interactions:

*Even in like there's a mom chat group for New Brunswick that's quite, like, people are constantly posting in it. I think once this group grows like that it will have the same effect, I think, that people will look to that first and they'll get the support from there.*

### Theme 5: Moderators as Contributing Members

Many participants described the influence of the group administrators and moderators. Most participants felt that the moderators were the primary contributors to the group. When asked about the contributions of the moderators, the participants reported seeing weekly discussion posts intended to maintain activity within the group and interactions with members' posts. These participants viewed the moderators as active members of the group who interacted with and facilitated discussions:

*I think they do a great job because I think see them comment on almost every comment. And, uh, I see that they, they put posts on there, you know trying to facilitate discussion or whatever, which I think is nice too.*

## Discussion

### Principal Findings

This study aimed to investigate how caregivers of children and youth with CCN used a Facebook-based P2P support group and explore factors related to its ongoing activity levels. The group attracted a total of 108 caregivers of children and youth with CCN over a period of 6 months upon implementation. Although members only made 40% (37/93) of the posts in the group during the observation period, members in the group were observed to engage with posts a total of 537 times, including 318 comments. These findings are consistent with previous research illustrating that activity within Facebook groups tends to consist of 10 times more interaction with posts (eg, likes and comments) than posts themselves [41].

The survey respondents were mostly women (29/39, 74%); although 26% (10/39) of the participants did not disclose their gender, none reported being men. This is consistent with previous research suggesting that White, female, and college-educated users are more likely to use social media for health-related support than men [43].

Nearly two-thirds of the survey and interview participants (23/39, 59%) reported belonging to multiple P2P support groups related to their role as caregivers of a child or youth with CCN. Many of these participants described using each of those groups for a specific purpose. For example, groups centered on a specific condition or set of symptoms often involved members from all over the world. These groups were considered helpful for informational support related to medical concerns and specific emotional support because of the often rare nature of a condition.

The Facebook group, developed for the purpose of this research, was viewed as an important source of informational support, specifically navigational support for local programs, services, resources, and activities. Most of the survey participants in this study (29/39, 74%) reported using Facebook daily. Previous studies posit that the more intensely an individual uses social media, the more perceived support they receive [44]. The participants in this study reported using the group for these informational support purposes and gaining insight from individuals whom they considered knowledgeable experts. It appeared that the interview participants valued the knowledge available from their peers, which they specifically attributed to the experiential knowledge of their peers [45]. The information obtained from peers within the group included their experience with various services, resources, programs, and activities as well as their opinions and suggestions, which were highly trusted by the participants; this trust in knowledge obtained from peers in similar situations has been previously observed [46].

Content analyses of the posts published to the group showed that inquiry-based posts (ie, those centered on a question) were the most common among group members, followed by informational and emotional posts. Most of the posts published to the group originated from group moderators (56/93, 60%) as a means to promote activity within the group and prevent it from becoming stagnant. However, over the course of the research period, the total number of posts published to the group was observed to increase each month. Despite the short time frame between the implementation and evaluation of the Facebook group, many interview participants also felt that the group was growing in membership and activity levels. Initial recruitment efforts to the group resulted in a corresponding surge in membership, yet membership continued to grow despite the conclusion of the recruitment period. This can be explained by an increase in word-of-mouth referrals made by participants who had joined the group and then shared it with other relevant groups on the Facebook platform.

Emotional posts received the most comments, likes, and loves from group members, specifically receiving the most comments. These posts also received the greatest number of likes and loves, suggesting that group members respond the most to posts based on an emotional support need. As expected, inquiry posts



received the next highest number of comments as these posts are generally centered on a question requiring insight from other members and usually develop into a discussion in the comment section.

The use of the Facebook group by caregivers for social support can be explained by the strength of weak ties theory [47]. This theory suggests that social support is exchanged within a social network through strong ties (eg, family and close friends) and weak ties (eg, acquaintances) but that weak ties may be particularly important for eliciting benefits. Where web-based communities with strong ties often result in information saturation, those with weak ties tend to be more heterogeneous and can result in greater access to diverse and stronger information support [48]. Moreover, weak ties can encourage individuals to disclose more personal or sensitive information because of the perception of less judgment [49,50]. Finally, weak ties can be perceived as helpful to individuals seeking informational support to deal with a health issue [51].

The administrators and moderators may have indirectly influenced how caregivers of children and youth with CCN used the group. Previous content analyses of P2P support groups have shown that members seek more emotional support from informal support groups, whereas they tend to seek more informational support from formal support groups led by professionals [52]. One of the explanations for this is that messages posted by trained health care workers are distinctly different from those posted by group members; specifically, messages from trained peer counselors tend to be more structured and detailed than those from peer members [53]. Given the research emphasis and professional experience of one of the moderators, caregivers in this investigation may have viewed the group as a formal support group. However, in a previous investigation of parents of children with special needs, Ammari et al [22] found that parents used geography-specific P2P support groups primarily for informational support needs over emotional support needs because of the collective knowledge of locally available services, resources, and programs among members. Therefore, although it is possible that the moderators influenced the type of support that members sought in this study, previous research supports the notion that geography-specific groups result in the exchange of more informational support.

Many participants expressed a desire to support other caregivers of children and youth with CCN by sharing their own knowledge and experiences. A participant described this lived experience as a collection of knowledge, their “backpack,” which could be shared with those who might be lacking information. Some of these participants expressed feeling compelled to help others, specifically regarding informational and navigational support. Previous investigations suggest that this reciprocity and sharing of knowledge and experiences can help foster friendships and promote positive health behaviors in persons who engage in health-related, web-based P2P support [54]. In this study, sharing one’s experiences was considered an important catalyst for social support.

The interview participants described varying levels of engagement with the Facebook group. Although previous

literature suggests that superusers (ie, users that consistently and actively engage with content on social media) are the foundation of activity within P2P support groups [55,56], most participants in this study described themselves as either moderate contributors or lurkers. This was supported by the survey findings, which revealed that most participants had never published a post to the group but had interacted with at least one to two posts within the group. Although many of the interview participants did not actively interact with the content in the group, many described using the group as a source of informational support. Specifically, the participants were often able to find answers to their questions through previous posts or comments, sometimes even using the search bar in the group to see if a topic had been discussed previously. These findings are contrary to previous research suggesting that lurkers do not gain as much from participation in groups as superusers [57] but support the notion that lurkers can benefit from passive interaction with support groups [58].

In this study, the *success* of the Facebook support group was determined by regular use of the group through user-level activity (eg, posts and associated interactions). An overview of the factors related to group activity as identified by the participants is shown in Table 2. Specifically, factors identified by the participants that contributed to their use of the group included the closed privacy designation of the group (ie, content was restricted to members) and the focus on NB caregivers. The geographic specificity of the group appeared to counteract the diversity found between the conditions experienced by caregivers within the group, which was identified as a potential barrier to activity and interactions. Most participants in the survey and interviews reported feeling comfortable posting within the group if they felt the need; those who reported feeling uncomfortable cited concerns related to the research focus. Importantly, only 5% (2/39) of the participants in the study described this as a concern.

The private designation of the Facebook group was an important consideration for attempting to protect the confidentiality of caregivers. Maintaining confidentiality was particularly important in this Facebook group, which consisted of members from a small geographic community. Concerns related to privacy have been identified by patients and caregivers who participate in web-based support [16,17]; however, the benefits associated with sharing such information are considered greater than the potential risks [15]. Privacy concerns related to the use of P2P support forums on social media do not appear to be consistent across all users and may depend on contextual factors [59].

The participants in this study perceived the group to be successful as a place for gathering caregivers of children and youth with CCN and providing a space for the exchange of support. Developing a group that can maintain active interactions among members over a period requires creating a space that is trusted by its members [41,60]. Variables identified in the literature to facilitate trust in Facebook groups include smaller and more homogeneous membership, long group tenure, identity-based groups, and age and gender homogeneity [41]. International diversity, for example, has been negatively associated with trust in Facebook groups [60]. Smaller group sizes with exclusive membership are known facilitators of trust



among web-based communities that increase opportunities for new connections within the group [41]. Specifically, groups with >150 members are considered less trustworthy than smaller

groups. Apart from the short group tenure, each of these factors was observed in this study of 108 caregivers, suggesting the potential for longevity.

**Table 2.** Identified factors that affected activity within the Facebook group.

|   | Barriers   | Facilitators   |
|---|--|--|
| Targeted conditions or diagnoses          | Group members identified as caregivers of children or youth with a diverse range of conditions or diagnoses, which limited the ability of some members to find disease-specific support. | Participants indicated common struggles and difficulties regardless of condition or diagnosis though all being caregivers of children or youth with CCN <sup>a</sup> . |
| Research emphasis                         | The emphasis on research was perceived as a possible deterrent to joining by some members.   | The presence of researchers in the group was perceived by some members as a unique factor that could be used for advocacy.   |
| Privacy of content                        | The “closed” group (ie, group content and membership list was not visible to nonmembers).  | Use of content within the group for research prevented some members from posting or interacting with posts.  |
| Group duration: time since implementation | Some members attributed the lack of group activity to the short period since the group’s launch.   | Group activity may be associated with group maturity.  |

<sup>a</sup>CCN: complex care needs.

The findings indicate that moderators were viewed by group members to be active contributors to the group, which then encouraged members to use the group; this supports earlier findings about the importance of moderators for network engagement [61]. Although moderators were perceived as the primary contributors to the group, this interaction by moderators appeared to facilitate group activity. Support groups are moderated by professionals (eg, care providers) [62,63] or peers (eg, other patients or users) [64,65]. This Facebook group was moderated by a patient navigator (care professional) and a member of the NaviCare/SoinsNavi PFAC who has experience being a caregiver of a youth with CCN. A limitation of moderators identified in the literature rests in their ability to answer certain questions from members [66]. Although moderators aimed to respond to posts by group members to ensure posts were never ignored, other group members often provided their unique insight into questions raised. Therefore, although the Facebook group was not solely a P2P support group, as the moderators did not represent the target population, responses from both the moderators and other caregivers integrated to form a unique perspective on issues raised by group members.

The use of Facebook groups to connect patients and caregivers is not without important ethical concerns. Salient among these are concerns regarding the potential to spread misinformation [17] and members’ ability to appraise information [63]. This issue may be less evident in groups that primarily exchange emotional support as these groups appear to exchange fewer posts related to medical information (ie, related to diagnoses, treatments, and medications) [67]. Moreover, research analyzing content in casual information-seeking environments such as web-based P2P groups has shown that the content self-corrects over time as individuals visiting the group validate or correct the posted information [68]. Moderators have been observed to reduce the spread of misinformation [68,69] by enforcing group rules and ensuring that posts remain on topic [70].

## Limitations

The limitations of this research include a time constraint between the implementation and evaluation of the Facebook group and small interview and survey sample sizes. The short recruitment and evaluation periods, for example, may have been a reason for our low overall sample size. This research may have oversampled caregivers who were more engaged in the needs of their children as the survey and interview participants came from a sample of the population who chose to become members of the Facebook group. Moreover, there was overlap between the participants who completed the web-based survey and interviews; specifically, 86% (12/14) of the interview participants also completed the web-based survey. However, the survey and interview questions were different; specifically, the interviews aimed to provide greater context for questions within the survey. The findings from this survey may have also been affected by the modest survey response rate (39/108, 36.1%). Finally, the questions used in the survey and interviews were developed for the purpose of this research and were not validated through a systematic process.

Demographic information was not obtained about members of the Facebook group because of privacy restrictions imposed by the Facebook platform. However, as the focus of the study was on the use of the support group by caregivers of children and youth with CCN, this information was not central to the goals of the study. The survey data suggested that the participants were primarily women (29/39, 74%); therefore, the male perspective is missing from this study. Although we attempted to cast a wide net across the province to recruit participants to the group, it is possible that we may have missed segments of the population, which may affect the generalizability of our findings. For example, the group may have remained unknown or inaccessible to those in rural or remote geographical locations or who are more comfortable speaking in languages other than English and French. Another potential concern is that the research focus of the Facebook group may have affected the way that prospective members approached it and the way it was used by group members. Specifically, concerns regarding privacy may have prevented members from posting content.

Moreover, one of the moderators was a patient navigator who did not identify as a caregiver of a child or youth with CCN. It is possible that the presence of a health professional within the group affected the dynamics of the P2P interactions.

Data were not obtained at the user level regarding the number of posts or interactions made by each group member. This was partly owing to the short time span (6 months) of the study period, during which the group experienced a surge in membership. Although prospective members were required to undergo a screening to ensure that the population was restricted to caregivers of children and youth with CCN in NB, this information was self-reported by users and could not be verified by group administrators. As a result, it was not possible to confirm that every member of the group was a caregiver of a child or youth with CCN and lived in the province of NB.

Although the group was developed before the COVID-19 pandemic, the Facebook-based P2P support group was implemented and examined during periods of stay-at-home orders and provincial restrictions. Caregivers of children and youth with CCN were particularly affected by social distancing measures, which led to increased caregiver stress and loneliness [71]. Moreover, disruptions in communication with health care providers and the risk of COVID-19 exposure led to increased stress among caregivers [72]. The unique circumstances presented by the pandemic may affect the generalizability of the findings of this study. For example, it is unclear whether caregivers would have used the group to the same extent outside of the parameters of such extreme circumstances. Many of the interview participants expressed concern about interacting with individuals from outside of their household because of their child or children's immunocompromised conditions; it is possible that these participants may have leaned on support from groups such as the one studied to fill in missing support. It is also possible that the COVID-19 pandemic will change the future use of P2P support groups for health-related communication on social media. The Facebook group, developed for the purpose of this research, continues to operate as a source of support for caregivers of children and youth with CCN in NB. Moderation of the group has been taken over by existing membership, and the group continues to welcome new members.

### Future Work

The Facebook group was identified as an important source of information as well as social interactions by caregivers in this study. Given the close proximity in geographical location between the caregivers in the Facebook group intervention, it is possible that some members of the Facebook group may express a desire to meet face to face at the conclusion of the COVID-19 social distancing measures. Although the caregivers in this study served as a source of information for members of the Facebook group, future research might examine the differences between web-based and offline social support when individuals initially connect on the web. For example, offline social support may result in additional instrumental or tangible support to complement the action-facilitating support exchanged on the web [73]. Moreover, future work might examine how web-based and offline social support networks may influence one another.

Despite the initial uptake of the Facebook group by caregivers of children and youth with CCN, few members reported regularly posting and engaging with content in the group. Previous work on the participation of web-based community members has noted a 1-10-90 pattern wherein 1% of members create 90% of the posts and 10% of members interact with those posts [57]. Although there appeared to be greater participation with content by caregivers in this study, the sample size was small. More research is needed on the presence of lurkers in web-based P2P support groups to better understand their experiences and possible barriers to participation.

One of the eligibility requirements for joining the P2P support group in this study was that members reside in NB, Canada. Through our observation of the group, we concluded that this factor may have created an environment for the exchange of primarily informational support, which is consistent with previous findings [22]. Freedom from geographic constraints is a benefit of using web-based P2P support compared with in-person support groups; however, the degree to which groups are limited by geography appears to affect how a group may be used for support. Future work is needed to determine how the self-reported geographical location of participants affects participation in web-based groups, particularly in comparison with condition-specific groups free of geographic constraints.

Considerations of patient- and caregiver-level characteristics and how they may influence the type of contributions made to groups is also needed. For example, individuals facing a new diagnosis versus those with more experience may use web-based support groups differently [70]. This study found that some caregivers intended to use the group as they faced transitions (eg, school or respite care). Future research might consider examining the experience of caregivers at various points in their care journeys; moreover, these differences in contributions may point to distinct needs between patient and caregiver populations. Future work may also consider determining the role that health professionals can play in Facebook-based groups to promote access to information and resources or programs. For example, health professionals might be engaged in addressing concerns regarding the potential disclosure of sensitive or dangerous information related to the care of vulnerable children or youth or the caregivers themselves.

Finally, the degree to which Facebook groups can be customized to the specific needs of a target population requires further investigation. This study involved a Facebook group created by a research team in response to an identified gap [32]; further examination of how such groups potentially differ from those created by caregivers or patients themselves is needed. This future work might consider engaging children or youth in a patient-oriented approach to determine how web-based support groups might further address their care needs.

### Conclusions

Patients and caregivers are increasingly engaging in web-based P2P communication to seek and provide support. Investigations into the use of these web-based groups have demonstrated the importance of these communities in meeting the support needs of diverse populations, such as caregivers of children and youth with CCN. P2P support through social media presents a low-cost

and accessible avenue for caregivers of children and youth with CCN to obtain needed and timely support. Determining the potential role that health professionals can play in these communities may improve information sharing and the well-being of families of children and youth with CCN.

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## Conflicts of Interest

None declared.

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## Abbreviations

**CCN:** complex care needs

**NB:** New Brunswick

**P2P:** peer-to-peer

**PFAC:** Patient and Family Advisory Council

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Original Paper

# Tele-Active Rehabilitation for Youth With Concussion: Evidence-Based and Theory-Informed Intervention Development

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## Abstract

**Background:** Active rehabilitation involving subsymptom threshold exercise combined with education and support promotes recovery in youth with concussion but is typically delivered in person, which may limit accessibility for families because of a lack of services in their communities or logistical challenges to attending in-person sessions.

**Objective:** This paper describes the evidence-based and theory-informed development of the Tele-Active Rehabilitation (Tele-AR) intervention for pediatric concussion, which was specifically designed for remote service delivery.

**Methods:** The intervention was designed by clinician-researchers with experience in pediatric concussion rehabilitation following the Medical Research Council guidance for developing complex interventions. Development involved a critical review of the literature to identify existing evidence, the expansion of the theoretical basis for active rehabilitation, and the modeling of the intervention process and outcomes.

**Results:** Tele-AR is a 6-week home exercise and education and support program facilitated through weekly videoconferencing appointments with a clinician. Exercise consists of low- to moderate-intensity subsymptom threshold aerobic activity and coordination drills that are individualized to participant needs and interests (prescribed for 3 days per week). Education includes the evidence-supported *Concussion & You* self-management program, which covers topics related to energy management, nutrition, hydration, sleep hygiene, and return to activity. Elements of self-determination theory are incorporated to support motivation and engagement. We present a logic model describing predicted intervention effects using a biopsychosocial conceptualization of outcomes after concussion.

**Conclusions:** The Tele-AR intervention may help to increase access to care that improves recovery and promotes a timely return to activity in youth with concussion. Future research is needed to evaluate the feasibility and efficacy of this approach.

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## KEYWORDS

concussion; pediatrics; active rehabilitation; telehealth; exercise; mobile phone

## Introduction

### Overview

Concussion is a common injury among children and adolescents that may result in physical, cognitive, emotional, or sleep-related symptoms [1-3]. Although many youth with concussion achieve

symptom resolution within 2 to 4 weeks after injury, approximately 30% continue to experience persistent symptoms beyond 4 weeks [3]. Youth experiencing persistent concussion symptoms report lower quality of life [4] and higher incidence of mental health disturbances [5] than noninjured peers.

## Occupational Performance and Participation in Youth With Concussion

Occupational performance, which refers to the ability to choose, organize, and satisfactorily perform meaningful occupations [6], is often impaired in youth with concussion [7]. Qualitative studies highlight that concussion symptoms limit performance in meaningful activities such as school, physical activity or sport, and social activities [8,9]. Youth with concussion report diverse occupational performance issues in the domains of self-care, productivity, and leisure that can be improved after rehabilitation, underscoring the utility of occupational performance as a measure of functional recovery [7]. Youth may also experience limitations in participation, defined as involvement in a life situation [10]. Although activities and participation generally improve within the first few months after concussion, a substantial portion (30%-60%) of youth continue to report lower participation than their peers at 6 months after injury [10]. Continued limitations in activities and participation may lead to physical deconditioning or threats to psychological well-being, including anxiety, depression, and social isolation [11,12].

Currently, recovery from concussion among children and adolescents is being reconceptualized to emphasize resumption of everyday activities and general well-being, rather than solely the resolution of postconcussion symptoms [13]. Evaluating occupational performance can help to identify limitations and inform active rehabilitation strategies to support youth in gradual resumption of meaningful activities, thus decreasing the impact of the injury and reducing risk for persistent sequelae [14,15].

### Active Rehabilitation for Youth With Concussion

Growing evidence supports an active approach to concussion rehabilitation involving guided physical activity. Several studies demonstrate the efficacy of subsymptom threshold aerobic exercise for reducing postconcussion symptoms [16-24]. Some active rehabilitation programs for youth have also included other components such as sport-specific coordination drills [25-31], balance training [32], visualization and relaxation [25-31], and education and support [25-31]. Results from these studies show that active rehabilitation reduces postconcussion symptoms and improves recovery [25-32].

The rationale for an active approach to concussion rehabilitation has been rooted in the benefits of physical exercise to promote biological recovery (ie, improve cerebrovascular autoregulation and increase neuroplasticity) and psychological well-being (ie, increase self-efficacy and improve mood) [28,33-35]. To date, outcome measurement has predominantly focused on changes in postconcussion symptoms [36]. However, evidence indicates that although concussion symptoms initially arise because of physiological changes, including metabolic and cerebral autoregulatory dysfunction, the strength of the relationship between the neurobiology of the injury and ongoing symptom experience diminishes over time, with noninjury factors playing an important role in the persistence of symptoms [37]. Recovery from concussion is therefore best understood through a biopsychosocial model in which psychological and social factors, including activity restriction, emotional reaction, and coping styles, interact with biological factors to maintain

symptoms and functional limitation after concussion [13,38-40]. Accordingly, an active rehabilitation approach should aim to restore performance in daily activities in addition to reducing postconcussion symptoms.

The theoretical model of active rehabilitation described by Gagnon et al [28] endorses a biopsychosocial perspective by emphasizing the physiological, psychological, and social benefits of controlled exercise in combination with education and motivation. However, although the biopsychosocial model helps to identify targets for intervention, it does not address how to support motivation, which is an important determinant of outcomes in pediatric rehabilitation [41] and is often reduced after brain injury [42]. Motivation is particularly important during active rehabilitation because the intervention typically involves a home program that youth complete independently. Extending the theoretical rationale for active rehabilitation could help to guide how to promote motivation and further address the impact of such interventions on performance of daily activities and general well-being.

### Barriers to Accessing Active Rehabilitation

To date, active rehabilitation has typically been conducted through in-person sessions at a specialty clinic or research facility [27,28,30,31]. However, access to specialty health care is often limited for youth in Canada because of a lack of specialty services in their geographic region, as well as financial and logistical barriers to parental accompaniment [43,44]. Telerehabilitation has emerged as an effective method of service delivery that may address challenges in access. In a systematic review, clinical outcomes from telerehabilitation were found to be similar to, or better than, those from traditional in-person interventions for a variety of conditions [45]. Measures of clinical process, including attendance, compliance, and satisfaction, were also generally high [45]. Among youth, reviews highlight telerehabilitation as an appropriate method of service delivery [46,47] that may be especially effective when targeting behavioral function using a coaching approach and exercise program [46]. The role of telemedicine in concussion care is currently expanding [48,49] but has yet to be explored in the delivery of an active rehabilitation intervention.

This paper describes the evidence-based development of, and theoretical rationale for, the Tele-Active Rehabilitation (Tele-AR) intervention for youth with concussion, which was specifically designed to promote return to activity in a remote service delivery format. A detailed overview of the intervention is also provided.

## Methods

### Ethical Approval

This study was approved by the University of Toronto Health Sciences Research Ethics Board (REB reference number 00039179). Participants provided informed written consent to participate in the study.

### Intervention Development Process

The Tele-AR intervention was designed by a team of clinician-researchers (kinesiologists and occupational therapists)

with experience in pediatric concussion rehabilitation, based on clinical experience and a critical review of published literature. The Medical Research Council (MRC) framework for developing and evaluating complex interventions [50,51] guided the development process.

According to the MRC framework, intervention development is an iterative process involving integration of current evidence and appropriate theory, followed by a phased testing approach involving a series of pilot studies before a definitive evaluation [50]. The development stage involves the following three key processes: (1) identifying the existing evidence base, (2) identifying or developing appropriate theory, and (3) modeling process and outcomes.

### Key Tasks

We drew on guidance from Campbell et al [52] and Faes et al [53] regarding key tasks for each of the MRC development

processes. According to Campbell et al [52], existing evidence should be used to develop an understanding of the problem and target context to identify opportunities for intervention. Key tasks include defining and quantifying the target population most likely to benefit, defining the health outcome and appropriate measures, understanding pathways that cause and sustain the problem, identifying similar interventions, and predicting barriers or design challenges [53]. Integrating appropriate theory involves specifying theory-based determinants of change and describing how the intervention will affect them [53]. Finally, the development of a conceptual or logic model is recommended to define intervention components and clarify anticipated mechanisms linking components to desired targets for change [52]. [Textbox 1](#) shows the application of the MRC framework and key tasks to development of the Tele-AR intervention.

**Textbox 1.** Application of key tasks from the Medical Research Council framework to the development of the Tele-Active Rehabilitation intervention.

#### Identifying existing evidence

- Define and quantify target population
  - Review of concussion epidemiology among youth
  - Project team consultation to determine target population
- Define health outcome and outcome measures
  - Review of current consensus definition of recovery from concussion
  - Identification of appropriate measurement tools
- Understand factors that cause and sustain the problem
  - Review of factors that influence concussion recovery in youth
  - Identification of existing biopsychosocial models of concussion
- Identify similar interventions
  - Critical review of literature pertaining to active rehabilitation interventions for youth with concussion
  - Review of best practice recommendations for telerehabilitation and telehealth self-management interventions
- Define target context
  - Review of guidelines for telemedicine in concussion management

#### Identifying appropriate theory

- Review of existing theoretical rationales for active rehabilitation
- Review of health behavior change theories
- Integration of health behavior change theory in the intervention

#### Modeling process and outcomes

- Project team consultation to design intervention components
- Development of logic model to describe anticipated effects of intervention components

## Results

### Developing the Intervention

Results from the development stage are described in the following sections, organized according to the MRC headings and key tasks identified in the *Methods* section.

### Identifying Existing Evidence

#### *Define and Quantify Target Population*

The Tele-AR intervention targets adolescents (aged 13-17 years) who continue to experience symptoms at least 2 weeks after concussion. All mechanisms of injury are considered, including sport, falls, and motor vehicle accidents.

In recent decades, health care usage for pediatric concussion has increased substantially in Canada [1] and the United States [54]. In Ontario, this increase has been most pronounced among adolescents [1], for whom the average annual incidence of physician-diagnosed concussion was approximately 1500 per 100,000 from 2008 to 2016 [55]. Adolescents are also known to be at high risk for prolonged recovery [56]. According to a Canadian multicenter prospective study, a substantial subset of adolescents, approximately 30%, continue to experience symptoms beyond 1 month after concussion [3], which may lead to mood disturbances [5], reduced quality of life [4], and impaired activity performance [7]. Results from the same multicenter study also indicate that symptom improvement occurs primarily within the first 2 weeks of injury and levels off 2 to 4 weeks after injury [57]. Exercise-based active rehabilitation programs initiated in the subacute phase of recovery (1-2 weeks after injury) are feasible and may reduce the risk of persistent symptoms [19,20,24,26]. The Tele-AR intervention therefore targets adolescents continuing to experience symptoms beyond 2 weeks after concussion who are at risk for developing secondary consequences related to mood, activity performance, and quality of life.

#### *Define Health Outcome and Outcome Measures*

Primary health outcomes for the Tele-AR intervention include postconcussion symptoms and perceived occupational performance, a measure of performance in daily activities.

The most recent (2016) international consensus statement on sports-related concussion defines recovery as the resolution of concussion symptoms and return to normal activities, including school, work, and sport [2]. Self-reported concussion symptoms remain the most common measure of recovery from concussion [58] and are measured in adolescents using an age-appropriate symptom scale such as the Postconcussion Symptom Inventory [59]. However, there is growing recognition that symptom reports do not always accurately reflect recovery [13]. Concussion-like symptoms (eg, fatigue, headache, and dizziness) are common in individuals without a history of concussion, and symptom reporting is influenced by a variety of noninjury factors such as personality, comorbid mood disorders, and familial factors [12]. Activity limitations are common among adolescents with concussion [7-9]; therefore, a measure of performance in daily activities (ie, occupational performance) is beneficial for evaluating recovery. The Canadian Occupational

Performance Measure has been identified as a useful tool for measuring functional recovery among youth participating in active rehabilitation [7]. Concurrent measurement of symptoms and occupational performance can provide a more complete assessment of recovery than symptom reduction alone.

### *Factors That Cause and Sustain the Problem*

Current evidence indicates that persistent symptoms and activity limitations after concussion are best understood through a biopsychosocial perspective [38,39,60]. A key tenet of the biopsychosocial model is that the interaction among biological, psychological, and social factors determines health outcomes and that these factors must therefore not be addressed in isolation [61].

Biological or physiological factors after concussion include autonomic nervous system and cerebral autoregulatory dysfunction [35], impaired balance and coordination [62], visual and vestibular dysfunction [63], sleep disturbances, and fatigue [64]. Exercise intolerance, which reflects autonomic and cerebrovascular dysfunction, is a prognosticator of recovery [65], as are visual and vestibular dysfunction [63].

There is growing recognition that psychological mechanisms related to cognitive, behavioral, and emotional reactions to concussion influence outcomes [39]. Negative illness perceptions, including beliefs about injury timelines, consequences, and level of control, are associated with poor outcomes [60,66]. Various cognitive biases may precipitate negative illness perceptions, including causal misattribution (ie, misattribution of common benign symptoms to concussion), catastrophizing (ie, misinterpretation of symptoms as dangerous), good-old-days bias (ie, tendency to overestimate preinjury health or function), and the nocebo effect (ie, concussion outcomes shaped by the expectations of illness or dysfunction after the injury) [39]. Negative illness perceptions often lead to maladaptive coping behaviors such as fear avoidance (ie, fear of provoking symptoms leads to avoidance of activities), endurance (ie, pushing through symptoms), or all-or-nothing behavior (ie, alternating between periods of extremely low and extremely high levels of activity) [60,67]. Emotional responses such as stress, anxiety, and depression can result from, or reinforce, negative perceptions and behaviors and have been shown to influence outcomes [68]. In youth, self-efficacy is also reduced after concussion [69], and lower levels of self-efficacy predict greater symptom burden [70]. Cognitive, behavioral, and emotional factors interact to form vicious cycles that maintain the experience of symptoms and functional limitation.

The social influences of concussion are poorly understood. Adolescents with concussion report limitations in school function and social activities [7-9]. Qualitative studies show that concussion has adverse effects on the interpersonal relationships of youth and that the influence of relationships on recovery can be positive or negative [8,71]. In the study by Kita et al [72], female adolescents with concussion identified their friends, parents, clinicians, and peers with personal histories of concussion as key providers of social support that mitigates various challenges in their recovery. Among collegiate athletes,



greater satisfaction with social support has been associated with lower postconcussion anxiety [73].

Access to appropriate clinical care may influence how these biological, psychological, and social factors are experienced by the individual and, in turn, their effects on recovery. A systematic review found several studies showing that earlier initiation of clinical care after concussion leads to quicker recovery [74]. Timely access to care allows for early initiation of supervised subsymptom threshold aerobic exercise [33,34]. Conversely, those without guidance may continue to rest until achieving spontaneous symptom resolution, which increases their risk for physical deconditioning and mood disturbances [11,12] or for engaging in levels of activity that may be harmful for recovery. Early education and reassurance from a health care provider can reduce unfavorable psychological responses to injury [75], whereas poor access to care may itself contribute to negative injury perceptions. Communication with a health care provider can also build the capacity of youth to seek social support by providing information about appropriate school accommodations, helping youth to communicate the nature of their injury and encouraging youth to engage those around them to support their recovery [72].

There are currently significant challenges to accessing timely appropriate care for concussion in Canada [49]. Studies have identified knowledge gaps regarding concussion management among primary care providers [76,77]. Access to specialized concussion care is also limited in Canada, especially among individuals in remote communities who may experience significant geographic or socioeconomic barriers and youth who are reliant on caregiver accompaniment. Studies from the United States reveal barriers to accessing pediatric concussion care among families in rural communities, including higher health care expenses [78] and indirect costs related to transportation and lost productivity [79]. Delayed access to care is problematic because it increases the risk of premature return to activity and potential reinjury or development of persistent symptoms and functional limitation.

### **Identifying Similar Interventions**

A critical review of the literature describing active rehabilitation approaches to concussion was performed in the fall of 2019. Key articles were located through search in Google Scholar and PubMed using keywords that included *active rehabilitation, exercise, physical activity, concussion, mild traumatic brain injury, youth, and adolescents*. Additional pertinent literature was identified through forward and backward searching of reference lists as well as literature previously known to the authors. Intervention characteristics among the studies included in the review are detailed in [Multimedia Appendix 1](#) [7,16-21,24-30,32,80] and briefly summarized in the following paragraphs.

Findings from the review indicated that active rehabilitation interventions typically last 6 weeks and involve a variety of components, including aerobic exercise [7,16,19,20,24-30,32,80-84], sport coordination drills [25-30,32,80,82,83], balance training [32], visualization or relaxation [25-30,80-83], and education and support [25-30,80-83]. The 6-week timeline was established by Gagnon

et al [29], who found that a mean intervention duration of 4.4 (SD 2.6) weeks was required to achieve symptom resolution. All the studies identified implemented individual interventions. Active rehabilitation has typically been evaluated through changes in postconcussion symptoms [16-18,24-30,32,82,84]. Improved mood [29,30,80], quality of life [17,30], and occupational performance [7] have also been reported.

Although key components are not fully understood, a study of multimodal active rehabilitation found that youth identified the education, aerobic exercise, and sport coordination drills as most helpful [81]. A combination of education regarding energy management and engagement in supervised physical activity is therefore essential to the approach [81]. Future iterations of active rehabilitation should consider a focus on self-management through education and supervised physical activity involving aerobic and coordination exercise.

Published active rehabilitation interventions typically involve a home exercise program performed several (3-7) days per week and weekly appointments with a clinician. Appointments have occasionally been conducted by telephone [17,31,32], which was reportedly appreciated by participants because the telephone appointments reduced travel requirements [17]. The identified studies required participants to attend in-person appointments for pre- and postintervention assessments, indicating an opportunity to explore interventions designed to be delivered entirely remotely and requiring no in-person appointments.

Systematic reviews of telerehabilitation [45-47] and remote self-management programs [85,86] were consulted to identify best practice recommendations regarding the remote service delivery model for the Tele-AR intervention. Consistent communication with a health care provider was identified as key to promoting retention and positive outcomes among remotely delivered self-management interventions [85]. Ongoing individualized education, lifestyle intervention, adherence support, and clinical review with feedback were also identified as important components [86].

The aforementioned literature provided the foundations for the design of the Tele-AR intervention. On the basis of this literature, it was determined that the intervention should be a 6-week program comprising aerobic exercise, coordination drills, and comprehensive individually tailored education and support to train self-management skills. Telehealth literature indicated that weekly appointments should involve a review of symptoms and activity performance with provider feedback, continued education regarding symptom management strategies, and support to promote motivation and adherence to the home program [85,86].

### **Defining Target Context**

Tele-AR could be an accessible intervention to reduce the burden of pediatric concussion, especially among those identified as high risk for prolonged recovery [3]. It complements ongoing telemedicine initiatives to improve access to pediatric concussion care in rural and remote Canadian communities [48,49].

Recommendations for the use of telemedicine in concussion management specify the need for initial in-person medical

assessment to confirm the diagnosis of concussion as well as regular medical follow-up [49,87]. Tele-AR is therefore designed to serve as an adjunct intervention for youth who have previously undergone in-person medical assessment and continue to receive medical follow-up, including appropriate referral for targeted treatments such as cervical or vestibular therapy. Although there is evidence that earlier initiation of supervised exercise (after 24-48 hours of initial rest) leads to quicker recovery [88], many without access to care continue to rest until symptom resolution, which may contribute to delayed recovery [12]. Remote delivery of active rehabilitation could increase access to care that enables earlier resumption of supervised physical activity and contributes to quicker recovery.

## Identifying and Applying Theory

### *Supporting Motivation During Active Rehabilitation*

We drew on self-determination theory (SDT) to expand the theoretical foundation for active rehabilitation to address motivation, a key determinant of engagement and outcomes in rehabilitation [41,89]. Motivation is a key facilitator of participation after childhood traumatic brain injury [90] but is often reduced among individuals with a brain injury [42]. Existing theoretical underpinnings of active rehabilitation recognize the importance of motivation [28] but do not address how to promote motivation.

SDT has been identified as a useful framework for conceptualizing motivation in pediatric rehabilitation [41]. SDT is a theory of human motivation that describes the influence of social and cultural factors on an individual's sense of volition (self-determination), performance, and well-being [91]. According to SDT, three psychological needs foster intrinsic motivation: competence (feeling mastery and success), autonomy (feeling of being able to choose one's own actions), and relatedness (feeling positive relationships with others) [91]. Systematic reviews demonstrate that health interventions designed using SDT can increase satisfaction of psychological needs, leading to improvements in physical and mental health outcomes [91,92]. Previous articles have highlighted the utility of SDT to identify factors that influence motivation during brain injury rehabilitation [42]. In adults, mild traumatic brain injury reduces fulfillment of psychological needs, suggesting that rehabilitation should address these variables [93].

The Tele-AR intervention is designed to support the 3 psychological needs outlined in SDT to promote motivation and engagement in the program and regular daily activities. Each element is briefly described in the following sections. [Table 1](#) provides examples of how the psychological needs are addressed in the Tele-AR intervention, using the SDT taxonomy from Teixeira et al [94].

**Table 1.** Self-determination theory (SDT) strategies in the Tele-Active Rehabilitation (Tele-AR) intervention.

| SDT strategy  | Application to Tele-AR intervention   |
|---|---|
| <b>Autonomy support</b>   |   |
| MBCT <sup>a</sup> 1: Elicit perspectives on condition or behavior | <ul style="list-style-type: none"> <li>Elicit perspectives of youth regarding their concussion and associated challenges</li> <li>Tailoring of education and support to address individual perspectives</li> </ul>  |
| MBCT 3: Use noncontrolling, informational language                | <ul style="list-style-type: none"> <li>Provide education using a nonjudgmental approach that emphasizes freedom of choice</li> </ul>  |
| MBCT 5: Providing meaningful rationale                            | <ul style="list-style-type: none"> <li>Provide rationale for active rehabilitation approach, including the role of exercise to support recovery, energy management techniques, and gradual return to activity</li> </ul>  |
| MBCT 6: Provide choice  | <ul style="list-style-type: none"> <li>Engage youth in coconstruction of the active rehabilitation program based on their individual needs and interests</li> <li>Empower youth to take responsibility for their own recovery through self-management skills and coping strategies</li> </ul>   |
| <b>Relatedness support</b>  |   |
| MBCT 8: Acknowledge and respect perspectives and feelings         | <ul style="list-style-type: none"> <li>Acknowledge perspectives of youth regarding the active rehabilitation approach and intervention components</li> </ul>  |
| MBCT 9: Encourage asking questions                                | <ul style="list-style-type: none"> <li>Encourage questions from participants during weekly appointments</li> </ul>  |
| MBCT 10: Show unconditional regard                                | <ul style="list-style-type: none"> <li>Express empathy and provide positive support regardless of exercise completion</li> </ul>  |
| MBCT 11: Demonstrate interest in the person                       | <ul style="list-style-type: none"> <li>Demonstrate interest in activity interests and experience of youth</li> <li>Integrate participants' needs and interests in home program</li> </ul>   |
| MBCT 12: Use empathic listening                                   | <ul style="list-style-type: none"> <li>Demonstrate active listening by maintaining eye contact and head nods</li> <li>Provide meaningful summaries of comments by youth and check understanding</li> </ul>  |
| MBCT 13: Provide opportunities for ongoing support                | <ul style="list-style-type: none"> <li>Provide telephone and email contact information for ongoing communication outside of regular appointments</li> </ul>   |
| MBCT 14: Prompt identification and seek available social support  | <ul style="list-style-type: none"> <li>Encourage social support seeking from parents, teachers, coaches, and friends</li> <li>Teach metaphors to communicate the experience of having a concussion, such as comparing energy levels to a cellphone battery</li> <li>Inclusion of friends in exercise program when possible</li> </ul>                                   |
| <b>Competence support</b>   |   |
| MBCT 15: Address obstacles to change                              | <ul style="list-style-type: none"> <li>Prompt identification of potential barriers and solutions</li> </ul>   |
| MBCT 17: Assist in setting optimal challenge                      | <ul style="list-style-type: none"> <li>Review return to sport and return to school protocols</li> <li>Discuss appropriate academic accommodations for return to school</li> <li>Support in setting goals for gradual increase in exercise and activity engagement</li> </ul>  |
| MBCT 18: Offer constructive, clear, and relevant feedback         | <ul style="list-style-type: none"> <li>Provide positive feedback and encouragement for successes with school, exercise, and other activities</li> <li>Discuss strategies used by other youth facing similar challenges</li> </ul>   |
| MBCT 19: Help develop a clear and concrete plan of action         | <ul style="list-style-type: none"> <li>Prompt participants to develop personal concussion toolbox recovery plan describing which strategies they intend to use</li> <li>Provide clear instructions for home exercise program</li> </ul>   |
| MBCT 20: Promote self-monitoring                                  | <ul style="list-style-type: none"> <li>Instruct to monitor perceived exertion and symptoms during exercise</li> <li>Prompt monitoring of activity duration to facilitate gradual progression</li> <li>Highlight progress toward exercise goals and activity resumption</li> <li>Draw attention to positive physiological and affective states after exercise</li> </ul> |
| MBCT 21: Explore ways of dealing with pressure                    | <ul style="list-style-type: none"> <li>Discuss relaxation and coping strategies such as diaphragmatic breathing, progressive muscle relaxation, and visualization</li> </ul>  |

<sup>a</sup>MBCT: motivation and behavior change technique (according to the self-determination theory taxonomy developed by Teixeira et al [94]).

**Competence**

The Tele-AR intervention aims to promote a sense of competence by helping adolescents set optimal challenges and increase self-efficacy. This involves gradually increasing experiences of success through participation in school, exercise, and other meaningful activities. An action plan is developed with each participant to identify how they will implement strategies to support recovery (eg, energy management and relaxation). Second, participants are taught to self-monitor exertion during activities to prevent significant symptom exacerbation. They are encouraged to monitor the time during which they engage in activities such as schoolwork and screen use to facilitate gradual progression. Third, the clinician provides feedback and encouragement during appointments using a strengths-based approach, whereby participants are prompted to discuss what has gone well and which strategies they used to support success. An opportunity is provided for participants to identify barriers they are encountering and explore potential solutions with the clinician. Finally, strategies are discussed for dealing with stressful situations that could undermine competence, such as relaxation techniques (eg, deep breathing, muscle relaxation, and visualization) and seeking help.

**Autonomy**

Autonomy is supported by providing meaningful rationales for active rehabilitation, integrating participant perspectives in program development, and providing choice. The rationale for the active rehabilitation approach is explained to participants at the beginning of the intervention. Education is provided using nonjudgmental language integrating participant perspectives and emphasizing freedom of choice (ie, which strategies to use and how to use them). Participants are engaged in coconstructing the home program based on their needs and interests, including choice about specific exercises. The Tele-AR intervention is designed to empower youth to take responsibility for their recovery through self-management and coping skills. In a previous study, parents reported that active rehabilitation helped

their children become more accountable for their recovery by teaching them to self-monitor their condition [81]. Remote service delivery may further enhance the accountability of youth by eliminating the need for parental accompaniment to appointments.

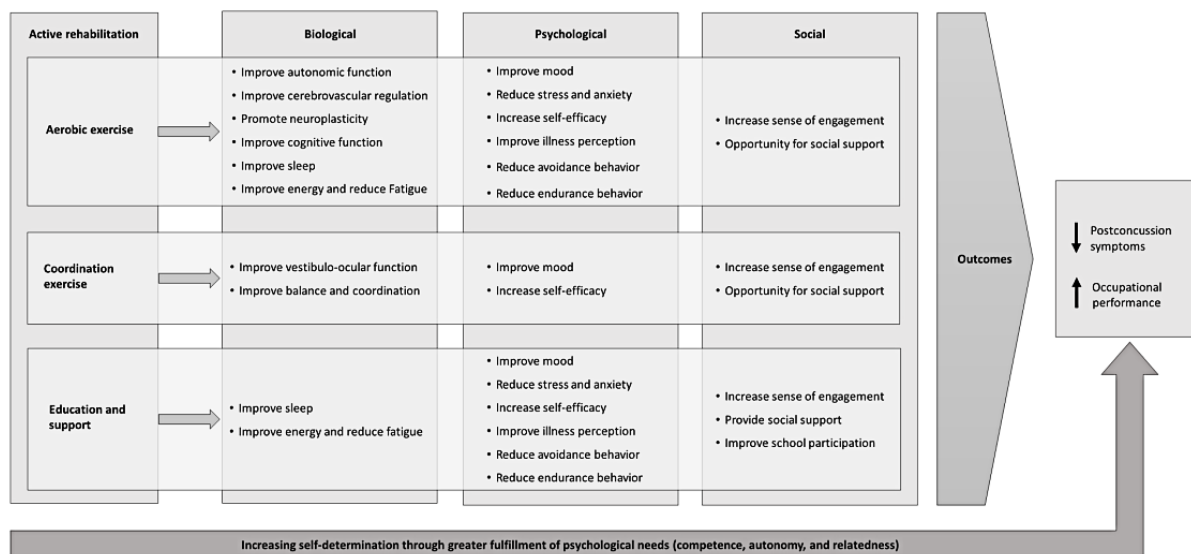
**Relatedness**

Relatedness (ie, feeling positive relationships with others) is fostered by the clinician through active listening, expressing empathy, and encouraging perspectives and questions from the participant. Studies from a variety of rehabilitation disciplines, including physiotherapy [95], occupational therapy [96], and psychology [97], demonstrate that therapeutic alliance can be developed effectively through videoconferencing. Weekly appointments foster a strong therapeutic relationship, which has been shown to influence adherence to home exercise programs [98]. In addition, the clinician encourages social support seeking from parents, teachers, coaches, and friends using strategies identified by Kita et al [72]. For example, because of the invisible nature of concussion, some adolescents report being called “fakers” by peers [9]. Participants may therefore be taught metaphors to help communicate their *invisible* injury, such as comparing energy levels to a cellphone battery [72]. Participants are also encouraged to involve friends in the exercise program where possible, such as having a friend join their walk or including a teammate in sport-specific coordination drills.

**Modeling Process and Outcomes**

Modeling aims to define intervention components, explain how they relate to each other, and describe the mechanism through which they influence desired intervention outcomes [51]. Figure 1 presents a logic model for the Tele-AR intervention. It describes the predicted effects of intervention components (ie, aerobic exercise, coordination drills, and education and support) based on the review by Gagnon et al [28] and published biopsychosocial models of concussion [38,39]. Descriptions of anticipated outcomes from each intervention component are provided in the following paragraphs.

**Figure 1.** Logic model for the Tele-Active Rehabilitation intervention.



Several reviews demonstrate the efficacy of aerobic exercise for reducing postconcussion symptoms [22,23]. Progressive

subsymptom threshold aerobic exercise improves autonomic function and cerebral blood flow regulation, which are impaired



after concussion [33-35]. Aerobic activity also facilitates neurological recovery by promoting neuroplasticity [99]. Cardiovascular fitness improves with aerobic training, which can reduce fatigue and improve energy levels [100]. The psychological benefits of aerobic activity include stress reduction, elevated mood, and increased self-efficacy [101]. Supervised exercise may also reduce avoidance and endurance behaviors, both associated with poor outcomes [67]. Graded and supervised subsymptom threshold aerobic exercise builds mastery experiences that challenge catastrophic assumptions about symptoms and activity, which may improve illness perception and reduce activity avoidance [17]. Teaching those who display endurance behavior to monitor exertion during exercise also supports pacing strategies that facilitate activity performance [15]. For individuals who are experiencing restrictions after concussion, exercise can provide a sense of engagement in meaningful activity and create opportunity for social connection [38,81].

According to Gagnon et al [28], the purpose of coordination exercises is to continue light exercise and reintroduce familiar activities in a successful context to improve mood and increase self-efficacy. Allowing choice in coordination exercises enables youth to participate in familiar meaningful activities. A previous study found that youth enjoy the coordination drills because they allow for gradual reintroduction of meaningful activities and help improve overall fitness [81]. These exercises may also target deficits in balance, coordination, and visual function that may occur after concussion [2]. Finally, sport-specific coordination training provides an opportunity for social connection because participants may complete the drills with a friend or teammate.

Education and support are essential components of concussion management consistently recommended among evidence-based guidelines [102]. Education about the nature of concussion and recovery timelines addresses important psychological variables that predict recovery, such as illness perception [66]. Energy management and sleep hygiene strategies may reduce fatigue and improve energy levels [81]. A cohort of youth who participated in active rehabilitation identified energy management as a key component, which parents believed improved their child's self-management [81]. Providing support and training in coping strategies may also reduce anxiety and emotional distress, which are common after concussion and predict poor outcomes [66]. Helping youth to identify appropriate accommodations and return-to-learn strategies can improve school participation and has been identified by families as a priority service need [103]. Families may also require

assistance modifying other activities to support a gradual return, such as playing an instrument or spending time with friends [7]. Ultimately, education and support may increase self-efficacy for activity performance after concussion, which has been associated with lower symptom severity in children and adolescents [70].

As described in the *Identifying and Applying Theory* section, the Tele-AR intervention is designed to foster satisfaction regarding competence, autonomy, and relatedness to strengthen motivation and self-determination. Fulfillment of these needs is believed to support participation in the program. It is also hypothesized that increased self-determination through active rehabilitation will directly contribute to symptom reduction and improved occupational performance.

## Tele-AR Intervention

### Intervention Overview

The Tele-AR intervention is a 6-week home program facilitated through weekly videoconferencing appointments with a rehabilitation clinician (kinesiologist, occupational therapist, or physical therapist). It consists of (1) aerobic exercise, (2) sport coordination drills, and (3) comprehensive concussion education and support. The following sections provide a detailed description of the intervention.

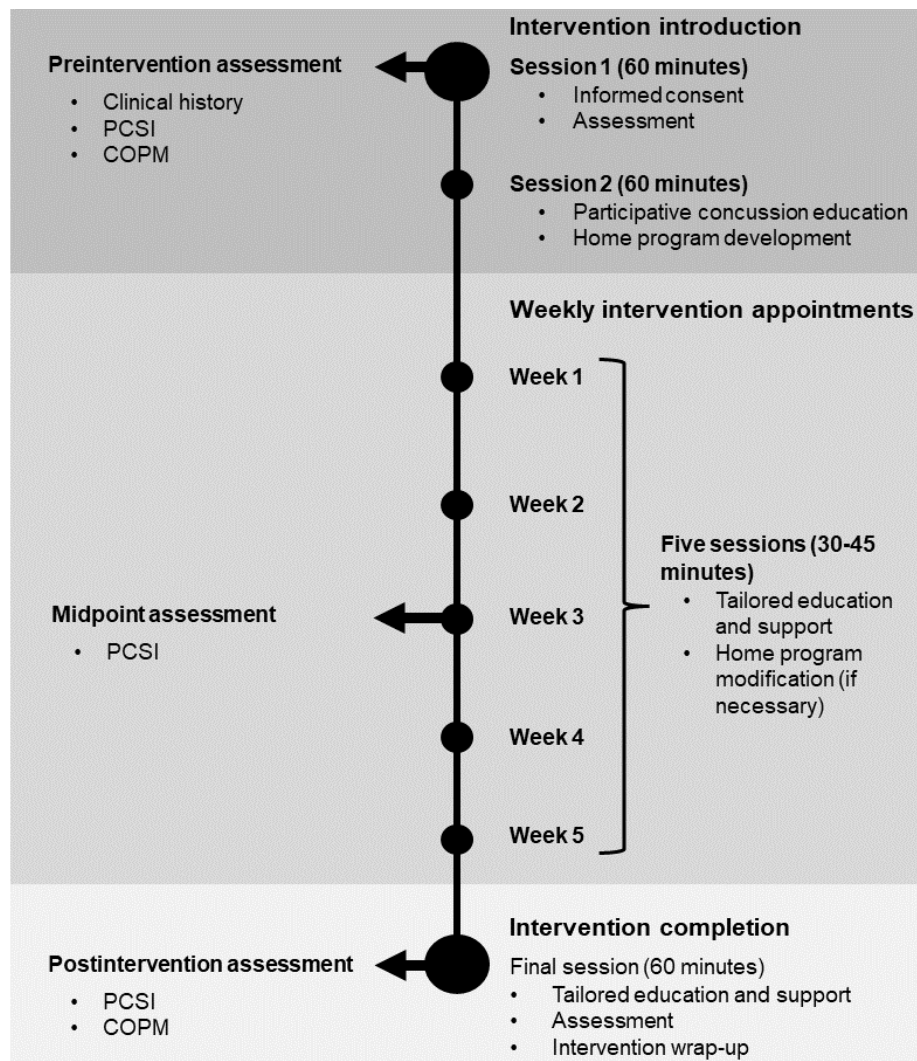
### Intervention Timeline

Figure 2 presents an overview of the timeline for the Tele-AR intervention. It begins with assessment and program introduction spread over 2 appointments, each lasting for 1 hour. The first appointment is dedicated to completing the informed consent procedures for the research study and preintervention assessments (see the *Assessment* section). The second appointment consists of a participative concussion education session and collaborative coconstruction of the home program, integrating the participant's individual needs and interests within the three components (aerobics, coordination drills, and education and support).

During weeks 1 to 6, participants are asked to perform the home exercise program 3 days per week and meet with the research clinician once per week. The purpose of weekly appointments is to provide continued education and support, modify the exercise program as appropriate, and strengthen motivation for engaging in the home program and other daily activities. The week 3 appointment includes symptom reassessment to evaluate interim changes. Significant deterioration at this point could indicate a need for in-person reassessment or referral to other providers [87]. Postintervention assessment occurs in week 6.



**Figure 2.** Overview of the Tele-Active Rehabilitation intervention. COPM: Canadian Occupational Performance Measure; PCSI: Postconcussion Symptom Inventory.



### Assessment

Preintervention assessment is conducted through a clinical interview with youth and their parents during the first appointment and is used to inform home program prescription. Assessment is repeated in week 6 to evaluate postintervention changes.

Assessment is intentionally targeted to ensure clinical application. It includes clinical history of injury details and factors known to affect recovery (eg, concussion history, medical and mental health history, and social history [3,58]), self-reported symptom rating (Postconcussion Symptom Inventory [59]), and self-perceived occupational performance, a measure of performance in daily activities (Canadian Occupational Performance Measure [104]). These measures reflect current understanding of concussion recovery and call for patient-reported outcome measures in concussion rehabilitation that focus on function and well-being [13,105].

### Intervention Components

#### Overview

The Tele-AR intervention comprises the following components: (1) aerobic exercise, (2) sport coordination drills, and (3)

comprehensive concussion education and support. Components are individually tailored to the specific needs of each participant. The exercise program is prescribed for 3 days per week to promote compliance by minimizing disruption to daily activities and to allow for comparison between days with and without exercise. Imhoff et al [32] showed that 3 sessions per week is sufficient to facilitate symptom reduction and was associated with high treatment adherence. A description of each component is provided in the following sections.

#### Aerobic Exercise

After initial assessment, each participant is prescribed aerobic exercise beginning with 10 minutes of low-intensity activity at level 4 (*Just feeling a strain*) on the Pictorial Children's Effort Rating Table (PCERT) [106]. Aerobic exercise may be completed on an exercise machine (treadmill, stationary bike, or elliptical trainer), indoor track, or outdoor space, depending on resources available. Participants are instructed to terminate exercise and rest upon symptom exacerbation (see *Safety* section); the time to symptom exacerbation becomes the new target duration. Exercise duration and intensity are progressed during weekly appointments if symptoms are well tolerated, following the standardized protocol presented in Table 2.

The initial aerobic prescription (10 minutes, PCERT level 4) is based on the time to symptom exacerbation reported by Gagnon et al [28] and Dobney et al [26] among youth initiating active rehabilitation. This prescription is consistent with other study protocols [31,107], as well as recommendations from literature reviews and clinical guidelines for exercise after concussion

[108,109]. Previous studies demonstrate the utility of perceived exertion as a method for prescribing exercise to youth with concussion [32,110]. The PCERT is a validated tool for assessing effort perception in youth [106] and has been used previously to facilitate the home program in active rehabilitation [26,29-31].

**Table 2.** Aerobic exercise progression<sup>a</sup> protocol.

| Week | Duration (minutes) | Intensity (PCERT <sup>b</sup> level) |
|------|--------------------|--------------------------------------|
| 1    | 10                 | 4                                    |
| 2    | 15                 | 4                                    |
| 3    | 15                 | 5                                    |
| 4    | 20                 | 5                                    |
| 5    | 20                 | 6                                    |
| 6    | 30                 | 6                                    |

<sup>a</sup>Progression was only recommended if significant symptom exacerbation did not occur in the previous week.

<sup>b</sup>PCERT: Pictorial Children's Effort Rating Table.

### Coordination Drills

Coordination drills are individualized based on participant interests and preintervention assessments. They may target balance, coordination, sport-specific skills, or general health exercises. For example, a basketball player may be given shooting drills first performed stationary and progressed to include dynamic movement. Coordination exercises are performed for up to 10 minutes at the same intensity as the aerobic component and are also terminated at the onset of any new or worsening symptoms. Participants are provided with written instructions outlining the details of their home exercise program.

### Education and Support

Individualized education and support regarding symptom management and return to activity are provided to participants throughout the intervention. The education curriculum is based on the evidence-supported *Concussion & You* self-management program [111], which covers topics that include energy management, relaxation, nutrition, hydration, sleep hygiene, and return to school and sport. Education material is delivered through a participative session and reviewed weekly with specific application to challenges experienced by participants in their daily life. Participants are also provided with the *Concussion & You* education handbook [112] to consolidate information.

### Technology

Appointments in the Tele-AR intervention are conducted through real-time videoconferencing using a secure platform that meets health privacy standards and allows for collaboration features such as screen sharing. The clinician uses a standard laptop or desktop computer, and participants may engage in the videoconferencing appointments using a computer, tablet, or smartphone.

Videoconferencing is believed to facilitate therapeutic rapport and is the most common method of communication in

telerehabilitation for children [46]. Mental health support for youth is acceptable and effective when delivered through videoconferencing [113], and a study in adolescents with concussion found similar ratings of therapeutic alliance and satisfaction between face-to-face and video telehealth visits [114]. Although some individuals with concussion experience screen sensitivity, current evidence does not indicate that strict avoidance of screens improves recovery [115], supporting instead an individualized approach to screen use within tolerable limits. Other screen-based interventions for concussion have been tolerated well, with no screen sensitivity issues reported [116,117]. Subsequent feasibility testing of this intervention will assess participant perceptions and experiences engaging in video-based appointments.

### Safety

Special attention must be paid to ensure safety in telehealth interventions. Safety considerations for the Tele-AR intervention are summarized in [Textbox 2](#).

Education regarding activity-related symptom exacerbation and the appropriate response is provided during program prescription. Evidence suggests that activity-related symptom exacerbations are transient and not detrimental to recovery [118]. Exercise-related symptom exacerbation generally resolves within 1 hour of rest [17,25,26]. Participants are instructed to terminate exercise upon significant symptom exacerbation, which is operationalized according to the definition from Leddy et al [119] as an increase of  $\geq 3$  points on a 10-point visual analog scale (VAS) [119]. Participants are familiarized with the Wong-Baker FACES pain rating VAS for symptoms [119]. The VAS is used by participants to rate their current overall symptom experience before exercise and monitor for any increase during the activity. Participants are instructed to contact the research team if any of the following occurs: (1) exercise-induced symptom exacerbation that does not subside within 24 hours of rest, (2) exercise-induced symptom exacerbation experienced during consecutive exercise sessions, and (3) the participant has concerns about exercise. In these scenarios, the research team

provides appropriate support, discusses potential exercise program modification, and considers referral to the primary care provider or other providers. The stopping rule described by

Dobney et al [26] is used, whereby the exercise program is suspended if symptom exacerbation occurs during 3 consecutive sessions despite exercise modification.

**Textbox 2.** Safety considerations for the Tele-Active Rehabilitation intervention.

#### Symptom exacerbation considerations

- Education regarding activity-related symptom exacerbation and appropriate response
- Participants instructed to terminate exercise and rest upon significant symptom exacerbation (an increase of  $\geq 3$  points on a 10-point visual analog scale)
- Suspension of exercise program pending medical clearance if symptom exacerbation occurs during 3 consecutive sessions despite exercise modification
- Participants instructed to contact the research team in the event of exercise-induced symptom exacerbation that does not subside within 24 hours of rest or exercise-induced symptom exacerbation during consecutive exercise sessions

#### Exercise safety considerations

- Preparticipation screening of contraindications to exercise
- Ensuring an open space for exercise free from tripping hazards
- Advising on use of support for balance (if needed)
- Considering parental supervision during exercise sessions

#### General telehealth considerations

- Confirming participant location, emergency contact information, and alternative methods of communication before appointment commencement
- Development of safety protocol in case of acute medical or mental health emergency

## Discussion

### Contributions

In this paper, we describe the development and theoretical foundation of the Tele-AR intervention for youth with concussion, specifically designed for remote service delivery. Development was guided by the MRC framework for complex interventions, involving the integration of existing evidence with appropriate theory [50]. Although growing evidence supports an active approach to concussion rehabilitation involving closely monitored progressive exercise combined with education and support, families often face several barriers that limit engagement in such care. The Tele-AR intervention was created to address these barriers. Intervention development is an iterative process, and results from an ongoing mixed methods feasibility study will inform further improvements.

The Tele-AR intervention builds on previous work advocating for a holistic approach to concussion care that emphasizes function and general well-being [13]. It is among the first interventions designed to improve activity and participation among youth with concussion [120]. Components are designed to concurrently address biological, psychological, and social aspects of concussion in a remote service delivery format. We emphasize education and support as essential to the intervention and expand the notion of active rehabilitation to facilitate motivation and performance in activities that are meaningful to the individual.

### Further Study

The logic model presented here requires further study. Evaluating changes in identified biopsychosocial constructs may improve clinical delivery of active rehabilitation. Continued efforts to reconceptualize recovery from concussion through a biopsychosocial lens with an emphasis on function and participation may also identify new targets for change in rehabilitation and inform a stronger theoretical framework [13]. The qualitative exploration of youth and parent perspectives regarding perceived needs from the Tele-AR intervention is addressed in the feasibility study, and it will help refine intervention components and delivery.

The development process involved extensive review of the literature to integrate current evidence. However, the literature review methodology was not systematic and thus may be subject to selection bias or missed publications. In addition, most of the literature was reviewed before the COVID-19 pandemic when telehealth use and scholarship rapidly increased. Given the breadth of active rehabilitation approaches described in the literature and rapid growth of research in this field, future work using a more intentional review methodology and original investigation is warranted to determine optimal intervention approaches. All studies identified in the review implemented individual interventions. Group interventions may foster a greater sense of relatedness and social support and should be explored in this population.

### Conclusions

Tele-AR complements ongoing telemedicine initiatives to improve access to concussion care [49] and may represent an accessible proactive intervention for those identified as high

risk for prolonged recovery. The literature reviewed here may also be helpful to clinicians and families of youth with concussion to inform remote care during the COVID-19 pandemic. Research to evaluate the feasibility of this

intervention is underway, and if warranted, more rigorous study should be undertaken to determine intervention effects and contribute to identifying best practices for telehealth concussion services that support youth in a timely return to activity.

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## Conflicts of Interest

NR is a holder of a Canada Research Chair (Tier 2) in Pediatric Concussion and reports receiving grants and research funding from the Canadian Institutes of Health Research, Ontario Neurotrauma Foundation, Public Health Agency of Canada, Parachute Canada, Special Olympics Canada, Greater Toronto Hockey League, Dr Tom Pashby Sport Safety Fund, Holland Bloorview Kids Rehabilitation Hospital, and Scotiabank. NR is an investigator in a multicenter study funded by the National Football League Scientific Advisory Board; NR does not receive any research funding or financial benefit. NR is a minority shareholder in 360 Concussion Care, an interdisciplinary concussion clinic.

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## Multimedia Appendix 1

Intervention characteristics among studies included in the review.

[\[PDF File \(Adobe PDF File\), 131 KB - pediatrics\\_v5i2e34822\\_app1.pdf\]](#)

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**Abbreviations**

**MRC:** Medical Research Council  
**PCERT:** Pictorial Children's Effort Rating Table  
**SDT:** self-determination theory  
**Tele-AR:** Tele-Active Rehabilitation  
**VAS:** visual analog scale

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Original Paper

# A Web-Based, Time-Use App To Assess Children's Movement Behaviors: Validation Study of My E-Diary for Activities and Lifestyle (MEDAL)

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## Abstract

**Background:** Existing modes of collecting self-reported 24-hour movement information from children, including digital assessments, have not been demonstrated to be of acceptable validity when compared to objective measurements. My E-Diary for Activities and Lifestyle (MEDAL) is an interactive web-based diary developed to collect time-use information from children aged 10 years and older.

**Objective:** This study evaluated the validity of MEDAL for assessing children's movement behaviors by comparing self-reported and accelerometer-measured time spent in movement behavior among children in Singapore aged 10-11 years.

**Methods:** Funding for this study was obtained in October 2017, and data were collected between April and August 2020. Participants recorded their daily activities using MEDAL over 2 specified weekdays and 2 weekend days and wore an Actigraph accelerometer on their nondominant wrist throughout the study to objectively assess movement behaviors. Spearman correlation coefficient and intraclass correlation coefficient (ICC) were used to compare the accelerometer measurements and self-reports for each movement behavior. Bland-Altman plots were generated to investigate trends of bias in the self-reports.

**Results:** Among the participants aged 10-11 years (29/49, 59% boys), we observed that children reported lower light physical activity (LPA) and higher moderate-to-vigorous physical activity (MVPA), inactivity, and night sleep than that measured by the accelerometer. There was a moderate-to-strong correlation between self-reported and accelerometer-measured MVPA ( $r=0.37$ ; 95% CI 0.20-0.54), inactivity ( $r=0.36$ ; 95% CI 0.18-0.54), and night sleep ( $r=0.58$ ; 95% CI 0.43-0.74); the correlation for LPA was poor ( $r=0.19$ ; 95% CI 0.02-0.36). Agreement was poor for all behaviors (MVPA: ICC=0.24, 95% CI 0.07-0.40; LPA: ICC=0.19, 95% CI 0.01-0.36; inactivity: ICC=0.29, 95% CI 0.11-0.44; night sleep: ICC=0.45, 95% CI 0.29-0.58). There was stronger correlation and agreement on weekdays for inactivity and night sleep; conversely, there was stronger correlation and agreement for MVPA and LPA on weekend days. Finally, based on Bland-Altman plots, we observed that with increasing MVPA, children tended to report higher MVPA than that measured by the accelerometer. There were no clear trends for the other behaviors.

**Conclusions:** MEDAL may be used to assess the movement behaviors of children. Based on self-reports, the children are able to estimate their time spent in MVPA, inactivity, and night sleep although actual time spent in these behaviors may differ from accelerometer-derived estimates; self-reported LPA warrant cautious interpretation. Observable differences in reporting accuracy exist between weekdays and weekend days.

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## KEYWORDS

children; accelerometer; MEDAL; web-based app; self-report; validity; physical activity; movement behavior; pediatrics; sleep; digital health; behavior

## Introduction

Identifying trends in children's time use to address problematic lifestyles has been recognized as a global priority to minimize the burden of noncommunicable diseases in adulthood [1]. As compelling evidence regarding the quality of children and adolescents' time use and its influence on health emerge, the World Health Organization [2] as well as several countries, including Singapore [3], have developed integrated movement guidelines to reinforce the importance of leading balanced and active lifestyles.

Understanding the lifestyle behaviors of children in relation to the integrated guidelines developed can potentiate the development of targeted behavioral interventions and programs aimed at improving and promoting healthy lifestyles that children can sustain and bring into adulthood. To do so, "adequate, affordable, and convenient" data collection measures to assess 24-hour movement behaviors are required [4].

Self-reported measures (eg, questionnaires, diaries) are commonly used for the collection of information on and assessment of movement behaviors [5,6]. They are inexpensive and easy to administer, however, are subject to the reliance on the respondent's memory, resulting in recall bias and social desirability bias [5,7]. Children have been found to struggle with reporting durations and intensities of activities [8] and often lack the motivation to complete questionnaires [9], limiting the validity of these measures [4,10,11]. Furthermore, most questionnaires are specialized and focus on single behaviors, often requiring a combination of questionnaires to assess all movement behaviors. Having multiple questionnaires may be tedious for researchers to administer and increases participant burden. There is thus a demand for assessments that can capture the full spectrum of movement behaviors (ie, moderate-to-vigorous physical activity [MVPA], light physical activity [LPA], sedentary behavior or inactivity, and sleep).

Objective methods, such as the use of accelerometers, offer a reliable and valid means of objectively capturing 24-hour movement behavior data [12,13]. However, they can be expensive and logistically challenging to administer [14], in that collecting, processing, and analyzing accelerometer data can be complex and require expertise [15]. In addition, accelerometers do not capture contextual information of these movements (eg, type and location of the activities undertaken) [11,14] and are unable to objectively assess screen-viewing, a pertinent behavior with well-established negative associations with the physical and psychosocial outcomes of children [16].

These limitations impede the understanding of children's behaviors and consequentially limit the development of targeted behavioral interventions.

The limitations of existing methods that assess movement behaviors warrant a need for a valid, low-burden, and cost-efficient data collection method to collect 24-hour movement information from children. Advancements in technology may circumvent some of the challenges of existing data collection methods, yet few digital assessments exist. Multimedia activity recall for children and adolescents (MARCA) [9], Synchronised Nutrition and Activity Program (SNAP) [17], and MyDailyMoves [4] are digital assessments developed to provide ease of collecting self-reported 24-hour movement behavior information from children. However, not all self-reported behaviors reported on these assessments have been validated against objective measurements; therefore, the utility of these assessments for collecting 24-hour movement behavior information in comparison to objective measures remains unclear. These applications were also developed for Western populations (ie, Australia, the United Kingdom, and the Netherlands, respectively), and the behavioral patterns of children in Western versus Asian populations may differ (eg, the prevalence of children attending tuition or shadow education) [18], limiting the relevance of existing applications to the Asian setting.

To bridge this gap, My E-Diary for Activities and Lifestyle (MEDAL), an interactive web-based diary, was developed to collect time-use information from children of at least 10 years of age in Singapore [18]. Usability testing suggests that MEDAL is a feasible application for capturing the movement behaviors of children aged 10 to 12 years [18]. We aimed to validate the use of MEDAL for assessing children's movement behaviors by comparing self-reported and accelerometer-measured time spent in MVPA, LPA, inactivity, and sleep among children aged 10 to 11 years in Singapore. We hypothesized that children at this age would be able to self-report their movement behaviors on MEDAL accurately although some differences between self-reported and objective measures would be expected.

## Methods

### Study Participants

Boys and girls aged 10 to 11 years (Primary 5 level) from 2 government schools in Singapore (referred to as schools A and B in the present study) were recruited between April and August 2020.

Of the 7 and 6 Primary 5 classes from schools A and B, respectively, 2 classes from each school (35 to 41 students per class) underwent convenience sampling to participate in this study based on logistical feasibility (ie, ease of administration of accelerometers). Students of the remaining classes were involved in the validation of other self-reported variables (ie, diet and outdoor time).

Funding for this study was obtained in October 2017, and data were collected between April and August 2020.

### **Ethics Approval and Consent To Participate**

The Singapore Ministry of Education approved of the collection of data from schools A and B, and the National University of Singapore Institutional Review Board (reference code #S-18-088) approved of the study. Written informed consent was obtained from parents or guardians, and all participants provided verbal assent.

### **Data Collection and Processing**

#### *Assessment of Movement Behaviors*

A demonstration session was conducted, where trained researchers demonstrated the use of and navigations in MEDAL. Participants were instructed to record the diet and activities that they engaged in from midnight to midnight of the recording day at home over 2 specified weekdays and 2 weekend days. A special arrangement was made for 1 participant in this study without access to the internet at home to complete his or her recording on MEDAL using the school computer.

The details and features of MEDAL have been reported elsewhere [18]. In brief, participants were instructed to enter the time they slept the previous day, the time they woke up, and all the activities in which they participated in chronological order until the time they went to bed. Participants could select from 6 broad activities: “Shower/Wash Up,” “Travelling,” “Eat & Drink,” “Nap/Sleep,” “Sitting Activities,” or “Active Activities” and were prompted to specify the mode of transport, types of sitting and active activities engaged in, and what they ate or drank. Participants were also allowed to select concurrent activities that occurred while engaged in “Travelling,” “Eat & Drink,” or “Sitting Activities.” When “Active Activities” was selected, the participants were prompted to report their perceived intensity of the activity based on the “Talk Test” [19]. Selecting “Just a little tiring—You can sing and talk during the activity” indicated that the activity was of light intensity, “Quite tiring—You can talk but cannot sing during the activity” indicated that the activity was of moderate intensity, and “Very tiring—You cannot say more than a few words without pausing” indicated that the activity was of vigorous intensity. All other activity entries (ie, excluding “Active Activities”) were coded as “night sleep,” “inactivity,” “light physical activity,” or “moderate-to-vigorous physical activity” based on previously established metabolic intensities [20] (Multimedia Appendix 1). All information collected was secure, in that only the investigators had access to the password-protected data.

Each participant involved in the movement behavior validation study was attached with a triaxial accelerometer (Actigraph wGT3X-BT) using a nonremovable strap on their nondominant

wrist during the demonstration session. The accelerometers were initialized to start recording raw acceleration data at a rate of 80 Hz from midnight of the day after the demonstration session. The participants were instructed to wear the accelerometers at all times, even when sleeping, for 6 to 7 days, which overlapped with the days that they were instructed to record on MEDAL. They were only advised to remove the accelerometers by cutting the nonremovable strap when they engaged in any activity that might have involved physical contact or when the wearing of devices was not allowed (eg, sports competitions). They were required to record the date and time the accelerometers were removed and were instructed to reattach the accelerometer after the activity using a spare strap provided. This allowed the objective measurement of their movement behaviors throughout the study period to validate their self-reported activities on MEDAL.

Data processing was conducted using an established protocol [21]. Raw data were downloaded using the ActiLife software (version 6.13.4) in GT3X format and processed in R version 4.0.2 (The R Project for Statistical Computing) with the GGIR package (version 2.0-0). After the raw accelerometer signals were auto-calibrated and converted into gravity-corrected vector magnitude units (Euclidean Norm Minus One [ENMO]), a wear time inclusion criterion of a minimum of 16 hours per day for at least 3 days was applied [21]. Nonwear time was detected using information on the SD and value range of each accelerometer axis at 60-minute windows in 15-minute increments. Accelerometer wear compliance was assessed for valid accelerometer wear days that corresponded with the day of MEDAL recording. Sleep duration was assessed using the method developed by van Hees and colleagues [22]. The term “sedentary behavior,” by definition refers to activities “ $\leq 1.5$  METs [metabolic equivalents] while in a sitting, reclining or lying posture” [23]. As wrist-worn accelerometers are unable to determine the posture of participants, the term “inactivity” was used as proxy for sedentary behaviors in this study. With that, activities during waking hours were classified as inactivity (ENMO  $< 35.0$  mg), LPA (ENMO 35.0-200 mg), or MVPA (ENMO  $> 200.0$  mg) based on acceleration thresholds developed for children aged 7 to 11 years by Hildebrand and colleagues [24,25], which have been applied in previous studies [21,26,27].

### **Demographic Data Collection**

During the first sign-in on MEDAL, participants were prompted to report their age and sex information. Primary schools in Singapore routinely measure the students’ height and weight to monitor growth. The most recent height and weight measurements taken by the school teachers were shared by the participating schools. BMI was calculated using the formula: weight (kg)/(height [m]  $\times$  height [m]). The subsequent value was then classified as underweight ( $< 5$ th percentile), healthy weight (5th to  $< 90$ th percentile), and overweight ( $\geq 90$ th percentile) based on the age- and sex-specific BMI reference data for Singaporean children [28].

### **Statistical Analyses**

MEDAL entries with implausible values reported were excluded from the analysis. Additionally, each participant’s graphical acceleration data were visually inspected, and days where sleep

period appeared inaccurate (eg, implausibly short sleep duration, early wake-up, or long interruptions during sleep period) were excluded, as the estimation of time spent in all movement behaviors would be affected. Descriptive statistics are presented as frequencies, percentages, or medians with IQR. The difference in distribution of characteristics between included and excluded participants was assessed by Fisher exact test. The correlation between accelerometer-measured and self-reported daily time spent in movement behavior (ie, MVPA, LPA, inactivity, and night sleep) were calculated using Spearman correlation coefficient test. Spearman correlation coefficients were interpreted as a poor ( $\leq 0.29$ ), moderate (0.30-0.39), strong (0.40-0.69), and very strong correlation ( $\geq 0.70$ ) [29]. Intraclass correlation coefficients (ICCs) were calculated to quantify the agreement between accelerometer-measured and self-reported daily time spent in each movement behavior (ie, MVPA, LPA, inactivity, and night sleep) using 2-way mixed-effects models. Based on previously established cutoffs [30], the strength of agreement was interpreted as poor ( $< 0.50$ ), moderate (0.50-0.74), good (0.75-0.90), or excellent ( $> 0.90$ ). Bland-Altman plots, which accounted for repeated measurements [31], were generated with

95% limits of agreement (LoA) to visualize agreement and investigate trends of bias in the self-reports when compared to accelerometer measurements. All statistical tests were performed using Stata Special Edition version 14.2 (StataCorp). All evaluations were made assuming a 2-sided test at a 5% level of significance.

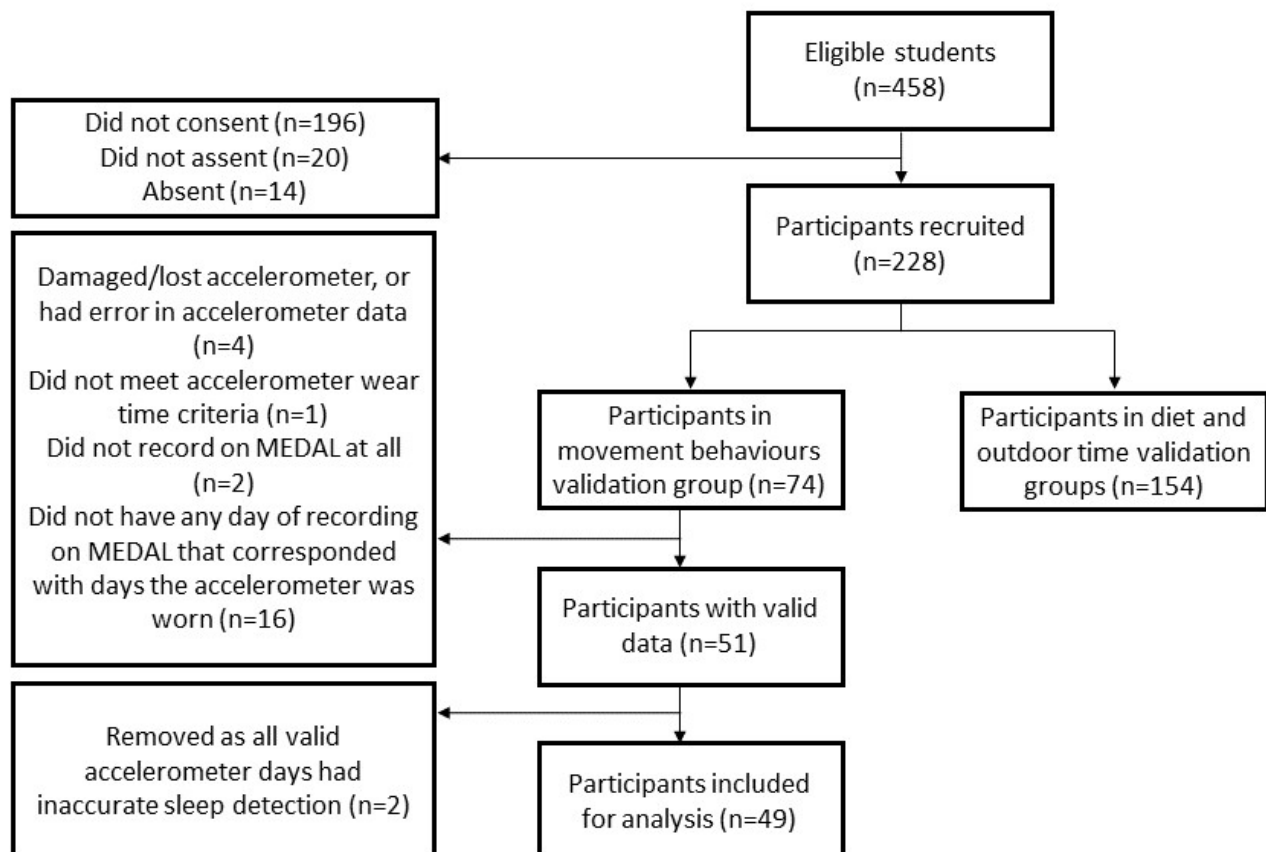
## Results

### Study Participants

There were 74 participants (48 participants and 26 participants from schools A and B, respectively) who took part in the movement behavior validation study, of whom 49 were included in the analysis (66%). Figure 1 summarizes the participant flow diagram of this study.

Participants were mostly males (29/49, 59%), of healthy weight (33/49, 69%), and had access to the internet (43/49, 98%). Compliance with accelerometer wear among included participants was excellent: 47 out of 49 participants (96%) had at least 90% valid accelerometer wear time per day (data not shown). Table 1 summarizes the demographic and compliance information of our sample.

**Figure 1.** MEDAL movement behaviors validation participant flow diagram. MEDAL: My E-Diary for Activities and Lifestyle (validation study).





**Table 1.** Demographic characteristics and accelerometer wear time of Primary 5 students participating in the My E-Diary for Activities and Lifestyle (MEDAL) movement behaviors validation study (N=49).

|   | Participants (N=49) <sup>a</sup> |
|---|----------------------------------|
| <b>Age, n (%)</b>                                       |                                  |
| 10 years  | 20 (41)                          |
| 11 years  | 28 (57)                          |
| 12 years  | 1 (2)                            |
| <b>Sex, n (%)</b>                                       |                                  |
| Females   | 20 (41)                          |
| Males   | 29 (59)                          |
| <b>BMI for age, n (%)</b>                               |                                  |
| Underweight (<5th percentile)                           | 10 (21)                          |
| Healthy (5th to <90th percentile)                       | 33 (69)                          |
| Overweight (≥90th percentile)                           | 5 (10)                           |
| <b>Internet access, n (%)</b>                           |                                  |
| Yes   | 43 (98)                          |
| No  | 1 (2)                            |
| Valid accelerometer wear time (hours/day), median (IQR) | 24.0 (23.7-24.0)                 |

<sup>a</sup>One participant had missing BMI-for-age information, and five participants had missing information on internet access.

### Accelerometer-Measured and Self-Reported Movement Behavior Durations

Table 2 presents the objectively measured and self-reported time spent in each movement behavior on weekdays and on weekend days.

In comparison to accelerometer measurements, the participants reported lower LPA (312.1 min/day vs 52.5 min/day) and higher

MVPA (53.5 min/day vs 60.0 min/day), inactivity (567.2 min/day vs 742.5 min/day), and night sleep durations (488.8 min/day vs 545.0 min/day) in MEDAL. Accelerometer-measured and self-reported MVPA, LPA, and inactivity on weekdays were higher than on weekend days, whereas accelerometer-measured and self-reported night sleep on weekend days was higher than on weekdays.

**Table 2.** Median accelerometer-measured and self-reported time spent in movement behaviors on average of all days, weekdays, and weekend days (minutes/day).

| Type of movement behavior | Average of all days (m/d <sup>a</sup> ), median (IQR) (n=49) |                     | Weekdays (m/d), median (IQR) (n=41) |                          | Weekend days (m/d), median (IQR) (n=45) |                     |
|---------------------------|--|---------------------|-------------------------------------|--------------------------|---|---------------------|
|                           | Accelerometer (IQR)  | MEDAL (IQR)         | Accelerometer (IQR)                 | MEDAL <sup>b</sup> (IQR) | Accelerometer (IQR)                     | MEDAL (IQR)         |
| MVPA <sup>c</sup>         | 53.5 (37.3-77.6)   | 60.0 (0.0-120.0)    | 62.3 (43.5-86.5)                    | 70.0 (32.5-150.0)        | 47.3 (32.8-73.0)                        | 42.5 (0.0-120.0)    |
| LPA <sup>d</sup>          | 312.1 (257.7-356.6)  | 52.5 (30.0-95.0)    | 345.2 (297.5-390.2)                 | 55.0 (32.5-77.5)         | 297.8 (243.3-328.7)                     | 45.0 (27.5-130.0)   |
| Inactivity                | 567.2 (510.5-640.3)  | 742.5 (650.0-807.5) | 612.4 (539.8-657.0)                 | 767.5 (720.0-870.0)      | 547.0 (495.2-604.6)                     | 715.0 (587.5-780.0) |
| Night sleep               | 488.8 (432.5-556.5)  | 545.0 (485.0-612.5) | 431.4 (389.2-468.6)                 | 492.5 (435.0-530.0)      | 546.1 (488.5-582.8)                     | 595.0 (540.0-657.5) |

<sup>a</sup>m/d: minutes per day.

<sup>b</sup>MEDAL: My E-Diary for Activities and Lifestyle.

<sup>c</sup>MVPA: moderate-to-vigorous physical activity.

<sup>d</sup>LPA: light physical activity.

### Correlation Between Accelerometer-Measured and Self-Reported Movement Behavior Durations

Spearman correlation tests revealed a strong correlation between accelerometer-measured and self-reported night sleep ( $r=0.58$ ;

95% CI 0.43-0.74). There was a moderate correlation for MVPA ( $r=0.37$ ; 95% CI 0.20-0.54) and inactivity ( $r=0.36$ ; 95% CI 0.18-0.54), and a poor correlation for LPA ( $r=0.19$ ; 95% CI 0.02-0.36). Correlation analyses stratified by weekdays and weekend days revealed that only weekend days' MVPA ( $r=0.44$ ;



95% CI 0.23-0.65) and LPA ( $r=0.33$ ; 95% CI 0.10-0.56) and weekday inactivity ( $r=0.36$ ; 95% CI 0.05-0.66) and night sleep ( $r=0.64$ ; 95% CI 0.45-0.84) demonstrated a moderate-to-strong correlation between accelerometer-measured and self-reported values. These results are presented in [Table 3](#).

**Table 3.** Spearman correlation and ICC between accelerometer-measured and self-reported time spent in each movement behavior.

| Type of movement behavior | Average of all days (n=49) |  | Weekdays (n=41)      |                      | Weekend days (n=45)  |                      |
|---------------------------|----------------------------|--|----------------------|----------------------|----------------------|----------------------|
|                           | $r$ (95% CI) <sup>a</sup>  | ICC <sup>b</sup> (95% CI) <sup>c</sup> | $r$ (95% CI)         | ICC (95% CI)         | $r$ (95% CI)         | ICC (95% CI)         |
| MVPA <sup>d</sup>         | 0.37 (0.20 to 0.54)        | 0.24 (0.07 to 0.40)                    | 0.15 (-0.16 to 0.47) | 0.05 (-0.23 to 0.33) | 0.44 (0.23 to 0.65)  | 0.35 (0.13 to 0.53)  |
| LPA <sup>e</sup>          | 0.19 (0.02 to 0.36)        | 0.19 (0.01 to 0.36)                    | 0.01 (-0.27 to 0.30) | 0.10 (-0.18 to 0.37) | 0.33 (0.10 to 0.56)  | 0.32 (0.09 to 0.51)  |
| Inactivity                | 0.36 (0.18 to 0.54)        | 0.29 (0.11 to 0.44)                    | 0.36 (0.05 to 0.66)  | 0.32 (0.05 to 0.55)  | 0.32 (0.09 to 0.55)  | 0.18 (-0.05 to 0.40) |
| Night sleep               | 0.58 (0.43 to 0.74)        | 0.45 (0.29 to 0.58)                    | 0.64 (0.45 to 0.84)  | 0.44 (0.18 to 0.64)  | 0.25 (-0.01 to 0.50) | 0.11 (-0.13 to 0.33) |

<sup>a</sup>Spearman correlation coefficients ( $r$ ) were interpreted as poor ( $\leq 0.29$ ), moderate (0.30-0.39), strong (0.40-0.69), or very strong ( $\geq 0.70$ ) correlations.

<sup>b</sup>ICC: intraclass correlation coefficient.

<sup>c</sup>ICCs were interpreted as poor ( $< 0.50$ ), moderate (0.50-0.74), good (0.75-0.90), or excellent ( $> 0.90$ ) agreement.

<sup>d</sup>MVPA: moderate-to-vigorous physical activity.

<sup>e</sup>LPA: light physical activity.

### Agreement Between Accelerometer-Measured and Self-Reported Movement Behavior Durations

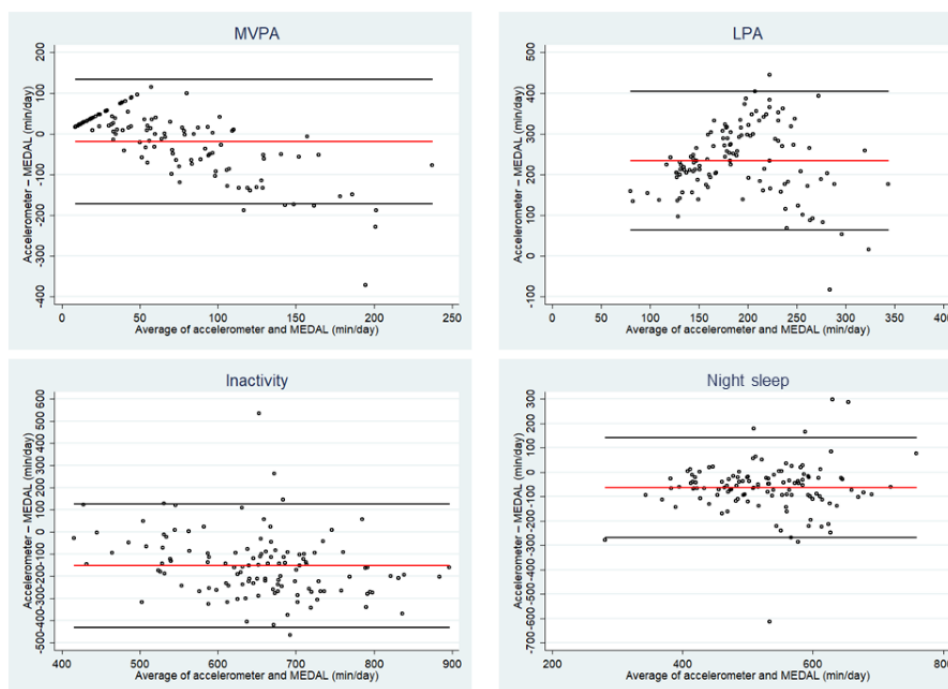
Agreement was poor between the measures for MVPA (ICC=0.24; 95% CI 0.07-0.40), LPA (ICC=0.19; 95% CI 0.01-0.36), inactivity (ICC=0.29; 95% CI 0.11-0.44), and night sleep (ICC=0.45; 95% CI 0.29-0.58). ICC analyses stratified by weekdays and weekend days demonstrated that there was poor agreement for both weekdays and weekend days in MVPA, LPA, inactivity, and night sleep. These results are presented in [Table 3](#).

The Bland-Altman plots ([Figure 2](#)) suggested that those with low MVPA (based on average of self-reported and accelerometer-measured MVPA) reported lower MVPA levels than those measured by the accelerometer. As MVPA levels

increased, reporting higher MVPA levels than those measured by the accelerometer was more common.

There were no clear trends for the other movement behaviors (ie, LPA, inactivity, and night sleep), as the plots appeared to be randomly distributed. Based on these plots, self-reported LPA was on average 234.1 minutes lower than that measured by the accelerometer (95% LoA 63.4-404.8 minutes). On the other hand, accelerometer-measured inactivity was on average 151.5 minutes lower than self-reported activity (95% LoA -430.5 to 127.6 minutes), and accelerometer-measured night sleep was on average 62.6 minutes lower than the self-reported night sleep (95% LoA -266.6 to 141.4 minutes). The plots stratified by weekday and weekend days did not differ meaningfully (figures not shown).

**Figure 2.** Bland-Altman plots between accelerometer-measured and self-reported (ie, MEDAL) MVPA, LPA, inactivity, and night sleep based on the average of all days. The black lines depict the 95% limits of agreement, and the red line depicts the mean difference. LPA: light physical activity; MEDAL: My E-Diary for Activities and Lifestyle (validation study); MVPA: moderate-to-vigorous physical activity.



## Discussion

In this study, we evaluated the validity of MEDAL by comparing self-reported time spent in each movement behavior reported (ie, MVPA, LPA, inactivity, and sleep) on MEDAL to accelerometer measurements among children in Singapore aged 10 to 11 years. We found that the children reported lower LPA, higher MVPA, higher inactivity, and higher night sleep durations than those measured by the accelerometer. Moderate-to-strong correlations were observed between accelerometer-measured and self-reported MVPA, inactivity, and night sleep, while LPA demonstrated a poor correlation. There was generally poor agreement between accelerometer-measured and self-reported values for all behaviors. Differences between weekdays and weekend days in correlation and agreement between self-reports and accelerometer measurements were also observed.

We demonstrated that some movement behaviors were better reported on MEDAL compared to others. In particular, LPA was most poorly reported, as it had the lowest correlation with accelerometer measurements, and a similar strength of correlation was reported previously ( $r=0.09$ ) [32]. The literature suggests that it is difficult to define LPA and, consequentially, difficult to capture LPA using subjective assessments such as self-reports, especially among children [33]. This is attributed to the sporadic and spontaneous nature of activity among children of this age [14]; periods of light activity may be intermittent in nature, which is attributable to children's short attention span and quick disinterest in continuous activity. These short bursts of light activity contribute to differences in objectively measured and self-reported physical activity and inactivity durations, as short periods of movement or inactivity might not be salient during their recall and thus, unintentionally

misreported. The strength of associations between self-reported and accelerometer-measured MVPA and inactivity was similar or better than that reported in other studies, respectively. Recent systematic reviews [10,11] found that self-reported MVPA durations among children aged around 10 to 11 years had moderate correlation with objective measurements ( $r=0.21-0.48$ ) [32,34-37], whereas correlations were poor for self-reported inactivity ( $r=0.06-0.14$ ) [35,38]. Remembering frequencies, durations, and intensities of all activities undertaken in a day is difficult for children [8], contributing to the recall bias that underlies observable differences in time spent in each movement behavior between objectively measured and self-reported measures.

Lastly, for sleep, we demonstrated that night sleep was better reported on MEDAL compared to the other behaviors. Based on a systematic review of sleep questionnaires developed for children and adolescents [39], the criteria for assessing sleep duration in previous studies differ from the current one, and thus the ability to make comparisons to other studies was limited. Notwithstanding, it has been established that sleep latency, defined as the time a person takes to fall asleep after going to bed, may influence reporting of sleep times [40]. Periods between bed time and falling asleep might be reported as sleeping but detected from accelerometer data to be otherwise, resulting in differences between objectively measured and self-reported sleep onset time and, consequentially, total sleep time.

Previous studies have typically only investigated the correlation between objective measurements and self-reports, which is a limitation when assessing validity, as correlation does not provide information on the strength of agreement between the methods [41]. In our study, we examined agreement and found

that while MVPA, inactivity, and night sleep demonstrated moderate-to-strong correlations between accelerometer measurements and self-reports on MEDAL, agreement for all behaviors was poor. To our knowledge, only MVPA has been examined previously in terms of agreement between objective measurements and self-reports [37,42]. The findings of our study were in line with these studies (ICC=0.06-0.25) in that agreement was poor. Although children are able to report some behaviors using MEDAL, actual time spent in these behaviors may differ from estimates by wrist-worn accelerometers.

Finally, we investigated whether the validity of MEDAL differed on weekdays and weekend days. This adds to the existing literature, as few studies have investigated differences in reporting accuracy on weekdays versus weekend days. Our study suggests that the children were able to report weekend days' physical activity better than weekdays'; conversely, they were able to report weekdays' inactivity and night sleep better than weekend days'. The greater correlation and agreement for inactivity and night sleep demonstrated on weekdays might be attributed to weekdays being more structured, characterized by consistent wake and bed times [43] as well as regular school-day routines in which the majority of activities are inactive (eg, lessons in school) [44], making them easier to recall. Explanations for differences in reporting accuracy for physical activity (MVPA and LPA) on weekdays compared to weekend days are less clear. Participants might have reported their physical education lessons or after-school sports trainings on weekdays as entirely physical activity (regardless of MVPA or LPA). In reality, these periods of "activity" might include organizing the lesson or game, watching demonstrations, or taking turns to rest and play [33]. The accelerometer only measured the amount of time when the individual was actually moving, resulting in the discrepancy between periods of physical activity reported on MEDAL and those measured by the accelerometers. Conversely, the participants might have participated in a specific sport and might have been active throughout the duration of the physical activity they reported, resulting in the greater correlation and agreement between accelerometer-measured and self-reported physical activity durations on weekend days. This hypothesis warrants further investigation.

Despite known limitations of self-reports relating to recall bias, self-reporting offers advantages that objective assessments of movement behaviors, like use of accelerometers, do not [6]. Objective assessments are independent of recall bias, while self-reported measures, like MEDAL, are easier to administer, process, and analyze, particularly when extended to population-based studies or large cohorts [45]. They also offer the potential of collecting information on screen-viewing and contextual information, such as location and type of activity, without the need for complementary questionnaires or devices (eg, a location tracker) [45], streamlining the assessment and identification of problematic health behaviors and possible contexts to target health behavior interventions. Hence, the impetus for selecting an appropriate method to assess movement behaviors, whether self-reports or objective assessments or a combination of both, is dependent on the research question [45].

Our findings suggest that based on self-reports on MEDAL, the children are able to estimate their time spent in MVPA, inactivity, and night sleep although actual time spent in these behaviors may differ from estimates by wrist-worn accelerometers. On the other hand, self-reported LPA on MEDAL warrants cautious interpretation. Finally, MVPA and LPA might be better reported by children on weekend days, and inactivity and night sleep might be better reported on weekdays.

There are several strengths of the present study. High compliance with accelerometer wear allowed activity patterns of a full or close to a full 24-hour day to be objectively measured for comparison with self-reports on MEDAL. The reporting of all 4 movement behaviors was investigated, allowing us to review the validity of MEDAL as a tool for capturing time use across the full movement spectrum of 24 hours. Stratifying the analyses by weekdays and weekend days provided additional interesting findings to contribute to the current literature.

However, there are limitations to be acknowledged. First, we note that some participants might have removed their accelerometers during certain sports and activities (eg, contact sports, martial arts); therefore, accelerometer-measured MVPA and LPA might have been underestimated. As our results demonstrate that participants reported much lower LPA than did the accelerometer, the underreporting may be more pronounced than reflected. Sleep duration detection algorithms for raw acceleration data have only been developed to detect the onset of sleep [22], which may differ from bed time and would be intuitively self-reported. The difference in time between sleep onset (ie, when the participant truly falls asleep) and bed time (ie, the time the participant goes to bed to go to sleep) would consequentially influence estimations of sleep durations. As accelerometers and MEDAL assessed different constructs of sleep (ie, sleep onset to wake time versus bed time to wake time), accelerometers might be less adequate as a means of comparison against self-reported sleep durations. We also removed 1 MEDAL entry of a participant whom we deemed to have reported implausible values. Sensitivity analyses, however, revealed that including the entry did not affect results substantially. We also acknowledge that the sample size of this study was modest, largely due to the exclusion of participants that did not have any day of recording on MEDAL that corresponded with the days the accelerometers were worn. Notwithstanding, MEDAL was reported previously to be feasible and acceptable among children of this age group [18]. Some differences in characteristics exist between participants included in our study and those recruited but not included (ie, those excluded from movement behavior validation analyses and those involved in the other validation studies; [Multimedia Appendix 2](#)). These may potentially limit the generalizability of the findings of this study to the population.

This is among the first studies to assess the validity of self-reported behaviors across the full movement spectrum and to compare reporting accuracy on weekdays versus weekend days. This study suggests that MEDAL may be useful in assessing movement behaviors of children aged 10 to 11 years although estimates may differ from wrist-worn accelerometer measurements. Self-reported estimates for inactivity and sleep

on weekdays might be more accurate than those on weekend days, whereas self-reported estimates for MVPA and LPA on weekend days might be more accurate than those on weekdays. Findings of this study will facilitate the interpretation of future data collected using MEDAL.

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## Data Availability

The data sets used and analyzed during this study are available from the corresponding author on reasonable request.

## Authors' Contributions

LPS, SMS, MFFC, and FMR conceived the study. SYXT and AC collected the data. PN and CMJLG assisted with data processing. SYXT conducted data analysis and interpretation, and wrote the first draft with contributions from BCT, MFFC, and FMR. All authors read and approved the final manuscript.

## Conflicts of Interest

None declared.

### Multimedia Appendix 1

Classification of activities reported on My E-Diary for Activities and Lifestyle (MEDAL) as inactivity, light physical activity, moderate-to-vigorous physical activity, and sleep.

[[DOCX File , 133 KB - pediatrics\\_v5i2e33312\\_app1.docx](#) ]

### Multimedia Appendix 2

Demographic characteristics of Primary 5 students included and those recruited but not included in the My E-Diary for Activities and Lifestyle (MEDAL) movement behaviors validation study.

[[DOCX File , 15 KB - pediatrics\\_v5i2e33312\\_app2.docx](#) ]

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## Abbreviations

- ENMO:** Euclidean Norm Minus One
- ICC:** intraclass correlation coefficient
- LoA:** limits of agreement
- LPA:** light physical activity
- MARCA:** multimedia activity recall for children and adolescents
- MEDAL:** My E-Diary for Activities and Lifestyle
- MET:** metabolic equivalents
- MVPA:** moderate-to-vigorous physical activity
- NUHS:** National University Health System.
- NUS:** National University of Singapore.
- SNAP:** Synchronised Nutrition and Activity Program

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Review

# Internet-Delivered Interventions for Depression and Anxiety Symptoms in Children and Young People: Systematic Review and Meta-analysis

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## Abstract

**Background:** Mental health difficulties in children and adolescents are highly prevalent; however, only a minority receive adequate mental health care. Internet-delivered interventions offer a promising opportunity to increase access to mental health treatment. Research has demonstrated their effectiveness as a treatment for depression and anxiety in adults. This work provides an up-to-date examination of the available intervention options and their effectiveness for children and young people (CYP).

**Objective:** In this systematic review and meta-analysis, we aimed to determine the evidence available for the effectiveness of internet-delivered interventions for treating anxiety and depression in CYP.

**Methods:** Systematic literature searches were conducted throughout November 2020 using PubMed, PsycINFO, and EBSCO academic search complete electronic databases to find outcome trials of internet-delivered interventions treating symptoms of anxiety and/or depression in CYP by being either directly delivered to the CYP or delivered via their parents. Studies were eligible for meta-analysis if they were randomized controlled trials. Risk of bias and publication biases were evaluated, and Hedges  $g$  between group effect sizes evaluating intervention effects after treatment were calculated. Meta-analyses used random-effects models as per protocol.

**Results:** A total of 23 studies met the eligibility criteria for the systematic review, of which 16 were included in the meta-analyses, including 977 participants in internet-delivered treatment conditions and 1008 participants in control conditions across 21 comparisons. Random-effects models detected a significant small effect for anxiety symptoms (across 20 comparisons; Hedges  $g$  = -0.25, 95% CI -0.38 to -0.12;  $P$  < .001) and a small but not significant effect for depression (across 13 comparisons; Hedges  $g$  = -0.27, 95% CI -0.55 to 0.01;  $P$  = .06) in favor of internet-delivered interventions compared with control groups. Regarding secondary outcomes, there was a small effect of treatment across 9 comparisons for impaired functioning (Hedges  $g$  = 0.52, 95% CI 0.24-0.80;  $P$  < .001), and 5 comparisons of quality of life showed no effect (Hedges  $g$  = -0.01, 95% CI -0.23 to 0.21;  $P$  = .94).

**Conclusions:** The results show that the potential of internet-delivered interventions for young people with symptoms of anxiety or depression has not been tapped into to date. This review highlights an opportunity for the development of population-specific interventions and their research to expand our current knowledge and build an empirical base for digital interventions for CYP.

**Trial Registration:** PROSPERO CRD42020220171; [https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=220171](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=220171)

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**KEYWORDS**

internet-delivered interventions; children and young people; depression; anxiety; digital health

## Introduction

### Background

Depression and anxiety disorders rank high among the difficulties for children and young people (CYP), contributing to significant disability, and are associated with lasting intellectual, academic, and social impairment [1-3]. Mental health issues, which often first present at a young age [4], can contribute to lifelong physical health difficulties and reduced quality of life in adulthood [5,6]. Failure to access treatment at such a critical developmental stage can result in serious negative consequences for functioning or even long-term disability [7]. Despite the high prevalence rates and worldwide recognition of the importance of strengthening mental health in CYP, demand still surpasses the capacity of services [8] and only a minority receive adequate mental health care [9]. In one study, after 4 weeks of referral, only 20% received treatment [10], presenting a major issue, as long waiting times have been associated with poorer outcomes, worsening of symptoms, and a greater chance of families disengaging from treatment [11].

Global inadequacies in the provision of mental health services have been attributed to three areas: access to services, implementation, and policy issues [9]. In England, mental health services for CYP are historically underfunded, seeing service cuts of up to 75% even as demand increases at a rate of approximately 11% per annum [12]. One core issue of access, which inhibits the expansion of service provision, is the scarcity of highly trained therapists and supporters to deliver therapeutic content [13], especially in relation to CYP [14]. In a 2017 review of mental health services for CYP in the United Kingdom, CYP reported concerns that the staff members were not adequately trained to meet their needs [15]. Additional personal barriers to young people receiving care can involve location-based or finance-based inaccessibility of services, feelings of embarrassment and perceived stigma, desire to be more self-reliant, and difficulties in recognizing mental health concerns [16].

Internet-delivered interventions are an increasingly popular way to address some of the barriers to access owing to their scalability, efficiency, and potential for personalization [17]. Furthermore, given young people's familiarity and avid consumption of technology and the internet [18], digital interventions present a possible way to reach larger numbers of young people. Young people use the internet to access information regarding mental health issues, to obtain support for issues when in need, and to connect with peers [19]. In addition to increasing access to care, the use of technology-based treatments has improved patient and family outcomes and quality of life [9]. Evidence has shown comparable effectiveness of internet-delivered interventions and face-to-face brief psychological interventions in treating depression and anxiety in adults (Palacios J, unpublished data, April 2022) [20] and some evidence for their use in CYP [21].

In general, studies of internet-delivered interventions for CYP have lagged behind adult equivalents, and previous systematic reviews have sought to address this [22,23]. However, the update from Grist et al [22] included any technology-delivered treatments, such as video games, which can vary substantially in the mode of delivery and support provided, not to mention design or psychotherapeutic approach, and therefore likely have different effects or mechanisms of change [13]. Hollis et al [17] also conducted a metareview including young adults aged  $\geq 18$  years but  $\leq 25$  years and defined broad inclusion criteria for therapy delivered over technological devices, such as CD-ROM, SMS text messaging, or videoconferencing. Considering the broad and highly varied nature of the interventions under this rubric, Hollis et al [17] recommended evaluating evidence-based, *core* components of digital-delivered interventions (ie, active ingredients of interventions associated with uptake, adherence, and clinical outcomes).

### Objectives

It is still not clear whether internet-delivered interventions are effective in treating depression and anxiety in CYP. Internet-delivered mental health interventions are rapidly advancing; therefore, we conducted a systematic review to provide an up-to-date analysis of the available intervention options and their effectiveness. Specifically, the aims of this systematic review are (1) to evaluate the current state of evidence for the effectiveness of internet-delivered interventions for childhood and adolescence anxiety and depression symptoms and (2) to assess whether internet-delivered interventions are effective in treating symptoms of anxiety and depression in children and adolescents.

## Methods

### Literature Search

This systematic review and meta-analysis was completed in line with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement [24]; for the corresponding checklist, refer to [Multimedia Appendix 1](#). Its protocol was prospectively registered at PROSPERO (reference number CRD42020220171). A systematic literature search for English language articles was conducted in early November 2020, and the final searches were conducted on November 19, 2020, across three electronic databases: PubMed, PsycINFO, and EBSCO academic search complete. Each database was searched individually with search terms specified by population, presenting the problem, intervention, and intervention medium (refer to [Table 1](#) for examples of the search terms used across databases). In addition, we reviewed references of other relevant review papers, checked trial registers for recent publications related to eligible trial protocols identified through the database searches, and drew on the expertise of the last author (DR) in the field to identify publications that may have been missed.

**Table 1.** Examples of search terms used across databases.

| Search category    | Examples of search terms  |
|--------------------|---|
| Population         | <i>Child<sup>a</sup> or adolescent<sup>a</sup> or parent<sup>a</sup> or parenting<sup>a</sup></i>   |
| Presenting problem | <i>Depression<sup>a</sup> or anxiety<sup>a</sup> or mental health<sup>a</sup></i>   |
| Intervention       | <i>Therapeutics<sup>a</sup> or psychotherapy<sup>a</sup> or intervention<sup>b</sup> or psychoeducat<sup>b</sup> or manag<sup>b</sup> or train<sup>b</sup></i>                                  |
| Medium             | <i>Internet<sup>a</sup> or computer<sup>b</sup> or web<sup>b</sup> or online<sup>b</sup> or technolog<sup>b</sup> or phone application<sup>b</sup> or app<sup>b</sup> or mobile<sup>b</sup></i> |

<sup>a</sup>MeSH (Medical Subject Headings) term.

<sup>b</sup>Key concept in PsycINFO or title term in PubMed.

## Selection of Studies

After duplicates were deleted via the reference manager Mendeley, entirely off-topic studies were excluded based on the title by one researcher (AL). Eligibility screening of the remaining papers was conducted by two researchers (NE and AL), and discrepancies were resolved via discussion between the researchers and consultation with a senior researcher (DR). The grounds for exclusion of studies were recorded according to a predefined hierarchy.

## Eligibility Criteria

To be included in the systematic review, studies had to (1) be outcome studies, providing at least pretreatment and posttreatment clinical outcome data pertaining to anxiety or depression; (2) be implementing a transdiagnostic or disorder-specific low-intensity intervention delivered remotely via the internet (eg, high-intensity interventions such as videoconference psychotherapy or CD-ROM-based interventions were excluded), targeting symptoms of anxiety and/or depression in children or young people (intervention could be delivered directly to the child or young person or via their parents or guardians); (3) report the average age of the CYP, for whose symptoms the intervention was primarily intended, to be aged  $\leq 18$  years; and (4) have only included CYP who presented with symptoms of anxiety and/or depression (individual study inclusion criteria needed to include current symptoms of anxiety and/or depression assessed via self-report measures or clinical interviews). Furthermore, to be included in the meta-analysis, studies needed to be individually randomized controlled trials (RCTs).

## Data Extraction

Extracted data from studies included (1) participant characteristics (percentage female, mean age, and age range of the sample), (2) study characteristics (country of setting, recruitment strategy, clinical eligibility criteria implemented, and type of control group), (3) intervention characteristics (intervention focus of anxiety and/or depression, intervention delivery to youth and/or parents, intervention theoretical orientation, intervention support delivered, number of modules in intervention and length of treatment, and average amount of the intervention completed by participants), and (4) means and SDs or equivalent intention-to-treat metrics facilitating the calculation of posttreatment and follow-up between-group effect sizes where applicable. Data were extracted by one researcher (AL or RW) and checked for accuracy by another researcher (NE).

For outcome data extraction, we created a hierarchy of instruments for our constructs of interest (primary: depression and anxiety; secondary: impaired functioning and quality of life) before data extraction to facilitate uniformity for studies implementing multiple measures for the same construct. Each hierarchy was composed of a list of relevant outcome measures ranked by their properties of interpretability, reliability, and validity. Given the primary interest in generic anxiety in this meta-analysis, generic anxiety measures were given preference over disorder-specific ones (eg, in 1 study [25], the Beck Anxiety Inventory was selected over the Social Phobia Screening Questionnaire for Children). Where there were multiple forms completed of the same measure (eg, Spence Children's Anxiety Scale-Parent Version and Child Version), the scores were averaged.

## Quality Assessment of Included Studies

The risk of bias was determined for each study included in the meta-analysis based on the CLEAR NPT (Checklist to Evaluate a Report of a Nonpharmacological Trial) checklist [26], which evaluates the quality of RCTs addressing nonpharmacological trials. This checklist has been successfully used in previous meta-analytic studies of internet-delivered interventions for depression [27] and anxiety [28]. This checklist features 10 questions and 5 subquestions, predominantly requiring an answer of yes, no, or unclear. The questions concerned the adequacy of randomization; availability of details of the interventions; appropriateness of supporters' skills; treatment adherence measurement; blinding of those involved or, if not, notification of steps taken to prevent bias; consistency across conditions' follow-up schedules; and whether an intention-to-treat principle of analysis was followed. Two researchers (RW and AL) independently completed the CLEAR NPT checklist for all studies on the primary outcomes of depression and anxiety. Conflicts were resolved by checking and discussing the given study and, if further clarity was required, by consulting the first author (NE). Risk of bias assessments were detailed narratively rather than incorporated into meta-analytic models, as the CLEAR NPT checklist does not provide an overall degree of study quality.

## Meta-analytic Procedures

Effect sizes were calculated either from observed means and SDs or estimated marginal means, SEs, and Cohen *d*, if available, with the latter taking precedence if both were reported within a given study. The formulas provided by Borenstein et al [29] were used to calculate Hedges *g* and its SE. In 3-arm



trials in which either both active arms met the inclusion criteria or 2 different types of control groups were implemented, the sample sizes of the group that was to be entered into the analysis twice was halved to allow for the calculation of separate effect sizes by trial arm [30]. For effect size, we implemented the following cut-off points: 0-0.32 for a small effect, 0.33-0.55 for a moderate effect, and 0.56-1.2 for a large effect [31].

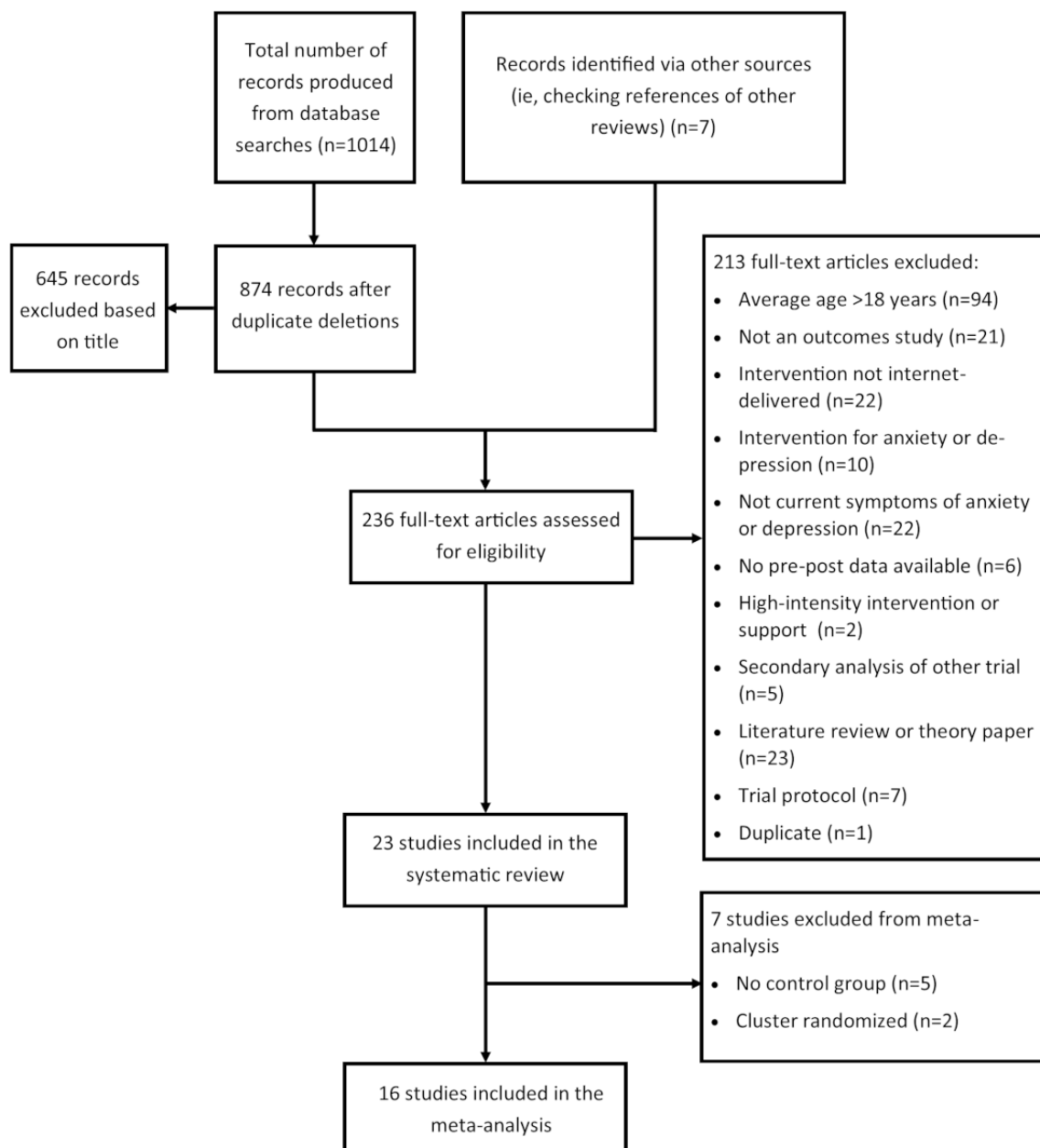
All analyses were conducted in R (R Foundation for Statistical Computing) using the *meta*, *metafor*, and *dmeta* packages [32-34]. In line with the protocol [35], random-effects models were used to pool effect sizes to account for the anticipated moderate to high levels of between-study heterogeneity. Between-study variance was estimated via restricted maximum likelihood, and heterogeneity was assessed using the  $Q$  value,  $I^2$  statistic, and prediction intervals (PIs). According to Higgins and Thompson [36], an  $I^2$  value of 0% indicates no heterogeneity, 25% indicates low heterogeneity, 50% indicates moderate heterogeneity, and 75% indicates high heterogeneity. The presence of outliers and model fit was assessed using diagnostic plots and statistics. Owing to the inclusion of studies with narrow and wide focus on intervention aim and content, forest plots detailing primary outcomes by intervention focus (anxiety, low mood and/or depression, or transdiagnostic) were selected to ensure reporting clarity. In a deviation from the registered protocol [35], follow-up between-group effects were assessed through the same models as posttreatment effects, where this was feasible (ie, a sufficient number of studies

included relevant data). Where multiple follow-up time points were available for one study, the longest follow-up time point was selected. To explore various potential moderators, mixed-effect models of primary outcomes (anxiety and depression) using the Knapp-Hartung method to reduce the chance of a type 1 error were conducted. Moderators were only explored statistically if there were at least six moderate to large studies with data available for any continuous moderator and four moderate to large studies per subgroup for categorical moderators [37]. Funnel plots and Egger [38] test were used to explore publication bias.

## Results

### Selection and Inclusion of Studies

The database searches resulted in 1014 articles, whereas an additional 11 results were obtained from other sources (refer to the *Literature Search* section). Duplicate removal left 874 articles, 645 of which were excluded based on the title. The full-text versions of the remaining 236 articles were assessed for potential eligibility, of which 213 did not meet the eligibility criteria and were excluded. Finally, 23 studies were deemed eligible for the systematic review, and an additional 7 studies were excluded from the meta-analysis because of not having conducted an RCT. A total of 16 studies met the inclusion criteria for meta-analysis. The study selection process and reasons for exclusion are summarized in [Figure 1](#).

**Figure 1.** Flow of selection and exclusion of studies.

## Description of Included Studies

### Overview

This review reports 16 RCTs and 7 non-RCTs published in English, the main characteristics of which are presented in [Tables 2](#) and [3](#). A total of 6981 participants were included, ranging in age from 3 to 21 years and recruited through school,

email, flyers, websites, local media (radio, newspaper, etc), social media, youth centers, guardians, or parent groups. A total of 11 studies involved recruitment from different care settings such as general practitioners, mental health professionals, mental health services, and clinics. Moreover, 6 studies were conducted in Sweden; 6 in Australia; 5 in the Netherlands; and 1 each in China, Canada, Denmark, Iran, New Zealand, and the United States.

**Table 2.** Study characteristics, constructs of interest, and outcome measures used across meta-analyses.

| Study and country                              | Sample size (N) <sup>a</sup>              | Age, mean (range) | Eligibility criteria  | Control (n)                          | Outcomes included in meta-analysis         |                    |                                    |   |
|--|---|-------------------|---|--------------------------------------|--|--------------------|------------------------------------|---|
|  |   |                   |   |                                      | Anxiety                                    | Depression         | Impaired functioning               | Quality of life                                 |
| <b>Anderson et al, 2012 [39]</b>               |   |                   |   |                                      |  |                    |                                    |   |
| Australia                                      | N=132 (female 70, male 62)                | 12.12 (7-18)      | Structured clinical interview   | No control group                     | — <sup>b</sup>                             | —                  | —                                  | —   |
| <b>Conaughton et al, 2017 [40]<sup>c</sup></b> |   |                   |   |                                      |  |                    |                                    |   |
| Australia                                      | N=42 (female 6, male 36)                  | 9.74 (8-12)       | Structured clinical interview   | Wait-list (n=21)                     | SCAS-C/P <sup>d</sup>                      | —                  | CGAS <sup>e</sup> -clinician rated | —   |
| <b>de Voogd et al, 2017 [41]<sup>c</sup></b>   |   |                   |   |                                      |  |                    |                                    |   |
| The Netherlands                                | N=119 (female 75, male 44)                | 15.68 (12-18)     | >16 SCARED <sup>f</sup> or >7 CDI <sup>g</sup>  | Placebo (n=39)                       | SCARED                                     | CDI                | —                                  | —   |
| <b>de Voogd et al, 2017 [42]<sup>c</sup></b>   |   |                   |   |                                      |  |                    |                                    |   |
| The Netherlands                                | N=108 (female 72, male 36)                | 14.45 (11-19)     | >16 SCARED or >7 CDI  | Placebo (n=32), wait-list (n=38)     | SCARED                                     | CDI                | —                                  | —   |
| <b>Hoek et al, 2012 [43]<sup>c</sup></b>       |   |                   |   |                                      |  |                    |                                    |   |
| The Netherlands                                | N=45, (female 34, male 11)                | 16.07 (12-21)     | Self-report (mild to moderate depressive and/or anxiety symptoms, NIMH DISC-IV <sup>h</sup> ) | Wait-list (n=23)                     | HADS-A <sup>i</sup>                        | CES-D <sup>j</sup> | —                                  | —   |
| <b>Ip et al, 2016 [44]<sup>c</sup></b>         |   |                   |   |                                      |  |                    |                                    |   |
| China  | N=257 (female 175; male 82)               | 14.6 (13-17)      | CESD-R score of 12-40   | Attention control (n=127)            | DASS-21 <sup>k</sup> anxiety sub-scale     | CESD-R             | —                                  | —   |
| <b>Jolstedt et al, 2018 [45]<sup>c</sup></b>   |   |                   |   |                                      |  |                    |                                    |   |
| Sweden   | N=131, (female 70, male 61)               | 9.75 (8-12)       | >Moderate anxiety disorder diagnosis  | Web-based child-directed play (n=65) | RCADS <sup>l</sup> -child and parent rated | —                  | CGAS-clinician rated               | KID-SCREEN <sup>m</sup> -child and parent rated |
| <b>Lindqvist et al, 2020 [46]<sup>c</sup></b>  |   |                   |   |                                      |  |                    |                                    |   |
| Sweden   | N=76 (female 61, male 15)                 | 16.6 (15-18)      | Unipolar major depressive disorder diagnosis (≥10 on the QIDS-A17-SRs <sup>n</sup> )          | Web-based supportive contact (n=38)  | GAD-7 <sup>o</sup>                         | QIDS-A17-SR        | —                                  | —   |
| <b>March et al, 2018 [47]</b>                  |   |                   |   |                                      |  |                    |                                    |   |
| Australia                                      | N=4425 (female 2938, male 1406, other=81) | 12.95 (7-17)      | ≥84th percentile or <i>t</i> score ≥60 on the CAS-8 <sup>p</sup>                              | No control group                     | —  | —                  | —                                  | —   |
| <b>Moeini et al, 2019 [48]</b>                 |   |                   |   |                                      |  |                    |                                    |   |
| Iran   | N=128 (female 128)                        | 16.2 (15-18)      | CES-D score of 10-45  | Cluster-randomized control only      | —  | —                  | —                                  | —   |
| <b>Morgan et al, 2017 [49]<sup>c</sup></b>     |   |                   |   |                                      |  |                    |                                    |   |

| Study and country                               | Sample size (N) <sup>a</sup>                         | Age, mean (range) | Eligibility criteria  | Control (n)  | Outcomes included in meta-analysis |  |                                     |                    |  |
|---|--|-------------------|---|--|------------------------------------|--|-------------------------------------|--------------------|--|
|   |  |                   |   |  | Anxiety                            | Depression                                 | Impaired functioning                | Quality of life    |  |
| Australia                                       | N=433 (female 228, male 205)                         | 4.8 (3-6)         | Temperamental inhibition (>30 on the Approach subscale of the STSC <sup>d</sup> )                                     | Wait-list (n=218)                                      | PAS-R <sup>f</sup> -parent rated   | —  | CALIS-PV <sup>g</sup> -parent rated | —                  |  |
| <b>Reuland and Teachman, 2014 [50]</b>          |  |                   |   |  |                                    |  |                                     |                    |  |
| United States                                   | N=18 (female 13, male 5)                             | 13 (10-15)        | Structured clinical interview   | No control group                                       | —                                  | —  | —                                   | —                  |  |
| <b>Rickhi et al, 2015 [51]<sup>c</sup></b>      |  |                   |   |  |                                    |  |                                     |                    |  |
| Canada  | Adolescent subgroup only<br>N=31 (female 26, male 5) | 15.3 (12-18)      | CDRS-R <sup>t</sup> score of 40-70  | Wait-list (n=13)                                       | —                                  | CDRS-R                                     | —                                   | —                  |  |
| <b>Silfvernag et al, 2015 [52]</b>              |  |                   |   |  |                                    |  |                                     |                    |  |
| Sweden  | N=11 (female 6, male 5)                              | 16.8 (15-19)      | Structured clinical interview   | No control   | —                                  | —  | —                                   | —                  |  |
| <b>Spence et al, 2011 [53]<sup>c</sup></b>      |  |                   |   |  |                                    |  |                                     |                    |  |
| Australia                                       | N=115 (female 68, male 47)                           | 13.98 (12-18)     | Primary diagnosis of generalized anxiety disorder, separation anxiety disorder, social phobia, or specific phobia     | Face-to-face CBT <sup>u</sup> (n=44), wait-list (n=27) | SCAS-C/P                           | —  | CGAS-clinician rated                | —                  |  |
| <b>Spence et al, 2017 [54]<sup>c</sup></b>      |  |                   |   |  |                                    |  |                                     |                    |  |
| Australia                                       | N=125 (female 75, male 50)                           | 11.29 (8-17)      | Structured clinical interview   | Wait-list (n=30)                                       | SCAS-C/P                           | —  | CGAS-clinician rated                | —                  |  |
| <b>Sportel et al, 2013 [55]</b>                 |  |                   |   |  |                                    |  |                                     |                    |  |
| The Netherlands                                 | N=240 (female 174, male 66)                          | 14.1 (13-15)      | Structured clinical interview   | Cluster-randomized groups only                         | —                                  | —  | —                                   | —                  |  |
| <b>Stasiak et al, 2016 [56]</b>                 |  |                   |   |  |                                    |  |                                     |                    |  |
| New Zealand                                     | N=42 (female 22, male 20)                            | 11.1 (7-15)       | Structured clinical interview   | No control group                                       | —                                  | —  | —                                   | —                  |  |
| <b>Stjerneklar et al, 2019 [57]<sup>c</sup></b> |  |                   |   |  |                                    |  |                                     |                    |  |
| Denmark   | N=70 (female 55, male 15)                            | 15 (13-17)        | Structured clinical interview   | Wait-list (n=35)                                       | SCAS-C/P                           | MFQ-S <sup>v</sup> -child and parent rated | CALIS <sup>w</sup> -child rated     | WHO-5 <sup>x</sup> |  |
| <b>Tillfors et al, 2011 [25]<sup>c</sup></b>    |  |                   |   |  |                                    |  |                                     |                    |  |
| Sweden  | N=19 (female 17, male 2)                             | 16.5 (15-21)      | Cutoff for social anxiety disorder (Social Phobia Screening Questionnaire for Children)                               | Wait-list (n=9)  | BAI <sup>y</sup>                   | MADRS-S <sup>z</sup>                       | —                                   | QOLI <sup>aa</sup> |  |
| <b>Topooco et al, 2019 [58]<sup>c</sup></b>     |  |                   |   |  |                                    |  |                                     |                    |  |
| Sweden  | N=70 (female 67, male 3)                             | 17.5 (15-19)      | Depressive symptoms (BDI-II <sup>ab</sup> score ≥14) or major depressive episode as per structured clinical interview | Minimal attention control (n=35)                       | BAI                                | BDI-II                                     | —                                   | BBQ <sup>ac</sup>  |  |

| Study and country                             | Sample size (N) <sup>a</sup> | Age, mean (range) | Eligibility criteria  | Control (n)                                  | Outcomes included in meta-analysis              |            |                      |                 |
|---|------------------------------|-------------------|---|--|---|------------|----------------------|-----------------|
|   |                              |                   |   |  | Anxiety   | Depression | Impaired functioning | Quality of life |
| <b>Topper et al, 2017 [59]<sup>c</sup></b>    |                              |                   |   |  |   |            |                      |                 |
| The Netherlands                               | N=251 (female 210, male 41)  | 17.45 (15-22)     | Excessive levels of worry and rumination as per population percentile cutoffs | In-person group CBT (n=82), wait-list (n=85) | MASQ-D30 <sup>ad</sup> anxiety arousal subscale | BDI-II     | —                    | —               |
| <b>Vigerland et al, 2016 [21]<sup>c</sup></b> |                              |                   |   |  |   |            |                      |                 |
| Sweden  | N=93 (female 51, male 42)    | 10.1 (8-12)       | Structured clinical interview   | Wait-list (n=47)                             | SCAS-C/P  | —          | CGAS-clinician rated | QOLI-C          |

<sup>a</sup>Where applicable, sample size is presented as the number male and female participants.

<sup>b</sup>Not available.

<sup>c</sup>Study included in the meta-analysis.

<sup>d</sup>SCAS-C/P: Spence Children's Anxiety Scale-Parent Version and Child Version.

<sup>e</sup>CGAS: Children's Global Assessment Scale.

<sup>f</sup>SCARED: Screen for Child Anxiety-Related Emotional Disorders.

<sup>g</sup>CDI: Children's Depression Inventory.

<sup>h</sup>NIMH DISC-IV: National Institute of Mental Health Diagnostic Interview Schedule for Children Version IV.

<sup>i</sup>HADS-A: Hospital Anxiety and Depression Scale (Anxiety Subscale).

<sup>j</sup>CES-D: Centre for Epidemiologic Studies Depression Scale (also CESD-Revised).

<sup>k</sup>DASS-21: Depression Anxiety and Stress Scale.

<sup>l</sup>RCADS: Revised Children's Anxiety and Depression Scale.

<sup>m</sup>KIDSCREEN-C/P: Health Related Quality of Life Questionnaire for Children and Young People and their Parents.

<sup>n</sup>QIDS-A17-SR: Quick Inventory of Depressive Symptomatology for Adolescents.

<sup>o</sup>GAD-7: Generalized Anxiety Disorder 7-item scale.

<sup>p</sup>CAS-8: Spence Children's Anxiety Scale-8 item Version.

<sup>q</sup>STSC: Short Temperament Scale for Children.

<sup>r</sup>PAS-R: Revised Preschool Anxiety Scale.

<sup>s</sup>CALIS-PV: Children's Anxiety Life Interference Scale-Preschool Version.

<sup>t</sup>CDRS-R: Children's Depression Rating Scale-revised.

<sup>u</sup>CBT: cognitive behavioral therapy.

<sup>v</sup>MFQ-S: Mood and Feelings Questionnaire.

<sup>w</sup>CALIS: Children's Anxiety Life Interference Scale.

<sup>x</sup>WHO-5: World Health Organization-Five Well-Being Index.

<sup>y</sup>BAI: Beck Anxiety Inventory.

<sup>z</sup>MADRS-S: Montgomery Åsberg Depression Rating Scale-Self-rated.

<sup>aa</sup>QOLI: Quality of Life Inventory (also QOLI-Child Version).

<sup>ab</sup>BDI-II: Beck Depression Inventory.

<sup>ac</sup>BBQ: Brunnsviden Brief Quality of Life Scale.

<sup>ad</sup>MASQ-D30: Mood and Anxiety Symptom Questionnaire.



**Table 3.** Description of recruitment strategies and interventions used within studies included in meta-analyses.

| Study and intervention (n)  | Recruitment source   | Number of modules and intervention duration           | Support   | Intervention engagement  |
|---|--|---|---|--|
| <b>Anderson et al, 2012 [39]</b>  |  |   |   |  |
| iCBT <sup>a</sup> for anxiety disorders delivered to youth and parents (n=132)  | Recruited via advertising in the media and referrals from guidance officers and mental health professionals  | 15-16 (10 youth and 5-6 parent modules) over 12 weeks | Weekly emails and one 15-minute telephone call with clinician                                     | Youth completed an average of 8.86 out of 10 sessions; parents completed an average of 4.76 out of 5 or 5.74 out of 6 sessions if assigned 6.                |
| <b>Conaughton et al, 2017 [40]<sup>b</sup></b>  |  |   |   |  |
| iCBT for anxiety disorders delivered to youth and parents (n=21)  | Recruited via advertising in the media and referrals from guidance officers, teachers, parents, GPs <sup>c</sup> , and mental health professionals and self-referral | 16 (10 youth and 6 parent modules) over 10 weeks      | Weekly web-based contact and one short phone call with a therapist                                | Youth completed an average of 6.7 out of 10 sessions; parents completed an average of 4.86 out of 6 sessions.  |
| <b>de Voogd et al, 2017 [41]<sup>b</sup></b>  |  |   |   |  |
| iCBM <sup>d</sup> for anxiety and depression delivered to youth (scenario training n=36; picture-based training n=44) | Recruited from 4 secondary schools   | 8 modules over 4 weeks                                | No support  | Those in scenario training completed an average of 5.56 out of 8 modules, and those in picture-based training completed an average of 5.91 out of 8 reviews. |
| <b>de Voogd et al, 2017 [42]<sup>b</sup></b>  |  |   |   |  |
| iABM <sup>e</sup> for anxiety and depression delivered to youth (n=38)  | Recruited from 4 secondary schools   | 8 modules over 4 weeks                                | No support  | Participants completed an average of 5.74 out of 8 modules.  |
| <b>Hoek et al, 2012 [43]<sup>b</sup></b>  |  |   |   |  |
| Internet-based problem-solving therapy for depression and anxiety delivered to youth (n=22)                           | Recruitment via advertising in schools, mental health clinics, and media and referrals from school doctors   | 5 modules over 5 weeks                                | Weekly automated emails and exercise feedback via email by mental health professional and authors | 6 participants completed 5 out of 5 modules, 10 completed ≥3, 5 completed 1-2, and 1 participant completed none of the modules.                              |
| <b>Ip et al, 2016 [44]<sup>b</sup></b>  |  |   |   |  |
| Integrative iCBT for major depression prevention (CATCH-IT <sup>f</sup> ) delivered to youth (n=130)                  | Recruited from 3 secondary schools (1 all-girls and 2 coeducational schools)   | 10 modules over 8 months                              | No support  | 26 participants completed 10 out of 10 modules; 55 participants completed 5 or more modules.   |
| <b>Jolstedt et al, 2018 [45]<sup>b</sup></b>  |  |   |   |  |
| Exposure-based iCBT for anxiety delivered to parents and youth (n=66)   | Recruited via advertising and referrals from mental health services  | 12 modules over 12 weeks                              | Weekly asynchronous web-based therapist support   | Those in treatment completed an average of 8.91 out of 12 modules.   |
| <b>Lindqvist et al, 2020 [46]<sup>b</sup></b>   |  |   |   |  |
| Internet-based, affect-focused psychodynamic therapy for depression delivered to youth (n=38)                         | Recruited via advertising on social media, youth centers, and clinics  | 8 modules over 8 weeks                                | Web-based feedback and 30-minutes weekly chat with a therapist                                    | Participants completed an average of 5.8 out of 8 modules and attended 6.6 out of 8 chat sessions.   |
| <b>March et al, 2018 [47]</b>   |  |   |   |  |
| iCBT for anxiety delivered to youth (n=4425)  | Recruited via self-referral, health or education staff, and advertising health information web sites   | 10 modules over 20 weeks                              | No support  | Average number of modules completed was 2.21 out of 10; 21.65% of participants did not complete the first module.  |
| <b>Moeini et al, 2019 [48]</b>  |  |   |   |  |

| Study and intervention (n)   | Recruitment source   | Number of modules and intervention duration            | Support  | Intervention engagement   |
|--|--|--|--|---|
| iCBT based on social cognitive theory applications for depression delivered to youth (n=64)            | Recruited from all-girls high schools  | 8 modules over 12 weeks                                | Web-based messages from psychiatrist   | — <sup>g</sup>  |
| <b>Morgan et al, 2017 [49]<sup>b</sup></b>   |  |  |  |   |
| iCBT (Cool Little Kids on-line) for anxiety delivered to parents (n=215)                               | Recruited via web-based advertising and flyers distributed to preschool services                                   | 8 modules over 24 weeks                                | Support-on-demand (psychologist)   | Average number of modules accessed was 4 out of 8.  |
| <b>Reuland and Teachman, 2014 [50]</b>   |  |  |  |   |
| iCBM for social anxiety delivered to only youth, only parent, or youth and parents concurrently (n=18) | Recruited via flyers, advertisements, and social networking  | 8 modules (duration: N/A)                              | Unsupported with 90-minute group meetings to obtain youth feedback on intervention | —   |
| <b>Rickhi et al, 2015 [51]<sup>b</sup></b>   |  |  |  |   |
| Spirituality-informed e-mental health tool for major depression delivered to youth (n=18)              | Adolescent subgroup recruited via email, posters, media, schools, health professionals, and youth organizations    | 8 modules over 8 weeks                                 | No support   | 4 out of 31 participants completed less than half of the modules, 2 completed more than half, and 25 completed all modules.                                 |
| <b>Silfvernag et al, 2015 [52]</b>   |  |  |  |   |
| Tailored iCBT for anxiety disorders delivered to youth (n=11)  | Referral via guardian, clinic, and self-referral   | 6-9 modules over 6-18 weeks                            | Telephone or face-to-face support (if needed)                                      | Average number of modules completed was 5.  |
| <b>Spence et al, 2011 [53]<sup>b</sup></b>   |  |  |  |   |
| iCBT for anxiety disorders delivered to youth and parents (n=44)                                       | Recruited via media advertising and referrals from school guidance officers, GPs, and mental health professionals  | 15 (10 youth and 5 parent session) over 12 weeks       | Email feedback after each session and one 15-minute phone review call by therapist | Average number of sessions completed was 7.5 out of 10 for youth and 4.48 out of 5 for parents.   |
| <b>Spence et al, 2017 [54]<sup>b</sup></b>   |  |  |  |   |
| Social anxiety-specific iCBT (n=47) and generic iCBT for anxiety (n=48) delivered to youth and parents | Recruited via schools, parent groups, mental health professionals, guidance officers, the media, and self-referral | 15-16 (10 youth and 5-6 parent sessions) over 12 weeks | Email feedback after each session and one 15-minute phone review call by therapist | Youth completed on average 4-4.75 out of 10 sessions, and parents completed on average 4.32 out of 6 or 3.18 out of 5 sessions.                             |
| <b>Sportel et al, 2013 [55]</b>  |  |  |  |   |
| iCBM for social anxiety delivered to youth (n=86)  | Recruited via 24 schools   | 20 over 10 weeks                                       | No support   | iCBM participants completed on average 8.5 out of 20 sessions.  |
| <b>Stasiak et al, 2016 [56]</b>  |  |  |  |   |
| iCBT for anxiety disorders delivered to youth (n=42)   | Recruited through referrals from GPs and school public health nurses   | 15-16 modules (10 youth and 5-6 parent) over 12 weeks  | Feedback to child and parent and one 30-minute phone call with therapist           | Average number of sessions completed by youth was 4.48 out of 10; it was 4.3 out of 6 for parents of children, and 2.3 out of 5 for parents of adolescents. |
| <b>Stjerneklar et al, 2019 [57]<sup>b</sup></b>  |  |  |  |   |
| iCBT (ChilledOut online) for anxiety delivered to youth (n=35)   | Recruited via advertising and referrals from local health services   | 8 modules over 14 weeks                                | Weekly phone calls (average 20 mins) with therapist                                | Participants completed on average 5.4 out of 8 modules (excluding 2 participants who dropped out).  |
| <b>Tillfors et al, 2011 [25]<sup>b</sup></b>   |  |  |  |   |
| iCBT for social anxiety delivered to youth (n=10)  | Recruited via advertising newspapers and in schools  | 9 modules over 9 weeks                                 | Email feedback after each homework assignment by therapist                         | Participants finished on average 2.9 out of 9 modules.  |

| Study and intervention (n)   | Recruitment source  | Number of modules and intervention duration     | Support   | Intervention engagement   |
|--|---|---|---|---|
| <b>Topooco et al, 2019 [58]<sup>b</sup></b>  |   |   |   |   |
| iCBT for depression delivered to youth (n=35)  | Recruited via social media posts, schools, youth centers, and clinics | 8 modules over 8 weeks                          | Weekly synchronous therapist support sessions via platform chat feature                     | Participants completed on average 6.2 out of 8 modules and 5.7 out of 8 chat sessions.          |
| <b>Topper et al, 2017 [59]<sup>b</sup></b>   |   |   |   |   |
| Rumination-focused iCBT for anxiety disorder and major depression prevention delivered to youth (n=84) | Recruited through 13 secondary schools and 2 universities             | 6 modules over 6 weeks                          | Clinical psychologist offered feedback after each session                                   | Those who started iCBT completed an average of 3.96 out of 6 sessions; 9.9% did not start iCBT. |
| <b>Vigerland et al, 2016 [21]<sup>b</sup></b>  |   |   |   |   |
| iCBT for anxiety disorders delivered to both youth and parents (n=46)                                  | Recruited via media advertisement and self-referral                   | 11 (4 youth and 7 parent) modules over 10 weeks | Web-based messages or feedback, 3 phone calls, and optional additional calls with therapist | Average number of modules completed was 9.7 out of 11.  |

<sup>a</sup>iCBT: internet-delivered cognitive behavioral therapy.

<sup>b</sup>Study included in meta-analysis.

<sup>c</sup>GP: general practitioner.

<sup>d</sup>iCBM: internet-delivered cognitive bias modification.

<sup>e</sup>iABM: internet-delivered attentional bias modification.

<sup>f</sup>CATCH-IT: Competent Adulthood Transition with Cognitive Behavioral Humanistic and Interpersonal Training (Chinese adaptation).

<sup>g</sup>Information not available.

### Description of Studies Included in the Meta-analysis

Across RCT studies, sample sizes ranged from 19 [25] to 433 [49], with 977 in internet-delivered treatment conditions and 1008 in control conditions. There were 21 comparisons conducted across the 16 RCTs, 13 of which featured a wait-list control and 8 implemented active controls (2 placebo bias modification programs, 2 attention controls, 1 internet-delivered child-directed play, 1 internet supportive contact, 1 face-to-face CBT, and 1 group CBT). A total of 12 active treatment comparisons implemented a form of internet-delivered cognitive behavioral therapy (iCBT), 3 featured internet-delivered cognitive or attentional bias modification interventions (internet-delivered cognitive bias modification [iCBM] or internet-delivered attentional bias modification), 1 implemented a problem-solving therapy, 1 implemented an affect-focused psychodynamic therapy, and 1 implemented a spirituality-informed intervention. Most of these interventions were delivered to CYP, and 5 interventions were also delivered to the parents; however, 1 intervention was delivered to parents only [49]. The RCTs included participants with at least mild to moderate symptoms or those who met the diagnostic criteria for a primary disorder of anxiety or depression assessed via structured clinical interviews or self-report measures. Most studies (12/16, 75%) provided some form of regular scheduled feedback or assistance from a therapist, psychologist, or mental health professional. One study provided support only when requested by participants [49]. Support provided across the range of studies consisted of email, treatment platform chat, or phone calls, or no support. The duration of treatment ranged from 4 weeks [41,42] to 8 months [44], whereas the number of intervention modules ranged from 5, offered to CYP only [43],

to 16, offered to both parents and CYP [40,54]. Tables 2 and 3 provide an overview of these findings.

### Description of Studies Excluded From the Meta-analysis

Of the studies not eligible for inclusion in the meta-analysis (n=7), the sample sizes ranged from 11 [52] to 4425 [47]. A total of 5 studies implemented a form of iCBT and 2 studies implemented iCBM, with treatment periods ranging from 6 [52] to 20 weeks [47], whereas the number of modules ranged from 6 [52] to 20 [55]. All non-RCTs used a clinical measure of the constructs of interest, either in a self-report format or through clinical interviews, to establish their eligibility criteria, which ranged from mild to moderate symptoms of depression or anxiety to diagnosis of clinical symptoms. Most interventions were website-based platforms, and 4 interventions provided some form of support from a qualified or soon-to-be qualified therapist, psychiatrist, or clinician. The aim of support was mainly to offer feedback, motivation, or assistance with the treatment content and consisted of email, webpage messaging, and telephone calls, and 1 study provided face-to-face support if needed. However, 3 non-RCTs were unsupported. The majority of interventions were delivered to CYP, 2 studies delivered the intervention to parents as well as CYP, and 1 of these included a comparison condition delivering the intervention to parents only [50].

### Meta-analysis of Primary and Secondary Outcomes

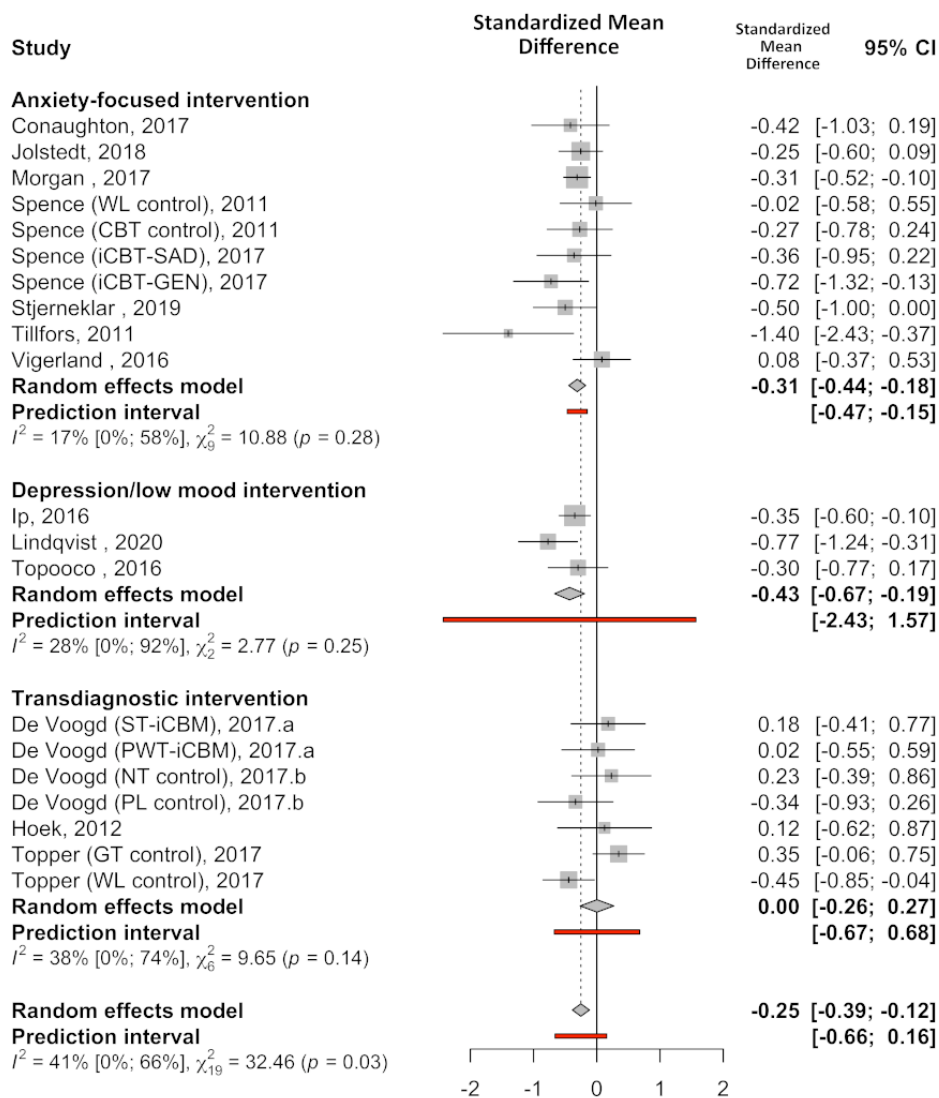
#### Random-Effects Model for Anxiety

On the basis of 20 comparisons (across 15 studies), including anxiety-focused interventions (n=8), depression-focused interventions (n=3), and transdiagnostic interventions (n=4), a

small effect on anxiety symptoms in favor of internet-delivered treatment was detected (Hedges  $g=-0.25$ , 95% CI  $-0.38$  to  $-0.12$ ;  $P<.001$ ). Heterogeneity in the observed effect sizes appeared moderate ( $Q_{19}=32.42$ ;  $P=.03$ ;  $I^2=41.4\%$ ), with the PI crossing the zero line of no effect (95% PI  $-0.66$  to  $0.15$ ). Model diagnostics suggested one potential outlier [59] (CBT group-treatment control arm). Excluding this study from the analysis resulted in a reduction of heterogeneity, a moderate effect estimate (Hedges  $g=-0.50$ , 95% CI  $-0.40$  to  $-0.20$ ;

$P<.001$ ;  $Q_{18}=23.29$ ;  $P=.18$ ;  $I^2=22.7\%$ ), and a narrower PI no longer crossing zero (95% PI  $-0.41$  to  $-0.19$ ). Testing for subgroup differences between anxiety-focused interventions, depression-focused interventions, and transdiagnostic interventions revealed significantly different effect estimates by intervention focus ( $Q_2=6.13$ ;  $P=.046$ ). Figure 2 [21,25,40-46,49,53,54,57-59] shows the meta-analysis outcomes overall and by intervention focus.

**Figure 2.** Posttreatment standardized mean difference (Hedges  $g$ ) between internet-delivered treatment and control groups for anxiety outcomes by intervention focus [21,25,40-46,49,53,54,57-59]. CBT: cognitive behavioral therapy; GT: group treatment; iCBT-GEN: generic internet-delivered cognitive behavioral therapy; iCBT-SAD: internet-delivered cognitive behavioral therapy for social anxiety disorder; NT: no treatment; PL: placebo; PWT-iCBM: picture-word training internet-delivered cognitive bias modification; ST-iCBM: scenario training internet-delivered cognitive bias modification; WL: wait-list.

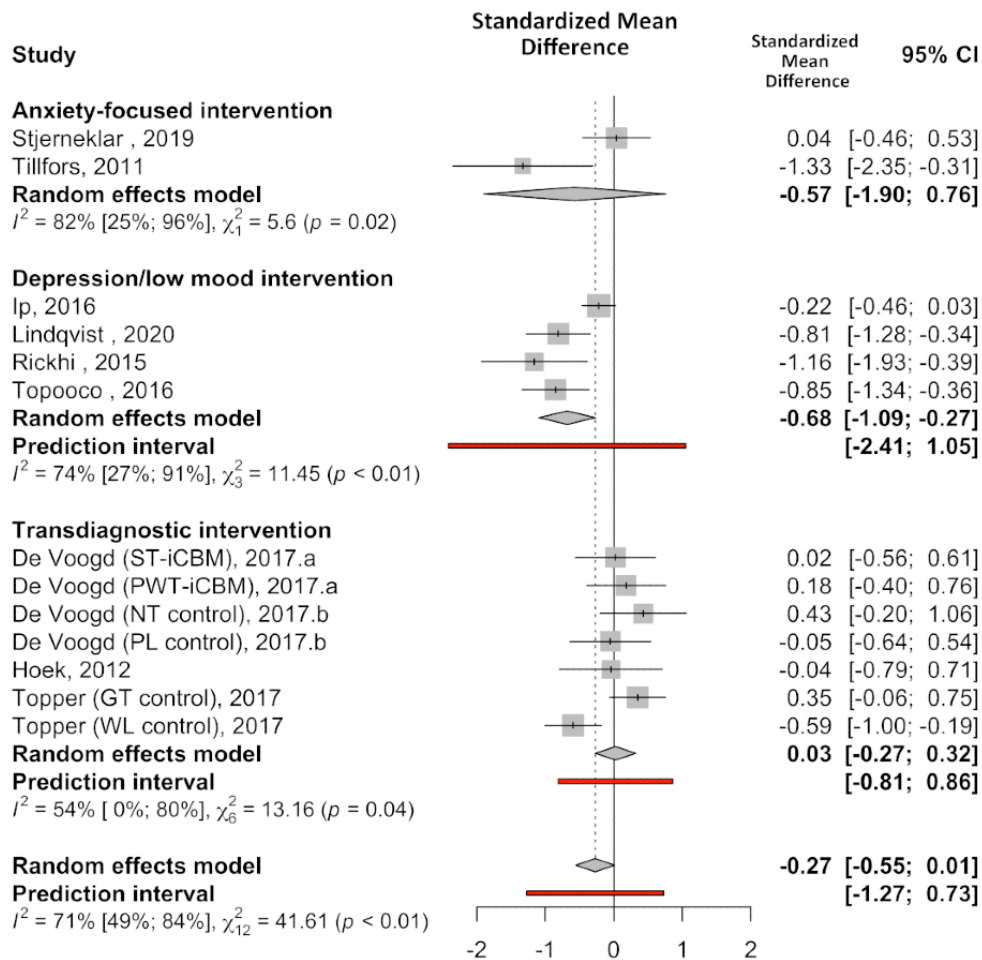


**Random-Effects Model for Depression**

Drawing on 13 comparisons (across 10 studies) and assessing depressive symptoms in the context of depression or low mood interventions (n=4), anxiety-focused interventions (n=2), and transdiagnostic interventions (n=4), a small effect bordering significance and favoring internet-delivered treatment was observed (Hedges  $g=-0.27$ , 95% CI  $-0.55$  to  $0.01$ ;  $P=.06$ ). There was a high amount of heterogeneity ( $Q_{12}=42.02$ ;  $P<.001$ ;

$I^2=71.4\%$ ), resulting in a wide PI spanning the zero line of no effect (95% PI  $-1.27$  to  $0.73$ ). The model diagnostics suggested the absence of outliers. Subgroup analyses suggested that effect sizes differed by intervention focus ( $Q_2=7.75$ ;  $P=.02$ ), with depression-focused interventions presenting with the largest effect estimate (Hedges  $g=-0.68$ , 95% CI  $-1.10$  to  $-0.27$ ;  $P=.001$ ). Refer to Figure 3 [25,41-44,46,51,57-59] for further details.

**Figure 3.** Posttreatment standardized mean difference (Hedges g) between internet-delivered treatment and control groups for depression outcomes by intervention focus [25,41-44,46,51,57-59]. GT: group treatment; NT: no treatment; PL: placebo; PWT-iCBM: picture-word training internet-delivered cognitive bias modification; ST-iCBM: scenario training internet-delivered cognitive bias modification; WL: wait-list.



**Random-Effects Model for Impaired Functioning**

The overall effect of treatment on levels of functioning across the 9 comparisons (7 studies) was moderate (Hedges  $g=0.52$ , 95% CI 0.24-0.80;  $P<.001$ ). Heterogeneity was moderate to high ( $Q_8=23.27$ ;  $P=.003$ ;  $I^2=65.6\%$ ), and the PI was wide (95% PI -0.38 to 1.43). One potential outlier [40] was detected, whose removal resulted in a smaller effect estimate (Hedges  $g=0.38$ , 95% CI 0.22-0.54;  $P<.001$ ) but significantly improved heterogeneity ( $Q_7=9.25$ ;  $P=.16$ ;  $I^2=29.6\%$ , 95% PI 0.06-0.70). Refer to Figure S1 in Multimedia Appendix 2 [21,40-45,53-55,57,59] for further details.

**Random-Effects Model for Quality of Life**

In terms of quality of life, outcomes across the 5 comparisons (5 studies) detected no significant effect of treatment (Hedges  $g=-0.01$ , 95% CI -0.23 to 0.21;  $P=.94$ ). The  $I^2$  and  $Q$  value metrics suggested little heterogeneity ( $Q_4=4.70$ ;  $P=.32$ ;  $I^2=14.9\%$ , 95% PI -0.41 to 0.39), and model diagnostics suggested no outliers. Refer to Figure S2 in Multimedia Appendix 2 for further details.

**Meta-analysis of Follow-up Outcomes**

For anxiety outcomes, pooling of 7 follow-up effect sizes (across 4 studies) revealed no significant effect (Hedges  $g=-0.17$ , 95% CI -0.58 to 0.24;  $P=.42$ ), with no heterogeneity or outliers detected ( $Q_6=0.70$ ;  $P=.99$ ;  $I^2=0\%$ , 95% PI -0.71 to 0.37). Refer to Figure S3 in Multimedia Appendix 2 for further details. A similar picture emerged for depression outcomes across 8 comparisons (5 studies). The effect estimate remained insignificant (Hedges  $g=-0.18$ , 95% CI -0.39 to 0.03;  $P=.09$ ), heterogeneity was low ( $Q_7=7.02$ ;  $P=.43$ ;  $I^2=0.4\%$ , 95% PI -0.61 to 0.25), and no outliers were detected. Refer to Figure S4 in Multimedia Appendix 2 for further details.

**Moderator Analyses**

Moderator analyses suggested a relationship between the percentage of a study’s sample that was identified as female and the depression effect sizes observed in these studies ( $F_{1,11}=6.04$ ;  $P=.03$ ). Higher percentages of females in the study were associated with larger between-group effect sizes for depression outcomes ( $b=-0.03$ ,  $SE=0.01$ ), accounting for 33.93% of the observed heterogeneity. All other moderator analyses were either insignificant (refer to Table S1 in Multimedia Appendix 2) or not feasible owing to a limited



number of studies falling into specific categories (ie, intervention delivered to parents only, iCBM intervention, and face-to-face treatment control group).

## Quality of Studies

### Risk of Bias

Following screening based on the criteria outlined in the CLEAR NPT checklist, the methodological quality assessment ratings were satisfactory across the included studies. The allocation sequence generation was considered adequate in 88% (15/17) of the studies; all studies provided clear descriptions of the intervention administered, and all studies quantitatively assessed participant adherence. All but one study [21] analyzed the outcomes using an intention-to-treat principle. The percentage of studies that adequately detailed their allocation concealment method was 82% (14/17). Clear documentation that care providers had appropriate experience or skill was given in 82% (14/17) of the studies, whereas for 18% (3/17) of the studies, this remained unclear.

As, by their nature, nonpharmacological trials and self-report outcome measures do not facilitate adequate blinding of participants, care providers, or outcome assessors to treatment allocation, this was often not feasible within the included studies. Therefore, the associated checklist items had the lowest quality ratings. Participants and care providers were blinded in only 18% (3/17) of the studies, with attempts made to blind outcome assessors in 65% (11/17) of studies. To aid in minimizing the risk of bias associated with inadequate blinding, subitems on the CLEAR NPT assessed the following items: for studies in which participants and care providers were not blinded, the provision of all other treatments and care in each randomized group were the same within 79% (11/14) of studies, and the number of participants withdrawn or lost to follow-up was the same in 71% (10/14) of studies. Where outcome assessors were not blinded, none of the studies provided a clear description of the specific methods used to avoid ascertainment bias, that is, systematic differences in outcome assessment. Only 53% (9/17) of studies adhered to the same follow-up schedule for randomized groups, with discrepancies often related to the provision of treatment to wait-list groups, perhaps owing to ethical considerations regarding the withholding of treatment. Refer to Figure S5 in [Multimedia Appendix 2](#) for the quality assessment ratings of the included studies.

### Publication Bias

Neither funnel plots nor Egger tests suggested the presence of any significant publication bias for anxiety (Egger funnel plot asymmetry:  $t_{18}=-0.29$ ;  $P=.77$ ) and depression outcomes ( $t_{11}=-0.96$ ;  $P=.36$ ). Refer to Figures S6A and S6B in [Multimedia Appendix 2](#) for further details. Owing to fewer studies addressing functional impairment and quality of life, it was not feasible to assess publication bias across these constructs.

## Discussion

### Principal Findings

The study sought to evaluate the state of published evidence for the effectiveness of internet-delivered interventions in

treating symptoms of anxiety and depression in CYP compared with control groups. We identified 23 studies of adequate quality examining internet-delivered treatments for anxiety and/or depression in CYP; only 16 of these were RCTs, and hence, they were included in the meta-analysis. Across these controlled comparisons, the anxiety posttreatment effect sizes were small (Hedges  $g=0.3$ ) and favored internet-delivered interventions. Depression outcomes were mixed, with the overall effect estimate based on anxiety-focused interventions, depression-focused interventions, and transdiagnostic interventions remaining insignificant. Among low mood and depression-specific interventions, the effect estimate was significant and large (Hedges  $g=0.7$ ), but given the limited number of studies ( $n=4$ ) falling into this subgroup, this finding should be considered preliminary. With regard to secondary outcomes, internet-delivered interventions were associated with moderate benefits (Hedges  $g=0.5$ ) in overall levels of functioning; however, no such effects were observed in terms of quality-of-life outcomes. Among the few studies that included controlled follow-up comparisons, there was no evidence for the continuance of the effects of internet-delivered interventions on anxiety and depression symptoms into follow-up.

### Findings in the Context of Previous Reviews

The small to moderate effect sizes observed in this study are somewhat smaller than those reported by previous meta-analyses comparing technology-delivered interventions with wait-list controls (Hedges  $g=0.45-0.68$  [21,22]) but more in line with equivalent comparisons against active control groups (Hedges  $g=0.07-0.29$  [21,22]). Overall, this study appears to paint a more pessimistic picture of the potential of internet-delivered interventions as they currently stand than previous meta-analyses. Specifically, the nonsignificant improvements in depression symptoms are in contrast with the previous findings of depression treatment effects (Hedges  $g=0.56$  [23]). Heterogeneity was considerable within the posttreatment analyses, especially regarding depression outcomes, which may have been due to the wide range of interventions included in the analyses on the one hand and the limited number of studies including depression-focused interventions on the other hand. Indeed, only the posttreatment anxiety outcome was assessed over a comprehensive number of studies and thus might be considered relatively robust (15 studies: 20 comparisons); however, the effect size was so small that one could question the clinical utility of the interventions. With regard to this, we note our more focused inclusion criteria compared with previous meta-analyses, in that we only included internet-delivered interventions (rather than interventions delivered via any form of technology) and we only included studies whose samples presented with current depression or anxiety symptoms (rather than studies that provided population-level or preventive intervention to entire classes in schools, for example). Our preliminary, yet inconclusive, evidence is reminiscent of the review by Hollis et al [17], who noted several methodological limitations preventing them from making definitive conclusions regarding digital health interventions for CYP.

The results of this study do not encourage the effectiveness of digitally delivered interventions for treating symptoms of depression and anxiety in CYP, with robust and consistent

between-group effect sizes being a common requirement for the endorsement of digital health interventions in routine care [60]. Furthermore, with little or no evidence for improving the quality of life or having sustained benefits, their utility is questionable. Considering the recent advances in building an evidence base for internet-delivered interventions for anxiety and depression in adults [20,61], this study highlights the lack of equivalent interventions for CYP. Recent systematic reviews and meta-analyses of digitally delivered CBT interventions for depression and anxiety in adults have included over 40 robust trials, yielding strong posttreatment and follow-up effects [27,62]. In contrast, the results from this review and analysis were weak in terms of the number of studies included, their robustness, and the effect sizes we observed. This is surprising given the advances in technology and research [63] as well as the high rates of CYP engagement with technology [64].

Owing to the large heterogeneity in the format of internet-delivered interventions, Vigerland et al [21] outline the apparent uncertainty in the literature regarding the optimal way to treat CYP and recommend consistency in reporting of advantageous factors. Much of the literature supporting internet-delivered interventions focuses on or provides evidence for CBT-based options [21-23], with the evidence sparser for other theoretical perspectives. There is great scope for future research to explore what works for whom in digitally delivered psychological interventions for CYP populations. Further comparisons of specific types of interventions or particular aims of the intervention may be informative and warranted once more research involving this population has been conducted. Here, exploring the differential effectiveness of parent versus CYP-delivered interventions, treatment versus preventive interventions, or between interventions with varying theoretical bases may be particularly interesting. For example, Pennant et al [65] found medium between-group effects for CBT-based digital treatment of symptoms and small effect sizes for prevention across general populations. In contrast, attentional bias modification-based or cognitive bias modification-based interventions were associated with smaller or no effects [22,65].

As mentioned above, increasing access to effective treatment is imperative. It is essential that studies consider accessibility, engagement, and cost-effectiveness. In line with best practice, and as supported iCBT has been associated with larger effects in adults than unsupported iCBT [66], the fact that most included studies provided a form of support is encouraging. However, no studies mentioned any specialist training in delivering treatment to CYP, a potential inadequacy of care.

Furthermore, access of caregivers to the treatment content may have a significant effect on outcomes [22,67], particularly for internet-delivered interventions that involve less therapist support and are usually completed at home, not at a clinic or dedicated practice. Active parental participation was

incorporated into 9 of the included studies, whereas, in general, *behind the scenes* parental involvement could encompass any form of social support such as technical help and time management. Parental support given to the CYP completing the intervention may aid engagement with the programs, understanding and learning of content, and the application of new skills [68]. Although this was not a focus of our review, with less than half of the studies directly addressing active parental involvement through delivery to parents alone or in conjunction with the CYP, future reviews should consider the important influence of active and indirect parental involvement on CYP outcomes following internet interventions.

### Limitations

An important limitation of this review was the small number of studies, particularly those assessing depression outcomes. Thus, these results should be interpreted cautiously and may not be a meaningful representation of the potential efficacy of internet-delivered interventions in treating childhood depression and anxiety. Similarly, owing to the limited number of studies, we could not properly evaluate the influence of various moderators, such as the effects of the type of intervention or control group, on our findings. In addition, the effect sizes after treatment were based on only 16 controlled studies, and we did not report any within-group comparisons. Therefore, this evidence must be considered as preliminary. In summary, more high-quality studies analyzing the outcomes for CYP are required. Future studies should include well-established outcome assessments, ensure adequate blinding of participants and outcome assessors when feasible, and balance differences between the treatment and control groups such as posttreatment assessment schedules. Perhaps, this would facilitate more detailed analyses and better estimate specific intervention effectiveness and factors associated with improved outcome analyses, such as type or format of intervention and degree of parental involvement.

### Conclusions

Internet-delivered interventions have the potential to increase the availability and access of CYP to much-needed mental health support. These interventions may be effective, but adult-associated effect sizes are often moderate to large and comparable with face-to-face treatments. This study potentially highlights an insufficient customization of the intervention for CYP needs. This remains a largely underresearched area, and it is important to investigate how interventions can effectively reach and support CYP experiencing anxiety and depressive symptoms. Identifying variables that benefit or interfere with successful treatment outcomes will aid in adapting and enhancing internet-delivered interventions. Future work on the development and research of digital interventions for this population should consider the value of incorporating caregivers and other allied health professionals in the lives of CYP.

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### Data Statement

The data set and code used for analysis in this study are available upon request by emailing the corresponding author (NE).

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## Authors' Contributions

NE and DR contributed to the conceptualization and development of the study methodology. NE led the execution of the study in terms of data curation, investigation, formal analysis, data visualization, and write-up. AL and RW contributed toward data curation and writing of the paper, with RW also being involved in the analysis and validation of results. DR provided supervision for the conduct of the study and contributed toward the reviewing and editing of the study write-up. All authors approved the final version of the manuscript.

## Conflicts of Interest

NE, RW, AL, and DR are or were employees of SilverCloud Health and developers of computerized psychological interventions for depression, anxiety, stress, and comorbid long-term conditions. Commercial departments within SilverCloud Health played no role in the design, collection, analysis, or interpretation of the data; manuscript preparation; or submission of the manuscript for publication. Since 2021, SilverCloud Health is a subsidiary of Amwell. DR is a shareholder in Amwell.

### Multimedia Appendix 1

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist.

[[DOCX File , 36 KB - \*pediatrics\\_v5i2e33551\\_app1.docx\*](#) ]

### Multimedia Appendix 2

Additional results tables and figures for secondary outcomes (impaired functioning, quality of life, follow-up anxiety and depression outcomes), moderator analysis and study bias assessments.

[[DOCX File , 882 KB - \*pediatrics\\_v5i2e33551\\_app2.docx\*](#) ]

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## Abbreviations

**CBT:** cognitive behavioral therapy

**CLEAR NPT:** Checklist to Evaluate a Report of a Nonpharmacological Trial

**CYP:** children and young people

**iCBM:** internet-delivered cognitive bias modification

**iCBT:** internet-delivered cognitive behavioral therapy

**PI:** prediction interval

**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses

**RCT:** randomized controlled trial

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Original Paper

# Electronic Discharge Communication Tools Used in Pediatric Emergency Departments: Systematic Review

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## Abstract

**Background:** Electronic discharge communication tools (EDCTs) are increasingly common in pediatric emergency departments (EDs). These tools have been shown to improve patient-centered communication, support postdischarge care at home, and reduce unnecessary return visits to the ED.

**Objective:** This study aimed to map and assess the evidence base for EDCTs used in pediatric EDs according to their functionalities, intended purpose, implementation context features, and outcomes.

**Methods:** A systematic review was conducted following PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) procedures for identification, screening, and eligibility. A total of 7 databases (EBSCO, MEDLINE, CINAHL, PsycINFO, EMBASE Scopus, and Web of Science) were searched for studies published between 1989 and 2021. Studies evaluating discharge communication-related outcomes using electronic tools (eg, text messages, videos, and kiosks) in pediatric EDs were included. In all, 2 researchers independently assessed the eligibility. Extracted data related to study identification, methodology, settings and demographics, intervention features, outcome implementation features, and practice, policy, and research implications. The Mixed Method Appraisal Tool was used to assess methodological quality. The synthesis of results involved structured tabulation, vote counting, recoding into common metrics, inductive thematic analysis, descriptive statistics, and heat mapping.

**Results:** In total, 231 full-text articles and abstracts were screened for review inclusion with 49 reports (representing 55 unique tools) included. In all, 70% (26/37) of the studies met at least three of five Mixed Method Appraisal Tool criteria. The most common EDCTs were videos, text messages, kiosks, and phone calls. The time required to use the tools ranged from 120 seconds to 80 minutes. The EDCTs were evaluated for numerous presenting conditions (eg, asthma, fracture, head injury, fever, and otitis media) that required a range of at-home care needs after the ED visit. The most frequently measured outcomes were knowledge acquisition, caregiver and patient beliefs and attitudes, and health service use. Unvalidated self-report measures were typically used for measurement. Health care provider satisfaction or system-level impacts were infrequently measured in studies. The directionality of primary outcomes pointed to positive effects for the primary measure (44/55, 80%) or no significant difference

(10/55, 18%). Only one study reported negative findings, with an increase in return visits to the ED after receiving the intervention compared with the control group.

**Conclusions:** This review is the first to map the broad literature of EDCTs used in pediatric EDs. The findings suggest a promising evidence base, demonstrating that EDCTs have been successfully integrated across clinical contexts and deployed via diverse technological modalities. Although caregiver and patient satisfaction with EDCTs is high, future research should use robust trials using consistent measures of communication quality, clinician experience, cost-effectiveness, and health service use to accumulate evidence regarding these outcomes.

**Trial Registration:** PROSPERO CRD42020157500; [https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=157500](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=157500)

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## KEYWORDS

emergency department; medical informatics; pediatric; systematic review; patient discharge summaries; patient-centered care; technology; hospital

## Introduction

### Communication Is the Cornerstone of Care

Pediatric patients account for a significant proportion of all emergency department (ED) visits (30% in Canada, 31.2% in Korea, and 20.5% in the United States) worldwide [1-3]. Previous studies and reports have reported that 58% [4] to 87% [5] of all pediatric patients visited the ED with nonurgent conditions, meaning that most are discharged home, where parents are expected to manage care. As a result, the discussions that ED staff have with patients and caregivers during the discharge process regarding what care is required after the ED visit is a significant component of safe practice and quality patient care [6].

Discharge communication among providers, parents, and patients occurs at multiple points during an ED visit, and sharing information related to diagnosis, prognosis, treatment plans, and anticipated course of illness is critical for successful discharge to home [7]. Poor compliance and lack of comprehension of discharge instructions have significant clinical implications, including unfinished treatment, poor pain management, and possible progression of illness [8]. Deficits in the understanding of discharge instructions are widely documented, ranging from 24% of discharged patients with poor understanding of their follow-up plan [9] to patients correctly identifying only 59% of instructions [10]. A review of 48 pediatric ED studies determined that one-third to almost half of the parents who had visited the ED with their child made medication dosing errors during post-ED home care [11]. Within the complex, fast-paced, highly stressful, and highly distracting ED environment, discharge communication can take place in as little as 76 seconds [12]. As a result, interventions to improve communication must balance reliability with flexibility across a wide range of clinical presentations.

### Using Technology to Improve Discharge Communication and Outcomes

The use of information and communication technologies (ICTs) in pediatric health care institutions is increasing, as are the multiple ways in which different technologies are deployed. Examples include computer kiosks, mobile apps, interactive

television and whiteboards, electronic health records, videos, websites, and automated email [13,14]. Technologies create new opportunities for communication and dynamic updates for patient care; however, at the same time, they can also introduce potential interruptions or changes in clinical workflow [15]. Greater emphasis on the interplay between the social (people, values, and norms), technical (tools, hardware, equipment, and processes), and behavioral (routines, roles, and tasks) aspects of ICT implementation in discharge communication could help address some of these barriers [16].

To improve the experience of care during and after an ED visit, there is a great need to better leverage the strengths of technologies to support efficient discharge processes, particularly for nonurgent visits. However, few guidelines exist to support health care institutions in decision-making and implementation planning for such technologies. Research on the use of ICT to support care transitions is predicted to grow rapidly as patients and clients increasingly demonstrate preferences for the use of these technologies in their care [17]. Health care providers also recommend better and more appropriate use of ICT to support families in self-managing care at home [18]. Despite the communication challenges faced by families during this transition point, strain on existing ED resources and the lack of standards and implementation guidelines remain significant barriers to the widespread adoption of electronic discharge communication tools (EDCTs) in pediatric emergency contexts. Systematic reviews of traditional pediatric discharge communication practices [19,20] and computer technology have enabled discharge communication outside the ED [21]; however, to our knowledge, there has not been a comprehensive review of how EDCTs are being used to support and guide pediatric emergency discharge communication.

### Objectives and Research Questions

This systematic review of academic literature was undertaken to identify, appraise, and describe the use of EDCTs in pediatric emergency contexts. Our goal is to advance the knowledge base for researchers, technology designers, and decision makers to anticipate the impact of their communication tools on the clinical workflow and the optimal ways to measure impact ([Textbox 1](#)).

**Textbox 1.** Guiding questions for review.

#### Guiding questions

- What electronic discharge communication tools (EDCTs) have been evaluated in pediatric emergency departments and published following peer review?
- What are the features and technical components of these EDCTs?
- What outcome measures are being examined in the EDCT literature?
- What is the methodological quality of the studies conducted on EDCTs?
- What are the implementation context features where EDCTs have been tested?
- What are the priority research, practice, and policy actions advocated by the authors of research in this domain?

## Methods

### Approach

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) [22] guidelines were followed, and the review was registered with PROSPERO CRD42020157500.

### Data Sources and Search Strategy

A comprehensive search strategy using the Population Intervention Comparator Outcome framework [23] was codeveloped with an experienced information technician. The search terms were intentionally broad to capture the range of EDCTs. Namely, terms included technology (eg, electronic documents or web-forms, mobile device apps, patient portals, notification systems, text messages or SMS notifications, interactive online decision trees, automated email, and video-based programs) used to prompt communication between caregivers/patients and ED staff about the ED visit, and structure the exchange of information, or promote compliance, education, and information sharing about what care should be given after the ED visit is over. A total of 7 databases of publisher-controlled and gray literature were searched: EBSCO, MEDLINE, CINAHL, PsycINFO, EMBASE, Scopus, and Web

of Science. The original search was conducted in June 2019 and was updated in August 2021 to capture current evidence. Records from 1989 onward were included. [Multimedia Appendix 1](#) presents the sample search strategy. The reference lists of systematic reviews were also hand searched for primary studies.

### Eligibility Criteria

We used a broad definition of EDCTs, including tools that prompt communication between caregivers and patients and ED staff about the ED visit and structure the exchange of information and promote compliance, education, and information sharing about what care should be given after the ED visit is over. We did not limit the search to a particular technology modality; therefore, tools including web-based documents or web-forms, mobile device apps, patient portals, notification systems, text messages or SMS notifications, interactive web-based decision trees, automated email, and video were eligible for inclusion. As telephone-based services are part of Health Canada's definition of eHealth, we included phone-based services under the broad umbrella of *electronic tools*.

Specific inclusion and exclusion criteria are presented in [Textbox 2](#).

**Textbox 2.** Inclusion and exclusion criteria.

#### Inclusion criteria

- Electronic discharge communication tools (EDCTs) designed for use during or after an emergency department (ED) visit
- Studies or abstracts that reported outcome data on at least one communication process or communication outcome targeted by the EDCT
- Studies conducted in pediatric ED
- Studies conducted in mixed EDs (adult and pediatric) as long as the EDCT was evaluated in a pediatric population, and outcomes were disaggregated for analysis
- Publicly available in English

#### Exclusion criteria

- Educational intervention given to the patient or caregiver while in the ED but not directly associated with the patient's illness presentation (ie, seatbelt safety)
- Tools only targeting health care provider to health care provider communication
- Reviews, meta-analyses, research protocols, editorials, and case-studies



## Screening

Eligibility screening was performed using Covidence software [24]. All titles and abstracts were independently reviewed by 2 reviewers. Discrepancies regarding which studies to include in full-text reviews were resolved by discussion. A total of 2 reviewers independently assessed the full texts for inclusion. Discrepant classifications were resolved through discussion.

## Data Abstraction and Analysis

The team co-designed and piloted a structured data extraction table with the 4 studies included in the review. The form included sections on (1) *study identification* (eg, type of publication, year, and author); (2) *methods* (eg, study design and sample size); (3) *delivery settings and demographics* (eg, ED features, age, setting characteristics, and computer proficiency); (4) *intervention design* (eg, design framework, frequency and duration of interaction, tailoring, bidirectional functionality, content, tool, and primary technology modality); (5) *outcomes* (eg, category of outcome measure, follow-up schedule, and covariates); (6) *implementation* (eg, who administered the tool, training requirements, interoperability, and cost); and (7) *practice, policy, and research implications* extracted verbatim from the Discussion and Conclusions sections.

As a broad range of study designs was anticipated, the Mixed Method Appraisal Tool (MMAT) version 2018 [25] was used for methodological quality appraisal. The MMAT is a 21-item checklist with 5 research designs. Each research design category has 5 quality criteria that are appraised as yes (criterion met) and no (criterion not met or cannot tell [unable to tell from text if the criterion was met or not]). Assigning studies an overall numerical score based on the ratings of each criterion is discouraged, because a single number cannot provide insight into which aspects of the study methodology are problematic [26]. Instead, we classified studies as having lower

methodological quality when they met  $\leq 60\%$  of the MMAT criteria and higher quality when they met  $>60\%$  of the criteria. This is consistent with the approaches outlined by the MMAT authors [26].

A reviewer independently conducted data extraction and MMAT scoring for all full-text articles. As a quality assurance measure and to ensure the accuracy of extraction, a second reviewer independently extracted data from a randomly selected subset of 30% of full texts. The results were compared, disagreements were resolved by discussion, and additional instructions for the coder were updated.

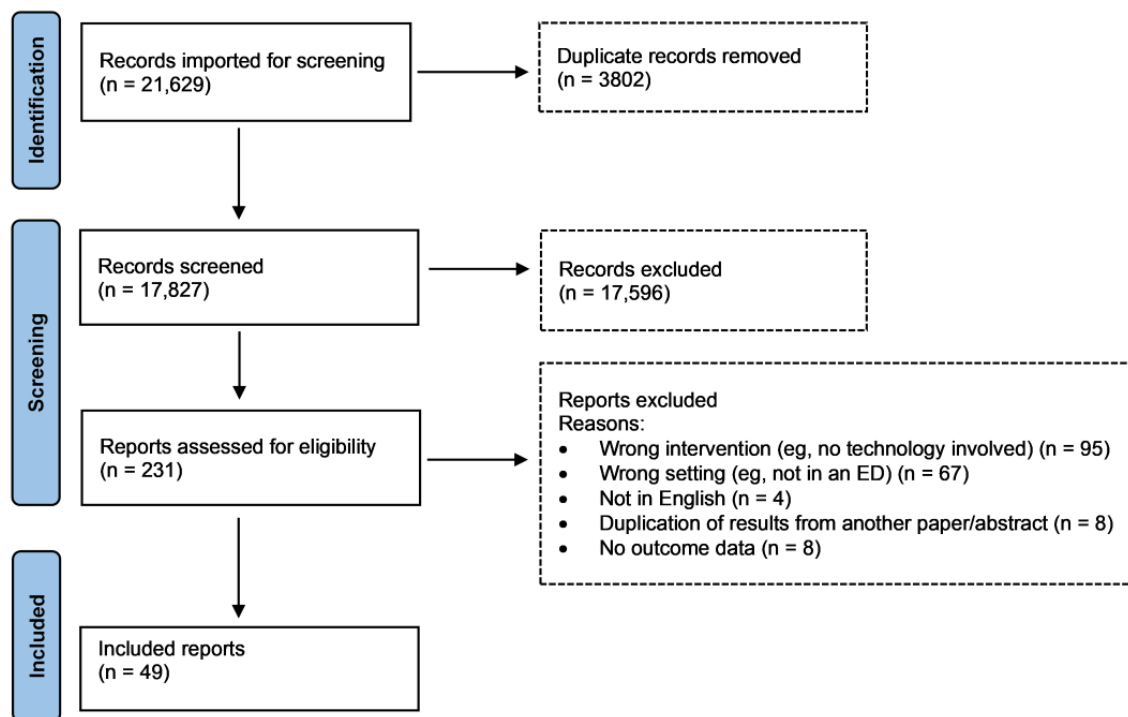
Following standard practices for systematic reviews—included [27] studies were synthesized using several approaches: (1) structured tabulation to explore patterns in the raw data, (2) vote counting of raw data (eg, reporting on the frequency of different study features), (3) constructing a common rubric to transform qualitative data (eg, lengthy descriptions of the technology features) into a simplified quantitative form (eg, assigning tools to a modality category), (4) descriptive statistics (eg, range, mean, or median) to summarize quantitative data, (5) inductive thematic analysis (eg, hierarchical coding of verbatim policy, practice, and research implications), and (6) visual depiction of summary data.

## Results

### Overview

Duplicates were excluded, and 17,827 potential reports were returned. Hand searching of the reference lists of 15 related systematic reviews produced no additional eligible full-text reports. A total of 231 reports were read in full, with 182 (78.8%) excluded, leaving 49 (21.2%) reports detailing findings for 55 unique EDCTs. A flowchart of the process is shown in Figure 1.

**Figure 1.** PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram for the systematic review detailing the database searches, the number of abstracts screened, and the full texts retrieved. ED: emergency department.



### Study Characteristics

The studies were conducted in 8 countries between 1989 and 2021 (Table 1). The intervention group sample size ranged from 3 to 4091 participants or events (median 95). In all, 62% (34/55) of the studies were conducted in the United States and 20% (11/55) in Canada, with the remainder (10/55, 18%) conducted

in Australia, China, the Netherlands, South Korea, and the United Kingdom. A study did not report the country of origin. Interventions were evaluated using randomized controlled trial designs in 58% (32/55) of the cases, nonrandomized trials and cohort designs in 22% (12/55), quantitative descriptive studies in 20% (10/55), and mixed methods at an instance 2% (1/55).

**Table 1.** Study characteristics and key features of the interventions.

| Module and author and year | Country       | Condition  | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose  | Focus  | Main outcomes   | Timing | Frequency       | Duration   |
|----------------------------|---------------|--|-----------------------------|-----------------|--|--|---|--------|-----------------|------------|
| <b>Kiosk</b>               |               |  |                             |                 |  |  |   |        |                 |            |
| Fine et al, 2009 [28]      | United States | Otitis media, urinary tract infection, head trauma, and asthma | 1072                        | Mixed           | Empower patients to electronically provide historical aspects of a child's illness and adhere to evidence-based care   | Produced summary forms for parent-provided historical data, suggestions about how to communicate proactively with staff, summary of the child's symptoms, medications, and allergies and listed a tailored action plan | During ParentLink use, documentation of pain significantly improved (28% incomplete [control] vs 15% [intervention]); <i>P</i> =.003) | During | NR <sup>c</sup> | 10 minutes |
| Joshi et al, 2009 [29]     | United States | Asthma   | 99                          | Pediatric       | Teach children about asthma and its management   | General education  | Tool was effective in improving the asthma knowledge of young patients and those having lower baseline knowledge                      | During | NR              | NR         |
| Kearns et al, 2021 [30]    | United States | Asthma   | 4191                        | Mixed           | To determine the impact of an electronic intervention on asthma care quality   | Measured patients' severity level and provided most appropriate care pathway based on severity score and provided prompts for medication   | Cumulative use was associated with significantly reduced odds of hospital admission   | During | Once            | NR         |
| Kwok et al, 2018 [31]      | United States | Asthma   | 31                          | Pediatric       | To (1) capture from caregivers the critical information necessary to categorize the child's asthma severity, (2) deliver asthma education to families, and (3) generate guideline-based chronic asthma management plans for the caregivers and ED physicians | General education  | Long-term controller medications prescribing and screening provision for 19 of 31 (61%) and 17 of 31 (55%) patients, respectively     | During | Once            | 7 minutes  |
| Morrison et al, 2021 [32]  | United States | Asthma   | 3084                        | Mixed           | To increase the number of families receiving asthma education and impact on workflow   | General education (signs and symptoms)   | Increase in number of families receiving education and trending decrease in ED visits   | During | NR              | NR         |

| Module and author and year  | Country       | Condition   | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose   | Focus  | Main outcomes   | Timing | Frequency | Duration   |
|-----------------------------|---------------|---|-----------------------------|-----------------|---|--|---|--------|-----------|------------|
| Mortenson et al, 2016 [33]  | Canada        | Mind-brain injury   | 38                          | Pediatric       | To reduce parental reports of postconcussion symptoms and caregiver anxiety and stress  | Service recommendations linked to e-mental health care based on needs. The resources were customized by patient age, sex, language, and region.  | No significant difference between the groups at 3 months after injury in postconcussion symptoms and family stress          | After  | NR        | NR         |
| Polihrinis et al, 2016 [34] | Canada        | Mental health   | 500                         | Pediatric       | Patient's perceived feasibility of using web-based screening tool to tailor discharge recommendations; newly developed web-based HEADS-ED <sup>d</sup> screening tool in the ED           | Unclear  | No significant differences in HEADS-ED scores were found between participants in phases 1 and 2                             | During | Once      | NR         |
| Porter et al, 2004 [35]     | United States | Asthma  | 65                          | Pediatric       | Designed a patient-centered interface to allow parents of children with asthma to be active providers of knowledge and promoters of quality of care in the ED and improve quality of care | Summarizes parent-provided historical data, likely ED-based actions and suggestions for the parent on proactive communication with ED providers. Creates a provider-centric form summarizing symptoms, medications, and allergies of the child and listing a tailored plan for evaluation and treatment on a single diagnostic category. | The tool successfully links patient's data to guideline recommendations and identifies data critical to health improvements | After  | NR        | 12 minutes |
| Porter et al, 2008 [36]     | United States | Head trauma; dysuria; ear pain; respiratory symptoms and history of asthma; fever | 654                         | Pediatric       | To determine impact of intervention on error rate of ordering and prescribing medication  | Parent enters information and is given a tailored summary form with all relevant history, suggestions for proactive communication, and a tailored list of suggestions for the provider to review.  | No significant difference between those using the tool and the control group  | During | Once      | NR         |

| Module and author and year | Country       | Condition    | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose   | Focus   | Main outcomes   | Timing | Frequency | Duration   |
|----------------------------|---------------|--------------|-----------------------------|-----------------|---|---|---|--------|-----------|------------|
| Sinha et al, 2014 [37]     | United States | Nonspecific  | 200                         | Pediatric       | To determine if a triage kiosk was more efficient than standard nurse-initiated triage and to compare accuracy of medical history and patient satisfaction                | Triage questions supplemented by audio prompts in the patient's language of choice.   | The mean (SD) time to enter medical history data by the kiosk group was significantly shorter than the standard nurse triage group (94.38, SD 38.61 vs 126.72, SD 62.61 seconds; $P=.001$ )   | During | Once      | 2 minutes  |
| Porter et al, 2006 [38]    | United States | Nonspecific  | 131                         | Pediatric       | To determine the effect of ParentLink parent satisfaction with care experience related to communication with providers and adoption of guideline-endorsed process of care | Parents report symptoms, medications, and unmet needs.  | No significant differences in partnership problems (ie, provider and caregiver communication)   | After  | Once      | NR         |
| <b>Video</b>               |               |              |                             |                 |   |   |   |        |           |            |
| Baker et al, 2009 [39]     | United States | Fever        | 140                         | Pediatric       | Improve knowledge and ability to home-manage fever and reduce medically unnecessary return ED visits for febrile episodes   | Methods for taking a temperature, outlines indications for contacting a physician, refutes common parental misconceptions about fever, and identifies methods to comfort a febrile child. | The fever video had a significant improvement in several measures relating to knowledge and attitudes about childhood fever   | During | Once      | 11 minutes |
| Belisle et al, 2019 [40]   | Canada        | Otitis media | 77                          | Mixed           | To determine if video discharge instructions were associated with improved symptomatology, functional outcome, and knowledge compared with a paper handout                | Instructions on management of pain and fever  | Median symptom severity score in the video group was significantly lower than the paper group, even after adjusting for preintervention AOM-SOS and medication (analgesics and antibiotics) given by caregivers 8 (7-13) vs 10 (7-13), respectively, $P=.004$ | During | NR        | NR         |



| Module and author and year      | Country       | Condition            | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose   | Focus   | Main outcomes  | Timing | Frequency | Duration                |
|---------------------------------|---------------|----------------------|-----------------------------|-----------------|---|---|--|--------|-----------|-------------------------|
| Bloch and Bloch, 2013 [41]      | United States | Fever                | 107                         | Pediatric       | Improve caregiver's comprehension of their child's medical condition, treatment, and follow-up and improve caregiver satisfaction | General education (eg, symptoms and treatment options)  | The group receiving video instructions scored significantly higher in the ED immediately following intervention (12.2 vs 8.9) and 2 to 5 days after discharge (11.1 vs 7.8)  | During | NR        | 3 minutes               |
| Bloch and Bloch, 2013 [41]      | United States | Vomiting or diarrhea | 68                          | Pediatric       | Improve caregiver's comprehension of their child's medical condition, treatment, and follow-up and improve caregiver satisfaction | General education (eg, symptoms and treatment options)  | Intervention group scored significantly higher on knowledge (12.2 vs 8.9) and 2 to 5 days after discharge (11.1 vs 7.8)  | During | NR        | 3 minutes               |
| Bloch and Bloch, 2013 [41]      | United States | Asthma               | 41                          | Pediatric       | Improve caregiver's comprehension of their child's medical condition, treatment, and follow-up and improve caregiver satisfaction | General education (eg, symptoms and treatment options)  | Intervention group video scored significantly higher on knowledge (12.2 vs 8.9) and 2 to 5 days after discharge (11.1 vs 7.8). At follow-up, 29% of the written and 42% of the video groups rated their discharge instructions as being extremely helpful. I | During | NR        | 3 minutes               |
| Boychuk et al, 2006 [42]        | United States | Asthma               | 590                         | Mixed           | Teach and reinforce basic self-management concepts  | Covers signs and symptoms of asthma, pathophysiology, treatment (including medications), how to use the asthma action plan, and demonstration of equipment use.                         | Number of patients possessing a written asthma action plan increased from 48 to 322  | During | NR        | 6 minutes               |
| Golden-Plotnik et al, 2018 [43] | Canada        | Fracture             | 117                         | Pediatric       | To determine whether an educational video was superior to standard care for pain management                                       | Recognition of pain, over-the-counter analgesic dosing and indications, risks and safety in children, and signs and symptoms of pain and misconceptions about treating pain in children | The educational video change in knowledge (delta)=2.3 (95% CI 1.3-3.3); $P<.001$   | After  | NR        | Unlimited for 120 hours |

| Module and author and year   | Country       | Condition          | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose   | Focus  | Main outcomes  | Timing | Frequency | Duration  |
|------------------------------|---------------|--------------------|-----------------------------|-----------------|---|--|--|--------|-----------|-----------|
| Hoek et al, 2020 [44]        | Netherlands   | Nonspecific        | 174                         | Mixed           | Determine whether written and video instructions improve recall on how to use analgesics  | Link to web-based video with information on analgesics dosing and scheduling aimed to refute prejudice about use | Significant difference in written over oral but video was only viewed by 5% of participants  | After  | Unlimited | NR        |
| Ismail et al, 2016 [45]      | United States | Fever; head injury | 31                          | NR              | Improve caregiver's comprehension of their child's diagnosis, treatment, and follow-up care   | Information about diagnosis, treatment, disease process, and discharge instruction.                              | The intervention group had a significantly higher percentage of correct answers on postintervention tests (median 99.89) than the control (median 75.73) $P<.001$          | During | Once      | 6 minutes |
| Jové-Blanco et al, 2021 [46] | Spain         | Gastroenteritis    | 69                          | Mixed           | To evaluate if the video improved comprehension; patients were satisfied and decreased return visits  | General education (eg, etiology, treatment, signs and symptoms, after-care, and reasons to reconsult)            | Greater improvement in knowledge among intervention group  | During | Once      | 2 minutes |
| Jung et al, 2011 [47]        | South Korea   | Head injury        | 95                          | Pediatric       | Improve discharge instruction comprehension   | General education  | Video explanation to parents with children with minor head trauma in the pediatric EDs can increase the satisfaction compared with previous paper-using instruction method | During | Once      | NR        |
| Ladde et al, 2013 [48]       | United States | Asthma             | 29                          | Pediatric       | To determine whether an educational video compared with standard reading materials would better educate pediatric asthma patient's primary caregivers and if this would affect 30-day ED revisits | General information  | Admit rate for visit was 24.1% (26.7% video vs 21.4% paper), $P=.74$   | During | NR        | NR        |

| Module and author and year | Country        | Condition   | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose  | Focus  | Main outcomes   | Timing          | Frequency | Duration   |
|----------------------------|----------------|-------------|-----------------------------|-----------------|--|--|---|-----------------|-----------|------------|
| Lawrence et al, 2009 [49]  | United States  | Nonspecific | 587                         | Pediatric       | To decrease the number of medically unnecessary return visits to the pediatric ED  | Reminder to take medication  | Of all return visits to the pediatric ED within 72 hours of discharge, 13% were deemed unnecessary for patients receiving handwritten instructions compared with 15% for patients receiving computer-generated instructions ( $P=.50$ )                     | After discharge | Daily     | NR         |
| Lion et al, 2015 [50]      | United States  | Nonspecific | 142                         | Mixed           | To determine the effect of video interpretation on comprehension, parent-reported quality of communication, and frequency of use of professional translators | Unclear  | Those in the video arm were more likely to name the child's diagnosis correctly than those in the telephone arm (85/114, 74.6% vs 52/87 59.8%; $P=.03$ ) and less likely to report frequent lapses in interpreter use (2/117, 1.7% vs 7/91, 7.7%; $P=.04$ ) | During          | NR        | NR         |
| Macy et al, 2011 [51]      | United States  | Asthma      | 53                          | Pediatric       | To increase asthma knowledge, parental sense of asthma control, parental report of asthma symptoms, and decrease health care use                             | Unclear  | Improvement in asthma knowledge at follow-up was realized for low-literacy parents regardless of the type of educational intervention ( $P<.001$ )  | During          | Once      | 20 minutes |
| Mian et al, 2016 [52]      | United Kingdom | Oncology    | 32                          | Mixed           | To decrease the time to recognize fever-neutropenia to reduce ED visits  | Discussion and recommendation for symptom management and activity participation. Families provided with additional web links and education | Education of the patient's caregiver improved their understanding by 84% and significantly decreased their time for symptom recognition and ED presentation   | During          | Once      | 8 minutes  |
| Stevens et al, 2012 [53]   | United States  | Pain        | 59                          | Pediatric       | To evaluate the effectiveness of a 6-minute instructional video for parents that targets common misconceptions about home pain management                    | General education  | Significantly more parents provided at least one dose of pain medication to their children after watching the educational video: 96% vs 80% (difference 16%, 95% CI 7.8%-31.3%)   | During          | NR        | NR         |

| Module and author and year  | Country       | Condition  | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose  | Focus  | Main outcomes  | Timing | Frequency | Duration       |
|-----------------------------|---------------|--|-----------------------------|-----------------|--|--|--|--------|-----------|----------------|
| Wood et al, 2017 [54]       | United States | Gastroenteritis; bronchiolitis; fever                    | 41                          | Pediatric       | To determine if the intervention improved knowledge about diagnosis, treatment, illness duration, and when to seek further medical care    | The videos described symptoms associated with the diagnosis, treatment of the symptoms expected illness duration, and when to seek further medical care. | Both groups showed improvement but video group had statistically more recall   | During | Once      | 3 to 5 minutes |
| Wood et al, 2020 [55]       | United States | Fever; gastroenteritis; bronchiolitis                    | 75                          | Pediatric       | To determine if adding a video component to standard care improved knowledge acquisition   | Information on child's diagnosis, treatment illness duration, and when to seek further care  | Video group achieved significantly higher scores on the posttest survey than the standard care group, particularly regarding treatment and when to seek further medical care | During | Once      | 5 minutes      |
| Zorc et al, 2009 [56]       | United States | Asthma   | 217                         | Pediatric       | To determine if the intervention would address beliefs and barriers to follow-up asthma care among inner-city families                     | General education on What is asthma? How can asthma be controlled? What are the benefits of controlling asthma?  | Intervention participants were more likely to endorse beliefs about the benefits of follow-up than controls  | During | Once      | 12 minutes     |
| <b>Phone</b>                |               |  |                             |                 |  |  |  |        |           |                |
| Bucaro and Black, 2014 [57] | United States | Nonspecific  | 630                         | Pediatric       | Increase parental understanding of ED discharge instructions so that parents can successfully and safely manage their child's care at home | General education (eg, symptoms and treatment options)   | In all, 93% of parents found that after the follow-up call, they had an improved understanding of their child's illness or injury  | After  | Once      | NR             |
| Chande and Exum, 1994 [58]  | United States | Pneumonia; croup, asthma; bronchiolitis; vomiting; fever | 133                         | Pediatric       | Improve parental compliance with primary care follow-up  | Reminders to fill their prescriptions, to call regular physicians, and to follow any other instructions documented on the discharge sheet                | No significant difference between groups on frequency of filling prescriptions   | After  | Once      | NR             |

| Module and author and year | Country       | Condition   | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose  | Focus   | Main outcomes  | Timing | Frequency                           | Duration |
|----------------------------|---------------|---|-----------------------------|-----------------|--|---|--|--------|-------------------------------------|----------|
| Goldman et al, 2014 [59]   | Canada        | Nonspecific                                       | 171                         | Pediatric       | To examine whether a follow-up telephone call by a non-health care provider from the ED within 24 hours after a child's discharge can reduce the rate of returning to the ED within 72 hours | Information about the child's medical condition after discharge and community follow-up and responding to parents' questions  | The outcome measure was found to be in contrary to our hypothesis. We found return visits to the ED in 24 (14%) of the children in the study group compared with only 14 (7%) in the control group ( $P<.03$ ) | After  | Up to 10 trials in difference hours | NR       |
| Jones et al, 1989 [60]     | United States | Otitis media                                      | 14                          | Pediatric       | To evaluate 2 clinical nursing interventions designed to increase compliance with follow-up care referrals for patients  | Health Belief Model phone intervention  | Participants who received the intervention were much more likely than control participants to comply with a follow-up referral appointment   | During | Once                                | NR       |
| Jones et al, 1989 [60]     | United States | Otitis media                                      | 12                          | NR              | To evaluate 2 clinical nursing intervention designed to increase compliance with follow-up care referrals for patients   | Health Belief Model phone intervention  | Participants who received the intervention were much more likely than control participants to comply with a follow-up referral appointment   | After  | Once                                | NR       |
| Khan et al, 2004 [61]      | Australia     | Asthma  | 136                         | Pediatric       | To improve asthma management and control   | Asthma severity information. Educational topics on self-management. Collected information about barriers to optimal care and engaged ED staff in selecting recommended preventive medications with an option to print | Intervention group children were significantly more likely than controls to possess (87.5% vs 72.3%; $P=.002$ ) a written action plan  | After  | Once                                | NR       |
| Wong et al, 2004 [62]      | China         | Fever, respiratory, or gastrointestinal condition | 395                         | Pediatric       | To determine if ED nurse follow-up (via phone call) helped to change health outcome and health care use  | Assessment of symptoms and decision on management options.  | Significantly different between intervention and control groups on improvement of the condition and ED visit within 30 days  | After  | Twice                               | NR       |

**Web-based**



| Module and author and year | Country       | Condition                   | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose   | Focus  | Main outcomes   | Timing | Frequency | Duration |
|----------------------------|---------------|-----------------------------|-----------------------------|-----------------|---|--|---|--------|-----------|----------|
| Babcock et al, 2017 [63]   | United States | Mild traumatic brain injury | 13                          | Pediatric       | Promote concussion recovery for adolescents through education and training in self-management and effective coping  | Symptom and activity monitoring to promote self-management. Educational modules that provided anticipatory guidance and techniques to effectively manage these consequences using cognitive reframing, relaxation training, and problem solving. | Significant improvement in symptoms over the 4-week program (adolescent: $P < .001$ ; parent $P = .004$ )   | After  | Unlimited | NR       |
| Goldman et al, 2005 [64]   | Canada        | Nonspecific                 | 303                         | Pediatric       | To determine whether the internet could be used to report information on bacterial cultures taken in the pediatric ED and whether parents would use the tool to gain access to personalized culture results                     | Access to the participant's culture results using a unique ID and password   | 186 (61%) parents accessed the internet-system after mean 94 hours (range 1 minute-611 hours) after posting | After  | NR        | NR       |
| Hart et al, 2019 [65]      | Canada        | Fever                       | 77                          | Pediatric       | To determine if web-based interventions improve recognition and management of fever at home, leading to decreased parental anxiety and possibly fewer unnecessary ED visits by measuring knowledge acquisition and satisfaction | Computer-automated feedback regarding childhood fever  | Mean pretest to immediate posttest gain score of 3.5 (SD 4.1); $P < .001$                                   | During | NR        | NR       |
| <b>Computer-based</b>      |               |                             |                             |                 |   |  |   |        |           |          |
| Alqudah, 2014 [66]         | Australia     | Fever                       | 95                          | Mixed           | Evaluate the impact of a health literacy-modified fever education program on parents or carers' fever knowledge, anticipated fever management practices, and ED or primary care presentations                                   | Pharmacological and nonpharmacological fever management practices, the correct way to measure a child's body temperature, and general knowledge about fever  | No statistically significant difference   | During | NR        | NR       |

| Module and author and year      | Country       | Condition | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose   | Focus  | Main outcomes   | Timing | Frequency                   | Duration                |
|---------------------------------|---------------|-----------|-----------------------------|-----------------|---|--|---|--------|-----------------------------|-------------------------|
| Alqudah, 2014 [66]              | Australia     | Fever     | 3                           | Mixed           | Evaluate the impact of a health literacy–modified fever education program on parents or carers' fever knowledge, anticipated fever management practices, and ED or primary care presentations | Pharmacological and nonpharmacological fever management practices, the correct way to measure a child's body temperature, and general knowledge about fever                          | No statistically significant difference   | During | NR                          | NR                      |
| Fernandez et al, 2011 [67]      | United States | Asthma    | 27                          | Pediatric       | Improve effectiveness and retention of asthma education for children  | General education  | Factors motivating participation included the need to be in the ED, parental involvement in the process, and effective use of technology. Barriers identified were fatigue of child, unavailability of parent, and ED visit during uncovered educator hours | After  | As many times as they liked | NR                      |
| Golden-Plotnik et al, 2018 [43] | Canada        | Fracture  | 111                         | Pediatric       | To determine whether a web-based module was superior to standard care for pain management at home   | General education  | The web-based module group showed change in knowledge ( $\Delta$ )=1.6 (95% CI 0.5-2.6); $P=.002$   | After  | NR                          | Unlimited for 120 hours |
| Hart et al, 2019 [65]           | Canada        | Fever     | 79                          | Pediatric       | To determine if web-based interventions improve recognition and management of fever at home, leading to decreased parental anxiety and possibly fewer unnecessary ED visits                   | Computer-automated feedback regarding childhood fever (noninteractive)   | Mean pretest to immediate posttest gain score of 3.5 (4.2); $P<.001$  | During | NR                          | NR                      |
| <b>Text message or SMS</b>      |               |           |                             |                 |   |  |   |        |                             |                         |
| Sockrider et al, 2006 [68]      | United States | Asthma    | 263                         | NR              | To determine if the intervention group would have greater confidence to manage asthma, better primary care follow-up, and fewer return ED visits  | The intervention includes universal and tailored content, and the educator has the flexibility to navigate the content based on the individual child or family's needs and questions | The confidence level to prevent asthma episodes and keep them from getting worse was significantly higher in the intervention group at 14 days after intervention   | During | Once                        | NR                      |

| Module and author and year | Country        | Condition                   | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose   | Focus  | Main outcomes  | Timing | Frequency | Duration |
|----------------------------|----------------|-----------------------------|-----------------------------|-----------------|---|--|--|--------|-----------|----------|
| Boyd et al, 2013 [69]      | United Kingdom | Fracture                    | 25                          | NR              | To investigate whether text message reminders improve pain management in children after discharge from the ED   | Reminders to improve pain management                                     | The mean number of analgesia doses administered to the text message group was 7.6 vs 4.9 in the control group, $P \leq .05$  | After  | Twice     | NR       |
| Lee et al, 2011 [70]       | United States  | Asthma                      | 7                           | Mixed           | To demonstrate that text message medication reminders will improve medication adherence   | General discharge information  | Results did not demonstrate a significant difference of means (paired 2-tailed $t$ test) between pre- and post-text messaging reminders  | After  | Multiple  | NR       |
| Malbon et al, 2013 [71]    | United States  | Nonspecific                 | 2440                        | Pediatric       | Encouraging primary care follow-up at an adolescent health center for adolescents who sought care at an ED  | Reminder   | Text messaging is a feasible and effective tool for increasing outpatient follow-up after an ED visit at a primary care facility, potentially relieving an additional burden on the ED and promoting health care in the transition to adult medicine | After  | Multiple  | NR       |
| Salinero, 2012 [72]        | United States  | Nonspecific                 | 61                          | Pediatric       | To evaluate whether a text message reminder to the caregivers after discharge from the pediatric ED improved compliance with recommended primary care follow-up | Reminder to follow-up with their primary care physician                  | There was no significant difference in follow-up in the standard treatment group 19/62 (31%) vs the text message intervention group 16/61 (26%); $P = .69$   | After  | Once      | NR       |
| Wolff et al, 2016 [73]     | United States  | Pelvic inflammatory disease | 47                          | Mixed           | To test the effect of text message reminders on adolescent patients' adherence to the recommended post-ED follow-up care  | Personalized reminders to reschedule and attend a follow-up appointment. | Patients receiving text message reminders were more likely to follow up compared with the standard group (relative risk=2.9, 95% CI 1.4-5.7)   | After  | 4 times   | NR       |

### Game-based

| Module and author and year | Country | Condition      | Sample size, N <sup>a</sup> | ED <sup>b</sup> | Purpose   | Focus  | Main outcomes  | Timing | Frequency | Duration |
|----------------------------|---------|----------------|-----------------------------|-----------------|---|--|--|--------|-----------|----------|
| Taylor et al, 2015 [74]    | Canada  | Nonspecific    | 533                         | Pediatric       | To determine level of patient satisfaction and improvement in pain management and treatment while in the ED | Patients and parents view videos selected by the triage nurse in response to perceived patient need. The videos reframe and demystify injury and illness, inform about medical procedures and processes, and introduce important coping skills. Permits individual messaging to both parents and patients via iPads. | Intervention participants showed significant improvements in pain control and both patient and parent satisfaction   | During | Once      | NR       |
| <b>Mobile app</b>          |         |                |                             |                 |   |  |  |        |           |          |
| Farooqui et al, 2017 [75]  | NR      | Asthma         | 98                          | NR              | Effect of reminders on health care use  | Reminders for medication and electronic treatment plan   | Reported improvement in asthma management was greater in AsthmaCare participants (79% vs 62%; $P=.06$ ), along with greater daily use of treatment plans (29% vs. 11%; $P=.01$ ) | After  | NR        | NR       |
| <b>Photo documentation</b> |         |                |                             |                 |   |  |  |        |           |          |
| Lund et al, 2013 [76]      | Canada  | Skin infection | 244                         | Pediatric       | To determine whether photo documentation improves the duration of outpatient treatment                      | Educational messages on basic facts about asthma, roles of medications, and patient skills.  | No differences in the rate for completion and therapeutic failure were observed (71% vs 68% and <1% for both, respectively)  | During | NR        | NR       |

<sup>a</sup>The sample size of only the group exposed to the intervention.

<sup>b</sup>ED: emergency department.

<sup>c</sup>NR: not reported.

<sup>d</sup>HEADS-ED: Home, Education, Activities, Drugs, Suicidality, Emotions, and Discharge.

MMAT appraisal was conducted on 37 studies (abstracts for which no full text was available were excluded). Overall, the methodological quality of the studies varied: 30% (11/37) of the studies met  $\leq 60\%$  of the criteria outlined by the MMAT (lower methodological quality), and 70% (26/37) of the studies met  $>60\%$  of the criteria (higher methodological quality) [26].

Reviewers' ratings for each methodological quality criterion are presented in [Multimedia Appendix 2](#) [28-33,35-39,41-46,49-51,54-66,68,73,74,76].

### Nature of Interventions

In all, 40% (22/55) of the EDCTs were designed for use after the ED visit when families were already at home. Over half of

the tools targeted a single specific presenting complaint with asthma (15/55, 27%), fever (6/55, 11%), fractures (3/55, 6%), head injury (3/55, 6%), and otitis media (3/55, 6%), being the most frequently cited. In 13% (7/55) of studies, the discharge communication tool could be used for multiple presenting complaints (eg, patients with fever or head injury). Finally, 20% (11/55) of the tools were designed for use in any illness presentation. Some tools focused on a specific task or a narrow aspect of discharge communication (eg, medication regimen adherence) [70], whereas other tools were multi-focused with broader education, symptom monitoring, and care plan elements [57].

### Features and Technical Components of EDCTs

EDCTs support diverse communication pathways among providers, caregivers, patients, and other health care providers. Most of the tools targeted communication between an ED health care provider and the parent and caregiver (52/55, 94%) with a smaller number (6/55, 11%) also including communication with other health care providers (eg, family physician). One study of the Texas Emergency Department Asthma Surveillance programs [68] was an example of a multi-audience tool. In the study, the ED asthma educator used a Microsoft-based platform to individualize an education package for the caregiver (eg, select relevant video segments, figures and graphs, skills training, and motivational messaging). The plan was shared and discussed with the caregiver and then printed and sent to the family's primary care provider. The educator could also generate and print a child-friendly version of the tailored written action plan for elementary-aged patients.

The primary technology modalities used were videos (20/55, 36%), kiosks (11/55, 20%), telephone calls (7/55, 13%), and text messaging (6/55, 11%). The remaining modalities include a wide range of offline stand-alone interactive computer programs and web platforms, mobile apps, interactive websites, and web-based games with multiple audiovisual elements. For example, a private multiplayer web-based social game called iCare Adventure uses noncompetitive gameplay for children and parents to explore therapeutic content on an iPad while in the ED waiting room [74].

A density map of presenting complaints targeted and primary technology modalities used to deliver the EDCT was generated (Tables S1 and S2 in [Multimedia Appendix 3](#)). Darker cells indicate where the largest number of studies have been conducted. Kiosks and videos are the 2 predominant modalities used as stand-alone asthma tools. Videos are the most studied modality for less frequently investigated medical concerns (eg, vomiting and pain).

There was substantial heterogeneity between the studies in the amount of time and effort required by patients and caregivers to use the tool. In all, 42% (23/55) of the tools required single-use, time-limited interaction (eg, watched one video once or entered information at a kiosk once). A total of 3 studies involved web platforms or interactive computer programs with larger educational components that allowed unlimited access (4/34, 12%). A program provided access over a specified follow-up period (eg, 120 hours after discharge) [43]. Multiple planned interactions with a tool typically involved a level of

automation (eg, 2 automated text messages twice a week for 4 weeks) [51] or chronologically sequenced learning modules. All text messaging interventions were automated 1-way messaging of reminders with no option of bidirectional texting directly with a health care provider.

Duration of contact with the EDCT (ie, how long it took end users to complete expected tasks) was reported in 31% (17/55) of the studies. Among those that did report, the length of contact time for the patient and caregiver ranged from 110 seconds at a kiosk [37] to 80 minutes (where the latter measured the time to complete 5 web-based modules) [63]. A total of 44% (7/17) of those reporting took  $\leq 5$  minutes to complete, (4/17, 24%) took between 6 and 10 minutes, and 24% (4/17) took  $>10$  minutes. The interventions (3/17, 18%) that took  $>12$  minutes all specifically targeted asthma. Caregiver perceptions of frequency and duration were explored in a study of 243 families where 66 (27.2%) reported they had "had no time" to enter the website [64].

### Reported Impacts of EDCTs

There was significant heterogeneity in the reported purpose of deploying the EDCT and subsequent outcomes measured. Tables S1 and S2 in [Multimedia Appendix 4](#) show a matrix of the outcomes measured per mode of EDCT technology delivered. The intensity of shading shows clusters (darker) versus gaps (lighter) within technologies.

The highest density of evidence was from the study of changes in caregiver knowledge after using video-based EDCTs (16 instances). The most assessed category of outcomes overall (including both primary and secondary) were caregiver and patient beliefs and attitudes (eg, confidence in managing at home and level of anxiety; 36 instances), knowledge and comprehension (eg, knowledge about symptoms; 29 instances), and health service use (eg, return visits to the ED; 25 instances). Health care provider satisfaction (5 instances) and cost (2 instances) were the least measured outcomes across all technology modalities.

Text message interventions were more likely to be measured on behavioral outcomes (eg, compliance with medication regime and follow-up appointment with primary care), whereas studies of video-based EDCTs typically used knowledge acquisition-related measures. A randomized controlled trial by Jové-Blanco et al [46] comparing video discharge instructions and standard verbal instructions for gastroenteritis showed that 49% of the intervention group and 18.6% of the control group answered all knowledge acquisition questions correctly ( $P<.001$ ) [48]. However, EDCTs with greater technological sophistication do not always produce better knowledge outcomes. In a head-to-head trial of a static website and an interactive website about fever, Hart et al [65] unexpectedly found that both modalities had comparable knowledge gains, although caregivers were significantly more satisfied with the interactive version.

Measurement of knowledge outcomes occurred largely through bespoke self-report questionnaires that assessed general knowledge about symptoms, treatment options, medication and activity adherence, and service use [29]. Validated measures were most often cited in relation to patient health status (eg,



Faces Pain Scale-Revised and Acute Otitis Media Severity of Symptom) and functioning (ie, Acute Asthma Behavioral Capability Questionnaire; Integrated Therapeutics Group Child Asthma Short Form). No adverse events were reported in any of these studies.

The directionality of primary outcomes pointed to positive effects for the primary measure (44/55, 80%) or no significant difference (10/55, 18%). Only one study reported negative findings with an increase in return visits to the ED after receiving the intervention compared with the control group ( $P < .03$ ) [59]. Often, the authors reported positive primary outcomes but mixed results across secondary measures. For example, a study by Baker et al [39] showed increases in parental knowledge about fever but no significant differences in subsequent health service use. Similarly, a study by Zorc [56] showed significant changes in beliefs about the benefits of follow-up, but medication adherence and ED visits did not significantly differ at follow-up. Parental satisfaction with EDCTs was consistently moderate to high across all technology modalities. However, in some instances, respondents in the control condition, typically verbal or written discharge instructions, also reported high levels of satisfaction [46].

The ability to tailor information via the EDCT was particularly well received by parents when this option was available. For example, tailored mental health recommendations facilitated by electronic screening were perceived by parents as more useful (69.5% vs 30.5%) and more practical (71.8% vs 28.2%) compared with verbal instructions [34]. In another study, 23% of caregivers' free text entries in the EDCT provided data that were not contained in the official electronic medical record [35].

Patient age [72], gender of caregiver [62], and parent education level [37] were the most frequently reported, statistically significant covariates vis-à-vis the primary outcome. Of note, only 3 studies reported collecting baseline data on the level of computer proficiency [28] and none in the past decade.

### Implementation Context Features Where EDCTs Have Been Used

In all, 42% (23/55) of the EDCTs were evaluated in at least one explicitly stated urban community. The majority were evaluated in pediatric EDs (37/55, 67%) or mixed ED settings (ie, both adult and pediatric populations, 13/55, 24%); the rest provided insufficient information to decide. English, Spanish, and Dutch were the only languages in which interventions were available and evaluated. No other culturally specific content or culturally adaptive features of the interventions were reported. The interventions (12/55, 22%) included baseline racial demographic factors, with most participants being African American or White. The EDCTs were most frequently delivered by research study staff (19/55, 35%), ED health care providers (15/55, 27%), or by computers or automated systems (8/55, 15%).

Very few interventions (3/55, 6%) were tested in studies that provided remuneration to participants. No studies have reported interoperability with other ICT systems within the ED or hospitals. The authors of 2 interventions (2/55, 4%) briefly mentioned sustainability planning, and 33% (18/55) stated that due consideration should be given to the technical performance

of the system. Only 2 interventions (2/55, 4%) included details of direct costs; a study reported that per patient mean cost for videos was US \$61 (SD US \$36) versus US \$31 (SD US \$20) for phones;  $P < .001$  [50]. Another study estimated the operating budget for the tool in "hundreds of dollars" [74]. Privacy and security were highlighted as necessary implementation context considerations in 11% (6/55) of the instances.

### Research, Practice, and Policy Implications Reported by Primary Authors

No direct policy or decision-making implications were explicitly discussed by the primary authors. High-level theming of future research directions posited by primary authors revealed three main directions: (1) more diverse sample populations that reflect a wider view of social determinants of health, (2) triangulation of data from sources outside of self-report (eg, primary care follow-up data and hospital administrative data), and (3) isolating the functionality of the tools to test the impact on engagement (eg, increase uptake). Practically, the authors generally endorsed the use of EDCTs, even if statistically significant findings were mixed or effect sizes were modest.

## Discussion

### Principal Findings

The primary aim of this review was to describe and assess evidence based on the EDCTs used in pediatric EDs. The evidence base included the principal features, measured outcomes, and implication contexts under which they were studied.

First, an important and promising finding of this review is that although the contextual complexity of EDs poses communicative challenges and risks, there is a growing body of evidence that EDCTs have been successfully integrated. Our review found at least five studies in each of the 4 major modality categories (ie, videos, kiosks, text messaging, and phone-based) and numerous presenting complaints that are among the most frequent reasons for ED visits reported in the literature (asthma, fever, head injury, fractures, pain, mental health, etc) [77]. In other words, there is growing breadth and depth of positive evidence.

The evidence base for newer technology modalities, kiosks, text messaging, and web-based games and apps is still maturing, with just under a third of all studies being conducted in the last 5 years. It is vital to monitor this evidence base as more automated and ambient technologies (eg, chat bots, wearables, and artificial intelligence) become normalized. Indeed, they are already being studied in ED communication for the adult population [78,79]. Our review adds to this dialogue by showing that technological sophistication may not necessarily result in clinically meaningful improvements. Videos and phone calls also produced positive changes. In fact, most EDCTs in this review reported at least some positive impact in 80% of cases and no adverse events. There is a need to move beyond demonstrating the known value of EDCTs and focus on *how* to optimize which tools for which populations, under which circumstances. This is supported by caregivers reporting high satisfaction regardless of modality or presenting concern. In

other words, the technology modality used to support caregivers in discharge planning may be less crucial than the opportunity to engage with them.

Second, our review has shown that EDCTs have been largely assessed for changes in cognition (knowledge and beliefs), meaning that we know less about their impact on behavior (adherence to treatment regime), therapeutic relationship (caregiver-provider rapport), or service use. Our findings and overall methodological quality appraisal results point to the need for future meta-analyses to explore the magnitude and direction of effects within specific modalities. Such an analysis could support decision makers in determining which tools are fit for different primary purposes, reduction in nonurgent visits versus improved experiences of care. Caregivers may be highly satisfied with a tool and experience improved recall and comprehension, but this may not translate into fewer nonurgent visits to the ED in the future. The lack of description provided in primary studies related to implementation and environmental context features contributes to gaps in knowledge about the sustainability of these tools, particularly the costs associated with setup and ongoing operations.

Another significant finding of this review is that outcomes related to caregiver-provider rapport were understudied across all modalities and for all clinical presentations. This gap in the evidence is exacerbated by the few studies that assessed health care provider satisfaction with the tools in general. Assessment of their expectations and experiences with EDCTs may help illuminate barriers and enablers to uptake, as well as predictors of positive and negative client experiences. Recent work on quality pediatric communication in EDs [80] points to gaps in measures of care experiences in a complex, high-stress environment. Given the diverse implementation contexts for EDCTs found in this review, the development of quality standards for discharge communication should consider the role of electronic tools, which will undoubtedly continue to mediate and moderate care experiences in the future.

Finally, research designs for EDCTs need to incorporate mediators and moderators related to technological functions (eg, synchronicity, automation, visual aesthetics, and gamification) to determine the minimum viable functions. Our findings suggest that technological complexity is not necessarily better. Augmenting quantitative self-report survey data with observational, qualitative, and administrative data could help make sense of the aspects of these tools (ie, mechanisms of change) that drive the desired change. For example, there was some evidence that tools take >5 minutes for caregivers to complete (impact on workflow) and were administered by research team members rather than health care providers, giving us a slightly skewed view of real-world implementation. More

work is needed to understand how the duration and frequency of interaction with tools (both provider and caregiver or patient) could be optimized for busy ED workflows without adding unnecessary complexity to the clinical pathways. Our review showed that over half of the EDCTs studied to date target a specific illness, but this could add burden to health care providers and caregivers who might then need to access and navigate a different tool for each presenting condition.

The findings of this review point to several high-impact future lines of research to address gaps, including (1) exploring how computer-mediated communication in pediatric emergency contexts impacts the quality dimensions of communication and rapport building (eg, sense of shared decision-making, empathy, and active listening), (2) meta-analysis of data subsets within a particular presenting illness field (eg, asthma) or within a single well-defined technology modality (eg, kiosks), (3) developing taxonomies for electronic discharge communication interventions that capture complex person-to-person and person-to-technology pathways, and (4) use of A or B (ie, split) testing to isolate specific technology features that may be driving outcomes so that the least intensive interventions necessary to achieve desired outcomes are pursued by developers and decision makers.

### Limitations

This study had several limitations. First, mapping the broad relevant literature parameters of *EDCTs* lacked clarity before the literature search. Terms related to technology, digital devices, and electronic communication were ambiguous in the literature, and our criteria were subject to significant revision during the initial search execution. This resulted in a less-focused initial title and abstract screening process. Second, the review included several study abstracts that were not published as full articles, limiting what data could be abstracted and fully analyzed. Finally, no taxonomies for presenting complaints have been validated or published in the literature; likewise, no taxonomies for electronic communication modalities are commonly used. Thus, our heat-map categorizations were based more on practical considerations and, to a lesser degree, on theoretically validated distinctions.

### Conclusions

To our knowledge, there has been no other systematic review of the broad evidence related to EDCTs in pediatric EDs. The findings demonstrate that a range of technologies are being used successfully. However, it is essential that trials of emerging technologies use robust and consistent measures of quality patient-provider communication, clinician experience, cost-effectiveness, and health service use so that influential evidence on these outcomes can accumulate.

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### Conflicts of Interest

None declared.

## Multimedia Appendix 1

MEDLINE @OVID search strategy.

[\[DOCX File , 13 KB - \*pediatrics\\_v5i2e36878\\_app1.docx\* \]](#)

## Multimedia Appendix 2

Mixed Method Appraisal Tool quality appraisal profile.

[\[DOCX File , 24 KB - \*pediatrics\\_v5i2e36878\\_app2.docx\* \]](#)

## Multimedia Appendix 3

Heat map of technology modalities and frequencies.

[\[DOCX File , 16 KB - \*pediatrics\\_v5i2e36878\\_app3.docx\* \]](#)

## Multimedia Appendix 4

Heat map of intervention outcomes and frequencies.

[\[DOCX File , 17 KB - \*pediatrics\\_v5i2e36878\\_app4.docx\* \]](#)

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## Abbreviations

**ED:** emergency department

**EDCT:** electronic discharge communication tool

**ICT:** information and communication technology

**MMAT:** Mixed Method Appraisal Tool

**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Original Paper

# Exploring Infant Fall Events Using Online Parenting Discussion Forums: Infodemiology Study

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## Abstract

**Background:** Falls represent the most common mechanism of injury requiring hospitalization among children under 12 months, and they commonly result in traumatic brain injury. Epidemiological studies exploring infant falls demonstrate the experienced burden, but they lack contextual information vital to the development of preventive interventions.

**Objective:** The objective of this study was to examine contextual information for falls involving children under 12 months, using online parenting discussion forums.

**Methods:** Online parenting forums provide an unobtrusive rich data source for collecting detailed information about fall events. Relevant discussions related to fall incidents were identified and downloaded using site-specific Google Search queries and a programming script. A qualitative descriptive approach was used to analyze the incidents and categorize contextual information into "precursor events" and "influencing factors" for infant falls.

**Results:** We identified 461 infant fall incidents. Common fall mechanisms included falls from furniture, falls when being carried or supported by someone, falls from baby products, and falls on the same level. Across the spectrum of fall mechanisms, common precursor events were infant rolling off, infant being alone on furniture, product misuse, caretaker falling asleep while holding the infant, and caretaker tripping/slipping while carrying the infant. Common influencing factors were infant's rapid motor development, lapses in caretaker attention, and trip hazards.

**Conclusions:** The findings define targets for interventions to prevent infant falls and suggest that the most viable intervention approach may be to target parental behavior change. Online forums can provide rich information critical for preventive interventions aimed at changing behavior.

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## KEYWORDS

falls; child injury; online discussion forums

## Introduction

Injury is a widespread and longstanding public health problem [1]. Globally, injury is a leading cause of child death and

hospitalization [2]. In Australia, children aged  $\leq 1$  year have the highest death rates due to injury among all children and have an injury hospitalization rate of 799/100,000 [3]. Falls are the most common injury mechanism in this age group, accounting

for almost 50% of all injury hospitalizations [3]. The head is the most commonly injured body region [4], and head injury often leads to traumatic brain injury [5]. Similar incidences and injury patterns occur in North America and Europe [6-8]. Traumatic brain injury in early childhood is associated with negative behavioral and cognitive outcomes [9]. While a number of interventions are effective for minimizing fall risk in older children [10,11], there is a paucity of evidence on effective countermeasures for falls in children aged  $\leq 1$  year.

Epidemiologic studies examining infant falls usually rely on administrative data or medical records [4,12,13]. These provide details on burden and demographic risk factors, but generally have limited or incomplete contextual information. This is a barrier for effective intervention development [14].

The best source of detailed contextual information about infant falls is from someone who witnessed the fall. However, one-on-one discussions and large sample sizes can be time and resource intensive. In other areas, the internet and social media have been successfully used to collect data from people participating in online forum discussions [15]. These also provide naturalistic data, as discussions occur without researcher involvement [16].

We aimed to use online parenting discussion forums to unobtrusively and cost-effectively access contextual information about infant falls in order to identify specific modifiable factors to prevent infant falls.

## Methods

### Study Design

This was an infodemiology study [17,18] using online forum data following a qualitative descriptive approach [19], with the objective of providing comprehensive summaries of infant fall events [20]. The data source was social media forums within an online parenting website. This website was established in 1999, and is owned and operated by a large Australian media company. The website provides parenting information in the form of media articles and forums across a broad range of noninjury/prevention-related child care topics. After obtaining required approvals, site-specific Google Search queries were chosen to identify URLs potentially containing discussions related to infant falls. These were “baby fall,” “baby falling,” “baby fell,” “baby dropped,” and “baby hurt.” This approach allowed us to search all forums on this website without placing too much burden on the website. A researcher manually screened the resulting URL list and compiled a list of possible URLs containing infant fall discussions. The discussions from the selected list of web pages were downloaded using a program script written in Python, and any potentially identifiable data

were removed. The search was completed on June 22, 2019, and included discussion threads ranging from November 22, 2003, to June 05, 2016.

Deidentified data were coded using QSR Nvivo12 software to identify relevant incidents. Relevant incidents were those relating to falls or near falls involving children aged  $\leq 1$  year, with age identified from words in the post (post specifically mentioned age as  $\leq 1$  year, post was from a forum specific to children aged 0-6 months or 6-12 months, fall incident was mentioned in response to other incidents describing infant falls where age 0-12 months was mentioned, or post had the words “newborn” or “tiny baby”).

### Ethics Approval

The study obtained approval from the website owner and ethics approval from the Human Research Ethics Committee (HC180295).

### Analysis

Fall mechanisms were categorized, described, and mapped to ICD-10-AM (International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification) codes (Table 1). Two researchers (NC and SLS) independently coded the data using fall mechanism categories (Table 1), and any differences were discussed until agreement was reached.

Coding of contextual information followed an inductive open-coding approach. Emerging codes were then classified as “precursor events” or “influencing factors.”

In recognition that fall circumstances are often multilayered, we separated likely causative factors leading to the fall into “precursor events” and other “influencing factors.” A “precursor event” was defined as the event/state immediately before the fall according to the literal meaning in the discussion. An “influencing factor” was defined as a factor that impacted the “precursor event” and therefore the occurrence of the fall.

One researcher (NC) compiled a list of factors categorized as a “precursor event” or “influencing factor,” and a second researcher (SLS) independently recoded the data using this list, adding new factors as necessary. The two researchers (NC and SLS) compared analyses, and differences were discussed until agreement was reached. To address potential coder biases and preconceptions, coding for each fall mechanism by each researcher was undertaken separately, and consensus was reached before moving onto coding for the next mechanism.

NC (a PhD student) and SLS (an undergraduate medical student) were supervised by senior co-authors experienced in injury and qualitative research methods.

**Table 1.** Fall mechanism categories derived from ICD-10-AM (International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification) codes.

| Fall mechanism category and detailed fall mechanism                       | ICD-10-AM <sup>a</sup> codes | ICD-10-AM code description  |
|---|------------------------------|---|
| <b>Fall from household furniture</b>                                      |                              |   |
| Fall from bed   | W06                          | Fall from bed   |
| Fall from chair/couch/sofa  | W07                          | Fall from chair   |
| Fall from changing table  | W08                          | Fall from other furniture   |
| Fall from table   | W08                          | Fall from other furniture   |
| <b>Fall from baby products</b>  |                              |   |
| Fall from baby capsules   | W08                          | Fall from other furniture   |
| Fall from bassinet/cot  | W08                          | Fall from other furniture   |
| Fall from bouncer   | W08                          | Fall from other furniture   |
| Fall from child car restraints  | W08                          | Fall from other furniture   |
| Fall from high chair/baby chair   | W08                          | Fall from other furniture   |
| Fall from portable baby bed   | W08                          | Fall from other furniture   |
| Fall from pram/stroller   | W08                          | Fall from other furniture   |
| <b>Fall while being carried or supported by someone</b>                   |                              |   |
| Fall when carried or supported by mother                                  | W04                          | Fall while being carried or supported by other persons                          |
| Fall when carried or supported by an unidentifiable parent                | W04                          | Fall while being carried or supported by other persons                          |
| Fall when carried or supported by an adult caretaker (other than parents) | W04                          | Fall while being carried or supported by other persons                          |
| Fall when carried or supported by an older child                          | W04                          | Fall while being carried or supported by other persons                          |
| <b>Fall on the same level</b>   |                              |   |
| Fall while infant standing  | W01                          | Fall on the same level from slipping, tripping, and stumbling                   |
| Fall while infant sitting   | W18                          | Other fall on the same level  |
| Fall while infant crawling  | W18                          | Other fall on the same level  |
| Other fall on the same level due to collision                             | W03                          | Other fall on the same level due to collision with or pushing by another person |
| <b>Fall related to stairs</b>   |                              |   |
| Fall on and from stairs and steps   | W10                          | Fall on and from stairs and steps   |
| <b>Fall between levels</b>  |                              |   |
| Fall from, out of, or through building or structure                       | W13                          | Fall from, out of, or through building or structure                             |
| Fall from a cliff   | W15                          | Fall from a cliff   |
| Other fall from one level to another                                      | W17                          | Other fall from one level to another  |
| <b>Other fall mechanisms</b>  |                              |   |
| Fall from mats or playmats  | W08                          | Fall from other furniture   |
| Fall involving play equipment   | W09                          | Fall involving playground equipment   |
| Fall from shopping cart   | W08                          | Fall from other furniture   |

<sup>a</sup>ICD-10-AM: International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification.

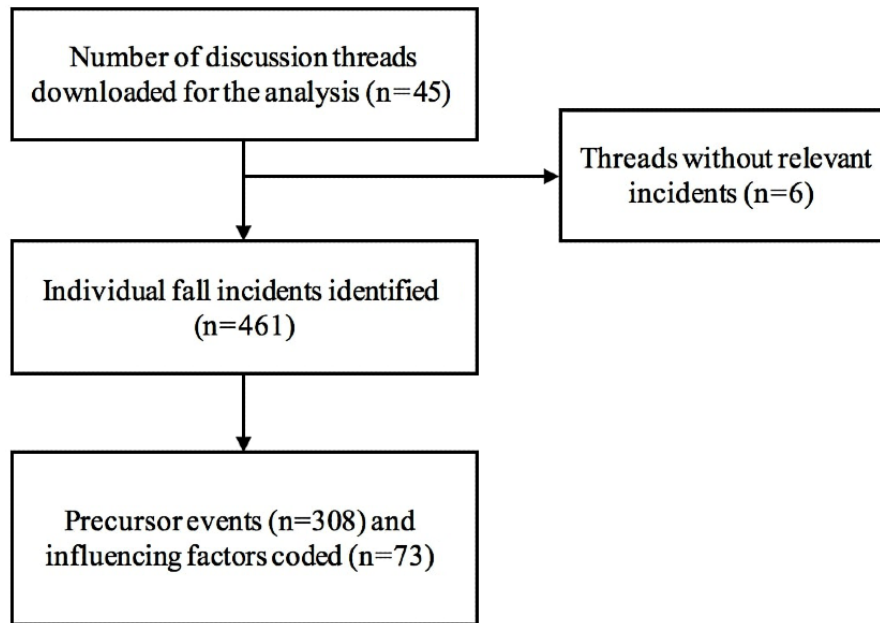
## Results

### Overview

Figure 1 summarizes the data capture process. Overall, 461 infant fall incidents were identified. The most common fall mechanisms were a fall from household furniture (270/461,

58.6%), followed by falls when being carried or supported by someone (92/461, 20.0%) and falls from baby products (55/461, 11.9%). Other mechanisms were a fall on the same level (28/461, 6.1%), fall on/from stairs (6/461, 1.3%), falls from playmats (4/461, 0.9%), falls from playground equipment (3/461, 0.7%), and falls from shopping carts (3/461, 0.7%).



**Figure 1.** Outcome of the data capturing process.

### Falls From Household Furniture

Detailed mechanisms for these falls included falls from beds (146/270, 54.1%), falls from changing tables (64/270, 23.7%), falls from chairs/couches/sofas (53/270, 19.6%), and falls from tables (6/270, 2.2%).

The most commonly mentioned precursor event for falls from household furniture was the infant rolling off the furniture. This was mentioned 71 times within the 270 (26.3%) incidents related to furniture falls.

*Yesterday, my little girl (6 months) rolled off the bed. She hit her head ... and screamed...*

The next most common precursor event involved the infant being left alone on furniture. This was mentioned in 36 of the 270 (13.3%) incidents.

*I left her in the middle of my queen bed while I did some vacuuming. As I got closer to my bedroom ... I could hear her screaming like she had never screamed before. I ran into the room and she was on the floor!...*

The caretaker falling asleep with the baby was another common precursor event mentioned in 18 of the 270 (6.7%) incidents.

*... I was breastfeeding him in bed and fell asleep with him on the outside. I woke up when I heard a thud and DS[Darling Son] cry.*

It was clear from some discussions that the precursor event of falling asleep was often unintentional (10/18, 55.6%), while in others (6/18, 33.3%), it was intentional or the intention was unclear (2/18, 11.1%).

For falls from changing tables, a common precursor event was the caretaker reaching for something while nappy changing, which was identified 11 times within the 64 (17.2%) incidents related to changing tables.

*I was changing him on the change table and all I did was slip one hand down to put the dirty nappy in the*

*nappy bag and ds launched himself off the table and landed on the floor...*

Unexpected or rapid changes in motor development were the most common influencing factor for furniture falls. This was identified in 29 of the 270 (10.7%) incidents.

*...when he had started to move - I underestimated how quick he was. I used to put him on our bed every morning while I got dressed. One day I turned my back for a second and in that time he pulled himself to the edge then did a somersault off the bed!*

Lapse in caretaker attention was the next most common influencing factor for this fall mechanism. This was identified in 20 of the 270 (7.4%) incidents.

*... honestly it can happen in the blink of an eye. Similar to your DH[Darling Husband] I looked away from the table, and over he went. It was so quick.*

### Falls When Carried or Supported by Someone

This was the second most common fall mechanism in the discussions (n=92). It commonly occurred when the child was carried or supported by the mother (39/92, 42.4%) or an unidentified parent (28/92, 30.4%), and when the child was carried or supported by an adult caretaker other than a parent (19/92, 20.7%), and less commonly occurred when the child was carried or supported by an older child (6/92, 6.5%).

The most common precursor for these falls was the caretaker tripping/slipping (29/92, 31.5%), and this often occurred on steps or stairs (18/29, 62.1%). Other environmental hazards within the home included slippery floors (2/29, 6.9%) and tripping hazards on the floor (2/29, 6.9%).

*I dropped my ds[Darling Son] he was about 10 months tripped up the back step he screamed has a giant bump...*

Another common precursor event for these falls was the person falling asleep while holding the infant (15/92, 16.3%), and it

often involved the child's mother falling asleep while feeding (12/15, 80.0%).

*...I was totally sleep deprived. Sat down on the couch to nurse her, dozed off with her snuggled low in my arms (basically in my lap) our dog barked and I startled awake – DD [Darling Daughter] rolled down my legs and into the coffee table.*

A tired caretaker is also a likely influencing factor; however, this was only overtly discussed a few times (2/15, 13.3%). Other commonly discussed influencing factors were inadequate holding of the child (13/92, 14.1%) and sudden unexpected movements of the child (9/92, 9.8%).

*A friend was holding my 6 month old he had his arm tucked behind his legs holding him up right and wasn't supporting his back when my LO flung back... ("LO" is assumed to mean "little one")*

### Falls From Baby Products

The most common products involved in falls were strollers/prams (21/55, 38.2%), bouncers (10/55, 18.2%), high chairs/baby chairs (9/55, 16.4%), and bassinets/cots (9/55, 16.4%). Less commonly involved were baby carriers/capsules (3/55, 5.5%), child car restraints (2/55, 3.6%), and portable baby beds (1/55, 1.8%).

Improper use was the most common precursor event for these falls. Nonuse or misuse of safety straps was common for many baby products (particularly for strollers/prams, baby bouncers, high chairs/baby chairs, child car restraints, and baby capsules/carriers). This was identified 30 times (55%, 15 cases of not using safety straps and 15 cases of apparent improper use of straps).

*Mother of the Year here took a few months to really internalise the 'strap them in' message and DD [Darling Daughter] I bounced herself face first out of the bouncer at about three months old*

Some other critical misuses identified were placing the cot base in a high position (5/55, 9.1%), unbalancing the stroller (3/55, 5.5%), not using strollers' brakes (2/55, 3.6%), and carrying the infant while in the bouncer/portable baby bed (2/55, 3.6%). Falls from cots were influenced by rapid motor development.

*...like he was balancing on the cot railing with his feet off the mattress suspended in mid air by piece of wood...*

### Falls on the Same Level

Four different types of falls on the same level were mentioned. Most common was a fall while the infant was standing (20/28, 71.4%). Falls while the infant was sitting, falls while the infant was crawling, and other falls due to being pushed by another person had less than five identified incidents each.

The common influencing factor for this fall mechanism was the child's underdeveloped motor skills (13/28, 46.4%).

*...Now that both are easily pulling themselves up against furniture to stand, they are doing it every chance they get. The only problem is once they get up they don't know how to get down or lose concentration, let go and fall...a lot of the time hitting their heads on the tiles.*

### Falls on or From Stairs

Falls on or from stairs were relatively uncommon (5 incidents). Two influencing factors for these were lapses in caretaker attention (3/5, 60%) and unexpected/rapid infant motor development (2/5, 40%).

*DS [Darling Son] I fell down the stairs - all 8 of them - when he was 4 months. He was lying at one end of the room, well away from the stairs. I put a book on the shelf and when I turned back he'd rolled across the room and I was just in time to see him disappear, screaming, down the stair well.*

### Other Fall Mechanisms

Other mechanisms identified from the discussions included falls from playground equipment and falls from shopping carts (10 incidents). The precursor event related to falls from shopping carts was the nonuse of straps (3/10, 30%).

*...didn't bother to buckle him in. I was squatting down looking at something when I heard a horrible splat sound, he had fallen face first onto the cement floor...*

There were no detailed discussions to identify causal factors for falls from playground equipment. Moreover, there were no discussions of falls between levels (eg, from windows).

**Table 2** summarizes the precursor events and influencing factors for different fall mechanisms.

**Table 2.** Precursor events and influencing factors for fall mechanisms.

| Fall mechanism                            | Precursor events  | Influencing factors   |
|---|---|---|
| Fall from furniture                       | <ul style="list-style-type: none"> <li>• Infant rolling off</li> <li>• Infant being left alone on furniture</li> <li>• Caretaker falling asleep with the infant</li> <li>• Reaching for something while nappy changing</li> </ul> | <ul style="list-style-type: none"> <li>• Unexpected or rapid changes in infant motor development</li> <li>• Lapse in caretaker attention</li> </ul> |
| Fall when carried or supported by someone | <ul style="list-style-type: none"> <li>• Caretaker tripping or slipping</li> <li>• Caretaker falling asleep while holding the infant</li> </ul>   | <ul style="list-style-type: none"> <li>• Inadequate holding of the child</li> <li>• Sudden unexpected movement of the infant</li> </ul>             |
| Fall from baby products                   | <ul style="list-style-type: none"> <li>• Nonuse or misuse of safety straps</li> <li>• Other product misuses</li> </ul>  | N/A <sup>a</sup>  |
| Fall on the same level                    | N/A   | <ul style="list-style-type: none"> <li>• Infant's underdeveloped motor skills</li> </ul>  |
| Fall on or from stairs                    | N/A   | <ul style="list-style-type: none"> <li>• Lapse in caretaker attention</li> <li>• Unexpected or rapid changes in infant motor development</li> </ul> |

<sup>a</sup>N/A: not applicable.

## Discussion

### Principal Findings

Using a novel qualitative infodemiological approach, we identified contexts requiring intervention to prevent the majority of falls in children aged  $\leq 1$  year. These are leaving children alone on furniture; misuse of changing tables and baby products, such as strollers, baby carriers, and baby chairs; slips and trips; and falling asleep while holding an infant. Furthermore, the richness of our data set allowed us to link specific influencing factors to specific precursor events for these fall types to identify modifiable factors to prevent falls. These include awareness of unexpected or rapid changes in infant motor development, lapses in caretaker attention, importance of adequately holding the infant, and reducing hazards in the home environment.

Our findings align well with previously reported studies using administrative data sets and medical record reviews [4,7,21-24]. While some identified factors have been noted previously [8,25-27], this is the first study to provide this level of detail and identify targets for intervention across the spectrum of fall mechanisms among infants of this age.

Contextual information like that identified in this work also provides evidence and adds to studies that have previously suggested using age appropriate injury prevention education for caregivers and home safety assessment programs [7,25]. However, currently, evidence on any effective interventions specifically targeting falls in this age group is rare [28]. Given the magnitude and potential impact of this problem [5,8], there is an urgent need to fill this gap and identify effective targeted interventions. The outcomes of this work identify modifiable factors to be targeted in these interventions.

While our findings demonstrate that no single intervention would prevent all falls, there is a common need for parent/caretaker behavioral change across many of the fall mechanisms. It therefore appears that a behavior change or an active approach, rather than a purely structural change (passive approach) [29], may be effective to prevent infant falls. For example, having a safety harness in a changing table is

structural, whereas the parent using it appropriately is behavioral. However, behavior change is complex, and educational interventions alone usually do not enact behaviors [30]. Behavior change interventions are more likely to be successful when based on behavior theory [31]. One challenge to developing effective behavior change interventions is that they require detailed understanding of the problem and target behaviors [32]. This study fills some of these gaps by identifying behaviors that need to change, and the circumstances where these behaviors occur.

In this study, we did not attempt to examine data by infant age, but it is clear from our earlier work [4] that risks of falls by different mechanisms change as children move through development stages in the first year of life. Different behavior change interventions are likely needed at different times through this year, and this needs to align with the infant's developmental stage [6]. For example it is possible that the risk of a mother falling asleep while feeding is higher in early infancy and the risk of rolling off the bed is higher when the infant is gaining motor skills. Intervening at a single time point may also not be as effective as a targeted strategy to deliver behavior change interventions at different time points over time.

Falls among infants on the same level were discussed relatively less commonly by parents in the forums than other falls, yet it is likely that these occur very commonly. As noted by Adolph and Berger [33], falling is a common by-product of children learning to walk, with children at this stage of development falling within the vicinity of 17 times an hour and 100 times a day. As we previously observed [4], these types of falls very rarely occur among infants hospitalized from a fall (<2% of all patients), and therefore, this lack of severity might underpin the lack of discussion in the forums. As these falls occur while children are developing an important motor skill, it would not be appropriate to try to prevent the activities leading to these. Instead, injury risk might best be reduced by paying attention to the environment in which children are placed during this stage of development.

Another aspect warranting further environmental examination is the adequacy of both the design and instructions of common

baby products used by parents of infants. Previous work identifying the influence of design defects in products, such as prams/strollers [34,35] and high chairs [34,36], has led to stringent safety standards. However, these types of design standards do not address how the products are ultimately used. Improper use was the most common precursor event for falls involving baby products. This aligns with findings from previous studies reporting the high frequency of nonuse or incorrect use of safety straps in products, such as prams/strollers and high chairs [34,37]. In other areas (eg, child car seats), it is becoming increasingly clear that correct use requires attention to how usage information is communicated and the interaction between the user and the inherent design of the product, in addition to the general behavior of the user [38]. Extension of this approach to all baby products may be useful.

### Limitations

As this is a qualitative study based on ad hoc reporting of fall types, the frequencies of different fall types reported might not reflect true frequencies. Frequencies are reported to give readers some idea of the commonality, mechanisms, influencing factors, and precursor events. While care was taken when extracting data to exclude conversations in separate threads related to the same fall incident, this could not be guaranteed. Therefore, this might also impact the accuracy of specific fall mechanisms reported. However, common fall mechanisms aligned with other epidemiological and medical record reviews [4,7,22]. Data used were from a convenience sample of online forum discussion participants, and the sample characteristics are unknown. The characteristics of parents who use social media are not well

understood in terms of how well they represent the full population of parents or their behavior in discussing injury events of different severities online. Therefore, this may introduce some unknown bias, and the findings may not be generalizable to the whole population or the full spectrum of injury severity. Data were also collected across a broad time period of 13 years, and there is no way to know the specific geographical locations of those contributing to the forum from which the data were collected. While to our knowledge, there were no significant changes in health promotion/injury prevention programs across this time period, it is possible that contributors were exposed to different types of health promotion activities depending on location. This may have also introduced some unmeasured bias in the data. Another limitation was the use of a single search engine. Different search engines may provide different result sets. Moreover, this kind of study collects data from a static point in time, which precludes active engagement with caregivers and the ability to clarify or obtain additional details from parents compared with other qualitative approaches. However, the unobtrusive nature of this data collection method may be a strength, as it provides data extracted from naturalistic parental discussions.

### Conclusion

This study used infant fall incidents from online parenting forums to identify precursor events and influencing factors leading to different fall types among infants aged  $\leq 1$  year. This information is paramount to the development of preventive interventions, particularly given that the findings suggest targeting parental behavior.

### Authors' Contributions

NC conceptualized and designed the study, did the site-specific searches, developed the web scripting script, downloaded and cleaned the data, carried out the analysis, drafted the initial manuscript, and reviewed and revised the manuscript. SLS analyzed the data, drafted the initial manuscript, and reviewed and revised the manuscript. SA, LK, and NN conceptualized and designed the study, coordinated and supervised the data collection, and critically reviewed the manuscript for important intellectual content. JB conceptualized and designed the study, coordinated and supervised the data collection and data analysis, drafted the initial manuscript, reviewed and revised the manuscript, and critically reviewed the manuscript for important intellectual content. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

### Conflicts of Interest

None declared.

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Original Paper

# Acceptability of Serious Games in Pediatric Asthma Education and Self-management: Pilot Study

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## Abstract

**Background:** Asthma is the most common chronic pediatric disease. Despite existing tools to manage asthma, 40%-55% of children with asthma experience uncontrolled asthma. Serious games (SGs) represent a novel approach in promoting asthma education and self-management for children.

**Objective:** In this qualitative pilot study with an embedded quantitative design, we aim to use focus groups and questionnaires to describe the perceived role of SGs in different aspects of asthma self-management by children and their parents. These aspects include asthma perception and knowledge, the impact of asthma and barriers to asthma self-management, and the support system for asthma self-management.

**Methods:** A total of 5 children with asthma and their parents were invited to participate in an organized gaming session. Children and their parents completed a pre-gaming questionnaire on their medical history and asthma knowledge. Then, they were invited to test 4 original SG prototypes, after which the children answered a post-gaming questionnaire on their asthma knowledge and perception of the SGs. Children and their parents subsequently participated in parallel focus groups, which were video-recorded or audio-recorded, transcribed verbatim, and analyzed by reaching consensus among members of the research team.

**Results:** The mean age of the children was 10.3 (SD 1.5) years, with 20% (1/5) of the children being male. Qualitative data from the transcripts were coded into three separate domains: asthma self-management perception and knowledge, impact of asthma and barriers to asthma self-management, and support system for asthma self-management. We specifically explored the perceived roles of SGs within each domain. A key takeaway message was identified for each of these three domains: heterogeneity of asthma knowledge and the ability of SGs to encourage knowledge transfer through games, consequences and limitations of asthma and the ability of SGs to allow for identification and management of real-life situations through games, and insufficient support system and the ability of SGs to encourage playing with others for support and shared knowledge.

**Conclusions:** Our pilot study explored the role of SGs in the self-management of asthma, as perceived by children and their parents. Our findings support the acceptability of SGs in asthma education and self-management in pediatrics and the necessity for future development in this field.

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## KEYWORDS

asthma; pediatrics; video games; eHealth; self-management

## Introduction

### Background

Asthma, characterized by persistent inflammation of the airways and limited airflow, is the most common chronic pediatric disease [1]. Worldwide, studies consistently report that 40%-55% of children with asthma have uncontrolled asthma in the outpatient setting, defined as frequent respiratory symptoms and exacerbations necessitating the use of health care resources [2-5]. Poor asthma control can compromise long-term lung function and increase the risk of exacerbations, which can negatively impact a child's school attendance and participation in activities [1,6-8] and is a major source of stress for families [1,9]. Despite existing tools for asthma education such as targeted one-on-one asthma education and accessible web-based or paper-based asthma information, inefficient knowledge transfer and poor adherence to prescribed therapy remain major contributors to poor asthma control [1,6,10,11]. For example, studies have shown that 50% of adults and children who are prescribed daily asthma medications do not take them as recommended [1,11], and that poor inhaler technique is common, with 70%-80% of patients using their inhalers incorrectly [1]. A study focused on patients' perspective of taking long-term asthma controller medication reported various barriers to adherence, including doubts about asthma severity, fears of addiction, and limited knowledge [12]. Thus, novel tools for asthma education are needed to ensure adequate asthma control.

Recent and ongoing technological advances have allowed the field of eHealth to prosper and evolve greatly. eHealth is the cost-effective use of technologies in various fields of health, namely, health education [13]. The Chronic Care Model (CCM), a validated framework for the management of patients with chronic illnesses, has recently been updated to create the eHealth Enhanced CCM (eCCM), highlighting the potential benefits that eHealth could have for such individuals [14]. This model presents various components that impact the management of chronic illnesses and eHealth applications, which can contribute to improved outcomes [14]. More precisely, it has been suggested that eHealth tools such as telehealth and mobile health apps could be useful in self-management support, resulting in more engaged and empowered patients [14]. Moreover, the eCCM includes eHealth education as a component of chronic care management, stressing the importance of health literacy and eHealth training [14]. The eCCM equally highlights the importance of having a patient who is informed and activated and a practice team that is prepared and proactive, with productive interactions between these 2 actors also contributing to improved outcomes [14].

### Previous Work

Although the eCCM focuses primarily on implementing eHealth tools, such as the use of internet for health information, mobile health, telehealth, electronic health records, and personal health records or patient portals, it does not specifically address the role of serious games (SGs) in health or in chronic illness management [14]. SGs are games that impart real-world skills, knowledge, or attitudes to the user through play [15]. They represent a cost-effective, accessible, unique, and dynamic approach within eHealth that can positively impact self-management support and eHealth education, which are 2 key components of the eCCM, through behavioral change by including simulation and management activities [14-17]. A systematic review of SGs in asthma education revealed that 90% of the children enjoyed them, and that most studies resulted in an improvement in the child's knowledge about asthma [15]. However, the vast majority of the games failed to demonstrate significant changes in behavior and clinical outcomes, possibly because they were directed uniquely at the children and not their parents, despite parents playing a major role in the treatment of their children [15]. Furthermore, previous SGs mainly focused on information delivery rather than simulations of real-life scenarios, which are more likely to promote behavior change. Finally, existing SGs are web-based or desktop computer-based, and their effectiveness may be enhanced if they are designed as accessible mobile apps [15].

### Goal of This Study

To evaluate how SGs can be integrated into the asthma management framework, we build and, in a pilot study, evaluate 4 open-source SG prototypes focused on recognizing asthma triggers and symptoms and taking appropriate actions during an asthma exacerbation or as part of control therapy. These games are developed to provide a novel technique to promote self-management of asthma in children, which is a key aspect of asthma action plans [2,18]. They represent different game genres, including action, role-playing, and simulation. This pilot study aims to evaluate the acceptability of these original bilingual (French and English) SGs and gather feedback to guide their further development by answering the following research question: what are the children's and their parents' perceptions of the role of SGs in the self-management of asthma?

## Methods

### Study Design

A qualitative study with a consensual qualitative design and an embedded quantitative component [19,20] was used to explore children's and their parents' perceptions of the role of SGs in different aspects of asthma self-management. We chose a

consensual qualitative design because we emphasized the agreement between members during focus groups and within the research team.

### Ethics Approval

The study obtained approval from the research ethics boards of both the Sainte-Justine University Health Center (ID 2019-2075) and Concordia University (ID 30010592). Written informed consent and written or oral assent for the study and video-recording or audio-recording were obtained from the parents and from age-appropriate children, respectively.

### Participants and Procedures

We identified children meeting the eligibility criteria through the appointment list and a chart review, and the families were consecutively approached by the research team for participation at the respiratory medicine or asthma clinic of the Sainte-Justine University Health Center, a pediatric tertiary care center. Participants were children (1) aged 8-12 years inclusively, (2) with physician-diagnosed asthma, (3) who were on a daily controller medication, and (4) who understood and spoke French or English. We excluded children with chronic conditions other than asthma, such as cardiovascular diseases, neuromuscular disorders, or developmental delay. The targeted sample size of this study was 14 children and one of each of their parents. This sample size was based on previous literature using focus groups in pediatric health care research [21-23], the expertise of a qualitative researcher on our team, and the feasibility for a pilot study.

## Data Collection

### Pregame and Postgame Questionnaires

Pregaming questionnaires were administered separately to both parents and children upon their arrival. The pregame questionnaires included questions pertaining to previous gaming experience (children), asthma perception (children and parents), asthma knowledge (children and parents), and medical history of the child (parents). Asthma perception was assessed through several statements about general health and asthma using a Likert scale. The asthma knowledge questionnaire included true or false questions pertaining to their knowledge of asthma. In the absence of a well-validated asthma knowledge questionnaire, we created this questionnaire based on previous studies [24-26]. The final questions were reviewed by the research team, which includes a pulmonologist, a pediatrician, and a public health specialist, for their relevance to childhood asthma. The asthma knowledge questions were identical for both the pregame and postgame questionnaires to evaluate the knowledge transfer achieved through the SGs. We asked the children to play the 4 SGs on a provided laptop for a total duration of approximately 60 minutes. In addition, we encouraged the parents to explore the games themselves, either on their own or by playing with their children. A description of the games is provided below (Table 1). After each game, we asked the children to answer a web-based survey based on a Likert scale, about their general opinions of the game. After the gaming experience, the children completed a postgame questionnaire, which included questions on the strengths and weaknesses of the games and the asthma knowledge questionnaire.

**Table 1.** Description of the 4 games used in this study.

| Name of the game | Game description  | Educational objectives                                 | Time allotted to play (minutes) |
|------------------|---|--|---------------------------------|
| Asthmonautes     | A game in which the child navigates through different scenarios and interacts with 9 characters to learn about asthma symptoms and management [27]                                | Understand asthma symptoms and management              | 30                              |
| Lung Launcher    | A game in which the character encounters different asthma triggers (customizable to the child) and the child must find the correct preventive method to address each trigger [28] | Identify asthma triggers and learn how to address them | 4                               |
| Asthma Heroes    | A game in which the player interacts with several characters to learn about their symptoms, treatment, and context and collects objects to help them manage their asthma [29]     | Understand asthma symptoms and management              | 30                              |
| Bloïd            | A game in which the player uses a breath-actuated sensor as an input device to guide a spacecraft and destroy meteorites in its path [30]   | Be aware of own breathing                              | 4                               |

### Focus Groups and Interviews

We conducted semistructured focus groups with children and parents separately. Individual interviews were conducted on one of the study days, as there were only 2 children and 2 parents present. Of note, the interviewers were not involved in the clinical care of the participants and were unfamiliar to them. The topic guides used to collect data considered the inclusion of probing questions that were used accordingly to obtain more detailed responses. The topic guide for the children's focus group included themes such as asthma in general, gaming experience, practical implications the games could have on their health including benefits and risks, and the potential of playing SGs at home. The topic guide for the parents' focus group

revolved around asthma management and challenges, available resources to help overcome their challenges, and the acceptability of SGs in health. The interview and focus group times ranged from 16-35 minutes. We aimed to achieve consensus among the participants during the focus groups.

### Data Analysis

We used the predetermined questionnaires for the quantitative part of the study and predetermined discussion topics to evaluate the topics of interest qualitatively. Then, the recordings were transcribed verbatim. For confidentiality purposes, all personal information was removed from the transcripts and participants were allotted a study identification number.

We described the participants' characteristics and information pertaining to their asthma. The analysis of the qualitative data was guided by the eCCM [14], which highlights important aspects of self-management and eHealth education in chronic illnesses. During the analyses, the members of the research team reached consensus to ensure validity and coherence of the results [19]. Specifically, the analytical process was divided into three major steps, including segmenting data from the transcripts into domains, abstracting data within the domains into core ideas, and performing a cross-analysis to develop themes across participants, which were agreed upon by the research team [20]. We used the software MAXQDA (version 12; VERBI Software) to support data analysis.

To ensure the validity of our study, we implemented various verification techniques throughout the analytical process [31]. By using multiple researchers for data analysis and different data collection methods (eg, questionnaires and focus groups), we were able to achieve analyst triangulation and methods triangulation, respectively, thereby ensuring a consensus among team members and maximizing the credibility and confirmability of our findings. In addition, peer debriefing was used to further establish credibility. Confirmability was further achieved by maintaining an audit trail and ensuring reflexivity by reporting biases, using multiple researchers, and using interviewers who are not involved in the care of the participants. Finally, we described the themes that emerged in this study by using quotes from the participants and their parents as evidence. As the

individual interviews and group discussions were conducted in French, the quotes were translated to their English equivalents.

## Results

### Study Participants

The targeted sample size of this pilot study was 14 children and one of each of their parents. We approached 37 potential participants and 14 (38%) families agreed to participate. Reasons for declining participation included lack of time, living far from the hospital, and scheduling conflicts. On the day of the focus groups, owing to unpredictable cancellations (extreme weather and scheduling conflicts), the final sample size was 36% (5/14) of the children and 6 parents (2 parents were present for one of the children). We invited participants to attend one of the 2 half-day sessions organized at the Sainte-Justine University Health Center.

Baseline characteristics of the participants are presented in Table 2. The mean age of the participants was 10.3 (SD 1.5) years, and only 20% (1/5) of the participants were male. None of the participants had any asthma-related hospitalizations or emergency department visits during the 12 months before the study. The average time spent on playing video games each day was 30-60 minutes for 40% (2/5) of the participants. Mobile phones and different consoles were found to be the most used devices for gaming, with 60% (3/5) of the participants using each device.

**Table 2.** Baseline characteristics of the children with asthma included in this analysis (N=5).

| Characteristics   | Values     |
|---|------------|
| Age (years), mean (SD)  | 10.3 (1.5) |
| Sex (male), n (%)   | 1 (20)     |
| Parental report of age of asthma diagnosis (years), mean (SD)                                 | 1.9 (1)    |
| Child report of age of first asthma exacerbation (years; for nonmissing data; n=3), mean (SD) | 2.2 (0.8)  |
| Asthma-related hospitalization during the past 12 months, median (IQR)                        | 0 (0)      |
| <b>Time spent on playing video games, n (%)</b>   |            |
| Never   | 1 (20)     |
| 0-30 minutes  | 1 (20)     |
| 30-60 minutes   | 2 (40)     |
| 60-90 minutes   | 0 (0)      |
| 90-120 minutes  | 0 (0)      |
| >2 hours per day  | 1 (20)     |
| <b>Device used to play games, n (%)</b>   |            |
| Mobile phone  | 3 (60)     |
| Tablet  | 2 (40)     |
| Computer  | 2 (40)     |
| Console   | 3 (60)     |

### Analysis of Qualitative Data

The analysis of the transcripts from the individual interviews and group discussions occurred in 3 major steps and was guided

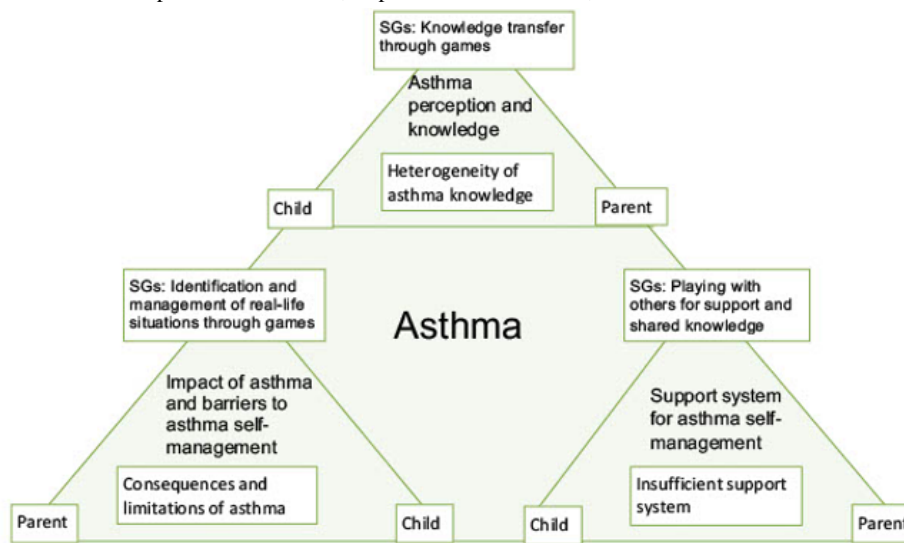
by the following research question: what are the children's and parents' perceptions of SGs in the self-management of asthma? The transcripts were analyzed by a primary research team composed of 4 coders (NS, AV, FB, and SMT). Transcripts



were first coded into 3 major domains, or topic areas, by one of the coders (NS) and then, verified by the remaining coders on the research team (AV, FB, and SMT). The domains reflected various components of the perceived reality of asthma by children and parents. They included (1) asthma self-management perception and knowledge, (2) impact of asthma and barriers to asthma self-management, and (3) support system for asthma self-management. The data in each domain were abstracted independently into core ideas by 4 coders (NS, AV, FB, and SMT), focusing on the role of SGs within each domain, as

perceived by children and parents. Then, the 4 coders worked together to perform a cross-analysis of the core ideas within the domains to generate common themes on the roles of SGs. The team discussed until consensus was achieved. Analysis was guided by the eCCM. After analysis, a visual model was created, illustrating the key interactions between asthma and SGs, as perceived by children and parents (Figure 1). This model complements the original eCCM model by integrating key concepts pertaining to pediatric care and the role of SGs.

**Figure 1.** Visual representation of the main results obtained in this study. Our results demonstrated a triangular relationship between a child with asthma, their parent, and the potential role of serious games (SGs) on the 3 domains of asthma management evaluated in this study. The major overarching issues identified during discussions with parents and children, respective to each domain, are also illustrated.



### Themes Identified From Interviews and Discussions

#### Overview

Table 3 shows the themes identified from the interviews and discussions.

**Table 3.** Study domains and corresponding themes identified from interviews and discussions with children and parents.

| Domain  | Themes  |   |
|---|---|---|
|   | Children  | Parents   |
| 1–The role of SGs <sup>a</sup> in asthma self-management perception and knowledge           | <ul style="list-style-type: none"> <li>Knowledge transfer achieved through the games</li> </ul>   | <ul style="list-style-type: none"> <li>Potential of learning about asthma through games and knowledge transfer</li> <li>Gain of knowledge depends on experience and onset of asthma</li> </ul>                  |
| 2–The role of SGs in addressing the impact of asthma and barriers to asthma self-management | <ul style="list-style-type: none"> <li>Knowledge on self-management through games</li> </ul>  | <ul style="list-style-type: none"> <li>Knowledge on self-management through games</li> <li>Utility of games at asthma diagnosis</li> <li>Games as a possible tool to evaluate ongoing asthma control</li> </ul> |
| 3–The role of SGs in the support system for asthma self-management                          | <ul style="list-style-type: none"> <li>Asthma awareness through SGs</li> <li>Openness to further discuss asthma with parents through games</li> <li>Interest and utility of playing the games with peers</li> </ul> | <ul style="list-style-type: none"> <li>Importance of parent and child playing together</li> <li>Interest and utility of playing the games with peers</li> </ul>   |

<sup>a</sup>SG: serious game.

### **Domain 1: The Role of SGs in Asthma Self-management Perception and Knowledge**

This domain included different themes pertaining to the role of SGs in children's and parents' asthma self-management perceptions and knowledge. On the basis of the pre-gaming questionnaires on asthma perception, we already noted some inconsistencies in the children's perceptions of their ability to manage their asthma. Only 40% (2/5) of the children agreed that they were able to recognize an asthma crisis, whereas 60% (3/5) of the children agreed that they were able to control their asthma adequately, and 80% (4/5) of the children agreed or strongly agreed that their asthma crises could be prevented. Parents were more confident about asthma management, with 80% (4/5) of parents agreeing that they knew how to manage their child's asthma crises and 80% (4/5) of the parents agreeing or strongly agreeing that they knew when to give each inhaler to their child.

Regarding asthma self-management knowledge, some parents expressed having a divergent perception of asthma severity as compared with that of medical professionals. This is illustrated by the following quote from a parent when questioned whether they were interested in participating in the game with their child:

*No, because for us, the only thing that gets our attention is when he isn't breathing well or when he has allergies. Otherwise, everything else for us is normal. Maybe we lack sensitivity.* [parent 03]

In addition, parents described the contrasting perceptions of asthma management between parents and their children with asthma, exemplified by the following quote:

*Sometimes it's like she thinks that she takes too many [medications] and she tries to say 'Oh, I'm going to tough it out, I am still able to breath well' before taking her pumps. And I tell her, 'Don't do that, take it [your pumps] right away'. And she says 'No, no. I can handle it myself.* [parent 08]

We also explored data on children's and parents' general asthma knowledge in this domain using quantitative data from the asthma knowledge questionnaire. Results from the pre-gaming questionnaires suggested that participants had a fair amount of asthma knowledge before participating in the study. However, some of the questions in the pre-gaming questionnaires were unanswered by the participants (Table 4), whereas none of the questions were left unanswered in the post-gaming questionnaire. During the discussions with the children, it was also evident that there was heterogeneity in their knowledge about asthma.

Some children demonstrated adequate knowledge about asthma, whereas other children expressed a lack of knowledge. Other children lacked knowledge about specific components of their illness, such as asthma management or asthma resources.

On the basis of current scientific knowledge of asthma, several false beliefs were identified among the parents, including that inhalers could lead to dependence or addiction (1/5, 20% agreed), it is not good for children to use the inhaler for very long (3/5, 60% strongly agreed or agreed), children should use asthma medications only when they have symptoms (1/5, 20% strongly agreed; 1/5, 20% neither agreed nor disagreed), inhalers should be used directly in the mouth (2/5, 40% agreed), and controller medications can be used intermittently (3/5, 60% strongly agreed or agreed). In contrast, parents understood other concepts well, with 80% (4/5) of them disagreeing that children with asthma should not exercise or participate in physical education class and that mild asthma attacks can be managed outside of emergency departments. Through the discussions with the parents, we also identified varying degrees of asthma knowledge present among them. Specifically, some parents acknowledged their reluctance to administer prescribed medications unless their child was acutely ill, as illustrated in the following quote:

*As long as I can survive without medication, I don't take any. But, when I see him [the child] suffering sometimes when he has his crises and everything, I am obliged. We even neglected the pump because I am anti-Ventolin because it's not good for his health in the long term.* [parent 03]

In contrast, several parents viewed their children's asthma specialists as important resources in the management of asthma.

Subsequently, we explored how children and their parents perceive SGs in asthma self-management and knowledge and extracted key themes from these data. After analyzing the discussions with the children, we concluded that they were able to identify the game objective correctly and that *knowledge transfer was achieved through the games*, a recurrent theme in the asthma self-management perception and knowledge domain. They were able to create links between the game and real life and understood the steps in medication use and trigger recognition. This knowledge transfer was equally objectified by the results of the post-gaming questionnaires (Table 4). In general, the results reflect that after playing the different SGs, the proportion of correct answers increased, notably regarding trigger recognition, medication use, and identification of when the controller or crisis medication must be used.

**Table 4.** Child knowledge of asthma before and after playing the serious games based on true or false questions (N=5).

| Child knowledge of asthma–questions  | Before game            |   | After game             | Discrepancy                                 |
|--|------------------------|---|------------------------|---|
|  | Correct answers, n (%) | Nonmissing data for pregameing questionnaire, n (%) | Correct answers, n (%) | Discrepancies between questionnaires, n (%) |
| Lots of children have asthma   | 5 (100)                | 5 (100)   | 5 (100)                | 0 (0)                                       |
| People with asthma can drink milk and eat yogurt                               | 5 (100)                | 5 (100)   | 5 (100)                | 0 (0)                                       |
| Having the flu can cause an asthma attack                                      | 2 (50) <sup>a</sup>    | 4 (80)  | 4 (80)                 | 2 (40)                                      |
| Smoking is OK for people with asthma   | 5 (100)                | 5 (100)   | 5 (100)                | 0 (0)                                       |
| People with asthma become hooked on their asthma drugs (cannot get off them)   | 0 (0)                  | 3 (60)  | 1 (20)                 | 1 (20)                                      |
| If you have asthma now, you will have asthma forever                           | 4 (80)                 | 5 (100)   | 5 (100)                | 1 (20)                                      |
| An asthma attack is caused by redness and swelling in the airways of the lungs | 3 (75) <sup>a</sup>    | 4 (80)  | 4 (80)                 | 1 (20)                                      |
| Most children with asthma are smaller than other children                      | 4 (100) <sup>a</sup>   | 4 (80)  | 5 (100)                | 1 (20)                                      |
| Asthma can be spread from person to person                                     | 5 (100)                | 5 (100)   | 5 (100)                | 0 (0)                                       |
| Medicines that keep asthma from happening should be taken every day            | 5 (100)                | 5 (100)   | 5 (100)                | 0 (0)                                       |
| The blue puffer (inhaler) should be used when a person has an asthma attack    | 4 (80)                 | 5 (100)   | 5 (100)                | 1 (20)                                      |
| Asthma happens more at night   | 3 (60)                 | 5 (100)   | 3 (60)                 | 0 (0)                                       |
| An asthma attack can happen suddenly without warning                           | 5 (100)                | 5 (100)   | 5 (100)                | 0 (0)                                       |
| When asthma is OK, all medicines can be stopped                                | 4 (80)                 | 5 (100)   | 4 (80)                 | 0 (0)                                       |
| With the right treatment, a child with asthma can live a normal life           | 4 (100) <sup>a</sup>   | 4 (80)  | 5 (100)                | 1 (20)                                      |
| Children with asthma can play sports   | 4 (80)                 | 5 (100)   | 4 (80)                 | 0 (0)                                       |
| The orange inhaler controls asthma   | 4 (80)                 | 5 (100)   | 5 (100)                | 1 (20)                                      |
| The blue inhaler helps with an asthma crisis                                   | 5 (100)                | 5 (100)   | 5 (100)                | 0 (0)                                       |
| The blue inhaler opens the airways in the lungs                                | 3 (60)                 | 5 (100)   | 5 (100)                | 2 (40)                                      |
| The orange inhaler prevents asthma crises                                      | 4 (100) <sup>a</sup>   | 4 (80)  | 5 (100)                | 1 (20)                                      |
| The blue inhaler helps the breathing during an asthma crisis                   | 5 (100)                | 5 (100)   | 5 (100)                | 0 (0)                                       |

<sup>a</sup>Sample size, n=4, owing to missing data.

The role of SGs on asthma perception and asthma knowledge as perceived by the parents was identified using the asthma perception questionnaire before playing the SGs and through the discussions with the parents. The questionnaire revealed that 40% (2/5) of parents agreed that health-related video games can help their child understand or manage their asthma, whereas the remaining parents neither agreed nor disagreed. Moreover, 100% (5/5) of the parents strongly agreed or agreed that they would accept that their child plays health-related video games

at home. The themes extracted from the discussions with the parents illustrated similar results. Similar to children, the theme *potential of learning about asthma through games and knowledge transfer* was identified by the parents. This theme is illustrated by the following quote from a parent, concerning how one of the SGs could be designed to show the level of respiratory distress:

*With the game, I think that she [their child] would realize 'Oh no, I think that maybe I should take it [medication] as soon as possible' rather than waiting.* [parent 08]

In addition, parents expressed that the *gain of knowledge depends on experience and onset of asthma*, with some parents indicating that the incentive to play may be lost after knowledge is gained from the games.

### **Domain 2: The Role of SGs in Addressing the Impact of Asthma and Barriers to Asthma Self-management**

This domain included different themes pertaining to the roles of SGs in addressing the impact of asthma and barriers to asthma self-management, as expressed by children and parents. Regarding the impact of asthma, the daily burden of asthma was a recurrent topic expressed by children. This is illustrated by the following quotes:

*For me it's also sports. I tire out before the others.* [child 08]

*We are in the middle of a game and I have to stop. I have to stop to take my pumps. Sometimes I'm scared that I'm a nuisance to my team.* [child 09]

Although the children recognized the importance of medications in controlling their asthma, they also identified poor adherence as a barrier to asthma self-management.

The impact of asthma and barriers to asthma self-management were also explored with the parents. Parents also referred to the daily burden of asthma on their child and family, as illustrated by the following quote:

*She spends every night out of breath. She is always gasping for air. She is always congested. There is no specific season that she is suffering, but it's almost every day. We almost always go to see the doctor. We have been in follow-up for years, but I see that things haven't changed. On the contrary, it's getting worse and worse.* [parent 09]

Parents expressed fear and anxiety related to exacerbations and, as identified in domain 1, showed different perceptions of the severity of their child's asthma. These were identified as barriers to asthma self-management. Another barrier is poor adherence secondary to burden of medications. Discussions with the parents revealed that forgetfulness was often a specific cause of poor adherence, along with fear of side effects associated with medication intake.

Children and parents explored the role of SGs in the impact of asthma and barriers to asthma self-management, particularly the identification of real-life situations within the games. Specifically, children acquired *knowledge on self-management through games*. This theme is illustrated by the following quote from a child when talking about what they learned in the games:

*Even if you are, for example, asthmatic, you can still do sports, but you have to take your pumps first before doing the sport.* [child 05]

Interestingly, children expressed being more aware of and able to focus on their breathing through the game, Bloïd, which uses

a breath-actuated game controller. Similar themes were identified from the discussions with the parents, who identified acquired *knowledge on self-management through games* as a beneficial effect of the SGs. This included a better understanding of medication use and the potential of games to help in trigger recognition. This theme is exemplified in the following quote:

*It [the SGs] was a practice even for me because I always mix up the blue and purple [pumps]. I ask myself 'Which does what?' And at a certain point [in the game], it was more visual for me and now the diagram is engraved in my brain.* [parent 06]

In addition, parents suggested that games may be particularly *helpful at the onset of asthma* and identified *games as a possible tool to evaluate asthma control* thereafter.

### **Domain 3: The Role of SGs in the Support System for Asthma Self-management**

This domain includes different themes pertaining to the role of SGs in the child's support system for asthma self-management, as perceived by children and their parents. Children expressed feeling alone with their asthma, whether it was among their peers or other family members. Children often refrained from discussing their condition with others. Parents expressed being supportive in their child's asthma management, but this consisted primarily of the parents offering reminders to their children to take their medication. Often, parents were unaware of their child's state of asthma knowledge and self-management.

Both parents and children identified the beneficial effects of SGs on their support systems for asthma self-management. Children highlighted how SGs could allow players to feel less alone with their asthma by increasing *asthma awareness through SGs*. In addition, the theme *openness to further discuss asthma with parents through games* was identified. This theme is illustrated by the following quote from a child when asked whether they would like to play the games with their parents:

*Maybe they would learn more with us. Most of the time, they are the ones that give me advice because they listen to the doctors more. They know a little more, because even if they aren't doctors, they know more about this subject. But we could interact at home and talk about what we thought [about the games].* [child 09]

A similar theme, *importance of parent and child playing together*, was also extracted from the discussions with the parents. This theme is illustrated by the following quote from a parent:

*I don't really play video-games, but I still learned things, not that I didn't know, but that maybe I hadn't absorbed. By playing, watching and participating with my daughter, I learned certain things.* [parent 06]

Parents appreciated the parent-child collaboration through gameplay, as it allowed them to be more aware of their child's asthma self-management skills. Both children and their parents separately identified an *interest and utility of playing the games with peers*. Children showed a desire to interact with peers about



their illness, whereas parents expressed the importance of sharing knowledge and playing with others as an incentive to learn and increase awareness among children without asthma.

## Discussion

### Principal Findings and Comparison With Previous Work

In this pilot study, we conducted qualitative individual interviews and group discussions with participants and their parents to evaluate the perceived role of SGs in asthma management and knowledge transfer achieved by these games. Our study identified the following domains, or components, that are key to asthma management: asthma self-management perception and knowledge, the impact of asthma and barriers to asthma self-management, and support system for asthma self-management. Within these domains, our team consensually identified various themes pertaining to the perceived role of SGs in the given components. In the following sections, we summarize our findings by identifying an overarching issue for each domain and explaining how SGs can be used to address this issue. The results are summarized in [Figure 1](#).

In the domain of asthma self-management perception and knowledge, the heterogeneity of asthma knowledge, which is related to asthma perception, was identified as the overarching issue for both children and parents. The discussions with the children and parents revealed that some participants had adequate knowledge about asthma, including trigger recognition and different medications, whereas other participants had poor understanding of asthma and even expressed several false beliefs. Specifically, some children were unaware of resources other than the inhalers that were available to them, such as books or educational websites. Several parents not only expressed being in denial of the severity of their child's condition but also displayed numerous misconceptions about asthma. The importance of health literacy, the capacity to understand and manage one's own health, is a component emphasized in the eCCM and is essential for the proper management of chronic diseases and the adequate use of eHealth services [14]. The importance of efficient asthma education is equally emphasized in a systematic review of SGs, stating that education is an important factor in treatment because it promotes considerable ameliorations in asthma control and reduces emergency room visits and hospital admissions [15]. To address this heterogeneity in knowledge, the children and parents expressed that SGs could improve knowledge transfer through games. Indeed, as highlighted by a comparative study between asthma educational videotapes and asthma self-efficacy digital games, interactive media with active participation are more effective in improving self-management than traditional teaching methods such as educational videos [32]. Moreover, our participants appreciated the real-life scenarios presented in the games and expressed that such animations would provide them the knowledge to react accordingly in different situations. Similarly, parents considered the games to be a valuable source of information to build a strong base for a child with limited knowledge about asthma. These findings corroborate with those of other studies that have demonstrated how traditional educational methods have little

appeal to children and the importance of using narratives as a novel educational tool [16,33]. Narratives have been shown to be a useful resource in promoting a great understanding of the impacts an illness can have and providing an emotional insight into the repercussions a disease can cause [33].

Within the domain pertaining to the impact of asthma and barriers to asthma self-management, the consequences and limitations of asthma surfaced as the overarching issue for both children and their parents. Despite having access to regular medical care, children and parents expressed being subject to the consequences of the child's asthma, specifically regarding activity limitation and fear and anxiety related to asthma exacerbations. According to the eCCM, having a patient who is empowered and in control of their illness is crucial to improve health outcomes [14]. The eCCM also emphasizes that a patient must be *activated*, a term that equates to an individual's level of skills, knowledge, and confidence in managing their disease [14]. As highlighted in our study, the model of a patient who is activated and empowered should also be extended to a child's caregiver in pediatric care, given that caregivers play an essential role in their child's treatment [15]. Although barriers to asthma self-management have been extensively discussed previously [12], we wanted to focus on how SGs could facilitate asthma self-management. Children and their parents expressed that SGs could provide an opportunity for the identification and management of real-life situations through games. SGs can aid in promoting self-management and patient empowerment through the social learning theory, which suggests that through self-modeling (ie, the players observe a character in the game who is a representation of themselves and who they control), the player is able to learn through his or her character and apply what they have learned to real-life situations [17]. In addition, a study concerning the application of health games to manage chronic pediatric diseases showed that, often, children with chronic health conditions experience low self-esteem and stigmatization from peers because of daily self-care and monitoring [32]. However, by presenting characters who have the chronic disease and who represent positive role models who achieve their missions in the SGs while simultaneously battling and managing their illness, children learn that their chronic disease can be overcome and that self-management is an achievable goal [32].

Finally, in the domain related to support system for asthma self-management, we identified an insufficient support system as the overarching issue among children and parents. In the case of children, family implication in the child's condition is essential, an idea that was equally mentioned by the children in our study, who viewed their parents as a source of support. Notably, effective parent-child collaboration in managing a child's asthma is a key element in improving medication adherence and positive health outcomes [7]. Children and parents expressed that SGs could provide an opportunity to play with others for support and shared knowledge. Indeed, both parents and children expressed an interest in playing the SGs presented in this study with each other, stating that this would also allow for more parent-child discussions about the condition. A study concerning the management of chronic pediatric diseases with health games found that 1 month after playing



asthma self-management games, the children experienced more self-efficacy in talking with their friends about asthma and showed increased communication with their parents about their condition, illustrating how SGs can help strengthen a child's support system [32]. Similarly, an inpatient study evaluating the impact of asthma self-management SGs revealed that, often, during gaming sessions, one child would explain asthma management strategies to another child, allowing both players to win the game together [32]. Therefore, SGs offer a unique, interactive, and enjoyable opportunity for children with asthma to learn and interact with their peers and parents.

### Strengths and Limitations

Our study has numerous noteworthy strengths and limitations. First, compared with previous studies in the field, the originality of our study stems from the inclusion of both children and their parents in the gaming sessions and discussion groups, allowing for the comparison and contrast of thoughts and perceptions. This is particularly important given the unique parent-child interactions in pediatric chronic disease management. Second, we based the development of our games on the theory of co-design, adapting our games based on the comments and input from users throughout their development. Thus, the versions presented to participants in this study have already taken the input of patients with asthma into account, making them even more pertinent to the study population. Third, the analysis of our qualitative data was achieved through consensual qualitative research, a research method that incorporates various validation methods to ensure the validity of the results (ie, member checking and discussing until agreement was reached).

However, despite these validation methods, a possibility of subjectivity in our results remains, emphasizing the need for more extensive member checking. The small sample size and inclusion of patients followed at a pediatric hospital may reflect potential selection bias and limit the generalizability of our results. Specifically, the feedback gathered from the limited sample of children may not reflect the perspectives of other

children with asthma. In addition, owing to the limited number of participants, we were unable to conclude any statistically significant changes in terms of pregame and postgame knowledge from the participant questionnaires. Thus, a large study is needed to better evaluate the impact of these SGs on asthma knowledge and to collect additional feedback from players. Given the design of the study, the time allotted to play was limited to a total of approximately 60 minutes, which may have affected the depth of the evaluation of the game by participants. Although we were able to gather valuable feedback, further studies are needed to evaluate the acceptability of the games in different settings (eg, at home or during free play).

### Continued Development of the SGs

Following this study, feedback from children and parents was integrated into the games, *Asthma Heroes* and *Asthmonautes*. Both games were translated and are now accessible in French, English, Spanish, Chinese, Russian, Arabic, Portuguese, Japanese, Vietnamese, Korean, Farsi, Turkish, German, and Italian. In addition, our team conducted a second study, where 158 children tested a game played using a breath-activated controller, which enables the assessment of one's breathing capacity [34].

### Conclusions

In conclusion, through discussions with children with asthma and their parents and consensus within our research team, we identified various themes pertaining to how SGs can address some of the perceived barriers related to asthma self-management. Although our pilot study was based on a limited number of participants and further studies are required to confirm our results, our findings support the acceptability of SGs by both children and their parents and their potential role in asthma education and self-management. The numerous potential benefits of SGs in various aspects of asthma management highlight the necessity for future developments in this field.

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## Conflicts of Interest

FB and YG cofounded the Breathing Games commons. FB is a chairperson of Breathing Games Association. The development of the games was led by Breathing Games.

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## Abbreviations

**CCM:** Chronic Care Model

**eCCM:** eHealth Enhanced Chronic Care Model

**SG:** serious game

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Original Paper

# Digital Technology and Media Use by Adolescents: Latent Class Analysis

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## Abstract

**Background:** Digital technology and media use is integral to adolescents' lives and has been associated with both positive and negative health consequences. Previous studies have largely focused on understanding technology behaviors and outcomes within adolescent populations, which can promote assumptions about adolescent technology use as homogeneous. Furthermore, many studies on adolescent technology use have focused on risks and negative outcomes. To better understand adolescent digital technology use, we need new approaches that can assess distinct profiles within study populations and take a balanced approach to understanding the risks and benefits of digital technology use.

**Objective:** The purpose of this study was to identify profiles of adolescent technology use within a large study population focusing on four evidence-based constructs: technology ownership and use, parental involvement, health outcomes, and well-being indicators.

**Methods:** Adolescent-parent dyads were recruited for a cross-sectional web-based survey using the Qualtrics (Qualtrics International, Inc) platform and panels. Technology use measures included ownership of devices, social media use frequency, and the Adolescents' Digital Technology Interactions and Importance scale. Parent involvement measures included household media rules, technology-related parenting practices, parent social media use frequency, and the parent-child relationship. Health outcome measures included physical activity, sleep, problematic internet use, and mental health assessments. Well-being indicators included mental wellness, communication, and empathy. We used latent class analysis (LCA) to identify distinct profile groups across the aforementioned 4 critical constructs.

**Results:** Among the 3981 adolescent-parent dyads recruited, adolescent participants had a mean age of 15.0 (SD 1.43) years; a total of 46.3% (1842/3981) were female, 67.8% (2701/3981) were White, and 75% (2986/3981) lived in a household with an income above the poverty line. The LCA identified 2 discrete classes. Class 1 was made up of 62.8% (2501/3981) of the participants. Class 1 participants were more likely than Class 2 participants to report family-owned devices, have lower technology importance scores, have household technology rules often centered on content, have positive parent relationships and lower parent social media use, and report better health outcomes and well-being indicators.

**Conclusions:** Findings from this national cross-sectional survey using LCA led to 2 distinct profile groups of adolescent media use and their association with technology use and parent involvement as well as health and well-being outcomes. The two classes included a larger Class 1 (*Family-Engaged Adolescents*) and a smaller Class 2 (*At-Risk Adolescents*). The findings of this study can inform interventions to reinforce positive technology use and family support.

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**KEYWORDS**

digital technology; adolescents; latent class analysis; social media; mobile phone



## Introduction

### Background

Digital technology and media use is integral to adolescents' lives; adolescents have been labeled digital natives given that they have had exposure to digital technology their entire lives. Previous studies on digital technology and media use have largely focused on assessing behaviors and outcomes within adolescents as a population, which does not allow for an understanding of the heterogeneity of adolescents' technology use. Few studies have examined specific subgroups to understand the nuances of digital technology and media use across and within adolescent groups [1-3].

Furthermore, many studies on adolescent technology and media use have focused on risk behaviors and negative outcomes. Previous studies have illustrated that digital technology and media use is associated with negative outcomes such as impaired sleep [4-6], decreased physical activity [5,7,8], problematic internet use (PIU) [9-11], and risk of depression [12]. Although several recent review articles have described both the benefits and risks of technology use [13,14], most individual studies take a risk-centered approach [15,16]. Since the COVID-19 pandemic, many teenagers have experienced social isolation as a result of quarantine and remote learning, making digital tools for connection to peers and family even more important.

Critical constructs to consider in the balance of the risks and benefits of technology and media use include factors such as device ownership, frequency of social media use, and the importance of use [17]. Furthermore, other underlying factors in an adolescent's offline environment may also be critical to consider. Evidence supports that technology use outcomes may also be affected by parental factors such as household rules around media use or the parent-child relationship [18]. To better understand adolescent digital technology and media use, new approaches that can assess distinct profiles within study populations, consider mitigating factors such as technology use and parental involvement, and take a balanced approach to understanding the risks and benefits of digital technology and media use are needed.

### Technology Devices and Media Use Quantity and Quality

Several aspects of adolescent technology use have been studied through previous research. In the area of device ownership, it is understood that US adolescents' smartphone access is nearly ubiquitous. The 2018 Pew Internet and American Life Project [19] estimated that 95% of US adolescents have their own personal smartphone. These rates increased from 2014-2015, when 73% of adolescents reported personal smartphone access [20]. The age at which teenagers obtain their first phone has also decreased over time, raising concerns that have prompted campaigns to encourage delaying ownership until an adolescent is in the eighth grade [21,22]. Less is known about other device ownership among teenagers. Although approximately 88% of adolescents report access to a desktop or laptop computer at home, it is less clear who owns these devices [19]. Device ownership may be a contributing factor to technology use

outcomes. For example, personal ownership of technology may provide more opportunities for frequent use compared with family-owned devices. Personal ownership of devices may also provide access within private spaces such as bedrooms, which are more challenging to regulate by parents [23]. Furthermore, little is known about access to or ownership of newer devices such as virtual reality (VR) headsets and personal assistant devices.

Another area of focus in previous studies is the quantity of adolescents' digital technology and media use. For adolescents, one way in which quantity of technology use can be measured is via the age at which they first started using technology, such as the age at which a youth acquired a personal smartphone. Earlier initiation to technology use has been associated with maladaptive outcomes such as problematic technology use [24], supporting that quantity of use over time may be an important factor in determining health outcomes. For adolescent populations, quantity of use is commonly measured by self-reporting hours per day spent using technology and media. However, designing research studies to assess quantity of technology use is not without challenges. In particular, self-reporting the quantity of use is subject to recall bias [25,26].

Increasingly, researchers and health care providers are emphasizing that quality of technology use, beyond just quantity of use, may be just as important if not more in understanding links between technology use and health outcomes. Quality of use could include motivations for use, importance of use, or types of web-based interactions. These quality of use concepts are tied to affordances, which describe properties of artifacts that illustrate how they can be used [27,28]. Affordances have been used to tie adolescents' digital technology use to their developmental milestones [29]. Grounded in an affordance framework, the Adolescents' Digital Technology Interactions and Importance (ADTI) scale measures the importance of specific technology interactions rather than platform use [17]. Combining quantity and quality measures of technology use may allow for new insights to better understand benefits and risks for adolescents. Thus, a comprehensive approach to understanding adolescent digital technology use patterns could include what devices an adolescent can own and access, the age at which an adolescent obtained their first smartphone, how often they interact with digital technology and media, and how important those technology interactions are to them.

### Parent Involvement and Relationship

The 2016 American Academy of Pediatrics (AAP) media policy statement, *Media Use in School-Aged Children and Adolescents*, emphasized the role of parents in adolescents' media lives [30]. A key role for parents is to serve as mediators of media use for their children, and studies suggest that parental efforts may have varied impacts on adolescents' media use [31]. Parents often struggle with setting and enforcing media rules such as removing technology from children's bedrooms [32,33].

Parents' own technology experiences may also affect their children. Studies have found that parents have varied attitudes toward technology and varied engagement with technology [34]. Parents who struggle with limiting their own technology use may have challenges in moderating their children's

technology use [35]. For parents who prioritize technology use, these behaviors may be modeled for their children. In fact, families with media-centric parents typically have children who report more media use [18].

Parenting style and parent relationship are additional factors in the balance of risk and beneficial outcomes that adolescents experience. Factors associated with positive media use in families have included positive general family functioning, parental involvement, and open communication styles between parents and adolescents [36]. Thus, although it is important to understand the role of technology use in influencing adolescent health and well-being, it is also critical to better understand how the family context affects adolescent technology-related outcomes.

### Health Outcomes

There are several health concerns that have been associated with digital technology and media use influence and affect. First, technology and media use has been shown to negatively affect sleep by delaying bedtime as well as through exposure to light from screens disrupting melatonin levels [4-6]. Second, decreased physical activity has been associated with the sedentary nature of most media use [5,7,8]. Third, PIU is defined as “Internet use that is risky, excessive or impulsive in nature leading to adverse life consequences, specifically physical, emotional, social or functional impairment” [37]. Studies support that components of PIU include compulsive use and anxiety when not able to access the internet [9].

Adolescents’ mental health has also been a common research topic related to potential negative consequences of media use. Studies have found associations between increased social media use and decreased life satisfaction [38,39], increased risk of depression [38,40], worsened body image and decreased self-esteem [40-42], increased fear of missing out (FOMO) [43], and reduced well-being [44]. These studies suggest that media use may have a negative impact on mental health for adolescents. However, other studies have found that social media use does not affect life satisfaction [45,46] nor depression [47]. Some have argued that data support that media use may negatively affect *some* adolescents but caution that overstating these relationships to apply to adolescents as a whole is not warranted [48].

### Well-being

Studies focusing on ways in which technology influences well-being have found positive associations with increased social support and learning [49,50]. Another study found that adolescents described their affective experiences on social media to include feeling happy and closer to friends, supporting adolescent well-being [50]. Youths may be motivated to adopt digital health technology that includes a social component as it enhances communication skills, enables a sense of belonging and perspective taking and thus increases social support [51,52]. These factors, in turn, may reduce stress or physical illness and improve psychological and physical well-being [53,54].

### Study Purpose

The purpose of this study was to understand patterns across adolescents’ digital technology and media use, including four evidence-based constructs: (1) technology ownership and use, (2) parental involvement, (3) health outcomes, and (4) well-being indicators. Most studies to date have focused on 1 outcome, such as depression, or on a category of outcomes, such as mental health. This study builds on that literature by using the power of latent class analysis (LCA) to examine critical constructs and understand patterns across and within groups. The emerging understanding that adolescents’ media use is not homogeneous and the critical role of parents in moderating youth media use informed this study’s purpose. The purpose of this study was to use LCA to develop profiles representing benefits and risks as well as parental influence associated with digital technology use.

### Methods

#### Study Design

A national Qualtrics (Qualtrics International, Inc) cross-sectional web-based research panel was engaged during February-March 2019 to collect data for this LCA study.

#### Ethics Approval

The Institutional Review Board at the University of Wisconsin approved this study (2018-0781).

#### Setting and Participants

Our goal was to achieve a national sample of youths to complete a web-based survey. Compared with traditional survey approaches such as in-person, phone, or mail recruitment, web-based survey panels offer broader reach and lower costs in data collection [55]. We selected the web-based survey platform Qualtrics for several reasons. First, although web-based survey platforms do not use weighting, previous studies have shown that web-based survey approaches using tools such as Qualtrics can achieve demographic attributes that are typically within a 10% range of their corresponding values in the US population [56]. Second, unlike other platforms such as Mechanical Turk, Qualtrics allows for the recruitment of youths via approaching parents for consent as a first step. Third, there is strong and growing literature around the use of Qualtrics to recruit youth samples in the United States, including studies on media [57,58].

Between February 2019 and March 2019 a Qualtrics survey manager recruited adult panel participants who indicated that they had adolescent children aged 13-18 years who spoke English. Parents who met these criteria were provided with information about the survey and an opportunity to complete informed consent forms for themselves. The informed consent process notified potential participants of the study purpose and research team, of the survey length, that the survey had questions for the parents and adolescents to answer independently, that the survey was voluntary, of the Qualtrics incentive points that would be provided upon completion, and of how the study data would be stored and used. The survey information section stated that the researchers would not request any personal information

about the participants. Parents also provided consent for their child's participation if the child was aged <18 years. Once parental consent was obtained, the parents completed early sections of the survey on the Qualtrics platform. After completing the parent portion, the parents were instructed to pass the device to the adolescent participant. The adolescent was provided with study information and an opportunity to provide assent. Adolescents who provided assent were allowed to begin the survey. Adolescents aged 18 years provided consent and were allowed to begin the survey.

The target population for this study was adolescents aged 13-18 years who were US residents and English-speaking. Using Qualtrics panels of adult participants (a *closed* survey population), we recruited parent-adolescent dyads to allow for parent as well as adolescent input. We established parameters for Qualtrics to recruit a sample consistent with the race and ethnicity representative of the US census population for adults [56]. Qualtrics representatives recruited parents from their panels using emails and SMS text messages. Qualtrics processes ensured that all recruited participants had completed enrollment in Qualtrics panels, and the participants could only complete the survey a single time.

Our sample size estimates were calculated using estimates for LCA [59,60], which supports approximately 1:3-1:4 ratios of number of items to number of participants to achieve a full range of potential number of latent classes with a minimum of 0.8 power. We estimated that approximately 70 items would be included in our LCA process, and we then increased our sample size to allow for investigation of differences in demographic factors such as adolescent age, gender, or race as well as to account for incomplete surveys affecting our final sample size for analysis. Thus, our planned sample size was 4000 parent-adolescent dyads (N=8000 participants).

## Survey Measures

### Overview

Our goal for this study was to include measures that represented four key constructs: (1) technology ownership and use, (2) parental involvement, (3) health outcomes, and (4) well-being indicators. These 4 constructs were identified based on the categorization of evidence in the literature describing critical and well-established factors associated with adolescent technology use. Our strategy to identify concepts or scales to assess within each construct involved conducting a review of the literature to identify validated scales or measurement tools within each topic area. We cross-referenced those validated scales or measurement tools with existing literature and review articles that described critical concepts in adolescent digital technology and media use. In cases in which a key concept was described repeatedly in the literature but no validated scale existed, we used existing items that had been used in large studies such as the Pew Internet and American Life Project.

For established measurement scales, our goal was to include categorical variables representing high- or low-score values. Thus, for scales with established cutoffs for the summary score, we used these to dichotomize or categorize scores for inclusion in the LCA. For scales without such empirical cutoffs, we

dichotomized scores at the median for inclusion in the LCA. In the paragraphs that follow, we describe survey measures and instruments according to the 4 key constructs of focus in this study. In the survey delivered to the participants, the order of measures delivered was randomized. Most survey pages included a single measurement tool or instrument. The participants were allowed to review and change their answers during the course of the survey.

### Technology Ownership and Use Measures

These survey measures were answered by the adolescent participants. Measures included individual questions about device ownership and age of first smartphone ownership, assessments of frequency of social media use, and the ADTI scale.

#### Personal and Family Device Ownership and Bedroom Access: Adolescent Participants

To assess technology device ownership, we modeled questions after those in previous Pew Internet and American Life surveys to assess device ownership of adolescents and of the family [19,20,61,62]. Furthermore, given that the AAP recommends limiting media device use in bedrooms [30,63], we included questions about which devices were allowed to be used in the adolescent's bedroom. The participants were asked, "Which of the following devices do you own? Select all that apply"; "Which of the following devices does your family own? Select all that apply"; and "Which of the following do you have access to in your bedroom? Select all that apply." Response options included television, computer, tablet, video games, smartphones with internet access, cell phones without internet access, VR devices, wearable devices (ie, smartwatches), personal assistants (ie, Alexa), other, and/or none. Each individual response regarding device ownership and bedroom access was included as a bivariate (yes or no) in the LCA.

#### Social Media Use Frequency: Adolescent Participants

Given that social media is a main component of adolescents' technology use [19], we assessed social media use frequency. Social media use can include two roles: consumer and creator of content. Thus, we asked about the frequency with which the adolescents checked social media and posted on social media modeled after the Pew Internet and American Life Project surveys [19]. Response options included *almost constantly*, *a few times an hour*, *once an hour*, *a few times a day*, *once a day*, *a few times a week*, *once a week*, and *never*. These responses were clustered into three categories: responses representing daily or more use, responses representing weekly but not daily use, and responses indicating less than weekly use.

#### Age of Acquiring a First Personal Smartphone

We asked the adolescents to report the age at which they acquired their first personally owned smartphone with internet access. We categorized the ages as follows: <11 years, 12-14 years, 15-17 years, or not yet having a smartphone of their own.

#### ADTI Scale: Adolescent Participants

Technology interactions and their importance were measured using the ADTI scale, which has been validated in previous work [17]. This scale includes 18 items and 3 factors. For each



item, the participants were asked *How important, if at all, is it for you to use media and technology platforms for the following purposes?* The participants responded using a 5-point Likert scale ranging from *not at all important* to *extremely important*. The three subscale factors and an example item for each included (1) technology to bridge online/offline experiences (example item: *look into or follow an event you may attend*), (2) technology to go outside one's identity or offline environment (example item: *explore your sexuality*), and (3) technology for social connection (example item: *direct message someone*). The Cronbach  $\alpha$  scores for the three subscales were .87 (factor 1), .90 (factor 2), and .82 (factor 3), and .92 for the total scale. The ADTI scores were included in the LCA as a total score and as 3 individual subscale scores.

### Parent Involvement

This section of questions included some measures answered by the parents and some answered by the adolescents.

### Household Technology Rules: Parent Participants

The parent participants were asked how strongly they agreed or disagreed with 7 statements related to the presence of or engagement in household technology rules at home. The statements were modeled after the suggested parent rules and role modeling of the AAP Family Media Use Plan [30]. These rules include three key concepts described in the literature regarding parenting technology behaviors: active mediation (communication), restrictive mediation (limits on time or content), and social co-use [64-66]. These statements were tested in a previous intervention [67]. For each item, the parent participants were asked whether the rule was present in their household. Example statements included *My house had rules about "friending" someone who is unknown off-line* and *My house has rules about viewing screens around bedtime*. The participants were asked to select from a 5-point Likert scale from *strongly agree* to *strongly disagree* for each of the statements. Responses were dichotomized into *agree* or *neutral/disagree* to represent whether the individual rule was or was not present at home for inclusion in the LCA.

### Parent Social Media Use Frequency: Parent Participants

Similar to the approach used with the adolescent participants, we asked the parents about the frequency with which they checked social media and posted on social media modeled after the Pew Internet and American Life Project surveys [19]. Response options included *almost constantly*, *a few times an hour*, *once an hour*, *a few times a day*, *once a day a few times a week*, *once a week*, and *never*. These responses were clustered into three categories: responses representing daily or more use, responses representing weekly but not daily use, and responses indicating less than weekly use.

### Internet-Specific Parenting Practices: Adolescent Participants

The adolescent participants were asked to complete the internet-specific parenting practices scale, which describes practices that their parents use to moderate their children's use at home [68]. This 12-item scale has 3 subscales. One subscale assesses rules regarding time on the web and has response options of never=1, rarely=2, sometimes=3, often=4, and very

often=5. The second subscale measures rules regarding content of internet use, and the third subscale assesses quality of communication regarding internet use. An example item from the third subscale is *When my parents/guardians and I talk about my internet use I feel I'm taken seriously*. The latter 2 subscales have response options using a 5-point Likert scale from *absolutely not true* to *absolutely true*. Responses for each subscale were dichotomized into high- or low-score categories based on the median for inclusion in the LCA published in the literature. The median score for subscale 1 (time) was 18, the median score for subscale 2 (rules) was 12, and the median score for subscale 3 (communication) was 12. This scale had good internal consistency, with a Cronbach  $\alpha$  of .85.

### Parent-Adolescent Relationship: Adolescent Participants

The adolescent participants completed the Parent-Adolescent Relationship Scale to assess the quality of the participants' relationship with their parents who also participated in this study [68]. This validated scale includes 8 items and 2 subscales. The first subscale measures the participant's identification with their parents and includes items such as *She/He is a person I want to be like*. Responses for this subscale use a 5-point Likert scale from *strongly disagree* to *strongly agree*. The second subscale assesses perceived parental supportiveness and includes items such as *How often does she/he praise you for doing well?* Responses use a 5-point Likert scale of *Never* to *Always*. The internal consistency of this scale was good as indicated by a Cronbach  $\alpha$  between .72 and .74 with mothers and of .82 with fathers. This measurement was dichotomized and included in the LCA as high and low parent-adolescent relationship based on the published cutoff of >24 indicating a high-quality parent-adolescent relationship.

### Digital Technology and Media-Related Health Outcomes

#### Overview

These survey items were all answered by the adolescent participants. These measures included a comprehensive set of physical and mental health concerns noted in the literature as being associated with digital technology and media use among adolescents. These measures included physical health outcomes, such as sleep and physical activity, as well as mental health outcomes, including PIU, depression, anxiety, FOMO, and body image concerns.

#### Physical Activity: Adolescent Participants

Physical activity was evaluated using the physical activity scale. This scale included 3 items assessing the frequency with which the adolescents participated in sports and exercised outside school [69]. For each item, the participants responded from *never* to *4 times or more a week*. The Cronbach  $\alpha$  for this scale is reported by age, including .69 for 13 years and .74 for 15 years. Responses were dichotomized as high or low physical activity using the median reported physical activity (9) for inclusion in the LCA.

#### Sleep: Adolescent Participants

Sleep was assessed using the validated Pediatric Daytime Sleepiness Scale [70]. This 8-item scale includes items such as *How often do you fall asleep or get drowsy during class periods?*

and *How often do you fall back to sleep after being awakened in the morning?* Response options include *neverseldom, sometimes, frequently, and always*. The Cronbach  $\alpha$  for this scale was .81. Responses were dichotomized as high or low level of sleepiness using the median reported level of sleepiness (13) for inclusion in the LCA.

### PIU: Adolescent Participants

PIU was measured using the validated 3-item Problematic and Risky Internet Use Screening Scale survey [71]. The participants responded to 3 questions related to internet use, including *how often do you experience increased social anxiety due to your internet use*, using a Likert scale. Response options included never=1, rarely=2, sometimes=3, often=4, and very often=5. The Cronbach  $\alpha$  for this scale was .96. A total score of  $\geq 3$  indicated a risk for PIU, and responses were dichotomized as at risk or not at risk for the LCA.

### Depression: Adolescent Participants

Depression was measured using the 9-item Patient Health Questionnaire (PHQ-9) [72]. This 9-item scale asks participants how often they have experienced the following symptoms in the past 2 weeks. Example items include *little interest or pleasure in doing things* and *feeling down, depressed, or hopeless*. Response options use a 4-point Likert scale from *not at all to nearly every day*. The PHQ-9 had a Cronbach  $\alpha$  of .82 [73]. We used the validated categorization of no depression (scores 0-4), minimal depression (scores 5-9), mild depression (scores 10-14), moderate to severe depression (scores 15-19), and severe depression (scores  $>20$ ) in the LCA.

### Anxiety: Adolescent Participants

Anxiety was measured using a validated reduced version of the Screen for Child Anxiety-Related Emotional Disorders scale [74]. This 5-item scale asks participants how true each of the items is for that participant, including statements such as *People tell me I worry too much, I am scared to go to school, and I am shy*. Response options include not true or hardly ever true=0, sometimes true=1, and true or often true=2. The Cronbach  $\alpha$  has been reported as .70 to .90. We used the cutoff score of 3 to categorize the participants as at risk or not at risk for inclusion of scores in the LCA.

### FOMO: Adolescent Participants

FOMO was measured using the Fear of Missing Out scale [75]. This scale includes 10 items that measure FOMO, or the fear that others are having more rewarding experiences that participants were absent from or missed. Example items include *I fear my friends have more rewarding experiences than me, I get anxious when I don't know what my friends are up to, and When I miss out on a planned get-together it bothers me*. Response options include a 5-point Likert scale from *Not at all true of me to Extremely true of me*. The FOMO scale had good internal consistency (Cronbach  $\alpha$ =.90). We dichotomized responses as high FOMO and low FOMO based on the median summary score (23) for the LCA.

### Body Image: Adolescent Participants

Body image was measured using the Body Image Scale [76]. This scale measures participants' general satisfaction or

dissatisfaction with their body and appearance. Example items include *By and large, I am satisfied with my looks* and *I would like to change a good deal about my body*. Items were rated with response options of 1=does not apply at all, 2=does not apply well, 3=applies somewhat, 4=applies fairly well, 5=applies well, and 6=applies exactly. The Cronbach  $\alpha$  for this scale was .82, indicating good internal consistency. We categorized responses as low body image and high body image based on the median summary score of 17 for the LCA.

### Well-being Indicators: Adolescent Participants

These measures were answered by the adolescent participants. Well-being indicators included the Mental Well-being scale [77], the Interpersonal Reactivity Index to measure empathy and perspective taking [78], a communication scale [79], the Comprehensive Inventory of Thriving (CIT) [80], and an assessment of extracurricular activities.

### Mental Well-being Scale: Adolescent Participants

Mental well-being was measured using the Short Warwick-Edinburgh Mental Well-being Scale [77]. This 7-item validated scale asks participants to indicate how often they agreed with the statement over the past 2 weeks. Example items include *I've been feeling optimistic about the future, I've been feeling relaxed, and I've been thinking clearly*. Response options include a 5-point Likert scale from *none of the time to all of the time*. The internal consistency reliability of the Short Warwick-Edinburgh Mental Well-being Scale was strong (Pearson Separation Index=0.84). We dichotomized the summary scores by the median (27) for inclusion in the LCA.

### Interpersonal Reactivity Index: Adolescent Participants

The Interpersonal Reactivity Scale was included, which has subscales to measure empathy and perspective taking [78]. This scale includes 14 items, 7 of which measure perspective taking, or the tendency to spontaneously adapt the psychological point of view of others. Items such as *I try to look at everybody's side of a disagreement before I make a decision* were included. The subsequent 7 items assess empathetic concern, or *other-oriented* feelings of sympathy and concern for unfortunate others. Items such as *I am often quite touched by things that I see happen* and *I often have tender, concerned feelings for people less fortunate than me* were included in the empathetic concern subscale. Response options use a 5-point Likert scale ranging from *Does not describe me well to Describes me very well*. The internal reliability of the scale was good (Cronbach  $\alpha$ =.71-.77). These 2 subscales were each dichotomized at the median values: 16 for perspective taking and 18 for empathetic concern.

### Communication Skills: Adolescent Participants

The Communication Skills Scale was used to measure communication skills [79]. This validated scale includes 23 items that assess the effectiveness of one's communication skills, with items such as *When talking to someone, I try to maintain eye contact* and *I try to see the other person's point of view*. Responses use a 5-point Likert scale from *Never to Always*. The internal reliability of this scale was good (Cronbach  $\alpha$ =.83). Summary scores were dichotomized as high and low communication skills based on the median summary score (52) to categorize for inclusion in the LCA [81].



### **CIT (Support, Learning, and Loneliness): Adolescent Participants**

The CIT was used with the subscales of support, learning, and loneliness [80]. This validated scale includes 9 items and 3 factors. For each item, the participants were asked to indicate their agreement with the statements. Example items for support include *There are people I can depend on to help me*, example items for learning include *Learning new things is important to me*, and example items for loneliness include *I often feel left out*. Responses use a 5-point Likert scale from *strongly disagree* to *strongly agree*. The Cronbach  $\alpha$  for these subscales was .88 for support, .84 for learning, and .90 for loneliness. We dichotomized the responses using the median score for each of the three subscales for inclusion in the LCA: the median for support was 14, the median for learning was 12, and the median for loneliness was 6.

### **Extracurricular Activities: Adolescent Participants**

We assessed involvement in extracurricular activities via the Involvement in Extracurricular Activities measure [82]. This 4-item scale asked the participants how many hours they spent during an average week on each statement. Example items include *...in clubs or organizations at school (other than sports)* and *...in clubs or organizations outside of school*. Response options include 0 hours, 1-2 hours, 3-5 hours, 6-10 hours, and  $\geq 11$  hours. This scale is described as being intended to describe diverse activities; thus, the validation paper recommends against a Cronbach  $\alpha$  [82]. This measurement was dichotomized as high or low extracurricular activity time based on the median summary score of 8 for inclusion in the LCA.

### **Demographic Variables: Adolescent and Parent Participants**

Demographic variables reported by the adolescent participants included self-reported age, which was dichotomized to represent older adolescents (aged 16-18 years) and younger adolescents (aged 13-15 years). The adolescents reported their gender identity, which was categorized as female identity (female sex and transgender females), male identity (male sex and transgender males), and nonbinary and other identities. The adolescents described their ethnicity as Hispanic or Latino or non-Hispanic or Latino. The adolescents selected all categories that described their race using the US census categories to include White, Black or African American, Asian, American Indian, Native Hawaiian, or Pacific Islander, multiracial, and other. On the basis of a previous study showing that religion mitigated what teenagers posted, religious identity was asked about and dichotomized into reporting a religion or not [83].

We asked the parent participants to report their annual household income. This variable was dichotomized using the US census data that defined poverty such that the participants were categorized as above or below the poverty line [84]. Parent demographics also included gender and marital status.

### **Analysis**

#### **Overview**

LCA is a nonparametric statistical method that characterizes otherwise unobservable groups based on individuals' response

patterns to multiple observable variables [85]. Thus, distinctive mutually exclusive subgroups within a population can be empirically identified using LCA [86]. Specifically, we used LCA to identify distinct participant profile groups of multifaceted constructs; in this study, these constructs included technology ownership and use, parental involvement, health outcomes, and well-being indicators. We included measures representing these constructs as well as items representing demographics as variables in the LCA.

#### **LCA Data Preparation**

Some measures were included in the LCA as individual items, such as demographic variables and individual digital device ownership items. Other measures included in the LCA were summary scores derived from validated scales, such as the PHQ-9 to assess depression. To address missing data, we used the following process. For measures that consisted of multiple items toward a summary score, if  $>70\%$  of items were present, we rescaled the total score based on the available items [87].

To prioritize the identification of subgroups representing distinct profiles as our outcome, we used all measurement scale outcomes as bivariate or categorical inputs for analysis. For scale scores with published cutoffs, we used those scores to create input categories. In cases in which there were no published score cutoffs, we used the median value to separate scores into high and low and included the high or low designations as inputs in the LCA. For demographic data on a continuous scale, we used the median as a cutoff to distribute the variables into 2 categories.

#### **LCA Procedure**

We planned to include items in the LCA with both relevance and frequency for our study purpose in our data set. We began our analysis procedures with all 68 items that were selected a priori for the survey. The Lo-Mendell-Rubin [88] likelihood ratio test was used to identify the number of classes. Specifically, the likelihood function of the LCA model with  $k$  classes was compared with the likelihood function of an LCA model with  $k - 1$  classes.  $P < .05$  indicated that the model with  $k$  classes provided a better fit than the model with  $k - 1$  classes.

After identification of an initial 2-class model, we used the Fisher exact test to compare items between classes for the preliminary model. Items with  $P < .10$  were reviewed. Some items with  $P < .10$  were identified as subitems from within larger concepts; thus, we retained those within the model. The final model included all 65 items. The statistical analyses were conducted using SAS software (version 9.4; SAS Institute Inc) and M-Plus software (version 8; Muthen & Muthen 1998-2017).

## **Results**

### **Participants**

A total of 4592 adolescent-parent dyads began the survey, of which 3981 (86.7%) completed the survey. Participants were excluded for not completing  $\geq 75\%$  of the survey, responding with single-response selections across multiple survey measures, and 13.3% (611/4592) of adolescent-parent dyads were excluded for these reasons. Regarding the included participants, the

adolescents had a mean age of 15.0 (SD 1.43) years, 46.3% (1842/3981) were female, 67.8% (2701/3981) were White, and 75% (2986/3981) lived in a household with an income above the poverty line (Table 1).

**Table 1.** Demographic information of the participants (N=3981).

| Variable and categories                             | Values       |
|---|--------------|
| <b>Adolescent demographic information</b>           |              |
| <b>Adolescent age (years), n (%)</b>                |              |
| 12-14   | 1589 (39.9)  |
| 15-18   | 2376 (59.7)  |
| Adolescent age (years), mean (SD)                   | 15.02 (1.43) |
| <b>Adolescent sex, n (%)</b>                        |              |
| Female (cisgender and transgender)                  | 1842 (46.3)  |
| Male (cisgender and transgender)                    | 2081 (52.3)  |
| Other (nonbinary)                                   | 58 (1.5)     |
| <b>Adolescent race, n (%)</b>                       |              |
| White   | 2701 (67.8)  |
| Black and African American                          | 586 (14.7)   |
| Native American and Alaskan Indian                  | 137 (3.4)    |
| Asian   | 197 (4.9)    |
| Multiracial   | 178 (4.5)    |
| Other   | 182 (4.6)    |
| <b>Adolescent ethnicity, n (%)</b>                  |              |
| Non-Hispanic  | 3222 (80.9)  |
| Hispanic  | 705 (17.7)   |
| <b>Adolescent identifies with a religion, n (%)</b> |              |
| Yes   | 2688 (67.5)  |
| No  | 1293 (32.5)  |
| <b>Parent demographic information, n (%)</b>        |              |
| <b>Household income below poverty line</b>          |              |
| No  | 2986 (75)    |
| Yes   | 975 (24.5)   |
| <b>Parent sex</b>                                   |              |
| Female (cisgender and transgender)                  | 2672 (67.1)  |
| Male (cisgender and transgender)                    | 1903 (47.8)  |
| Other (nonbinary)                                   | 17 (0.4)     |
| <b>Parent relationship status</b>                   |              |
| Married or partner                                  | 2902 (72.9)  |
| Not married or partner                              | 1047 (26.3)  |

## LCA Findings

### Overview and Class Structure

The LCA revealed two distinct classes to describe our four areas of focus for this study: (1) technology ownership and use, (2) parental involvement, (3) health outcomes, and (4) well-being indicators. Class 1 represented approximately two-thirds of the

participants (2501/3981, 62.8%), and Class 2 represented approximately one-third of the participants (1480/3981, 37.2%).

Regarding demographic variables, Class 1 tended to be slightly older and identify as female compared with Class 2, which had more male and nonbinary participants. There were some statistically significant differences between the 2 classes in terms of ethnicity and race. Class 1 participants more often described themselves as non-Hispanic, Black, multiracial, or

other races compared with Class 2 participants. In contrast, Class 2 participants often described themselves as Hispanic, Asian, or Native American. Class 1 participants were more

likely to be religious and live below the poverty line compared with Class 2 participants. Table 2 presents demographic comparisons between the 2 classes.

**Table 2.** Distribution of demographic variables included in the latent class analysis in the 2-class model (N=3981).

| Variable  | Class 1 (n=2501; %) | Class 2 (n=1480; %)      | P value <sup>a</sup> |
|---|---------------------|--------------------------|----------------------|
| <b>Age (years)</b>  |                     |                          | .06                  |
| 13-14   | 38.9                | <i>41.9</i> <sup>b</sup> |                      |
| 15-18   | <i>61.1</i>         | 58.02                    |                      |
| <b>Sex</b>  |                     |                          | <.001                |
| Female  | <i>48.3</i>         | 42.8                     |                      |
| Male  | <i>51.2</i>         | <i>54.05</i>             |                      |
| Other   | <i>0.48</i>         | <i>3.11</i>              |                      |
| <b>Ethnicity</b>  |                     |                          | <.001                |
| Hispanic and Latino   | 16.1                | <i>21.11</i>             |                      |
| Non-Hispanic and non-Latino                                 | <i>83.92</i>        | 78.9                     |                      |
| <b>Race</b>   |                     |                          | .002                 |
| White   | <i>67.7</i>         | <i>68.04</i>             |                      |
| Black or African American                                   | <i>15.35</i>        | 13.6                     |                      |
| Asian, Asian Indian, or other Asian                         | 2.9                 | <i>4.39</i>              |                      |
| American Indian, Native Hawaiian, or other Pacific Islander | 4.2                 | 6.2                      |                      |
| Multiracial   | <i>4.9</i>          | 3.7                      |                      |
| Other   | <i>4.9</i>          | 4.1                      |                      |
| <b>Religion</b>   |                     |                          | .02                  |
| Religious   | <i>33.8</i>         | 30.3                     |                      |
| Nonreligious  | <i>66.21</i>        | <i>69.7</i>              |                      |
| <b>Parent relationship status</b>                           |                     |                          | .08                  |
| With a partner  | <i>72.54</i>        | <i>75.1</i>              |                      |
| Not with a partner  | <i>27.5</i>         | 24.9                     |                      |
| <b>Household socioeconomic status</b>                       |                     |                          | .07                  |
| Above poverty line  | <i>74.43</i>        | 77                       |                      |
| At or below poverty line                                    | <i>25.6</i>         | <i>22.99</i>             |                      |

<sup>a</sup>P value from chi-square test.

<sup>b</sup>Italicization denotes the class with the majority percentage for each measure.

### Technology Ownership and Use

Regarding media use variables, Class 1 participants were more likely to report *family ownership of technology devices* for most devices, including computers, tablets, video game consoles, televisions, and smartphones. Class 2 participants were more likely to report that they, as adolescents, owned *personal technology devices*, including televisions, computers, tablets, and video games, compared with Class 2 participants. Furthermore, Class 2 participants were more likely to report both family and individual ownership of newer devices such as VR headsets, wearable devices, and personal assistants. Class 2 participants were also more likely to report access to their devices in their bedrooms compared with Class 1 participants.

Regarding age at which the first smartphone was acquired, Class 1 participants were more likely to report acquiring their first smartphone between the ages of 12 and 14 years as well as being more likely to report not having a smartphone compared with Class 2 participants. Class 2 participants were more likely to report acquiring their first smartphone either early (before the age of 11 years) or later (ages 15-17 years). Furthermore, Class 2 was also more likely to report both checking and posting on social media daily compared with Class 1.

Assessing the importance of technology interactions using the ADTI, Class 1 consistently had lower scores and, in some cases, only half of the summary scores for all ADTI subscales compared with Class 2. Table 3 presents these findings.

**Table 3.** Distribution of technology behaviors included in the latent class analysis in the 2-class model (N=3981).

| Variable   | Class 1 (n=2501; %) | Class 2 (n=1480; %) | P value |
|--|---------------------|---------------------|---------|
| <b>Family device ownership</b>                               |                     |                     |         |
| Television   | 98.4 <sup>a</sup>   | 89.1                | <.001   |
| Computer   | 85.9                | 78.8                | <.001   |
| Tablet   | 74.9                | 68                  | <.001   |
| Video game console   | 80.8                | 72.2                | <.001   |
| Smartphone with internet access                              | 94.8                | 79.4                | <.001   |
| VR <sup>b</sup> devices (such as Samsung Gear VR and Oculus) | 15.9                | 28.1                | <.001   |
| Wearable devices (such as smartwatches and fitness trackers) | 34.4                | 32.2                | .15     |
| Personal assistants (such as Alexa and Google Home)          | 33.9                | 34.3                | .78     |
| <b>Adolescent device ownership</b>                           |                     |                     |         |
| Television   | 57.2                | 63.4                | <.001   |
| Computer   | 40.7                | 54.5                | <.001   |
| Tablet   | 41.3                | 46.8                | <.001   |
| Video game console   | 48.5                | 53.1                | .005    |
| Smartphone with internet access                              | 83.2                | 69.7                | <.001   |
| VR devices (such as Samsung Gear VR and Oculus)              | 6.8                 | 18.5                | <.001   |
| Wearable devices (such as smartwatches and fitness trackers) | 13.4                | 18.2                | <.001   |
| Personal assistants (such as Alexa and Google Home)          | 8.9                 | 11.8                | .003    |
| <b>Adolescent device access in bedroom</b>                   |                     |                     |         |
| Television   | 71.8                | 69.2                | .08     |
| Computer   | 37.9                | 52.4                | <.001   |
| Tablet   | 38.9                | 45.5                | <.001   |
| Video game console   | 42.3                | 51.1                | <.001   |
| Smartphone with internet access                              | 76.3                | 66.4                | <.001   |
| VR devices (such as Samsung Gear VR and Oculus)              | 5.7                 | 16.5                | <.001   |
| Wearable devices (such as smartwatches and fitness trackers) | 11.6                | 16.5                | <.001   |
| Personal assistants (such as Alexa and Google Home)          | 8.7                 | 12.1                | <.001   |
| <b>Age of first smartphone (years)</b>                       |                     |                     |         |
| <11  | 27.7                | 34.4                | <.001   |
| 12-14  | 56.8                | 51.2                |         |
| 15-17  | 10.3                | 12.5                |         |
| Does not own a smartphone                                    | 5.2                 | 1.9                 |         |
| <b>Adolescent social media checking frequency</b>            |                     |                     |         |
| Once a day or more   | 71.8                | 87.7                | <.001   |
| Once a week or more  | 15.5                | 9.3                 |         |
| Less than once a week or never                               | 12.8                | 2.9                 |         |
| <b>Adolescent social media posting frequency</b>             |                     |                     |         |
| Once a day or more   | 48.4                | 81.9                | <.001   |
| Once a week or more  | 22.1                | 10.9                |         |
| Less than once a week or never                               | 29.5                | 7.2                 |         |
| <b>Adolescent importance of technology interactions</b>      |                     |                     |         |
|  |                     |                     | <.001   |

| Variable  | Class 1 (n=2501; %) | Class 2 (n=1480; %) | <i>P</i> value |
|---|---------------------|---------------------|----------------|
| Subscale 1: technology to bridge online/offline experiences and preferences                   | 37.4                | 71.8                |                |
| Subscale 2: technology to assist in going beyond one's current identity, mood, or environment | 33.2                | 84.5                |                |
| Subscale 3: technology for social connection  | 42.8                | 67.7                |                |

<sup>a</sup>Italicization denotes the class with the majority percentage for each measure.

<sup>b</sup>VR: virtual reality.

### ***Parent Involvement***

Regarding parent involvement, Class 1 parent participants were more likely to report all categories of household rules compared with Class 2 parent participants. Class 2 parent participants were more likely to report no household rules or boundaries around technology use. Parents in Class 2 were also more likely to report more than daily social media checking and posting compared with parents in Class 1.

Regarding internet-specific parenting styles, adolescents in Class 1 were more likely to report strict rules around internet content and positive parental communication about media use. In comparison, adolescents in Class 2 were more likely to report strict internet rules around time spent on technology and were less likely to experience high-quality communication with their parents about technology. [Table 4](#) illustrates the findings on parent involvement and rules previously described. Finally, adolescents in Class 1 were more likely to report a higher-quality parent relationship compared with adolescents in Class 2.



**Table 4.** Distribution of parent involvement and rules included in the latent class analysis in the 2-class model (N=3981).

| Variable   | Class 1 (n=2501; %) | Class 2 (n=1480; %) | P value |
|--|---------------------|---------------------|---------|
| <b>Household media rules: parent-reported</b>  |                     |                     |         |
| My house has no rules or boundaries for media use.   | 9.1                 | 13.4 <sup>a</sup>   | <.001   |
| My house has rules about what social media profiles are acceptable.  | 67.3                | 53.02               | <.001   |
| My house has rules about what privacy settings should be set for social media.   | 60.4                | 44.9                | <.001   |
| My house has rules about “friending” someone who is unknown offline.   | 67.9                | 43.7                | <.001   |
| My house has rules about “screen-free zones” (rooms or places in the house, such as a bedroom) where no one is allowed to use screens, including televisions, computers, and smartphones.            | 25.3                | 24.9                | .84     |
| My house has rules about screen-free times (times when no one is allowed to use media, such as dinnertime) when no one is allowed to use screens, including televisions, computers, and smartphones. | 45.5                | 25.9                | <.001   |
| My house has rules about viewing screens around bedtime.   | 43.1                | 20.8                | <.001   |
| <b>Parent social media checking frequency</b>  |                     |                     |         |
| Once a day or more   | 78.2                | 92.8                | <.001   |
| A few times a week   | 11.5                | 4.5                 |         |
| Less than once a week  | 10.2                | 2.7                 |         |
| <b>Parent social media posting frequency</b>   |                     |                     |         |
| Once a day or more   | 24.6                | 61                  | <.001   |
| A few times a week   | 31.8                | 21.3                |         |
| Less than once a week  | 43.6                | 17.7                |         |
| <b>Internet time rules: adolescent-reported</b>  |                     |                     |         |
| Strict internet time rules   | 54.4                | 62.9                | <.001   |
| Not strict internet time rules   | 45.6                | 37.1                |         |
| <b>Internet content rules: adolescent-reported</b>   |                     |                     |         |
| Strict internet content rules  | 66.2                | 27.2                | <.001   |
| Not strict internet content rules  | 33.8                | 72.8                |         |
| <b>Communication about internet: adolescent-reported</b>   |                     |                     |         |
| High-quality communication about the internet  | 74.5                | 47.6                | <.001   |
| Low-quality communication about the internet   | 25.5                | 52.4                |         |
| <b>Parent-adolescent relationship: adolescent-reported</b>   |                     |                     |         |
| More positive parent-adolescent relationship   | 77.8                | 25.3                | <.001   |
| Less positive parent-adolescent relationship   | 22.2                | 74.7                |         |

<sup>a</sup>Italicization denotes the class with the majority percentage for each measure.

### Health Outcomes

Regarding health-related variables, Class 1 participants reported lower levels of physical activity compared with Class 2

participants. However, Class 1 participants also reported *lower* rates of PIU, sleep impairment, depression, anxiety, FOMO, and poor body image compared with Class 2 participants. [Table 5](#) presents these findings.

**Table 5.** Distribution of adolescent health measures included in the latent class analysis in the 2-class model (N=3981).

| Variable                     | Class 1 (n=2501; %) | Class 2 (n=1480; %) | P value |
|------------------------------|---------------------|---------------------|---------|
| <b>Physical activity</b>     |                     |                     | <.001   |
| More physical activity       | 53.2                | 58.9 <sup>a</sup>   |         |
| Less physical activity       | 46.8                | 41                  |         |
| <b>Daytime sleepiness</b>    |                     |                     | <.001   |
| Low                          | 66.9                | 16.9                |         |
| High                         | 33.1                | 83.1                |         |
| <b>Depression</b>            |                     |                     | <.001   |
| No depression                | 47.9                | 8.2                 |         |
| Minimal depression           | 40.7                | 13.6                |         |
| Mild depression              | 9.6                 | 21.9                |         |
| Moderate depression          | 1.6                 | 21.4                |         |
| Moderately severe depression | 0.2                 | 19.2                |         |
| Severe depression            | 0.1                 | 15.6                |         |
| <b>Anxiety</b>               |                     |                     | <.001   |
| Not at risk                  | 86.6                | 30.7                |         |
| At risk                      | 13.4                | 69.3                |         |
| <b>Fear of missing out</b>   |                     |                     | <.001   |
| Low                          | 70.5                | 14.9                |         |
| High                         | 29.5                | 85.2                |         |
| <b>Body image</b>            |                     |                     | <.001   |
| High                         | 70.4                | 15.8                |         |
| Low                          | 29.7                | 84.2                |         |

<sup>a</sup>Italicization denotes the class with the majority percentage for each measure.

### Well-being

Participants in Class 1 scored *higher* on well-being, support, learning, perspective taking, empathetic concern, and

communication skills than those in Class 2. Class 1 participants reported less time spent on extracurricular activities compared with Class 2 participants. [Table 6](#) presents these findings.

**Table 6.** Distribution of well-being measures included in the latent class analysis in the 2-class model (N=3981).

| Variable   | Class 1 (n=2501; %) | Class 2 (n=1480; %) | P value |
|--|---------------------|---------------------|---------|
| <b>Mental well-being</b>                               |                     |                     | <.001   |
| High   | 62.9 <sup>a</sup>   | 39                  |         |
| Low  | 37                  | 60.9                |         |
| <b>Interpersonal reactivity: perspective taking</b>    |                     |                     | <.001   |
| High   | 56.4                | 41.4                |         |
| Low  | 43.6                | 58.6                |         |
| <b>Interpersonal reactivity: empathetic concern</b>    |                     |                     | <.001   |
| High   | 68.9                | 23.9                |         |
| Low  | 31.1                | 76                  |         |
| <b>Communication skills</b>                            |                     |                     | .001    |
| High   | 52.7                | 47.5                |         |
| Low  | 47.3                | 52.6                |         |
| <b>Comprehensive Inventory of Thriving: support</b>    |                     |                     | <.001   |
| High   | 75.6                | 23.2                |         |
| Low  | 24.4                | 76.8                |         |
| <b>Comprehensive Inventory of Thriving: learning</b>   |                     |                     | <.001   |
| High   | 68.9                | 50.2                |         |
| Low  | 31.1                | 49.8                |         |
| <b>Comprehensive Inventory of Thriving: loneliness</b> |                     |                     | <.001   |
| High   | 87.1                | 32                  |         |
| Low  | 12.9                | 69                  |         |
| <b>Extracurricular activities</b>                      |                     |                     | <.001   |
| More participation                                     | 64.3                | 44.7                |         |
| Less participation                                     | 35.8                | 55.3                |         |

<sup>a</sup>Italicization denotes the class with the majority percentage for each measure.

## Discussion

This study used LCA to develop profiles of media use and parent involvement and their associations with health outcomes and well-being indicators. Although previous studies have illuminated links between media and individual health outcomes [4,89], the LCA classification method provides a rich understanding of the patterns in which adolescents use technology and media as well as an opportunity to understand these patterns alongside the role of parents and health and well-being indicators.

### Previous LCA Findings

Our study findings can first be considered in the context of the few previous studies that have used LCA approaches to study adolescent media use. One previous study focused on quality of life among Swiss adolescents and found 5 distinct classes, with a high social technology use class scoring lowest on moods but highest on social support [90]. Another study focused on technology behaviors, including gaming and internet and smartphone use, among Korean teenagers and assessed psychosocial measures [91]. They found several subtypes,

including “dual problem users” who scored highest for addictive technology behaviors and other psychosocial issues. A third study of Australian adolescents found 3 clusters, 1 focused on “instrumental” computer use related to email and general computer use and 2 clusters related to gaming [92]. A fourth study examined physical activity, screen-based media, and self-harm among Chinese adolescents and found that the highest-risk group had low physical activity, high media use, and high self-harm [93]. Our study advances the field by including parents as well as physical health, mental health, and well-being measures. Our study is aligned with previous literature, such as the finding that adolescents who struggle in one domain, such as addictive technology behavior, often have lower health behaviors in other areas, such as psychosocial issues, and concerning health outcomes, such as sleep impairment [93].

### Study Findings in the Context of Previous Literature

Previous studies exploring the potential of media use to negatively affect adolescents have produced mixed results, leading some to argue that these effects are present for *some* adolescents but not others. Research suggests that the effects

of social media on adolescent well-being vary so widely that media use has positive effects on some adolescents and negative effects on others [94]. This finding has prompted a call for research to consider a differential susceptibility model to identify those individual differences that are likely to have susceptibility to negative impacts [95].

Our study builds upon and expands on these previous findings in several ways. First, our study includes both negative and positive impacts, here defined as risk and health outcomes, using previous evidence to define these categories. Aligned with the differential susceptibility model, we found a 2-class model illustrating that most adolescents who use media do well across health behaviors and outcomes. A smaller proportion of adolescents are at higher risk, and this risk extends across their technology behaviors as well as health behaviors. A critical difference between Class 1 and Class 2 was their reported level of sleepiness, with Class 2 participants reporting far greater sleep impairment compared with Class 1 participants. Given the substantial impact that sleep can have on both mental and physical health [96,97], this finding bears further exploration and could be considered a target of future interventions to reduce negative health consequences.

Second, our study included parents as a key construct in understanding the links between technology use and health outcomes. Parents are also the gatekeepers of device acquisition and ownership. We assessed the role of parents as moderators, supporters, and role models in the relationship between adolescent technology use and health and well-being outcomes. Compared with Class 2 participants, we found that Class 1 participants were more likely to have family-owned devices than personally owned devices. Furthermore, adolescents in Class 1 were more likely to have household rules that were often centered on content, coviewing, and communication. Class 2 parents were more likely to report no rules, although Class 2 adolescents were more likely to report strict rules around screen time. These mixed findings may suggest that, for some families, the rules are unclear or are stated but not reinforced. Parents in Class 2 were also more likely to report high levels of their own daily social media use. Finally, Class 1 adolescents were more likely to report positive parent-child communication about technology use and a more positive parent-child relationship in general compared with Class 2 adolescents. The consistency and conceptual connection between these variables is a critical finding of our study and a significant advancement in how we understand the balance of health and risk from adolescents' technology use. This study's findings support the positive role that engaged parents can play in promoting health and preventing harm among adolescents related to technology use. Thus, we propose to name the larger Class 1 *Family-Engaged Adolescents* and the smaller Class 2 *At-Risk Adolescents*.

### Study Findings in the Context of Emerging Paradigms

When seeking to frame the role of technology in our health and well-being, one often hears terms such as *online and offline* or *online and in-real-life*. These terms promote a separation of our daily lives into 2 distinct worlds. News stories often frame technology as something that should be reduced or avoided, which could influence a view of technology as a risk behavior

itself. However, today's teenagers have digital tools woven into the fabric of their everyday existence. For adolescents, technology may be seen as within and not separate from their world and as something that can lead to healthy and less healthy outcomes and experiences. To go beyond this dichotomous view of technology, many researchers, policy makers, and families seek new frameworks to consider and describe the role of technology in how we navigate today's world. Our study supports this more comprehensive viewpoint as the findings illustrate the strong alignment within each of our 2 classes across physical health behaviors, technology behaviors, parenting engagement, and mental and well-being outcomes.

An emerging framework that aligns with our study findings is the Human Experience framework (HX) [98]. The HX approach seeks to define technology as part of the human experience. As such, it can be associated with both everyday and special interactions and with both positive and negative experiences. Applying HX to our approach to youth technology use may allow us to avoid oversimplified categorizations of technology use as *bad* or a *risk behavior* and see technology use as a multifaceted activity that may be used in healthy and unhealthy ways. Thus, the HX approach may be a step toward a more comprehensive approach to understanding the role of technology in young people's lives and their differential susceptibility to its benefits and risks based on their lived experience. Furthermore, the HX approach may be a useful lens for technology developers to see their products as part of a larger set of life experiences that may affect or influence the adolescent developmental period.

### Limitations

The first limitation of this study is that our results may not generalize beyond the study population of early adolescents recruited via Qualtrics. Recruiting from a web-based panel of participants meant that we could designate the study population size and criteria but limited our ability to assess the external validity of the sample. However, the Qualtrics platform and panels have been used in other studies of early adolescents [58], and the panels have been found to have close approximations to the US population [56]. Second, LCA provides a systematic approach to creating profiles representing critical variables, although our interpretations of those profile groupings may have inaccuracies. Furthermore, other unmeasured variables such as other family or school factors may have influenced our study outcomes. This study used cross-sectional data, which is common within the LCA approach but does not allow for an understanding of long-term predictors or consequences. All measures were self-reported, and future studies including other novel measurement approaches, such as biological or cognitive studies, are needed.

Finally, it may be notable to readers that we did not investigate any specific platforms in this study. Rather, we focused on technology devices and social media use frequency. Furthermore, we incorporated the technology use importance scale (ADTI), which assesses critical interactions and functions of technology that may apply to many different platforms. This was a purposeful approach toward better understanding the

mechanisms underlying technology use rather than the role of specific platforms.

### Implications and Future Directions

This study raises important implications for how we approach the topic of adolescent technology use in health care, policy, and research. Too often, the dialogue around adolescent technology use has been to frame it as a negative risk behavior that all adolescents should cease [99]. Our findings support that, for a smaller group of adolescents in this study who made up *At-Risk Adolescents* (Class 2), their higher rates of technology ownership and use were associated with higher rates of health risks and lower scores on well-being indicators. However, our findings suggest that two-thirds of the adolescents who made up *Family-Engaged Adolescents* (Class 1) in our study integrated technology into their lives in ways that were not associated with higher rates of depression, anxiety, or other poor health outcomes. Thus, the study findings indicate that most adolescents using technology do so in ways that do not lead to increased risk of negative health consequences.

We propose that a critical factor that affected *Family-Engaged Adolescents'* (Class 1) health and well-being was the role of parents. *Family-Engaged Adolescents* were more likely to have household media rules at home regarding media and technology use. Participants in this group were more likely to report that the rules they had at home were aligned with the recommendations of the AAP on content, communication, and covieing. *Family-Engaged Adolescents* were more likely to communicate with their parents about their technology use and, overall, they reported a positive relationship with their parents compared with the *At-Risk Adolescents* (Class 2). Furthermore, Class 1 parents used social media less frequently compared with Class 2 parents, highlighting the integral aspect of role modeling that parents have regarding technology use.

There are several concrete recommendations that this study supports. First, consistent with AAP recommendations, we recommend a shift away from rules centered on screen time. Our evidence supports that household rules focused on content, communication, and covieing were more likely to be associated with lower health risk and improved well-being (see

[Multimedia Appendix 1](#) for more information). The findings of this study can direct pediatricians' and other health care providers' counseling toward parents and encourage them to leverage these approaches at home. Providers can also partner with parents to ensure that messaging around media is culturally relevant and developmentally appropriate. Health care providers may benefit from using technology within the clinic visit to share these recommendations, such as through electronic health record prompts to ask about technology behaviors and home rules and after-visit summary resources, including recommendations and links to resources.

These resources may include tools that can support parents in creating media rules at home. First, the Family Media Use Plan of the AAP has content, communication, and covieing as key elements, and this approach is without cost. Other for-profit web-based tools such as Circle and Bark may integrate content restrictions into family rule development, although these programs are also at a cost and often focus predominantly on screen time. Including adolescents in the discussion and selection of rules is a critical tactic to obtaining their buy-in for setting limits and boundaries.

Second, health care providers and researchers should consider the integral role that parents play in their children's media use. In addition to recommending that parents create and enforce household media rules, pediatricians can support parents in developing positive relationships with their adolescents. These approaches may include covieing media. Counseling parents about having awareness of their own technology use and their role modeling of technology behaviors may be a critical recommendation to influence health outcomes. Researchers designing interventions must consider the role of parent support, both related to technology and likely more broadly in adolescents' lives, if they want to truly affect adolescent well-being. Finally, we encourage future research and policy to consider technology as integrated into adolescents' daily lives. Our study supports the exploration of new frameworks such as the HX approach toward the design of new policies and studies to advance adolescent health (see [Multimedia Appendix 2](#) for more information).

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### Conflicts of Interest

None declared.

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#### Multimedia Appendix 1

Parent tip sheet.

[[PDF File \(Adobe PDF File\), 361 KB - `pediatrics\_v5i2e35540\_app1.pdf`](#) ]

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#### Multimedia Appendix 2

Tech tip sheet.

[[PDF File \(Adobe PDF File\), 223 KB - `pediatrics\_v5i2e35540\_app2.pdf`](#) ]

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## Abbreviations

**AAP:** American Academy of Pediatrics  
**ADTI:** Adolescents' Digital Technology Interactions and Importance  
**CIT:** Comprehensive Inventory of Thriving  
**FOMO:** fear of missing out  
**HX:** Human Experience framework  
**LCA:** latent class analysis  
**PHQ-9:** 9-item Patient Health Questionnaire  
**PIU:** problematic internet use  
**VR:** virtual reality

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Original Paper

# Classifying Autism From Crowdsourced Semistructured Speech Recordings: Machine Learning Model Comparison Study

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## Abstract

**Background:** Autism spectrum disorder (ASD) is a neurodevelopmental disorder that results in altered behavior, social development, and communication patterns. In recent years, autism prevalence has tripled, with 1 in 44 children now affected. Given that traditional diagnosis is a lengthy, labor-intensive process that requires the work of trained physicians, significant attention has been given to developing systems that automatically detect autism. We work toward this goal by analyzing audio data, as prosody abnormalities are a signal of autism, with affected children displaying speech idiosyncrasies such as echolalia, monotonous intonation, atypical pitch, and irregular linguistic stress patterns.

**Objective:** We aimed to test the ability for machine learning approaches to aid in detection of autism in self-recorded speech audio captured from children with ASD and neurotypical (NT) children in their home environments.

**Methods:** We considered three methods to detect autism in child speech: (1) random forests trained on extracted audio features (including Mel-frequency cepstral coefficients); (2) convolutional neural networks trained on spectrograms; and (3) fine-tuned wav2vec 2.0—a state-of-the-art transformer-based speech recognition model. We trained our classifiers on our novel data set of cellphone-recorded child speech audio curated from the *Guess What?* mobile game, an app designed to crowdsource videos of children with ASD and NT children in a natural home environment.

**Results:** The random forest classifier achieved 70% accuracy, the fine-tuned wav2vec 2.0 model achieved 77% accuracy, and the convolutional neural network achieved 79% accuracy when classifying children's audio as either ASD or NT. We used 5-fold cross-validation to evaluate model performance.

**Conclusions:** Our models were able to predict autism status when trained on a varied selection of home audio clips with inconsistent recording qualities, which may be more representative of real-world conditions. The results demonstrate that machine learning methods offer promise in detecting autism automatically from speech without specialized equipment.

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**KEYWORDS**

autism; mHealth; machine learning; artificial intelligence; speech; audio; child; digital data; mobile app; diagnosis

## Introduction

Autism spectrum disorder (ASD, or autism) encompasses a spectrum of disorders characterized by delayed linguistic development, social interaction deficits, and behavioral impairments [1]. Autism prevalence has rapidly increased in recent years: according to the Centers for Disease Control and Prevention, autism rates have tripled since 2000 to 1 in 44 children in 2018 [2]. In the United States alone, over 5 million individuals are affected [3], and nearly 75 million are affected worldwide. Despite the increasing prevalence of autism, access to diagnostic resources continues to be limited, with 83.86% of all American counties not having any [4]. These nationwide inadequacies in autism resources are compounded by the lengthy nature of diagnosis. On average, the delay from the time of first consultations with health care providers to the time of diagnosis is over 2 years. Such extensive delays often cause diagnosis at a later age (usually  $\geq 4$  years old) [5], which may result in greater lifelong impacts, including a higher likelihood of psychotropic medication use, lower IQ scores, and reduced language aptitude [6,7]. Given that timely autism identification and intervention has been shown to improve treatment success and social capabilities, research has focused on its early detection [7-11].

Although symptoms vary across individuals, prosody abnormalities are among the most notable signs of autism, with multiple studies suggesting that affected children display peculiarities including echolalia, monotonous intonation, and atypical pitch and linguistic stress patterns [12-14]. Given this, an effective artificial intelligence sound classifier trained to detect speech abnormalities common in children with autism would be a valuable tool to aid autism diagnostic processes.

Prior research [15,16] investigated prosodic disorders in children with autism to varying degrees of success. Cho et al [17] developed models that achieved 76% accuracy on a dataset of recorded interviews between children and unfamiliar adults, trained on data recorded at a consistent location using a specialized biosensor device with 4 directional microphones. Similarly, Li et al [18] achieved high accuracies when training on speech data recorded with multiple wireless microphones, providing high purity recordings at a central recording location (a hospital). However, both used data collected in centralized, unfamiliar locations with high-quality recording equipment. Such research, while promising, does not accelerate the process of autism detection because it requires the use of specialized equipment and centralized recording locations to provide

consistent audio quality, posing significant barriers to the widespread availability of automatic diagnosis tools. Additionally, interacting with unknown adults in foreign environments could be stressful and possibly affect the behavior of children with autism, thus leading to observations that are not generalizable to the real world.

In this work, we propose a machine learning-based approach to predict signs of autism directly from self-recorded semistructured home audio clips recording a child's natural behavior. We use random forests, convolutional neural networks (CNNs), and fine-tuned wav2vec 2.0 models to identify differences in speech between children with autism and neurotypical (NT) controls. One strength of our approach is that our models are trained on mobile device audio recordings of varying audio quality. Therefore, unlike other studies, our approach does not necessitate specialized high-fidelity recording equipment. Additionally, we attempt to capture naturalistic speech patterns by recording children playing educational games with their parents in a low-stress home environment. Finally, our approach does not require a trained clinician to converse with the child. To our knowledge, our method is the first to aurally detect symptoms of autism in an unstructured home environment without the use of specialized audio recording devices.

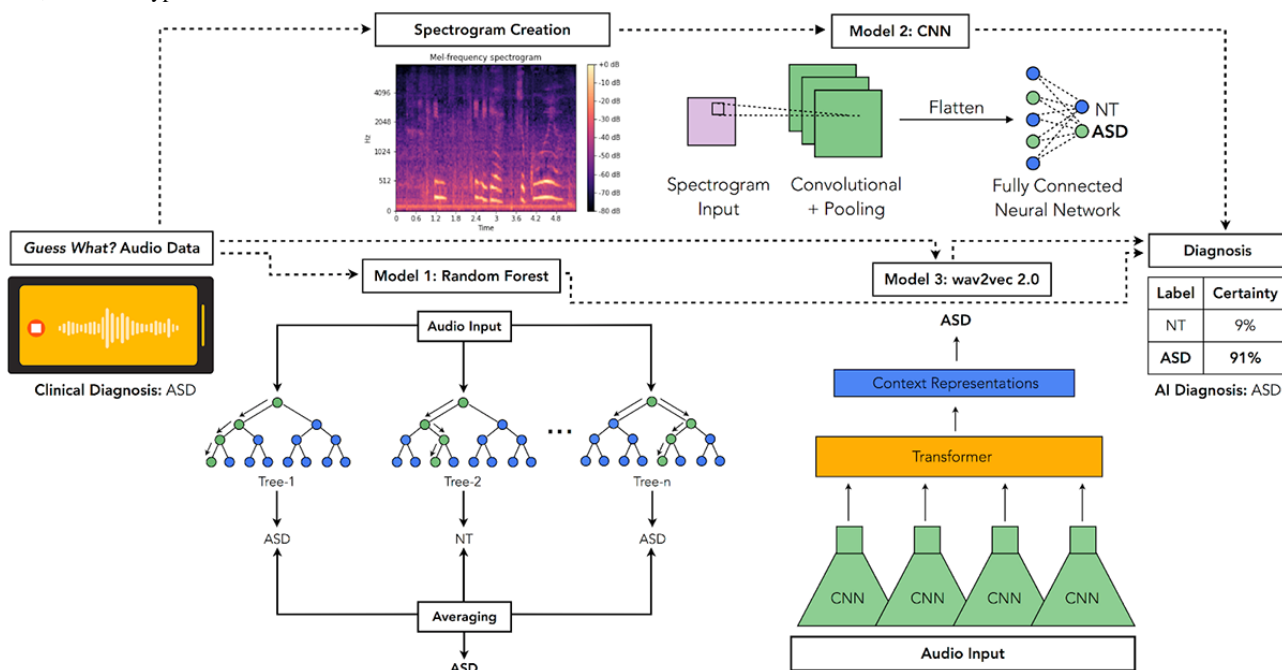
## Methods

### Data Acquisition

#### Process

We obtained audio data of NT children and children with autism in a home environment through *Guess What?*, a mobile game designed for prosocial play and interaction at home between 2- to 8-year-old developing children and their parents [19-23] (Figure 1, "Guess What? Audio Data"). During a game session, parents and children choose either a charades game (acting out emotions, characters, sports, chores, or objects) or a simple quiz game (identifying colors, shapes, numbers, and word spellings). Children are directed to follow the rules of gameplay, while parents serve as game mediators. Throughout the session, parents record their children by placing their smartphones on their foreheads with the front-facing camera oriented toward the child. After each 90-second session, parents are given the option to view their child's game session video recording and share it with our research team.

**Figure 1.** Overview of audio-based AI detection pipeline. First, the educational video game *Guess What?* crowdsources the recording of videos of NT children and children with ASD from consenting participants. Audio of children’s speech is manually spliced from the videos and 3 models are trained on this audio data. The first is a random forest classifier, which uses an ensemble of independently trained decision trees. The second is a CNN. The third is a fine-tuned wav2vec 2.0 model. Model 1 takes commonly used speech recognition features as input, model 2 learns from spectrograms of the audio, and model 3 takes the raw audio data itself as input. AI: artificial intelligence; ASD: autism spectrum disorder; CNN: convolutional neural network; NT: neurotypical.



**Distribution of Demographics**

We collected a total of 77 videos of 58 children participating in gameplay, recorded in the span of 4 years from 2018 to 2021. The participants ranged in age from 3-12 years old and included 20 children with ASD (19 male and 1 female) and 38 NT children (15 male, 22 female, and 1 unspecified). The median age of the children with ASD was 5 years; the median age of the NT children was 9.5 years. Parents involved in the study consented to sharing their videos with our research team and provided their child’s age, sex, and diagnosis.

**Advantages**

This pipeline offers several benefits over traditional diagnostic workflows. Since only a smartphone is necessary, more children can be assessed for autism than through in-lab procedures, with lower costs of time and health care resource use. Through *Guess What?*, a traditionally time-intensive health care process for diagnosis could potentially be transformed into a quick and enjoyable process. Furthermore, children recorded at home may be more likely to behave in a naturalistic manner.

**Table 1.** Distribution of 850 audio clips across 5 folds. Each of the 3 models was trained on the same distribution of clips with 5-fold cross-validation.

| Group                    | Fold 0 | Fold 1 | Fold 2 | Fold 3 | Fold 4 |
|--------------------------|--------|--------|--------|--------|--------|
| Neurotypical             | 87     | 87     | 81     | 83     | 87     |
| Autism spectrum disorder | 87     | 87     | 81     | 83     | 87     |

**Classifiers**

We investigated 3 machine learning methods to predict autism from audio, each represented in Figure 1.

**Data Preprocessing**

Home videos are naturally variable in quality; their data contains a number of irregularities that must be addressed prior to analysis. In particular, parents or children would often join in gameplay simultaneously, resulting in a variety of voices, sometimes overlapping with one another. This overlap of voices can complicate the isolation and extraction of the child’s voice. In order to remove adult speech, we manually sampled only child speech from each video, ensuring that each resulting clip did not include any voice other than the child’s. Each child contributed a mean of 1.32 videos and 14.7 clips, resulting in a total data set size of 850 audio clips, representing 425 ASD and 425 NT clips. The 850 clips were split into 5 folds, as shown in Table 1, in preparation for 5-fold cross-validation. When creating the folds, we included the restriction that all clips spliced from a given child’s video had to be included in the same fold to prevent models from learning from child-specific recording idiosyncrasies, including environmental background noise and audio quality.

**Random Forest**

We trained random forests on a set of audio features (Mel-frequency cepstral coefficients, chroma features, root mean square, spectral centroids, spectral bandwidths, spectral rolloff,

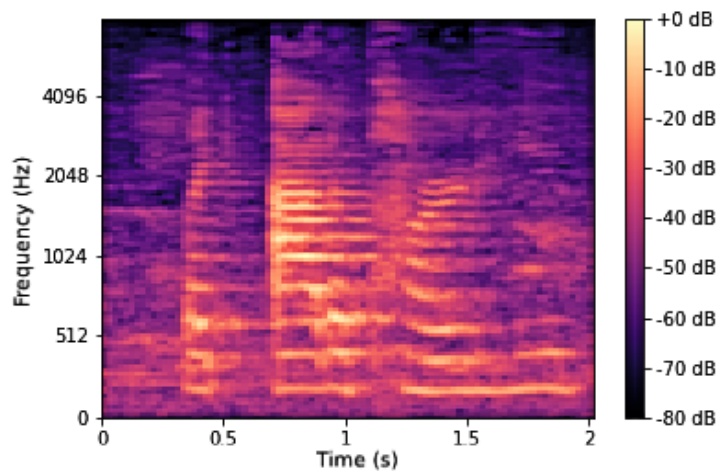
and zero-crossing rates) typically used in traditional signal processing speech recognition. We also tried training other models (including logistic regression, Gaussian Naive Bayes, and AdaBoosting models), which did not perform as well. We implemented the random forest model in scikit-learn and used the following manually chosen hyperparameters:  $\text{max\_depth}=20,000$ ,  $n_{\text{estimators}}=56$ ,  $\text{max\_features}=15$ ,  $\text{min\_samples\_split}=10$ ,  $\text{min\_samples\_leaf}=20$ ,  $\text{min\_weight\_fraction\_leaf}=0.1$ .

### CNN Model

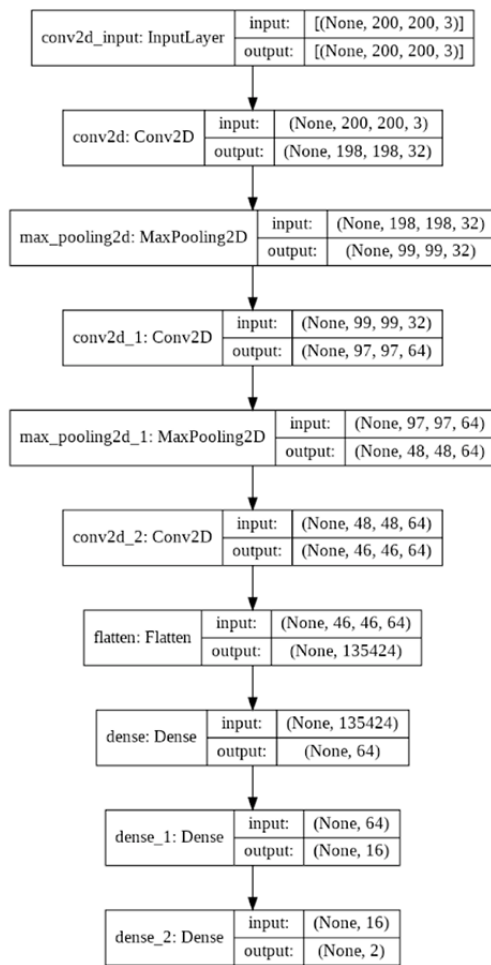
We trained a CNN using spectrograms of our data as input [24,25]. Our spectrograms were synthesized via the Python

package Librosa. Figure 2 shows an example of the spectrograms used to train the CNN. The CNN, represented in Figure 3, consists of 9 layers each with alternating convolution and max pooling layers, as well as 3 dense layers with a L2 regularization penalty of 0.01. We investigated both training a small CNN (~8 million parameters) from scratch and fine-tuning the image recognition model Inception v3 (with ~33 million parameters) trained on ImageNet [26]. However, our CNN model with 8 million parameters ultimately performed slightly better than the transfer learning approach, likely due to the irrelevance of ImageNet features to spectrograms. Our final CNN model, which we train for 15 epochs (until training performance stopped improving), has 8,724,594 parameters.

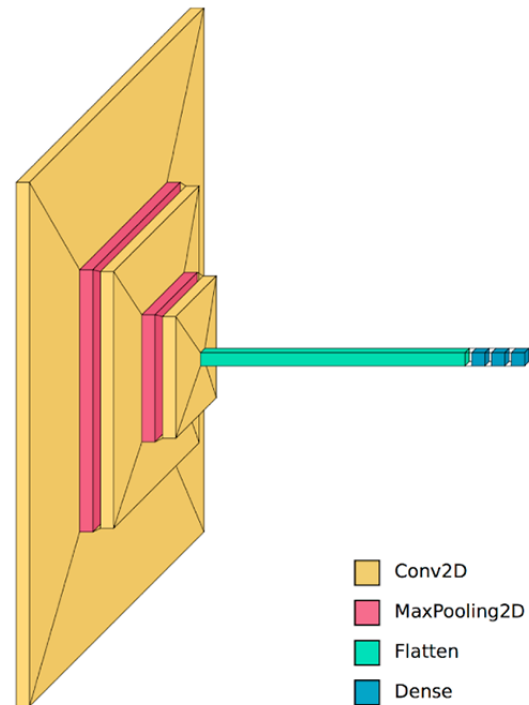
**Figure 2.** Mel-frequency spectrogram for a neurotypical child speech segment, spliced from a *Guess What?* gameplay video. This spectrogram was one of 850 used to train the convolutional neural network model with 8 million parameters, which yielded the highest accuracy of the 3 best-performing models.



**Figure 3.** (A) and (B) represent the same 8M CNN model architecture. This architecture performed best out of all of our tested architectures, including a fine-tuned Inception v3 model. (B) was in part created with the Python package Visualkeras. 8M CNN: convolutional neural network with 8 million parameters.



A) 8M CNN Architecture



B) 8M CNN Architecture Visualized

### Wav2vec 2.0

We fine-tuned wav2vec 2.0, a state-of-the-art transformer model pretrained on a self-supervised audio denoising task [27]. Although wav2vec 2.0 is typically used for speech-to-text decoding, prior work [28] has demonstrated its utility for suprasegmental tasks such as emotion prediction. We used the facebook/wav2vec2-base variant and fine-tuned for 264 steps. The final model has 95 million parameters.

### Summary

For each method, we trained and evaluated using 5-fold cross-validation. We ensured that clips from a child are maintained in one fold to prevent the model from artificially performing better by learning user recording idiosyncrasies (eg, background noise). For each fold, we saved the weights for the highest performing model after training and reported mean accuracy (with threshold 0.5), precision, recall,  $F_1$  score, and area under the receiver operating characteristic curve (AUROC), averaged over the 5 folds.

### Results

Of our models, the best-performing model was the CNN model with 8 million parameters, achieving 79.3% accuracy, 80.4% precision, 79.3% recall, 79.0%  $F_1$  score, and a mean AUROC score of 0.822 (Table 2). Our wav2vec 2.0 model performed comparably with our best CNN, achieving 76.9% accuracy, 78.2% precision, 74.6% recall, and 76.8%  $F_1$  score, and a mean AUROC score of 0.815. On the other hand, our highest performing lightweight machine learning model (random forest) performed somewhat worse than the other 2 models, with 69.7% accuracy, 68.7% precision, 74.4% recall, 69.4%  $F_1$  score, and a mean AUROC score of 0.740.

Our receiver operating characteristic (ROC) curves for the top 3 highest performing models of each category are included in Figure 4, panels A, C, and E. In each figure, ROC curves for each individual fold and the mean curve are reported. One point of interest is that each figure has variation in area under the curve (AUC) values between folds to some degree. Moreover, these variation trends are similar between models: for instance, each model appears to perform well on fold 2 while performing



relatively poorly on fold 3. This suggests that the data in each fold may be too limited, resulting in folds that have differences in content that cause varying model performance from fold to fold. This disparity between AUC values is the greatest in Figure 4A, perhaps explainable by the random forest classifier’s small size and lightweight traits. The wav2vec model (Figure 4E) has the most unvarying results, implying that it is better at consistently performing well at classifying unseen data than either of the other two models. This is expected, given that the

wav2vec model contains far more parameters than either of the other two models and is more robust.

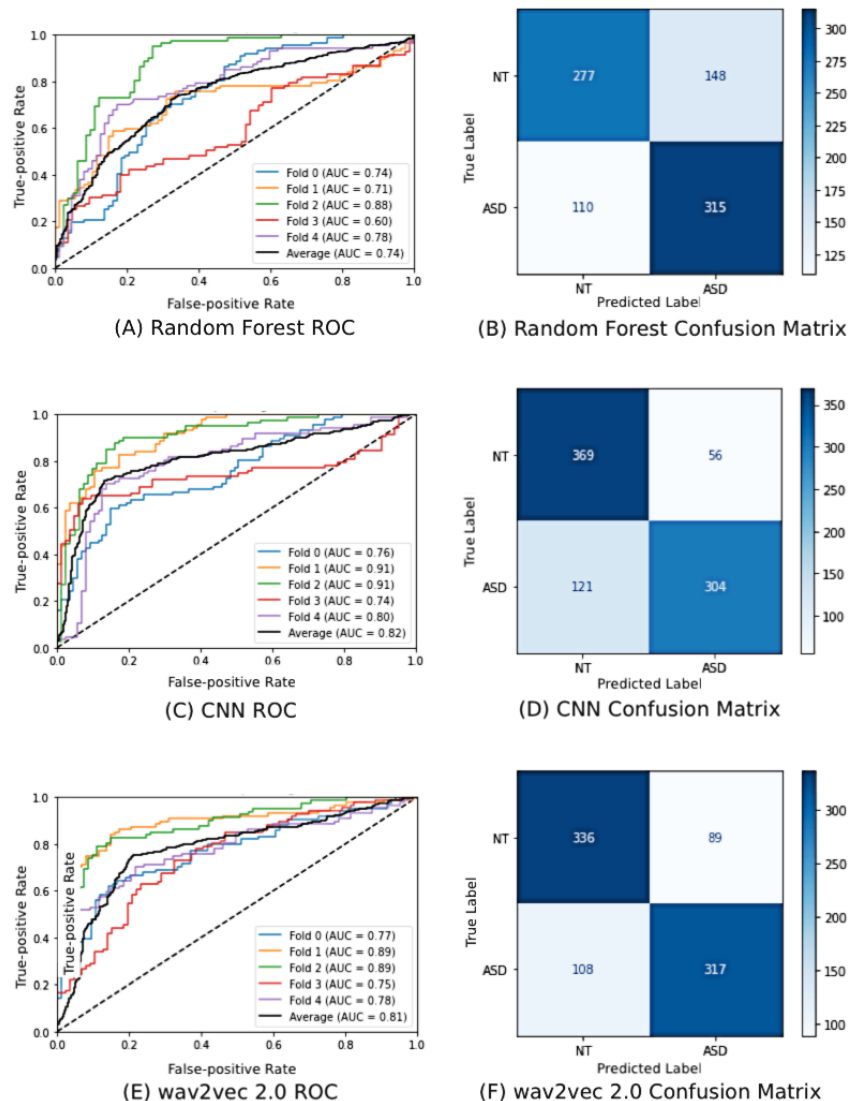
In Figure 4, panels B, D, and F, we provide confusion matrices for all 3 highest performing models. Figure 4D and Figure 4F show that both the CNN and wav2vec models have relatively few false positive predictions, while Figure 4B shows that the random forest classifier has a relatively large number of false positive predictions. All models have similar false negative prediction rates.

**Table 2.** Performances on *Guess What?* data set. Results are reported with standard deviation over 5 different runs for each model.

| Model                        | Accuracy, mean (SD) | Precision, mean (SD) | Recall, mean (SD) | F <sub>1</sub> score, mean (SD) | AUROC <sup>a</sup> , mean (SD) |
|------------------------------|---------------------|----------------------|-------------------|---------------------------------|--------------------------------|
| Random forest                | 0.697 (0.013)       | 0.687 (0.010)        | 0.744 (0.247)     | 0.694 (0.013)                   | 0.740 (0.09)                   |
| Convolutional neural network | 0.793 (0.013)       | 0.804 (0.014)        | 0.793 (0.014)     | 0.790 (0.014)                   | 0.822 (0.010)                  |
| Wav2vec 2.0                  | 0.769 (0.005)       | 0.782 (0.021)        | 0.746 (0.031)     | 0.768 (0.006)                   | 0.815 (0.077)                  |

<sup>a</sup>AUROC: area under the receiver operating characteristic curve.

**Figure 4.** (A) ROC curve for random forest model. (B) Confusion matrix for random forest model. (C) ROC curve for 8M CNN. (D) Confusion matrix for CNN. (E) ROC curve for wav2vec 2.0 model. (F) Confusion matrix for wav2vec 2.0 model. All models were tested and trained on the *Guess What?* audio data set, composed of child speech segments taken from educational gameplay videos. 8M CNN: convolutional neural network with 8 million parameters; ASD: autism spectrum disorder; AUC: area under the curve; NT: neurotypical; ROC: receiver operating characteristic.



## Discussion

### Principal Results

We trained multiple models to detect autism from our novel data set of audio recordings curated from the educational video game *Guess What?* We presented a set of systems that classify audio recordings by autism status and demonstrated that both CNNs and state-of-the-art speech recognition models are capable of attaining robust performance on this task, with lightweight statistical classifiers still achieving reasonable results.

### Privacy

One consideration for any recorded audio medical diagnosis is privacy [29-31], which is particularly important for studies involving commonly stigmatized disorders like autism [32]. We note that since our proposed models are relatively lightweight, they could feasibly be deployed at home on mobile devices, allowing for private offline symptom detection as well as privacy-preserving federated learning approaches [33]. Prior work investigated using federated learning techniques to preserve privacy while boosting model performance on a functional magnetic resonance imaging classifier task; a similar framework might be feasible for autism diagnosis, affording a greater degree of privacy for parents who wish for a diagnostic signal but hesitate to share videos with strangers [34].

### Limitations

One limitation of our approach is the relative imbalances in the gender distribution of children who comprised our speech data set. Our data set included a split between 95% males with ASD and 5% females with ASD for autistic speech segments, as well as a 39% NT male, 58% NT female, and 3% NT unknown gender split for NT speech segments. Our data set had a sizable imbalance in terms of the relative proportion of males and females with ASD represented. Although some imbalance is to be expected due to the naturally skewed autism sex ratio, our imbalance was larger than the observed real-world 4:1 to 3:1 male-to-female incidence ratio, which would result in a data set containing an 80%-75% male and 20%-25% female split for ASD segments [35,36]. Therefore, despite being closer to replicating actual conditions than prior work, our data set may still not be completely representative of real-world conditions. Additionally, while we require parents to disclose their child's clinical diagnosis by choosing from options not widely known to those who have not received a clinical evaluation, these labels are self-reported and thus unverified.

Another limitation of our work is that we evaluated on a relatively small data set. Additionally, manually splicing videos

to isolate child voices is a time-intensive process that may not be scalable to larger data sets. The alternative—automatically isolating voices through blind signal separation—is an exceptionally challenging task [37,38]. However, it poses a potential area of interest and is possibly a necessary hurdle to overcome to develop widely available and consistently effective autism machine learning diagnosis resources.

### Future Work

One strength of our approach is the relatively small amount of data required to train the model. Our models were trained on clips spliced from a total of 115.5 minutes of audio yet still yielded relatively accurate results, implying that training on more data may improve performance.

Therefore, future directions include testing our models' performance with additional data from a wider selection of both children with autism and NT children. One particular area of interest may be wearable devices such as Google Glass [39,40]; previous work [41-44] investigated delivering actionable, unobtrusive social cues through wearables. Such approaches have been demonstrated to improve socialization among children with ASD [10,45], suggesting that they could also be used to collect naturalistic data similar to this experiment in an unobtrusive way.

Another area of interest for future work may be examining the possibility of leveraging a distributed workforce of humans for extracting audio-related features to bolster detection accuracy. Previous work examined the use of crowdsourced annotations for autism, indicating that similar approaches could perhaps be applied through audio [31,46-51]. Audio feature extraction combined with other autism classifiers could be used to create an explainable diagnostic system [52-64] fit for mobile devices [60]. Previous work investigated using such classifiers to detect autism or approach autism-related tasks like identifying emotion to improve socialization skills; combining computer vision-based quantification of relevant areas of interest, including hand stimming [58], upper limb movement [63], and eye contact [62,64], could possibly result in interpretable models.

### Conclusions

Use of automatic audio classification could help to accelerate and improve the accuracy and objectivity of the lengthy diagnosis process for autism. Our models were able to predict autism status by training on a varied selection of home audio clips with inconsistent recording quality, which may be more representative of real-world conditions. Overall, our work suggests a promising future for at-home detection of ASD.

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### Conflicts of Interest

DPW is the founder of Cognoa.com. This company is developing digital health solutions for pediatric health care. All other authors declare no competing interests.

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## Abbreviations

**ASD:** autism spectrum disorder

**AUC:** area under the curve

**AUROC:** area under the receiver operating characteristic curve

**CNN:** convolutional neural network

**NT:** neurotypical

**ROC:** receiver operating characteristic

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Original Paper

# Improved Digital Therapy for Developmental Pediatrics Using Domain-Specific Artificial Intelligence: Machine Learning Study

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## Abstract

**Background:** Automated emotion classification could aid those who struggle to recognize emotions, including children with developmental behavioral conditions such as autism. However, most computer vision emotion recognition models are trained on adult emotion and therefore underperform when applied to child faces.

**Objective:** We designed a strategy to gamify the collection and labeling of child emotion-enriched images to boost the performance of automatic child emotion recognition models to a level closer to what will be needed for digital health care approaches.

**Methods:** We leveraged our prototype therapeutic smartphone game, GuessWhat, which was designed in large part for children with developmental and behavioral conditions, to gamify the secure collection of video data of children expressing a variety of emotions prompted by the game. Independently, we created a secure web interface to gamify the human labeling effort, called HollywoodSquares, tailored for use by any qualified labeler. We gathered and labeled 2155 videos, 39,968 emotion frames, and 106,001 labels on all images. With this drastically expanded pediatric emotion-centric database (>30 times larger than existing public pediatric emotion data sets), we trained a convolutional neural network (CNN) computer vision classifier of happy, sad, surprised, fearful, angry, disgust, and neutral expressions evoked by children.

**Results:** The classifier achieved a 66.9% balanced accuracy and 67.4% F1-score on the entirety of the Child Affective Facial Expression (CAFE) as well as a 79.1% balanced accuracy and 78% F1-score on CAFE Subset A, a subset containing at least 60% human agreement on emotions labels. This performance is at least 10% higher than all previously developed classifiers evaluated against CAFE, the best of which reached a 56% balanced accuracy even when combining “anger” and “disgust” into a single class.

**Conclusions:** This work validates that mobile games designed for pediatric therapies can generate high volumes of domain-relevant data sets to train state-of-the-art classifiers to perform tasks helpful to precision health efforts.

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## KEYWORDS

computer vision; emotion recognition; affective computing; autism spectrum disorder; pediatrics; mobile health; digital therapy; convolutional neural network; machine learning; artificial intelligence

## Introduction

Automated emotion classification can serve in pediatric care solutions, particularly to aid those who struggle to recognize

emotion, such as children with autism who have trouble with emotion evocation and recognizing emotions displayed by others [1-3]. In prior work, computer vision models for emotion recognition [4-6] used in digital therapeutics have shown

significant treatment effects in children with autism [7-17]. The increasing use of signals from sensors on mobile devices, such as the selfie camera, opens many possibilities for real-time analysis of image data for continuous phenotyping and repeated diagnoses in home settings [18-33]. However, facial emotion classifiers and the underlying data sets on which they are trained have been tailored to neurotypical adults, as demonstrated by repeatedly low performance on image data sets of pediatric emotion expressions [34-39].

The Child Affective Facial Expression (CAFE) data set is currently the most popular facial expression data set pertaining to children. Prior machine learning efforts that do not include CAFE images in the training set have reached 56% accuracy on CAFE [36,37,39], even after combining facial expressions (eg, “anger” and “disgust”) into a single class, thus limiting granularity. We do not discuss prior publications that report higher accuracy using subsets of the CAFE data set in the training and testing sets. This overall lack of performance in prior work highlights the need for developing facial emotion classifiers that work for children. With a lack of labeled data being the fundamental bottleneck to achieving clinical-grade performance, low-cost and speedy data generation and labeling techniques are pertinent.

As a first step toward the creation of a large-scale data set of child emotions, we have previously designed GuessWhat, a dual-purpose smartphone app that serves as a therapeutic for children with autism while simultaneously collecting highly structured image data enriched for emoting in children. GuessWhat was designed for children aged 2 and above to encourage prosocial interaction with a gameplay partner (eg, mom or dad), focusing the camera on the child while presenting engaging but challenging prompts for the child to try to act out [40-43]. We have previously tested GuessWhat’s potential to increase socialization in children with autism as well as its potential to collect structured videos of children emoting facial expressions [44]. In addition to collecting videos enriched with emotions, GuessWhat gameplay generates user-derived labels

of emotion by leveraging the charades-style gameplay structure of the therapy.

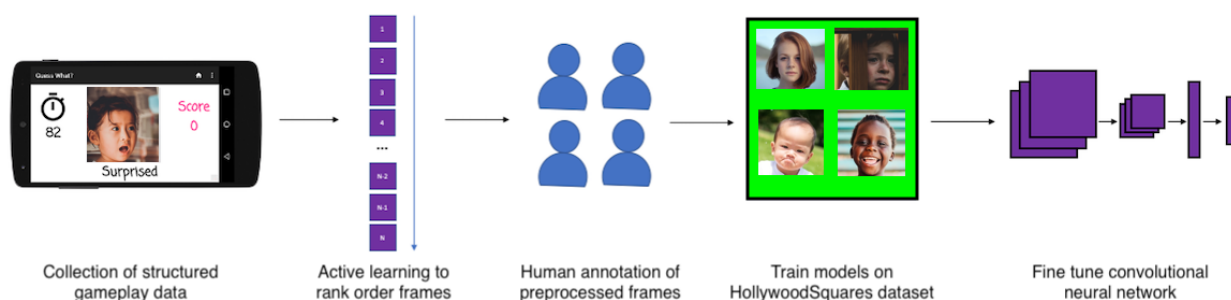
Here, we document the full pipeline for training a classifier using emotion-enriched video streams coming from GuessWhat gameplay, resulting in a state-of-the-art pediatric facial emotion classifier that outperforms all prior classifiers when evaluated on CAFE. We first recruited parents and children from around the world to play GuessWhat and share videos recorded by the smartphone app during gameplay. We next extracted frames from the videos, automatically discarding some frames through quality control algorithms, and uploaded the frames on a custom behavioral annotation labeling platform named HollywoodSquares. We prioritized the high entropy frames and shared them with a group of 9 human annotators who annotated emotions in the frames. In total, we have collected 39,968 unique labeled frames of emotions that appear in the CAFE data set. Using the resulting frames and labels, we trained a facial emotion classifier that can distinguish happy, sad, surprised, fearful, angry, disgust, and neutral expressions in naturalistic images, achieving state-of-the-art performance on CAFE and outperforming existing classifiers by over 10%. This work demonstrates that therapeutic games, while primarily providing a behavioral intervention, can simultaneously generate sufficient data for training state-of-the-art domain-specific computer vision classifiers.

## Methods

### Data Collection

The primary methodological contribution of this work is a general-purpose paradigm and pipeline (Figure 1) consisting of (1) passive collection of pre-labeled structured videos from therapeutic interventions, (2) active learning to rank the collected frames leveraging the user-derived labels generated during gameplay, (3) human annotation of the frames in the order produced in the previous step, and (4) training a classifier while artificially augmenting the training set. We describe our instantiation of this general paradigm in the following sections.

**Figure 1.** Pipeline of the model training process. Structured videos enriched with child emotion evocation are collected from a mobile autism therapeutic deployed in the wild. The frames are ranked for their contribution to the target classifier by a maximum entropy active learning algorithm and receive human labels on a rating platform named HollywoodSquares. The frames are corresponding labels that are transferred onto a ResNet-152 neural network pretrained on the ImageNet data set.



### Ethical Considerations

All study procedures, including data collection, were approved by the Stanford University Institutional Review Board (IRB

number 39562) and the Stanford University Privacy Office. In addition, informed consent was obtained from all participants, all of whom had the opportunity to participate in the study without sharing videos.

**Recruitment**

To recruit child video subjects, we ran a marketing campaign to gather rich and diverse video inputs of children playing GuessWhat while evoking a range of emotions. We posted advertisements on social media (Facebook, Instagram, and Twitter) and contacted prior study participants for other digital smartphone therapeutics developed by the lab [13-15]. All recruitment and study procedures were approved by the Stanford University IRB.

**User Interfaces**

***GuessWhat Smartphone Therapeutic***

GuessWhat is a mobile autism therapy implemented on iOS and Android, which has been previously documented as a useful tool for the collection of structured video streams of children behaving in constrained manners [40-44], including evocation of targeted emotions. GuessWhat features a charades game where the parents place the phone on their forehead facing the child, while the child acts out the emotion prompt displayed on the screen. The front-facing camera on the phone records a video of the child in addition to corresponding prompt metadata. All sessions last for 90 seconds. Upon approval by the parent, each session video is uploaded to a Simple Storage Service (S3) bucket on Amazon Web Services (AWS). The app has resulted in 2155 videos shared by 456 unique children. Parents are asked to sign an electronic consent and assent form prior to playing GuessWhat. After each gameplay session, parents can (1) delete the videos, (2) share the videos with the research team only, or (3) share the videos publicly.

**Emotions Considered**

We sought labels for Paul Ekman’s list of six universal emotions: anger, disgust, fear, happiness, sadness, and surprise [45-48]. Ekman originally included contempt in the list of emotions but has since revised the list of universal emotions.

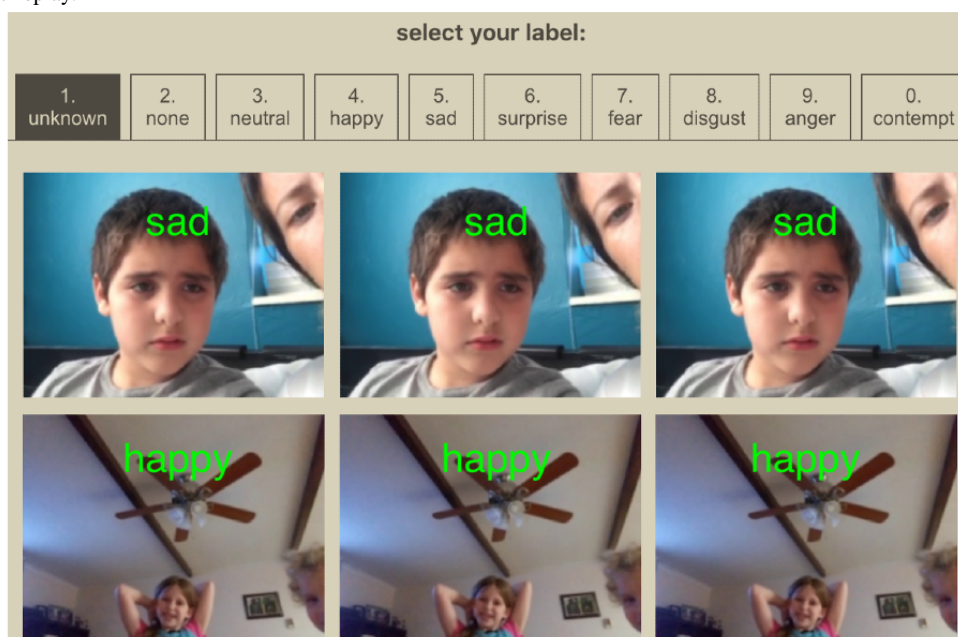
Because CAFE does not include labels of contempt, we did not train our classifier to predict contempt. We added a seventh category named neutral, indicating the absence of an expressed emotion. Our aim was to train a 7-way emotion classifier distinguishing among Ekman’s 6 universal emotions plus neutral.

***HollywoodSquares Frame Labeling***

We developed a frame-labeling website named HollywoodSquares. The website provides human labelers with an interface to speedily annotate a sequential grid of frames (Figure 2) that were collected during the GuessWhat gameplay. To enable rapid annotation, HollywoodSquares enables users to label frames by pressing hot keys, where each key corresponds to a particular emotion label. To provide a label, users can hover their mouse over a frame and press the hot key corresponding to the emotion they want to label. As more frames are collected by GuessWhat, they continue to appear on the interface. Because the HollywoodSquares system displays over 20 images on the screen at once, it encourages rapid annotation and enables simultaneous engagement by many independent labelers. This permits rapid convergence of a majority rules consensus on image labels.

We ran a labeling contest with 9 undergraduate and high school annotators, where we challenged each annotator to produce labels that would result in the highest performing classifier on the CAFE data set. Raters were aged between 15 and 24 years and were from the Bay Area, Northeastern United States, and Texas. The raters included 2 males and 7 females. For the frames produced by each individual annotator, we trained a ResNet-152 model (see Model Training). We updated annotators about the number of frames they labeled each week and the performance of the classifier trained with their individual labels. We awarded a cash prize to the annotator with the highest performance at the end of the 9-week labeling period.

**Figure 2.** HollywoodSquares rating interface. Annotators use keyboard shortcuts and the mouse to speedily annotate a sequence of frames acquired during GuessWhat gameplay.





HollywoodSquares was also used for a testing phase, during which iterations of the frame-labeling practices were made between the research and annotation teams. All the labeled frames acquired during this testing phase were discarded for final classifier training.

All annotators were registered as research team members through completion of the Health Insurance Portability and Accountability Act of 1996 and Collaborative Institutional Training Initiative training protocols in addition to encrypting their laptop with Stanford Whole Disk Encryption. This provided annotators with read-only access to all the videos and derived frames from GuessWhat gameplay that were shared with the research team.

The final labels were chosen by the following process. If all annotators agreed unanimously about the final frame label, then this label was assigned as the final frame label. If disagreements existed between raters, then the emotion gameplay prompt associated with that frame (the “automatic label”) was assigned as the final label for that frame, as long as at least 1 of the human annotators agreed with the automatic label. If disagreements existed between raters but the automatic label did not match any human annotations, then the frame was not included in the final training data set.

## Machine Learning

### Model Training

We leveraged an existing CNN architecture, ResNet-152 [49], with pretrained weights from ImageNet [50]. We used categorical cross entropy loss and Adam optimization with a learning rate of  $3 \times 10^{-4}$ , with  $\beta_1$  set to .99 and  $\beta_2$  set to .999. We retrained every layer of the network until the training accuracy converged. The model converged when it did not improve against a validation data set for 20 consecutive epochs. We applied the following data augmentation strategies in conjunction and at random for each training image and each batch of training: rotation of frames between  $-15$  and  $15$  degrees, zooming by a factor between 0.85 and 1.15, shifting images in every direction by up to 1/10th of the width and height, changing brightness by a factor between 80% and 120%, and potential horizontal flipping.

The CNN was trained in parallel on 16 graphics processing unit (GPU) cores with a p2.16xlarge Elastic Cloud Compute instance on AWS using the Keras library in Python with a Tensorflow 2 backend. With full GPU usage, the training time was 35 minutes and 41 seconds per epoch for a batch size of 1643, translating to US \$14.4 per hour.

We trained 2 versions of the model, with 1 exclusively using non-GuessWhat public data set frames from (1) the Japanese Female Facial Expression (JAFFE) [51], (2) a random subset of 30,000 AffectNet [52] images (a subset was acquired to avoid an out of memory error), and (3) the Extended Cohn-Kanade

(CK+) data set [53]; the other model was trained with these public data set frames plus all 39,968 labeled and relevant GuessWhat frames.

### Model Evaluation

We evaluated our models against the entirety of the CAFE data set [54], a set of front-facing images of racially and ethnically diverse children aged 2 to 8 years expressing happy, sad, surprised, fear, angry, fearful, and neutral emotions. CAFE is currently the largest data set of facial expressions from children and has become a standard benchmark for this field.

Although existing studies have evaluated models exclusively against the entirety of the CAFE data set [34-39], we additionally evaluated them on Subset A and Subset B of CAFE, as defined by the authors of the data set. Subset A contains images that were identified with an accuracy of 60% or above by 100 adult participants [54], with a Cronbach  $\alpha$  internal consistency score of .82 (versus .77 for the full CAFE data set). Subset B contains images showing “substantial variability while minimizing floor and ceiling effects” [54], with a Cronbach  $\alpha$  score of .768 (close to the score of .77 for the full data set).

## Results

### Frame Processing

The HollywoodSquares annotators processed 106,001 unique frames (273,493 including the testing phase and 491,343 unique labels when counting multiple labels for the same frame as a different label). Of the 106,001 unique frames labeled, 39,968 received an emotion label corresponding to 1 of the 7 CAFE emotions (not including the testing phase labels). [Table 1](#) contains the number of frames that were included in the training set for each emotion class, including how many children and videos are represented for each emotion category. The frames that were not included received labels of “None” (corresponding to a situation where no face or an incomplete face appears in the frame), “Unknown” (corresponding to the face not expressing a clear emotion), or “Contempt” (corresponding to the face not expressing an emotion in the CAFE set). The large number of curated frames displaying emotion demonstrates the usefulness of HollywoodSquares in filtering out emotion events from noisy data streams. The lack of balance across emotion categories is a testament particularly to the difficulty of evoking anger and sadness as well as disgust and fear, although to a lesser extent.

Of the children who completed 1 session of the Emoji challenge in GuessWhat and uploaded a video to share with the research team, 75 were female, 141 were male, and 51 did not specify their gender. [Table 2](#) presents the racial and ethnic makeup of the participant cohort. Representative GuessWhat frames and cropped faces used to train the classifier, obtained from the subset of participants who consented explicitly to public sharing of their images, are displayed in [Figure 3](#).



**Table 1.** Emotions represented in the HollywoodSquares data set, including how many children and videos are represented for each emotion category.

| Emotion  | Frequency | Number of children | Number of videos |
|----------|-----------|--------------------|------------------|
| Anger    | 643       | 28                 | 62               |
| Disgust  | 1723      | 46                 | 95               |
| Fear     | 1875      | 41                 | 89               |
| Happy    | 13,332    | 73                 | 228              |
| Neutral  | 16,055    | 87                 | 289              |
| Sad      | 947       | 31                 | 93               |
| Surprise | 5393      | 52                 | 135              |

**Table 2.** Representation of race and ethnicity of children whose who played the “Emoji” charades category and uploaded a video to the cloud.

| Race/ethnicity     | Frequency |
|--------------------|-----------|
| Arab               | 6         |
| Black or African   | 16        |
| East Asian         | 16        |
| Hispanic           | 36        |
| Native American    | 7         |
| Pacific Islander   | 5         |
| South Asian        | 14        |
| Southeast Asian    | 7         |
| White or Caucasian | 100       |
| Not specified      | 60        |

**Figure 3.** Example of frames collected from GuessWhat gameplay, including examples of cropped (A) and original (B) frames. We have displayed these images after obtaining consent from the participants for public sharing.

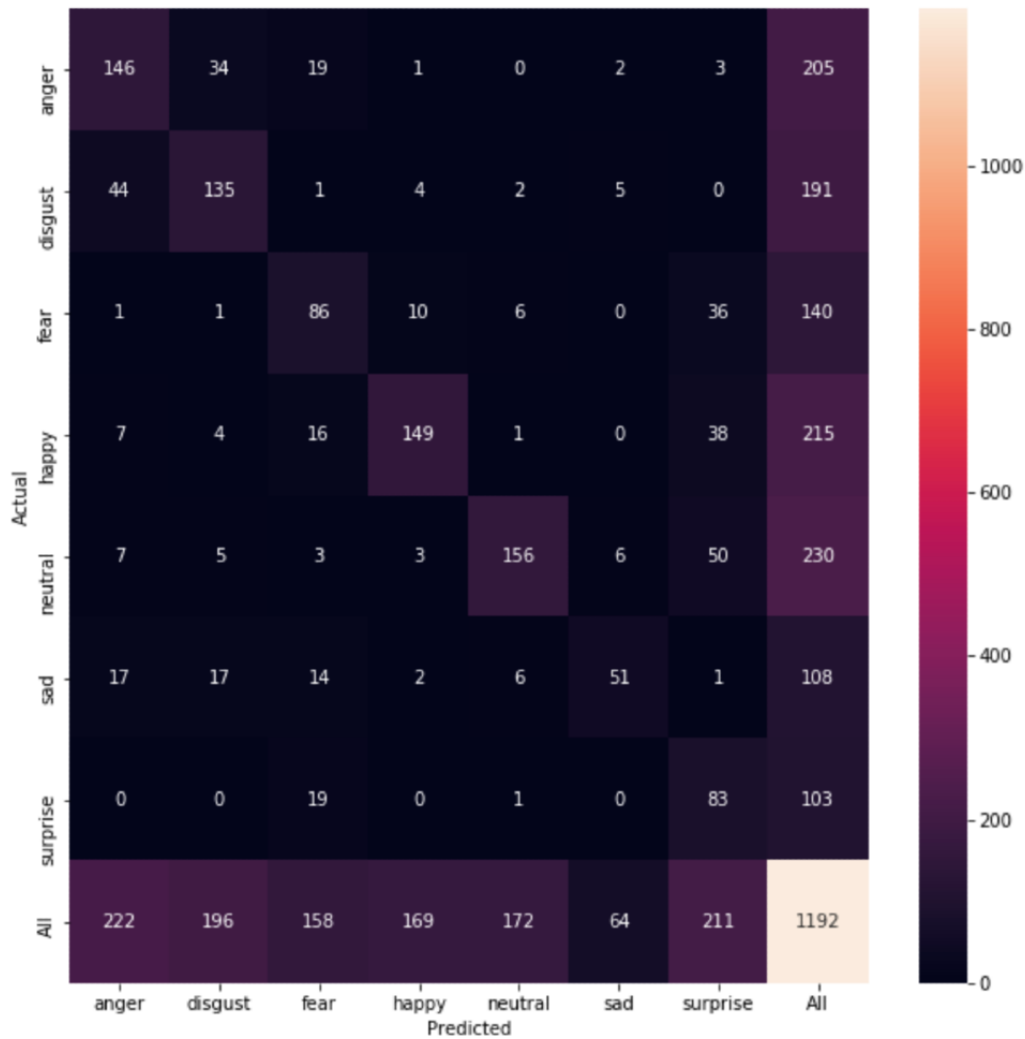


**Performance on CAFE, CAFE-Defined Subsets, and CAFE Subset Balanced in Terms of Race, Gender, and Emotions**

The ResNet-152 network trained on the entire labeled HollywoodSquares data set as well as the JAFFE, AffectNet subset, and CK+ data sets achieved a balanced accuracy of

66.9% and an F1-score of 67.4% on the entirety of the CAFE data set (confusion matrix in Figure 4). When only the HollywoodSquares data set was included in the training set, the model achieved a balanced accuracy of 64.12% and an F1-score of 64.2%. When only including the JAFFE, AffectNet subset, and CK+ sets, the classifier achieved an F1-score of 56.14% and a balanced accuracy of 52.5%, highlighting the contribution of the HollywoodSquares data set.

**Figure 4.** Confusion matrix for the entirety of the Child Affective Facial Expression data set.



To quantify the contribution of the neural network architecture itself, we compared the performance of several state-of-the-art neural network architectures when only including the HollywoodSquares data set in the training set (Table 3). We evaluated the following models: ResNet152V2 [49], ResNet50V2 [49], InceptionV3 [55], MobileNetV2 [56], DenseNet121 [57], DenseNet201 [57], and Xception [58]. The same training conditions and hyperparameters were used across all models. We found that ResNet152V2 performed better than the other networks when trained with our data, so we used this model for the remainder of our experiments.

The performance improved, resulting in a balanced accuracy of 79.1% and an F1-score of 78% on CAFE Subset A (confusion matrix in Figure 5), a subset containing more universally accepted emotions labels. When only including the non-GuessWhat public images in the training set, the model achieved a balanced accuracy of 65.3% and an F1-score of 69.2%. On CAFE Subset B, the balanced accuracy was 66.4% and the F1-score was 67.2% (confusion matrix in Figure 6); the balanced accuracy was 57.2% and F1-score was 57.3% when exclusively training on the non-GuessWhat public images.

**Table 3.** Comparison of several popular neural network architectures trained on the same data set<sup>a</sup>.

| Model                               | Balanced accuracy (%) | F1-score (%) | Number of network parameters |
|-------------------------------------|-----------------------|--------------|------------------------------|
| ResNet152V2; He et al [49]          | 64.12                 | 64.2         | 60,380,648                   |
| ResNet50V2; He et al [49]           | 63.67                 | 63.12        | 25,613,800                   |
| InceptionV3; Szegedy et al [55]     | 59                    | 59.66        | 23,851,784                   |
| MobileNetV2; Sandler et al [56]     | 57.63                 | 58.19        | 3,538,984                    |
| DenseNet121; Huang et al [57]       | 58.2                  | 59.19        | 8,062,504                    |
| DenseNet201; Huang et al [57]       | 57.02                 | 58.95        | 20,242,984                   |
| Xception; Chollet and François [58] | 58.16                 | 60.58        | 22,910,480                   |

<sup>a</sup>Default hyperparameters were used for all networks.

**Figure 5.** Confusion matrix for Child Affective Facial Expression Subset A.

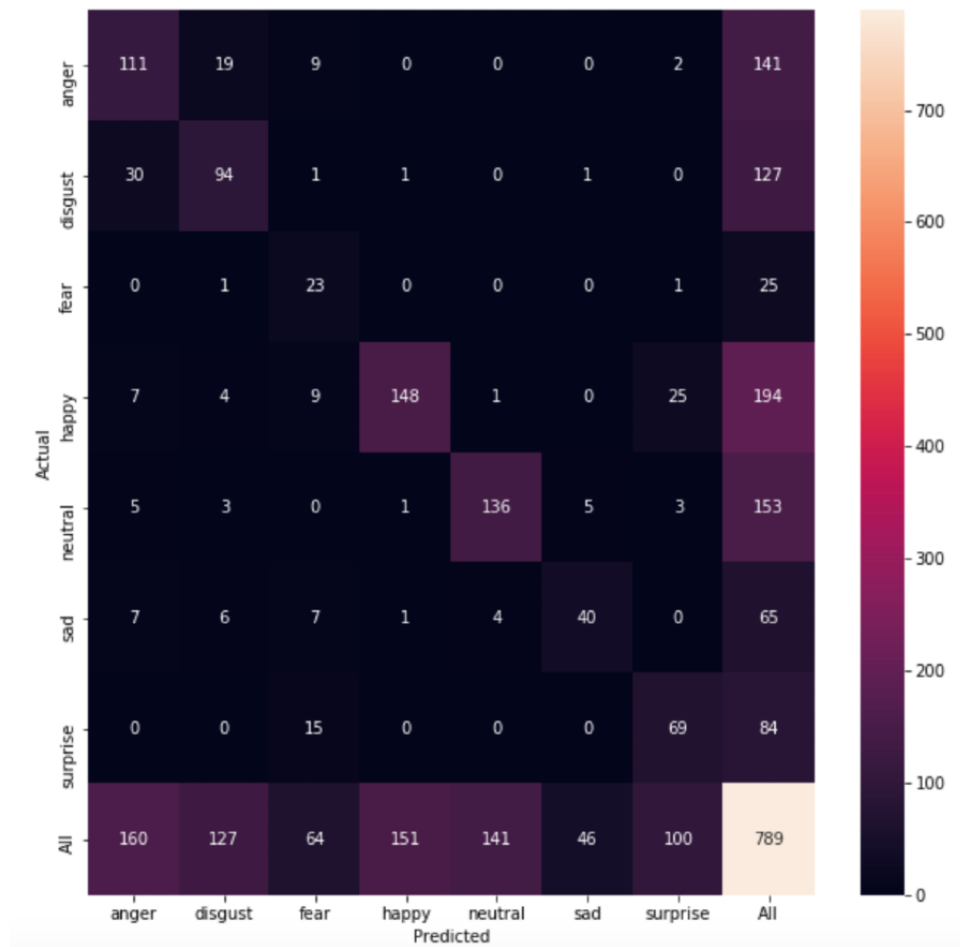
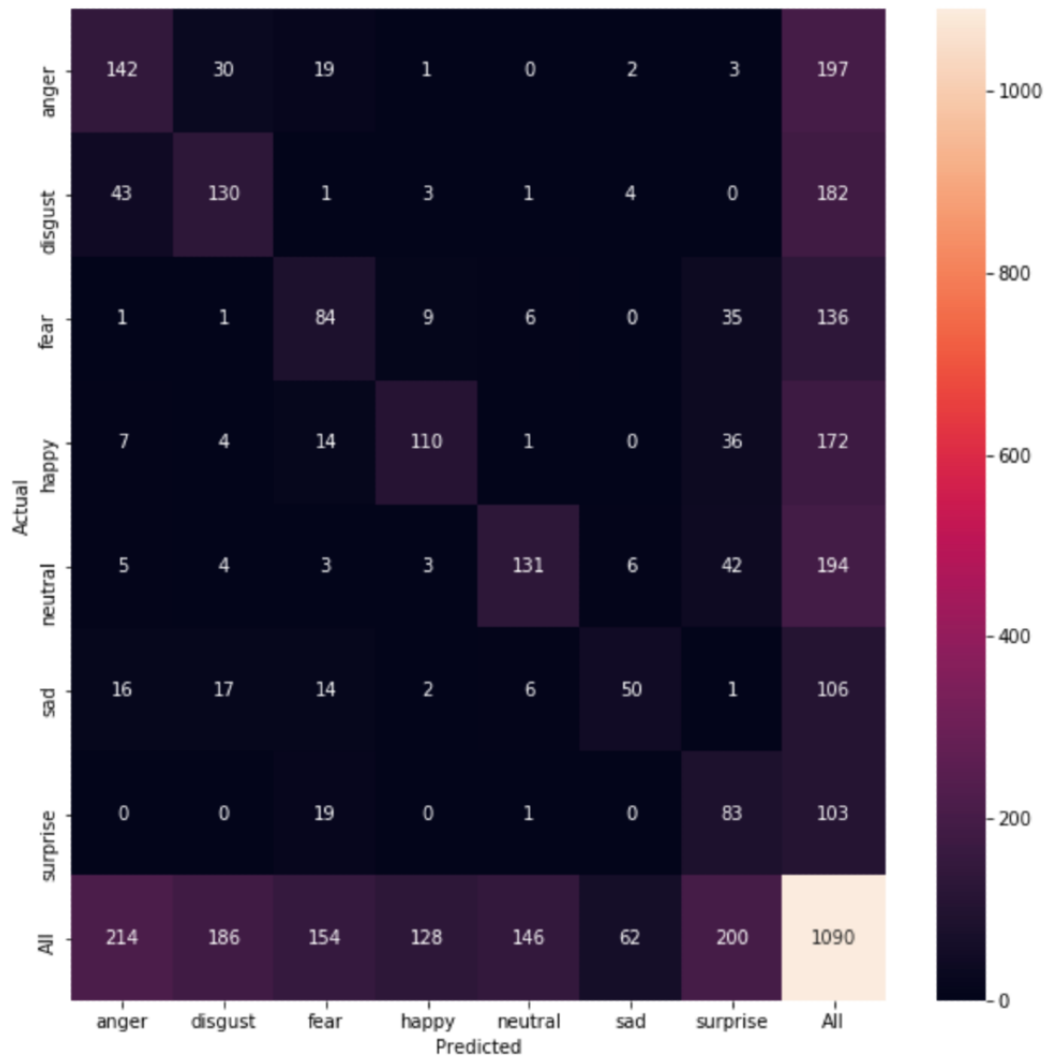


Figure 6. Confusion matrix for Child Affective Facial Expression Subset B.



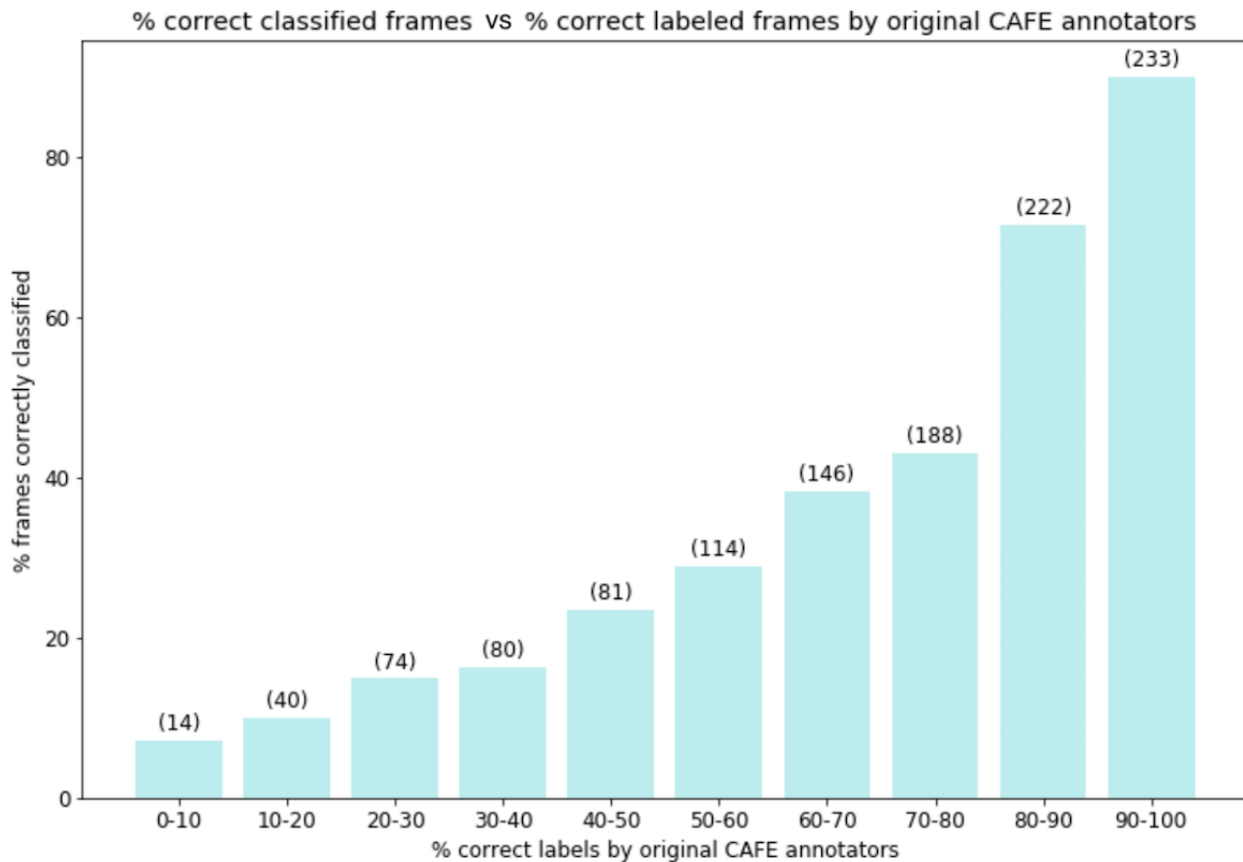
**Classifier Performance Based on Image Difficulty**

CAFE images were labeled by 100 adults, and the percentage of participants who labeled the correct class are reported with the data set [54]. We binned frames into 10 difficulty classes (ie, 90%-100% correct human labels, 80%-90% correct human labels, etc). Figure 7 shows that our classifier performs exceedingly well on unambiguous images. Of the 233 images

with 90%-100% agreement between the original CAFE labels, our classifier correctly classifies 90.1% of the images. The true label makeup of these images is as follows: 131 happy, 58 neutral, 20 anger, 9 sad, 8 surprise, 7 disgust, and 0 fear images. This confirms that humans have trouble identifying nonhappy and nonneutral facial expressions. Of the 455 images with 80%-100% agreement between the original CAFE labels, our classifier correctly classifies 81.1% of the images.



**Figure 7.** Classifier performance versus original CAFE annotator performance for 10 difficulty bins. The classifier tends to perform well when humans agree on the class and poorly otherwise. The numbers in parentheses represent the number of images in each bin. This highlights the issue of ambiguous labels in affective computing and demonstrates that our model performance scales proportionally to human performance. CAFE: Child Affective Facial Expression.



## Discussion

### Principal Results

Through the successful application of an in-the-wild child developmental health therapeutic that simultaneously captures video data, we show that a pipeline for intelligently and continuously labeling image frames collected passively from mobile gameplay can generate sufficient training data for a high-performing computer vision classifier (relative to prior work). We curated a data set that contains images enriched for naturalistic facial expressions of children, including but not limited to children with autism.

We demonstrate the best-performing pediatric facial emotion classifier to date according to the CAFE data set. The best-performing classifiers evaluated in earlier studies involving facial emotion classification on the CAFE data set, including images from CAFE in the training set, achieved an accuracy of up to 56% on CAFE [36,37,39] and combined “anger” and “disgust” into a single class. By contrast, we achieved a balanced accuracy of 66.9% and an F1-score of 67.4% without including any CAFE images in the training set. This is a clear illustration of the power of parallel data curation from distributed mobile devices in conjunction with deep learning, and this approach can possibly be generalized to the collection of training data for other domains.

We collected a sufficiently large training sample to alleviate the need for extracting facial keypoint features, as was the case in prior works. Instead, we used the unaltered images as inputs to a deep CNN.

### Limitations and Future Work

A major limitation of this work is the use of 7 discrete and distinct emotion categories. Some images in the training set might have exhibited more than 1 emotion, such as “happily surprised” or “fearfully surprised.” This could be addressed in future work by a more thorough investigation of the final emotion classes. Another limitation is that similar to existing emotion data sets, our generated data set contains fake emotion evocations by the children. This is due to limitations imposed by ethics review committees and the IRB who, understandably so, do not allow provoking real fear or sadness in participants, especially young children who may have a developmental delay. This issue of fake emotion evocation has been documented in prior studies [4,5,59,60]. Finding a solution to this issue that would appease ethical review committees is an open research question.

Another limitation is that we did not address the possibility of complex or compound emotions [61]. A particular facial expression can consist of multiple universal expressions. For example, “happily surprised,” “fearfully surprised,” and even “angrily surprised” are all separate subclasses of “surprised.” We have not separated these categories in this study. We

recommend that future studies explore the possibility of predicting compound and complex facial expressions.

There are several fruitful avenues for future work. The paradigm of passive data collection during mobile intervention gameplay could be expanded to other digital intervention modalities, such as wearable autism systems with front-facing cameras [7,8,11,13-17]. This paradigm can also be applied toward the curation of data and subsequent training of other behavioral classifiers. Relevant computer vision models for diagnosing autism could include computer vision-powered quantification of hand stimming, eye contact, and repetitive behavior, as well as audio-based classification of abnormal prosody, among others.

The next major research step will be to evaluate how systems like GuessWhat can benefit from the incorporation of the

machine learning models back into the system in a closed-loop fashion while preserving privacy and trust [62]. Quantification of autistic behaviors during gameplay via machine learning models trained with gameplay videos can enable a feedback loop that provides a dynamic and adaptive therapy for the child. Models can be further personalized to the child's unique characteristics, providing higher performance through customized fine-tuning of the network.

## Conclusions

We have demonstrated that gamified digital therapeutic interventions can generate sufficient data for training state-of-the-art computer vision classifiers, in this case for pediatric facial emotion. Using this data curation and labeling paradigm, we trained a state-of-the-art 7-way pediatric facial emotion classifier.

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## Conflicts of Interest

DPW is the founder of Cognoa.com. This company is developing digital health solutions for pediatric care. AK works as a part-time consultant with Cognoa.com. All other authors declare no conflict of interests.

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## Abbreviations

- AWS:** Amazon Web Services  
**CAFE:** Child Affective Facial Expression data set  
**CK+:** Extended Cohn-Kanade data set  
**CNN:** convolutional neural network  
**GPU:** graphics processing unit  
**IRB:** Institutional Review Board  
**JAFFE:** Japanese Female Facial Expression data set

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Original Paper

# The Effectiveness of the Buzzy Device for Pain Relief in Children During Intravenous Injection: Quasirandomized Study

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## Abstract

**Background:** Intravenous injection is the most common medical treatment and the main cause of pain in hospitalized children. If there is no appropriate health care for pain relief, the proportion of moderate and severe pain often exceeds 70%. With nonpharmaceutical-based pain management, Buzzy is recognized as an effective device for rapidly relieving injection pain in hospitalized children. However, Buzzy is not widely used in Asia and very few experimental studies in Asia have addressed the effectiveness of the Buzzy device at treating needle pain in hospitalized children.

**Objective:** The main purpose of this study was to investigate the effectiveness of the Buzzy device for diminishing pain levels among hospitalized children in Taiwan.

**Methods:** We applied a quasiexperimental design with random assignment. According to the time of admission, child participants were randomly assigned to treatment and nontreatment groups. The Buzzy device was applied as an intervention in this study. The samples size was 30 per group. The study participants were recruited from the pediatric ward of a medical center in northern Taiwan. The research data were collected longitudinally at three time points: before, during, and after intravenous injection. Three instruments were used for assessment: a demographic information sheet, the Wong-Baker Face Scale (WBFS), and the Faces Legs Activity Cry Consolability (FLACC) scale. The data were analyzed by descriptive analysis, the Mann-Whitney *U* test, the Wilcoxon signed-rank test, and the  $\chi^2$  test.

**Results:** A total of 60 hospitalized children aged 3 to 7 years participated in this study, including 30 participants in the treatment group and 30 participants in the nontreatment group. The average age of children in the treatment and nontreatment groups was 5.04 years and 4.38 years, respectively. Buzzy significantly mitigated pain in children during intravenous injection with a significant difference between the two groups in pain-related response (FLACC) and actual pain (WBFS) ( $Z=-3.551$ ,  $P<.001$  and  $Z=-3.880$ ,  $P<.001$ , respectively). The children in the treatment group had a significantly more pleasant experience than those in the nontreatment group ( $Z=-2.387$ ,  $P=.02$ ). When Buzzy was employed, the children experienced less pain than they did during previous intravenous injections ( $Z=-3.643$ ,  $P<.001$ ).

**Conclusions:** The intervention of using the Buzzy device was effective in reducing pain levels of intravenous injection among hospitalized children. The specific focus on children in Asia makes a valuable contribution to the literature. For clinical application, the reliable pain relief measure of Buzzy can be used in other Asian children to help health care providers improve noninvasive

care among children. For future applications, researchers could integrate Buzzy into therapy-related games and a technology-based app to increase the efficiency of use and provide more data collection functions.

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## KEYWORDS

hospitalized children; intravenous injection; pain; Buzzy

## Introduction

### Background

Hospitalization is an extremely stressful process for children, who may exhibit degenerative or aggressive behavior when undergoing medical treatments such as intravenous injections. The related literature indicates that intravenous injection is the most common medical treatment and the main cause of pain and fear in hospitalized children [1-3]. Intravenous injection often causes stress to both children and nurses, resulting in difficulty of the cannulation process and a higher likelihood of multiple attempts being required. Researchers reported that administering an intravenous injection to hospitalized children is highly difficult; two or more attempts were needed in 67.3% of cases [4,5]. The average number of attempts for intravenous insertion was found to be 4.2 [2]. During repeated attempts, a child experiences moderate or severe pain, with the pain rating reaching up to 71.0%-79.6% [6,7]. This not only wastes medical supplies and nursing time but also heightens the tension and affects the trust relationship between nurses and hospitalized children [8,9]. With respect to other long-term impacts, researchers have found that 62.3% of children fear the pain caused by injection and 62.9% have negative memories of injection [8], resulting in a negative experience that affects their behavioral response to pain during future invasive treatments [10-12]. Therefore, it is crucial for nurses and health care providers to effectively relieve children's pain during injections and to mitigate their fear as well as to affect a positive experience of injection [13].

With nonpharmaceutical-based pain management, Buzzy is recognized as an effective device to be used for rapidly relieving injection pain in hospitalized children. Through a cooling sensation and vibration, Buzzy is easy use, inexpensive, and fast-acting for reducing procedural pain [14-16]. Buzzy does not require substantial preparation time before the injection and provides effective pain relief. Buzzy is increasingly used during various medical procedures, including intravenous injections [12,14,17,18], the drawing of blood [15,19-22], and vaccination [23,24]. Buzzy successfully mitigates treatment-related pain, fear, and anxiety in pediatric patients. Whelan et al [20] discovered that Buzzy not only relieved pain in children but that 80% of children further wished to use the device during their next injection.

Numerous benefits of the Buzzy device have been reported, such as its short preparation time and ease of use, along with benefits of the cute design in distracting children to reduce pain and fear during injections [17,23,25]. However, Buzzy is not widely used in Asia. According to a literature review, there are very few experimental studies in Asia to address the effectiveness of the Buzzy device at treating needle pain in

hospitalized children [26]. No clinical study has been reported in applying the Buzzy device in hospitalized children in Taiwan. Hence, in this study, we used Buzzy during intravenous injections in hospitalized children and determined its effectiveness at pain relief. Empirical data from this study can provide clinical evidence to understand the effectiveness of Buzzy devices for the clinical work environment in regions of Asia. Given the specific focus on children in Asia, this study should make a valuable contribution to the literature for researchers and health care providers.

### Research Purpose and Hypotheses

The main purpose of this study was to investigate the effectiveness of the Buzzy device for diminishing pain levels among hospitalized children in Taiwan. The specific aims of the study were to determine (1) the pain levels of pediatric patients during intravenous injections, (2) the effectiveness of Buzzy for pain relief during intravenous injection in pediatric patients, (3) relevant factors that affect the effectiveness of Buzzy, (4) the degree of influence that injection experience has on needle pain in preschool children during intravenous injection, and (5) the demographics of children with different pain levels during intravenous injection.

According to the purpose of the study, the following six research hypotheses were tested:

1. The pain level of pediatric patients is lower when Buzzy is used during intravenous injection.
2. The actual pain experienced by those given intravenous injection using Buzzy is lower than the expected pain.
3. Intravenous injection in pediatric patients takes less time when Buzzy is employed.
4. More pediatric patients report a satisfactory experience with intravenous injection when Buzzy is employed.
5. If a child has had an unpleasant injection experience in the past, their pain level during the present injection will be higher.
6. The younger the child, the higher the pain level will be during intravenous injection; the pain level during intravenous injection is higher for girls than boys.

## Methods

### Study Design

This was a quantitative study with a quasiexperimental design. Patient participants were alternately assigned to each group upon admission. According to their time of admission and order of recruitment, the children were randomly assigned to the treatment or nontreatment group. For example, the first child to arrive was assigned to the treatment group and the second

child to arrive was assigned to the nontreatment group. Each case was assigned a number to protect patient privacy.

The research data were collected longitudinally. The treatment and nontreatment group data were collected at three time points: before, during, and after intravenous injection. Before injection, a questionnaire and interview were used to understand the injection experience of the participant. The Wong-Baker Face Scale (WBFS) was used to measure the expected pain of the children before their intravenous injection. The Face, Legs, Activity, Cry, Consolability (FLACC) scale was used to measure the behavioral response of the children to pain during intravenous injection. The WBFS was used after the injection to measure the actual pain felt by the children during intravenous injection. In the treatment group, the Buzzy device was placed on the participant 5 cm above the intravenous site before needle insertion.

## Participants

The inclusion criteria of the study were as follows: (1) age 3-7 years, with the child accompanied by their parent; (2) required to receive intravenous injection during hospitalization; (3) could speak Mandarin or Taiwanese with clear consciousness; and (4) participation consent of the patient or parent(s). The exclusion criteria were (1) cognitive or developmental delay or

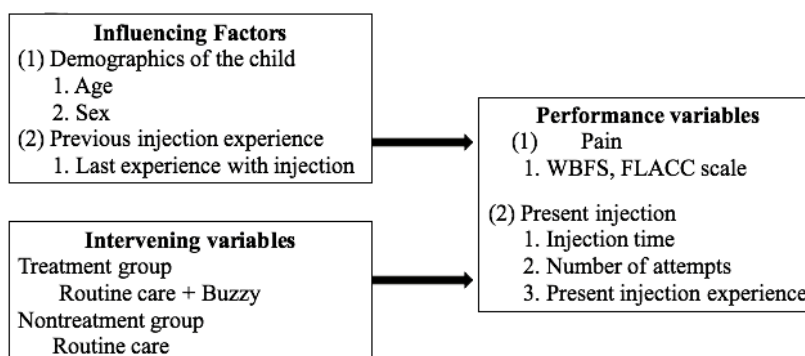
an inability to speak clearly, (2) chronic disease, (3) operation required because of external injury or inflammatory condition, and (4) refusal to complete the pain assessment scales and resistance to measurement of vital signs.

The estimated number of participants for this study was calculated according to the previous study of Moadad et al [12] and the method of estimating sample sizes in two-group comparisons [27]. Based on previous clinical research of the Buzzy device for pain management, Moadad et al [12] indicated that a total sample size of 50 was acceptable. With a power of 0.8, an acceptable two-sided 5% significance level, and a difference of  $d=0.07$ , the sample size required per group in the two-group comparison was calculated to be 33 [27]. According to this previous research and considering the potential case turnover rate, the samples size was determined to be 40 per group in this study.

## Framework

On the basis of the research purpose and results of a literature review, the conceptual framework of the study displayed in Figure 1 was proposed to elucidate the effects of Buzzy on the pain felt by children aged 3-7 years during intravenous injection. The pain level was then related to demographics and injection experience.

**Figure 1.** Study framework. FLACC: Faces, Legs, Activity, Cry, Consolability; WBFS: Wong-Baker Face Scale.



## Study Instruments

### Overview

The research tools employed in this study were demographic information analysis, a questionnaire regarding injection experience, the WBFS and FLACC scale for assessing pain level, and Buzzy.

### Demographic Data

The demographic information and injection experience questionnaire collected data on the basic information of the child (age, sex, and education level), the accompanying primary caregiver, previous injection experience (number of hospitalizations and last injection experience), present injection experience (injection duration and number of attempts), and experience and feelings about the present injection.

## Pain Scales

### Wong-Baker Face Scale

The WBFS [28] is a face scale displaying six cartoon faces depicting, from left to right, no pain to the highest pain, with respective pain scores of 0, 2, 4, 6, 8, and 10. The recruiter would point with their finger at the leftmost face and move rightward, explaining to the child that the faces toward the right indicate “more painful.” They asked the children to point to the face that best described their pain and the recruiter recorded the corresponding score. The pain scores were classified into mild pain (0-3), moderate pain (4-6), and severe pain (7-10). The reliability and validity of the WBFS have been confirmed by expert scholars, and the scale has reliable construct validity, convergent validity, and predictive validity. The Cronbach  $\alpha$  is .82-.92 [29,30].

### FLACC Scale

Using the FLACC scale [31], the recruiter observed the behavior of the children during intravenous injection: their facial expression, leg movement, activity, crying, and consolability.

The child was assigned a score ranging from 0 to 2 for each behavior type, and the five scores were summed and recorded. A total score of 0 denoted that the child was relaxed and comfortable, a score of 1-3 denoted slight discomfort, a score of 4-6 denoted moderate discomfort, and a score of 7-10 denoted severe discomfort.

### **Buzzy Device**

Buzzy is a device developed by the emergency pediatrician Amy Baxter, MD, in 2011. Buzzy is mainly based on the gate control theory of pain, aiming at the effect of cold and vibration at the injection site to achieve pain relief. The Buzzy device is approximately 8×5×2.5 cm in size, and its exterior design is in the shape of a bee (Figure 2). A thin ice bag resembling a wing

is attached to the bottom of the main body of the device, which can be directly fixed above the injection site. Turning on the Buzzy device within 30 seconds to 1 minute before injection can significantly improve the pain of injection. The Buzzy device has demonstrated clear effects on pain and can be used for needle-related treatments, including intravenous injection, preventive injection, and blood draws [17,21,23,32].

In the treatment group, the recruiter secured Buzzy on the participant at a location 5 cm above the site of intravenous injection. The device was placed as close as possible to the site without affecting the injection process and results. The Buzzy device was switched on 1 minute before the injection and was turned off after completion of the injection.

**Figure 2.** Image of the Buzzy device.



### **Data Collection**

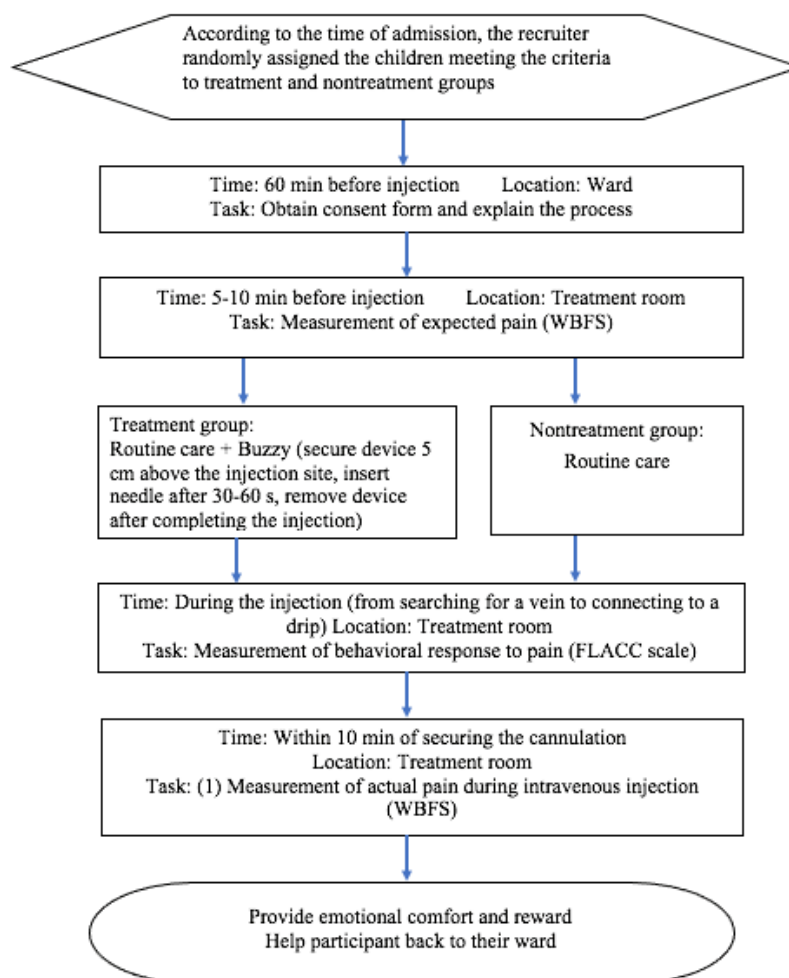
The recruiter explained the research purpose, methods, and content to the ward head nurse and nursing staff. The recruitment of participants and data collection were performed without affecting nursing care activities. Two nurses with 3 years of nursing experience were recruited for this study and participated in the study briefing workshop so as to understand the purpose of the study and the steps to perform it.

The recruiters invited children that met our inclusion criteria to participate in the study and randomly assigned them to the treatment or nontreatment group according to their time of admission and order of recruitment. The recruiters explained the research purpose and method to the children and their caregiver(s), and after obtaining consent, the caregiver was asked to sign a consent form. For the treatment group, the

recruiter explained the Buzzy device to the caregiver and child using a video and the Buzzy device. The data collection procedure is illustrated in Figure 3.

In the treatment group, the implementation of the intervention consisted of three main steps. First, a video was used to explain the Buzzy device and its operating procedures to the caregivers and the hospitalized children, while allowing the children to touch the Buzzy device and experience its vibration and coldness. Second, when the child came to the treatment room, the nurse and the recruiter fixed the Buzzy device with a belt to 5 cm above the injection site of the patient. Third, the Buzzy device was turned on within 1 minute before the injection so that the child could be attracted by the vibration and coldness of the device. The recruiter turned off the device when the nurse completed the injection.

**Figure 3.** Flowchart of the study procedure. FLACC: Faces, Legs, Activity, Cry, Consolability; WBFS: Wong-Baker Face Scale.



## Data Analysis

We used SPSS Statistics version 22.0 for statistical analysis. The collected data were organized, assigned serial numbers, and then input to a computer system. According to the nature of the research variables, descriptive statistics (frequency distribution, mean and SD, and percentage) were obtained. The normality of the data in this study was checked before applying inferential statistical analysis. Tests for normality showed a nonnormal distribution of pain scales (WBFS, FLACC), duration, number of attempts, and previous and current intravenous experience. Therefore, group comparisons of these data were performed using the  $\chi^2$  test, Mann-Whitney *U* test, Wilcoxon signed-rank test, and Kruskal-Wallis test. This study used two-tailed tests with significance set at  $P < .05$ .

## Ethics Approval

This study program obtained prior approval from the Chang Gung Medical Foundation Institutional Review Board (201701889A3).

## Results

### Participant Characteristics

Our research participants were children aged 3-7 years that required intravenous injection during hospitalization. The

recruitment period was January 30 to May 10, 2018, during which 64 children who met our criteria were invited to participate. Four primary caregivers declined. A total of 60 children/caregivers agreed to participate. According to their time of admission and order of recruitment, the participants were randomly assigned to the treatment or nontreatment group. Each group comprised 30 participants.

The average age of the treatment and nontreatment group was 5.04 years and 4.38 years, respectively. The treatment group had more male participants (19/30, 63%), whereas the nontreatment group had more female participants (18/30, 60%). In the treatment group, 24 participants (80%) had previously been hospitalized, whereas only 19 (63%) participants in the nontreatment group had previously been hospitalized. In the treatment group, 19 of the 30 participants (63%) had a previous unpleasant experience with intravenous injection, and 19 of 23 participants (83%) in the nontreatment group reported a previous unpleasant experience. The average duration of injection of the treatment and nontreatment groups was 6.63 and 6.57 minutes, respectively, which was not significantly different ( $\chi^2_2=3.42$ ,  $P=.18$ ). The injection was successful at the first attempt for most children in both groups: 26/30 (87%) in the treatment group and 23/30 (77%) in the nontreatment group. Two attempts were required for the remaining children and more than two attempts were not required for any participant. The  $\chi^2$  tests of



demographic information revealed no significant intergroup differences ( $P>.05$ ) regarding age, sex, hospitalization experience, last injection experience, injection duration, and number of attempts, as detailed in [Table 1](#).

**Table 1.** Demographic information of research participants (N=60).

| Variable  | Treatment group (n=30), n (%) | Nontreatment group (n= 30), n (%) | $\chi^2$ | df | P value |
|---|-------------------------------|-----------------------------------|----------|----|---------|
| <b>Age (years)</b>                                  |                               |                                   | 7.38     | 3  | .06     |
| 3-4   | 5 (17)                        | 13 (43)                           |          |    |         |
| 4-5   | 6 (20)                        | 7 (23)                            |          |    |         |
| 5-6   | 14 (47)                       | 9 (30)                            |          |    |         |
| 6-7   | 5 (17)                        | 1 (3)                             |          |    |         |
| <b>Sex</b>  |                               |                                   | 3.27     | 1  | .07     |
| Male  | 19 (63)                       | 12 (40)                           |          |    |         |
| Female  | 11 (37)                       | 18 (60)                           |          |    |         |
| <b>Inpatient experience</b>                         |                               |                                   | 2.05     | 1  | .15     |
| No  | 6 (20)                        | 11 (37)                           |          |    |         |
| Yes   | 24 (80)                       | 19 (63)                           |          |    |         |
| <b>Previous experience of intravenous injection</b> |                               |                                   | 2.38     | 1  | .12     |
| Good (3-5)  | 11 (37)                       | 4 (17)                            |          |    |         |
| Poor (0-2)  | 19 (63)                       | 19 (83)                           |          |    |         |
| <b>Injection duration (minutes)</b>                 |                               |                                   | 3.42     | 2  | .18     |
| <5  | 20 (67)                       | 16 (53)                           |          |    |         |
| 5-10  | 4 (13)                        | 10 (33)                           |          |    |         |
| >10   | 6 (20)                        | 4 (13)                            |          |    |         |
| <b>Number of attempts</b>                           |                               |                                   | 1.00     | 1  | .31     |
| 1   | 26 (87)                       | 23 (77)                           |          |    |         |
| 2   | 4 (13)                        | 7 (23)                            |          |    |         |

## Level of Pain Relief With Buzzy

### *Expected Pain Before Employing Buzzy During Intravenous Injection*

In the treatment room before injection, the WBFS was used to determine the pain that the children were expecting from the intravenous injection. The median pain score was 6.00 in the

treatment group. Moderate pain, with a score of 4-6, was indicated by 46.67% (n=14) of the children, and severe pain, with a score of 7-10, was indicated by 36.67% (n=11) of the children; thus, overall, 83.34% of the children were expecting moderate or severe pain. The Mann-Whitney *U* test revealed no significant difference between the groups regarding the expected pain, as shown in [Table 2](#).

**Table 2.** Comparison of pain scores between the treatment and nontreatment groups (N=60).

| Variable   | Treatment group (n=30), median | Nontreatment group (n=30), median | Z      | P value |
|--|--------------------------------|-----------------------------------|--------|---------|
| Expected pain before injection (WBFS <sup>a</sup> )                | 6.00                           | 6.00                              | -0.659 | .51     |
| Behavioral response to pain during injection (FLACC <sup>b</sup> ) | 4.00                           | 6.00                              | -3.551 | <.001   |
| Actual pain after injection (WBFS)                                 | 2.00                           | 8.00                              | -3.880 | <.001   |

<sup>a</sup>WBFS: Wong-Baker Face Scale.

<sup>b</sup>FLACC: Faces, Legs, Activity, Cry Consolability.

### *Pain-Related Response When Using Buzzy During Injection*

Pain during injection denoted the pain experienced by the children from applying the tourniquet until needle insertion was

completed and the drip was connected. During injection, the FLACC scale was used to score the behavioral responses of the children to pain. The median pain score was 4.00 in the treatment group; overall, 37% (n=11) of the children experienced moderate pain (score of 4-6) and 20% (n=6) experienced severe

pain (score of 7-10). Thus, 57% (n=17) of the children experienced moderate or severe pain, which was 40% lower than the percentage in the nontreatment group. In the treatment group, 43% more children reported a pain score of less than 4 (mild pain) in comparison with the nontreatment group. The Mann-Whitney *U* test showed a significant difference between the two groups in behavioral responses to pain during injection (Table 2). Thus, Buzzy significantly ameliorated the children's behavioral response to pain during injection.

### **Actual Pain Felt and Reported After Using Buzzy During Intravenous Injection**

In the treatment room after injection, the WBFS was used to measure the actual pain felt by the children during the intravenous injection. The median pain score was 2.00 in the treatment group; 27% (n=8) of the children experienced moderate pain and 17% (n=5) experienced severe pain. Overall, 43% experienced moderate or severe pain, which was 47% lower than that in the nontreatment group. The Mann-Whitney

*U* test revealed that the pain score after injection was significantly different between the two groups (Table 2). Thus, Buzzy significantly mitigated pain during intravenous injection.

### **Comparison of Expected Pain With Actual Pain When Buzzy Was Employed**

The median expected pain before intravenous injection, determined using the WBFS, was 6.00 in the treatment group; 83% (n=25) of children reported a pain score of 4 or greater. The median actual pain score, reported after the intravenous injection and again using the WBFS, was 2.00 in the treatment group and 43% (n=13) of children reported a pain score of 4 or greater. The Wilcoxon signed-rank test showed a significant difference between expected and actual pain in the treatment group but not in the nontreatment group (Table 3). When Buzzy was employed, the actual pain was lower than the expected pain, confirming that Buzzy reduced the pain experienced during intravenous injection in children.

**Table 3.** Comparison of expected and actual pain (Wong-Baker Face Scale) in the two groups (N=60).

| Group                     | Expected pain, median | Actual pain, median | Z      | P value |
|---------------------------|-----------------------|---------------------|--------|---------|
| Treatment group (n=30)    | 6.00                  | 2.00                | -2.652 | .008    |
| Nontreatment group (n=30) | 6.00                  | 8.00                | -1.689 | .09     |

### **Duration of Intravenous Injection, Number of Attempts, and Injection Experience When Buzzy Was Employed**

The median duration of the injection procedure was 5 minutes in both the treatment and nontreatment groups, with no significant difference (Table 4). Thus, use of Buzzy did not lengthen the duration of the injection procedure. The median number of attempts was 1.00 in both the treatment and nontreatment groups, with no significant difference (Table 4). Therefore, use of Buzzy did not significantly affect the number of attempts at needle insertion.

The children were asked to rate their present intravenous injection experience using a rating scale of 0-5: extremely poor (0), very poor (1), poor (2), satisfactory (3), good (4), and excellent (5). The children in the treatment group rated their experience with the present intravenous injection significantly higher than that of children in the nontreatment group (Table 4). Therefore, the use of Buzzy provided pain relief during the injection and resulted in a less painful experience compared with that experienced when the device was not used.

**Table 4.** Table 4. Comparison of duration, number of attempts, and previous and present intravenous injection experiences (N=60).

| Variable   | Treatment group (n=30), median | Nontreatment group (n=30), median | Z      | P value |
|--|--------------------------------|-----------------------------------|--------|---------|
| Injection duration (minutes)                           | 5.00                           | 5.00                              | -1.393 | .16     |
| Number of attempts                                     | 1.00                           | 1.00                              | -0.993 | .32     |
| Previous intravenous injection experience <sup>a</sup> | 1.50                           | 1.00                              | -0.996 | .32     |
| Present intravenous injection experience <sup>a</sup>  | 4.00                           | 2.50                              | -2.387 | .02     |

<sup>a</sup>Rated on a scale of 0-5 from "extremely poor" to "excellent."

### **Degree of Influence of Injection Experience on Needle Pain**

The interview and asked the children about their previous experiences of intravenous injection. After their injection, the children were requested to rate their experience with the injection on the previously mentioned scale of 0 (extremely poor) to 5 (excellent). The Mann-Whitney *U* test was used to determine the difference between the groups regarding their previous and present intravenous injection experiences. Regarding previous intravenous injection experiences, no

significant difference was discovered between the groups (Table 4).

However, the use of Buzzy in the present intravenous injection gave the treatment group a less painful experience than the nontreatment group, representing a significant difference (Table 4). The Wilcoxon signed-rank test was applied to compare the experience of the previous and present injection within the groups, showing that both groups experienced less pain in the present intravenous injection than in previous intravenous injections ( $Z=-3.643, P<.001; Z=-2.348, P=.02$ ). In summary, both groups had mostly negative previous experiences with

intravenous injection, and the Buzzy device not only mitigated pain during the injection but further improved the children's experience of the injection, generating positive experiences.

### Demographic (Sex and Age) Effects on Pain Level

The children were divided into four age groups: 3-4, 4-5, 5-6, and 6-7 years. Age group-based differences in experience with the present intravenous injection, expected pain before the injection, pain-related response during the injection, and actual pain felt were analyzed. The Kruskal-Wallis test revealed no significant differences between age groups regarding these variables ( $P > .05$ ).

The Mann-Whitney  $U$  test was employed to determine the differences in experience between the sexes regarding their present intravenous injection, pain-related response during the injection, and actual pain felt. In the nontreatment group, experience with the present intravenous injection and pain-related response during the injection were significantly different between the sexes ( $Z = -2.441$ ,  $P = .02$ ;  $Z = -2.566$ ,  $P = .01$ ); however, no sex-based differences were significant in the treatment group.

## Discussion

### Effectiveness of Buzzy at Pain Relief

According to the results of Moadad et al [12] and Canbulat et al [17], the use of Buzzy significantly mitigates pain in children during intravenous injection. Our study obtained similar findings, with the two groups having significantly different ( $Z = -3.551$ ,  $P < .001$ ;  $Z = -3.880$ ,  $P < .001$ ) pain-related responses and actual pain. Our findings are consistent with those of previous studies, showing that Buzzy reduces needle pain in children. Additionally, Lin et al [10] revealed that the expected pain before intravenous injection predicted the pain level felt during an intravenous injection with 63.4% of the variance explained. In our study, the average expected and actual pain scores in the nontreatment group were greater than 6, indicating that the children's expectations of pain were met; that is, the actual and expected pain were not significantly different ( $Z = -1.689$ ,  $P = .09$ ). However, when Buzzy was employed, the actual pain level was lower than the expected pain level ( $Z = -2.652$ ,  $P = .008$ ), revealing that Buzzy reduced needle pain in the children during intravenous injection.

In summary, in the absence of an effective intervention measure, the children experienced moderate or severe needle pain during intravenous injection, whereas when Buzzy was used, the behavioral response to pain during injection (FLACC score) and actual pain felt were significantly lower. We also discovered that although the purpose and operation of Buzzy had been explained to the children, because they had not previously seen or used Buzzy, the children remained anxious about needle pain, and therefore the expected pain was not significantly different between the two groups. During injection when Buzzy was employed, the children were more cooperative during the injection process; these children also reported less pain and a significant difference was achieved in comparison with that of the nontreatment group. The children also wished to use the device during their next injection.

### Degree of Influence of Buzzy on the Present Injection

Moadad et al [12] reported that the duration of intravenous injection did not differ between their treatment and nontreatment groups. The injection duration in this study was defined as the time from applying the tourniquet until the intravenous tube was connected to the drip. Buzzy was switched on 15 seconds to 1 minute before the injection was initiated and was switched off after the injection was complete. The entire procedure took less than 7 minutes for both groups, and the duration did not significantly differ between the groups ( $Z = -1.393$ ,  $P = .16$ ). This can be attributed to the injection being successful at the first attempt in most of the children, regardless of group (treatment group: 87%; nontreatment group: 77%). The intergroup difference in the rate of successful injection was nonsignificant ( $Z = 0.993$ ,  $P = .32$ ). We thus found that using Buzzy did not affect the rate of successful injection or injection duration; however, the children in the treatment group were more cooperative during the injection process. This could increase the willingness of clinical staff to use Buzzy.

### Degree of Influence of Intravenous Injection Experience on Needle Pain

Hsieh et al [8] reported that 62.9% of children had an unpleasant experience of injection in the past. In our study, 19 children in both the treatment (63%, 19/30) and nontreatment (83%, 19/23) groups had a previous unpleasant experience, showing that most of the child participants had experience of intravenous injection and most of these experiences were unpleasant.

The literature suggests that hospitalized children have the ability to expect pain during injections, and combined with their previous experiences, each injection affects their attitude and feelings toward the next injection. This experience also affects their response to painful treatment in the future, and according to unpleasant previous experiences, the children have the same emotions and some may even resist treatment [10,33]. The children in our treatment group had a significantly more pleasant experience than those in the nontreatment group ( $Z = -2.387$ ,  $P = .02$ ). When Buzzy was employed, the children experienced less pain than they did during previous intravenous injections ( $Z = -3.643$ ,  $P < .001$ ). These findings indicate that a reliable pain relief measure should be used when administering intravenous injection to children to prevent an unpleasant experience from affecting their next injection. The pediatric wards of medical centers should thus use pain relief measures and consider including them as part of routine nursing procedures.

### Age- and Sex-Based Differences in Pain Levels

Karakaya and Gozen [30] reported that the particular age of preschool children did not affect their pain levels. However, some studies discovered that older children experience less pain ( $P = .03$ ) [18] and younger children self-report stronger pain [10,12,34]. When an effective intervention was employed for pain relief, no significant age- and sex-based differences were discovered in one study [22]. In this study, the average age of the children in the treatment and nontreatment groups was 5.04 years and 4.38 years, respectively. The  $\chi^2$  test revealed no significant difference in age ( $\chi^2_3 = 7.38$ ,  $P = .06$ ) between the two groups. We divided the children into four age groups and

determined whether the children in these four age groups had different injection experiences, expected pain before injection, pain-related response during injection, and actual pain. The Kruskal-Wallis test revealed no significant age-based differences in either group. The child participants in our study were limited to hospitalized children aged 3-7 years; therefore, our results cannot fully indicate whether age was an influencing factor. Future studies could explore this issue.

Some scholars have reported that sex does not affect the pain levels felt by children [22,30,34], whereas others have reported that girls experience greater levels of pain [23,35], revealing inconsistency regarding the effect of sex on pain level. In our study, the treatment group included more boys (n=19, 63%), whereas the nontreatment group had more girls (n=18, 60%); the  $\chi^2$  test showed no significant difference between the two groups ( $\chi^2_1=3.27$ ,  $P=.07$ ). The Mann-Whitney  $U$  test was performed to determine whether children of different sexes had differing injection experiences, pain-related response during injection, and actual pain. In the nontreatment group, injection experience and pain-related response during injection were significantly different between the boys and girls ( $Z=-2.441$ ,  $P=.02$ ;  $Z=-2.566$ ,  $P=.01$ ), whereas in the treatment group, significance was not achieved in any of these three aspects. This result showed that the use of Buzzy closed the gap between the sexes regarding pain level. This result is consistent with that of another study in which an intervening measure was employed to reduce pain [22].

## Implementation

### Clinical Practice

The use of Buzzy is noninvasive and can be employed independently by nurses without medical advice. Before use, a simple assessment of suitability was performed in this study, and the device was then illustrated and its operation explained to the children. This obtained their trust and enhanced their cooperation during the process to achieve maximum pain relief. The Buzzy device is worthy of consideration and application by nurses. The device has a cute appearance; nurses could integrate it into therapy-related games by giving it a human voice, which is often effective with hospitalized children. Buzzy can also be considered for use during other invasive procedures such as intramuscular injection and blood sugar measurement.

According to our results, measures for relieving pain during intravenous injection should have certain characteristics, including being suitable for most children, easy to use, having a short preparation time, and not affecting the rate of successful injection or procedural duration; additionally, no discomfort or injury should occur as a result of using the tool. Pain relief during injections should be proactively provided and routinely included in procedures. Use of an intervening measure enhances the emotional preparedness of the child and in turn enhances the measure's acceptability. Effective pain relief results in a satisfactory injection experience and prevents unpleasant experiences from affecting every injection, thereby enhancing the quality of care and building a high-quality nurse-patient relationship.

## Future Research

This study did not find age-related differences. In the absence of the pain relief measure, the girls reported a poorer injection experience and greater pain than the boys, but no significant difference was determined between the sexes when Buzzy was used. However, our participants were recruited on the basis of order of admission and need for injection; thus, the research design could not control or ensure an equal number of cases for each age group and sex. These two influencing factors should be considered in further exploration. In the future, researchers could consider controlling for age and sex. For future application, researchers could integrate the Buzzy device into a technology-based app for increasing the efficiency of use and provide more data collection functions.

## Policy

From this study, we conclude the need to consider using pain relief measures during intravenous injection in children during routine nursing procedures. Additionally, adequate equipment should be provided and relevant in-service education and experience-sharing organized to ensure the capability of clinical staff in equipment operation. An example of an effective measure is the Buzzy device, which was used in this study. Legitimate devices should be obtained through official channels, and users must pay attention to the safety of the device. The device should not be used on patients with paresthesia or at an injection site that has broken skin. Usage guidelines and indications must be formulated for the device, including those regarding the principle of the cold sensation, device disinfection, and regular maintenance. Attention must be paid to individual differences among children to ensure that a device or measure is suitable for a given child.

## Limitations and Recommendations

Surgical operations can affect pain assessment, and children with cognitive impairment cannot adequately and correctly express themselves; thus, we did not include children with these conditions. Our results cannot be extrapolated to these populations. Additionally, studies have indicated that fear is lower when pain relief is satisfactory [13,36], revealing that pain and fear affect each other. The age group of our participants was preschool children. This study used the WBFS to measure pain because children may be confused about their feelings and the WBFS is a clear and simple measurement method. However, this study only measured pain, and the degree of fear of the participants could not be inferred. Further research should be conducted on this aspect.

We recruited participants from only one medical center because of time and human resource considerations. However, the medical treatment of children varies according to region and institution habits, which could lead to differences in demographics, previous injection experiences, and present injection experiences. Additionally, our study did not employ random sampling, and therefore the results cannot be extrapolated to the total hospitalized child population of Taiwan. We recommend performing a controlled experiment with random group allocation if recruitment is easy and the sample is large. Moreover, to determine whether sex affects pain level,



we recommend employing sex as a control variable in analyses to reduce errors. The age range of participants should be expanded to elucidate whether needle pain differs with age.

### Conclusion

The participants of our study were hospitalized children. Most of these children had experience of intravenous injections and expected to feel pain. In the present medical environment in Taiwan, most clinical institutions do not have time to instruct and console patients, which could reduce needle pain. Our study discovered that most of the children had unpleasant experiences of injection, and because an intervening measure was not employed, the children felt moderate or severe pain during intravenous injection. Most of the children and parents wished for an effective pain relief measure. In our study, the Buzzy device effectively reduced needle pain in the children; the pain-related response during injection (FLACC score) and actual reported pain of the treatment group were significantly different from those of the nontreatment group. The pain-related response

of the children during injection was reduced, indicating a satisfactory experience.

The use of Buzzy in our study did not affect the rate of successful injection or the injection duration; this result could increase the willingness of clinical staff to use the device and boost the utilization of pain relief measures during injections to prevent children from having negative experiences. We also discovered that although some children had unpleasant injection experiences, Buzzy could still reduce needle pain. Effective pain relief measures during intravenous injections should be routinely administered.

Our research participants were limited to hospitalized children aged 3-7 years. Although we could not determine whether age was a factor affecting pain level, the use of Buzzy reduced the degree of pain to the same degree for boys and girls. Researchers could use this result as a reference when selecting research participants in Asian areas, as well as when considering the influencing factors in future research.

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### Conflicts of Interest

None declared.

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**Abbreviations****FLACC:** Faces, Legs, Activity, Cry, Consolability**WBFS:** Wong-Baker Face Scale

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Original Paper

# Explaining Adherence to American Academy of Pediatrics Screen Time Recommendations With Caregiver Awareness and Parental Motivation Factors: Mixed Methods Study

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## Abstract

**Background:** With the increasing integration of technology into society, it is advisable that researchers explore the effects of repeated digital media exposure on our most vulnerable population—infants. Excessive screen time during infancy has been linked to delays in language, literacy, and self-regulation.

**Objective:** This study explores the awareness of and adherence to the American Academy of Pediatrics' (AAP) recommendations related to avoiding screen time for infants younger than 2 years and the motivational factors associated with screen time exposure.

**Methods:** A mixed methods survey design was used to gather responses from 178 mothers of infants younger than 2 years. The measures included infant screen time use and duration, maternal awareness of screen time use recommendations, and motivations related to screen time exposure. A variety of statistical procedures were used to explore associations between caregiver awareness of and adherence to AAP guidelines for screen time exposure, motivations related to screen time for infants, and the duration of infant screen time exposure.

**Results:** The results indicated that 62.2% (111/178) of mothers were aware of the AAP screen time recommendations, but only 46.1% (82/178) could cite them accurately, and most mothers learned of them via the internet or from a medical professional. Mothers who were aware of the guidelines allowed significantly less screen time for infants than those who were unaware ( $P=.03$ ). In addition, parents who adhered to the AAP guidelines reported significantly less infant screen time per day than those who did not adhere ( $P<.001$ ). Among mothers who reported not adhering to the guidelines, the greatest motivation for allowing screen time was perceived educational benefits. Less educated mothers rated an infant's relaxation as a motivational factor in allowing screen time significantly higher than more highly educated mothers ( $P=.048$ ). The regression analysis indicated that none of the parental motivation factors predicted daily infant screen time.

**Conclusions:** These results indicate 2 key approaches to improving adherence to screen time recommendations. First, the awareness of the AAP recommendations needs to be increased, which tends to improve adherence. Second, the myth that screen time can be educational for infants needs to be dispelled.

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**KEYWORDS**

infancy; screen time; screen time recommendations; mothers and infants; American Academy of Pediatrics recommendations; parental motivations

## Introduction

### Background

Exposure to screen time during infancy has become prevalent in the past few decades as advances in technology have merged with educational and entertainment products targeting infants and their caregivers. Informed by research showing that screen time can be detrimental to infant development, researchers and pediatricians recommend that children younger than 2 years be strictly limited in their screen time exposure or even better, have no sedentary exposure to electronic media at all [1-6]. Recommendations by entities such as the American Academy of Pediatrics (AAP) are intended to provide useful guidelines for parents and caregivers when making decisions about how to manage screen time exposure for young children [5]. However, their utility is limited if caregivers are not aware of or do not adhere to the guidelines. To address this problem, we explored mothers' awareness of and adherence to the AAP's recommendations and the motivational factors associated with screen time exposure.

### Problem Statement: Adverse Effects of Screen Time Exposure for Infants

Previous research has demonstrated that infants and toddlers gain more developmentally beneficial skills through play time with physical objects than through devices that use screens [2-4,6-11]. Screen time deprives infants from learning and developing adaptive skills that can only be obtained through human interaction, and it does not allow them the creative freedom experienced during free play [5,12]. A rapidly growing body of literature has linked screen time to delays in both language development and emotional regulation [3,4,9,12-15]. Even 1 hour of television viewing can negatively affect an infant's language capacity, as an estimated 52 minutes of interaction between the infant and their caregiver are lost during that 1 hour [12]. The presence of background media has also been shown to reduce caregiver interactions with infants [16,17].

Empirical research on educational media suggests limited benefits for language learning, prompting some researchers to conclude that there are no beneficial effects of watching programs for children younger than 2 years [1,4,10,18]. Although many parents believe that educational media are helpful for language learning, research suggests that infants are not able to learn from screen time the way they learn from real-life experiences. Vandewater [19] found no differences in language development between infants (aged 8-15 months) who were regularly shown an infant-directed language DVD and those who were not. In a study of 6- to 36-month-old children, Taylor et al [20] found that reading was associated with a larger vocabulary, whereas screen media had no impact on vocabulary. The one type of media that is seen as making a positive contribution to development is live human interaction via video chat, which the AAP classifies as an exception to the *no screen time* rule [13]. The reason video chat is an exception is that a

substantial amount of contingent interaction with the infant in the form of communication takes place during the call [13].

When screen time reduces interaction with caregivers and other children, deficits in self-regulation and other forms of socioemotional learning can result. Self-regulation is a preacademic skill that undergoes great gains during infancy and toddlerhood [21]. When self-regulation is poorly developed, an individual will struggle to stay focused on a task, lack the ability to inhibit automatic responses, and have a decreased capacity for long-term and working memory [21]. Screen time supplants the human interaction necessary to develop these fundamental skills [4,12,22]. Both experimental and large-scale longitudinal survey studies have found that screen time negatively impacts self-regulation abilities [22-24]. Although screen time may be moderately engaging for young children, the effects of screen time are likely to be detrimental across developmental domains.

### Caregiver Awareness and Motivations as Impediments to the Current Solution

To minimize the adverse impact of screen time on infants, multiple professional organizations recommend avoiding infant screen time exposure as much as possible. However, this approach has not resulted in widespread reductions in infant screen time. Despite research documenting the negative effects of screen time and the AAP recommending minimal screen media use for children younger than 2 years, parents continue to allow and even encourage its use by their infants and toddlers. Currently, it is unclear whether the lack of adherence stems from caregivers being unaware of these guidelines or believing that screen time has benefits for their families. To support more optimal child outcomes, our study explores the impact of awareness and caregiver motivation for screen time on infants' screen time durations. By better understanding the context in which caregivers receive screen time guidelines, medical organizations and practitioners will have a better sense of how to advocate for reduced screen time more effectively and increase adherence to recommendations.

Caregivers use a variety of sources to gather information regarding the process of raising children, including for both immediate problems and general advice [25-27]. Through a survey of 1240 parents, Radey and Randolph [28] found that parents typically gather information from multiple sources when looking for general parenting knowledge, including a combination of professional, nonprofessional, and media sources. Looking at the relative impact of various sources through an interview-based study, van der Gugten et al [27] found that although parents used the internet most frequently to gather information about a child's issues, they relied on physician recommendations to alleviate worries.

Although these few studies explore sources that caregivers commonly use, studies on parental awareness of the AAP screen time recommendations have produced mixed results. Funk et al [29] surveyed 94 parents of preschool-aged children and

found that just one-third (34%) of them were able to correctly identify current screen media recommendations for young children. In contrast, Adamiak [30] found that 76% of a sample of 126 parents of preschool-aged children were aware of age-specific AAP recommendations for media use. Our study adds to this scholarship by testing relationships between awareness of and adherence to guidelines.

A lack of awareness may not be the only factor associated with higher infant exposure to screen time. Parents exhibit a variety of motives in exposing their children to screen time in the early years, restricting access sometimes, whereas encouraging such use at other times. [31]. Cingel and Krcmar [32] have called for more work in this area, noting that “little work has systematically examined parents’ motives for media use for their young children.” In their study, parents ranked child enjoyment of media, perceived educational benefits, and need to do other tasks as the most important motives for facilitating child media use [32]. Brown and Smolenaers [2] used interviews to investigate the motivational factors behind exposing children younger than 2 years to screen time, finding that child enjoyment, availability of screens, need to do other tasks, and coping with child upset were all seen as reasons for permitting infant screen time use. Our study investigates motivational factors across a larger sample, testing for relationships between motivational factors and caregivers’ adherence to screen time recommendations.

### Study Context and Research Questions

Major professional organizations focused on child health and well-being, specifically the AAP, have conducted reviews of research and published guidelines intended to foster best practices in raising young children [29,33]. However, the implementation of such recommended practices is contingent on parental awareness of, adherence to, and motivations related to such guidelines. Therefore, in this study, our goal is to recruit a sample of parents with infants younger than 2 years and assess these variables in relation to the topic of screen media recommendations laid out by the AAP.

Given the nascent stage of research on parental awareness and motivation for infant screen time use, we seek to apply a mixed methods survey approach (quantitative and qualitative elements) to further explore the variables of awareness, adherence, and motivation for screen media exposure among parents (mothers) of infants (age  $\leq 2$  years). We seek to investigate several research questions (RQs) as follows:

- RQ 1: What is the level of awareness that parent caregivers express related to AAP’s recommendations on limiting screen time exposure for infants?
- RQ 2: What is the level of adherence to AAP screen time recommendations by parent caregivers and does the level of adherence influence infant screen time exposure?
- RQ 3: What is the association, if any, between parent caregivers’ awareness of AAP screen time recommendations for infants and adherence to such guidelines in parental behavior?
- RQ 4: In circumstances of nonadherence to AAP screen time recommendations for infants, what are mothers’

motivations for allowing their young children to use screen media and does maternal education influence such motives?

- RQ 5: Do parental motivation factors among parents not adhering to AAP screen time recommendations predict screen time exposure for their infants?

In exploring these questions, we anticipate some possibilities based on previous research and pragmatic considerations. With regard to awareness of AAP screen time recommendations, we suspect that although many caregivers have likely heard about such recommendations, there might be an inaccurate understanding of the guidelines [2]. We use a qualitative approach to further assess this possibility. Furthermore, we feel it is likely that some mothers would allow or facilitate screen time (ie, not adhere to AAP recommendations) and thus want to better understand how awareness is linked with adherence. Finally, as previous research has articulated some parental motivations for facilitating screen time exposure for young children [2,32], we seek to understand how such motives may take precedence over a desire to follow AAP screen time recommendations.

## Methods

### Design

Information for this study was gathered using a descriptive, cross-sectional design with a mixed measures approach (questionnaire) among a population in the upper midwestern United States. The survey included both quantitative and qualitative elements and was distributed via a web-based platform (Qualtrics; Qualtrics International Inc) to parents of at least one infant child between the ages of 0 and 2 years. To maintain consistency with previous research discussed in the literature review, fathers were excluded from our study, as most of the work in this area is only examined with primary caregivers, who are usually mothers. Collaborating entities in the research project were the Infant Cognitive Development Lab at North Dakota State University (NDSU), the NDSU Extension Service, and the Early Head Start program of North Dakota.

### Ethics Approval

Approval for the study was obtained from the institutional review board of NDSU (HE19122).

### Participants

A total of 178 mothers of an infant younger than 2 years were selected for inclusion in the final sample for the study. Potential participants were informed of the study and recruited for involvement via information shared through one of the collaborating entities. To be eligible for inclusion in the study, participants needed to be a female primary caregiver and care for an infant aged 0-23 months. Initially, a total of 220 individuals completed the survey. Individuals excluded from the final sample were those who were male (34/220, 15.5%), those who did not categorize themselves as primary caregivers (3/220, 1.4%), and those who did not complete the survey questions beyond the demographics section (5/220, 2.3%). Once these individuals were excluded, 80.9% (178/220) of the female caregivers of infants aged 0-2 years remained in the final sample.



Participants responded to a variety of demographic questions that included age, relationship to the infant, age of the infant, number of children, race or ethnicity, partnership status, education level, employment status, and annual family income. Of the 178 primary caregivers, nearly all reported their relationship to the target infant as biological mother or adoptive mother (174/178, 97.7%), whereas 1 (0.6%) each reported as stepmother, grandmother, aunt, and foster parent. Caregivers'

ages ranged from 18 to 56 years (mean 29.5, SD 5.57 years). Reported mean age of the focal infant was 12.5 (SD 6.62) months. In addition, participants had an average of 2.07 (SD 1.07) other children in the home. Remaining participant characteristics are presented in Table 1. It is important to note that participants were allowed to opt out of the questions given in the survey, including annual family income.

**Table 1.** Characteristics of caregivers of infants aged 0-2 years (N=178).

| Caregiver characteristic                               | Value, n (%) |
|--|--------------|
| <b>Race or ethnicity</b>                               |              |
| White  | 153 (85.9)   |
| Black or African American                              | 6 (3.4)      |
| Native American or native Alaskan                      | 8 (4.5)      |
| Asian  | 4 (2.2)      |
| Hispanic or Latino                                     | 4 (2.2)      |
| Multiracial  | 3 (1.7)      |
| <b>Partnership status</b>                              |              |
| Married  | 115 (64.6)   |
| Single   | 24 (13.5)    |
| Significant other (not engaged)                        | 21 (11.8)    |
| Significant other (engaged)                            | 14 (7.9)     |
| Divorced or separated                                  | 4 (2.2)      |
| <b>Education level</b>                                 |              |
| High school or equivalent degree or less               | 33 (18.5)    |
| Some college or associate degree                       | 52 (29.2)    |
| Bachelor's degree                                      | 58 (32.6)    |
| Postgraduate degree                                    | 32 (17.9)    |
| Other  | 3 (1.7)      |
| <b>Employment status</b>                               |              |
| Not seeking outside employment                         | 39 (21.9)    |
| Seeking employment                                     | 6 (3.4)      |
| Employed <25 hours per week                            | 18 (10.1)    |
| Employed 26-39 hours per week                          | 22 (12.4)    |
| Employed >40 hours per week                            | 93 (52.2)    |
| <b>Annual family income (US \$; n=173<sup>a</sup>)</b> |              |
| 0-20,000   | 34 (19.6)    |
| 20,001-40,000  | 29 (16.7)    |
| 40,001-60,000  | 27 (15.6)    |
| 60,001-80,000  | 24 (13.9)    |
| 80,001-100,000   | 29 (16.8)    |
| >100,001   | 30 (17.3)    |

<sup>a</sup>Five mothers opted to not provide their income details.

## Procedure

Collaborating partners distributed study information by emailing a project link and QR code to contact families, displaying flyers around the local area or offices, supporting local recruitment events, and making the survey available for eligible participants on an accessible computer in their office locations. A convenience sampling strategy was used and supplemented by purposive sampling with families eligible for the Early Head Start program to reach a population with broader socioeconomic backgrounds. Data were collected from May 2019 to January 2020.

The survey was made available electronically via Qualtrics, and participants were able to reach it via an email link or QR code specific to the survey. Mothers took the survey in a location of their choice, including the Infant Cognitive Development Lab or the Early Head Start program offices. Participants were prompted with a brief paragraph explaining the purpose of the study, an informed consent page, and a questionnaire link. The survey took approximately 15-25 minutes for participants to complete. Upon completion, participants were thanked and then provided a code word, which they could use to redeem for a compensation baby item at any of the collaboration sites.

## Measures

### Overview

Participant information was gathered through completion of a questionnaire that included questions regarding participant characteristics, infant screen media exposure, parental knowledge of media guidelines, and parental motivation related to infant media use. Responses were collected in various formats including Likert-type scales, short entry or drop-down lists, and short essay responses. This combination of approaches allowed mothers to answer some of the questions in their own words and provide insight into their awareness and thought patterns. A number of specific measures were used to assess participants' responses.

### Infant Screen Time Exposure

To measure screen time exposure of infants, participants were asked to report the duration of the focal infant's average daily screen time use in multiple-choice format with 5 options from 1 (0-1 hour) to 5 (>4 hours). A total of two questions were asked (4 in total) for screen time duration, 1 related to television and 1 related to other digital devices, for both the average *weekday* and the average *weekend day*. An example question was as follows: "On an average *weekday*, how much time does your child spend on a digital device (e.g., cellphone or tablet) while under your supervision?" Screen time was measured in 1-hour increments (eg, 0-1 hour) with no true zero. As the responses were recorded in ranges of time, results should be interpreted as a median approximation of time with every 0.5 equating to 30 minutes of screen time. To calculate an infant's average screen time per day, we computed a variable by adding the reported estimate of screen time on each of 2 different types of devices (eg, television) that infants were exposed to on an average *weekday* and multiplying this value by 5. Then, the estimated amount of screen time per *weekend day* was multiplied by 2. Next, these 2 values were added together and

divided by 7 to give an overall daily average (with a possible range from 0-10 hours). Mothers who selected 0-1 hour and also responded "I never allow screen time" were coded as 0 hours. This computed *screen time per day* variable was used as a dependent variable for multiple analyses. The questions on infant screen time exposure were developed specifically for this project.

### Caregiver Awareness of Infant Screen Time Use Recommendations

To assess caregiver awareness of the current AAP recommendations on screen time for children aged <2 years, participants were asked a multiple-choice question: "How did you find out about the American Academy of Pediatrics' recommendation?" Six possible options included lack of awareness, unlisted source, or four other possibilities (medical professional, other community member, web, and book). First, responses were coded dichotomously as *aware* or *unaware* based on their self-report, with all participants indicating "I did not know about the recommendation" being coded as *unaware*, whereas the remaining responses (eg, "I read it online" and "A medical professional informed me") being coded as *aware*. Next, further analysis was conducted, and responses were coded into 6 categories reflecting the accuracy of awareness and confidence in their assessment of the guidelines by examining open-ended responses. Participants were asked an additional open-ended question: "In your own words, what is the current American Academy of Pediatrics' recommendation for use of digital media or television by children under the age of two?" This question allowed caregivers to reveal their knowledge about the current guidelines. The questions on caregiver awareness of AAP recommendations were developed specifically for this project.

### Caregiver Adherence to Infant Screen Time Use Recommendations

To assess caregiver adherence to AAP infant screen time recommendations, participants were given a clear statement of current AAP guidelines on the topic and informed that parents often vary in following this guideline. Then, caregivers were asked, "How often do you adhere to this recommendation?" Response options ranged on a 5-point scale from 1 (*never*) to 5 (*always*). On the basis of their responses, skip logic led to the next prompt that asked participants to explain if they adhere, partly adhere, or do not adhere to the AAP recommendations in their own words. For analysis, adherence to the AAP's guideline was recoded into a dichotomous variable as *adherent* or *nonadherent*. Caregivers who followed the AAP guideline *most of the time* (rating=4) or *always* (rating=5) were coded as *adhering*, but those who reported adhering *never* (rating=1), *sometimes* (rating=2), or *about half the time* (rating=3) were coded as *not adhering*. The questions on caregiver adherence to AAP recommendations were also developed specifically for this project.

### Parental Motivations Scale

A slightly adapted version of the Parental Motivations Scale [32] was used in this study. The Parental Motivations Scale by Cingel and Krcmar [32] was developed based on a qualitative

interview study on parent motivations in relation to screen time for young children conducted by Rideout et al [34]. The Parental Motivations Scale was originally validated through an exploratory factor analysis that used a varimax rotation, which identified 5 dimensions with eigenvalues >1 and Cronbach  $\alpha$  scores ranging from .77 to .92 [32]. These dimensions were *chores* (to get chores done), *education* (for educational purposes), *reward* (as a reward for good behavior), *relax* (to help children calm down or relax), and *enjoyment* (because the child enjoys or asks for screen time). The scale starts with the prompt "I let my child use media..." and then lists a variety of reasons, such as "...because it is educational" or "...to help alleviate my stress." A higher score on each scale construct indicates that respondents are more likely to let children use media based on that particular parental motive. Participants responded using an expanded 19-item Likert scale matrix table rating each item from 1 (*strongly disagree*) to 7 (*strongly agree*). Owing to technology advancement and evolving parental standards, we solicited input from local parent groups to identify other potential motivators. On the basis of this input, we created 3 exploratory scale items. These items fit into the factors of chores and education ([Multimedia Appendix 1](#)). One additional question was added as a screening question, which allowed mothers to indicate that they never allow their infants screen time. Reliability analysis for this sample for each factor indicated high reliability (Cronbach  $\alpha$ =.82-.93). When the exploratory questions were included, internal consistency for the education factor remained the same (Cronbach  $\alpha$ =.92), but that for the chores factor increased from the original Cronbach  $\alpha$ =.88 to Cronbach  $\alpha$ =.92. Thus, the additional questions improved the internal consistency of the chores subscale.

## Analysis

Results were calculated using the final sample of female caregivers (N=178). However, we noted that beyond the screening questions (eg, consent, having an infant younger than 2 years, gender of the participant, and indicating they were the primary caregiver), questions were elective, meaning that some caregivers may have opted out of answering certain questions. All analyses used raw scores and unedited short-answer responses. All quantitative analyses were conducted using SPSS 27.

For RQ 1, descriptive statistics were used to identify the number of caregivers who were aware of the AAP's recommendations. Furthermore, brief thematic analyses of short-answer responses were coded on the basis of correctness and confidence level. Coding was completed by a primary investigator (SML) manually inserting responses into the corresponding categories within a Microsoft Excel file. After a thorough review of the coding was conducted by the secondary investigator (CAP), percentages were calculated for each category of correctness and confidence level. Finally, caregivers identified the sources from which they learned the AAP's recommendations, and descriptive statistics provided the frequencies of each source.

For RQ 2, caregivers were told the current screen time guidelines for infants aged <2 years and asked about their adherence practices. Descriptive statistics were used to analyze the caregivers' adherence practices. Responses were dichotomized

in which ratings of 4 (*most of the time*) or 5 (*always*) were coded as *adhering*, whereas ratings from 1 (*never*) to 3 (*about half the time*) were coded as *not adhering*. Next, a univariate ANOVA was used to compare adherent and nonadherent mothers' infant screen times.

Next, for RQ 3, we sought to identify whether there was an association between awareness of the AAP's recommendations and parental adherence. Each of the relevant variables was coded as a dichotomous variable in this analysis, and a chi-square analysis was used to explore whether difference between adherent and nonadherent caregivers was significant owing to awareness. Furthermore, a univariate ANOVA was used to examine potential contrasts in infant screen time exposure between caregivers who were aware and those who were unaware of the guidelines.

For RQ 4, when examining parental motivation factors related to infant screen time exposure, a filter was applied in which only caregivers who indicated infant exposure to screen time were analyzed (86/172, 50%). Descriptive statistics were used to investigate the participants' ratings for each parental motivation factor. Maternal education was another variable explored in this section, and this item was recoded dichotomously for analysis purposes (eg, *low education level* was defined as lesser than a bachelor's degree and *high education level* was defined as a bachelor's degree or more). Independent sample *t* tests (2-tailed) were used to identify any differences among parental motivation factors based on caregiver's education level.

Finally, for RQ 5, we sought to identify the parental motivation predictors of infant screen time exposure. Linear regressions were conducted on each parental motivation factor with respect to infant screen time exposure as a dependent variable.

## Results

### Demographics

Mothers completed a number of questions in the survey that collected information about participant characteristics. Specific items included age, relationship to the infant, age of the infant, number of children, race or ethnicity, partnership status, education level, employment status, and annual family income.

### RQ 1: Mothers' Awareness of the AAP's Recommendations on Infant Screen Time

Of the 178 participants, 172 (96.6%) participants responded to the survey question exploring their awareness of the current AAP's recommendations on screen time for children younger than 2 years. Descriptive statistics indicated that many mothers were aware of the AAP's screen time recommendations for infants (107/172, 62.2%). We conducted further qualitative analysis of responses to the question, "In your own words, what is the current American Academy of Pediatrics' recommendation for use of digital media or television by children under the age of two?"

Of those who responded, 55.8% (96/172) showed full or partial awareness of the AAP screen time recommendations that was accurate. Results of this analysis demonstrate that 38.4%

(66/172) of mothers knew the guidelines confidently and in their entirety (eg, “No screen time under the age of two” and “video chat with family members is ok, [but] should be limited. Everything [else] should be avoided.”). It is important to note that 7.6% (13/172) of mothers were correct but not confident in their knowledge of the guidelines (eg, “I believe it says very minimal or none?” and “I have no idea but I would guess none”). In addition, 9.9% (17/172) of mothers were partially correct (eg, “no TV at all” and “limit screen time or not have it at all”). The qualitative analysis further revealed that 30.2% (52/172) of mothers did not know the recommendations (eg, “I don’t know” and “less than one hour per day”). Finally, 14.5% (25/172) of mothers failed to answer the question, instead they either expressed their opinions or knowledge on the topic (16/25, 64%; eg, “Children learn best through play not media and videos” and “Unrealistic”) or gave nonapplicable responses (8/25, 32%; eg, “?” or “4-month-old baby”).

Participants responded to a follow-up question regarding how they learned of the AAP’s guidelines on infant screen time exposure. A substantial portion of mothers indicated they did not know about the recommendations at all (65/172, 37.8%); however, 3 out of 5 caregivers noted that they learned about the guidelines from a variety of sources (107/172, 62.2%). Most mothers in this group read about the AAP recommendations on the web (41/172, 23.8%), closely followed by being informed by a medical professional (38/172, 22.1%), and then followed by awareness via other sources such as news, Facebook, or childcare centers and so on (20/172, 11.6%). A few respondents learned the guidelines from someone other than a medical professional (6/172, 3.5%) or they read about them in a book (2/172, 1.2%).

### RQ 2: Adherence to the AAP’s Recommendations on Infant Screen Time

A second RQ investigated the adherence of infant caregivers to AAP screen time recommendations and whether such adherence influences daily infant screen time exposure. Participants (172/178, 96.6%) read a statement that clearly stated the AAP recommendations (eg, “children under the age of two should not use any digital media or watch television”), a sentence that explained parents vary in adherence to this guideline, and then were asked how often they adhered to this recommendation on a 5-point scale ranging from 1 (*never*) to 5 (*always*).

Adherence to the AAP’s recommendations on screen time exposure for infants was recoded into a dichotomous variable as *adherent* or *nonadherent*. Mothers who responded that they followed the screen time guidelines with ratings of 4 (*most of the time*) or 5 (*always*) were coded as *adhering*, whereas mothers who indicated following the guideline with ratings from 1 (*never*) to 3 (*about half the time*) were coded as *not adhering*. Descriptive statistics revealed that mothers who adhered to the AAP’s recommendations on infant screen time were exactly comparable in numbers with mothers who did not adhere (both 86/172, 50%), whereas 3.5% (6/172) of the mothers declined to answer whether they adhered to the guidelines.

To investigate the effect of caregiver adherence to the AAP recommendations on self-reported screen time exposure for infants, a univariate ANOVA was conducted to compare

adherent and nonadherent mothers. The univariate ANOVA yielded a significant difference in infants’ average daily screen time exposure between parents who adhere and those who do not adhere to the AAP’s guidelines ( $F_{1,169}=22.55$ ;  $P<.001$ ;  $\eta_p^2=0.12$ ). Mothers who reported adhering to the guidelines indicated lower amounts of infant screen time per day (mean 0.65, SD 0.48 hours/day) compared with mothers who reported not adhering to the guidelines (mean 1.25, SD 1.06 hours/day), suggesting both higher levels of screen time exposure and greater variance in such exposure for children in households not adhering to AAP guidelines on the topic.

### RQ 3: Association Between Caregiver Awareness, Caregiver Adherence, and Infant Screen Time

The next RQ in this study explored whether there is any association between caregiver awareness of AAP screen time recommendations for infants and adherence to such guidelines in parental behavior. To further examine this question, we conducted a chi-square analysis of the association between caregiver awareness of AAP screen time recommendations and adherence to such AAP guidelines in allowing infant screen time exposure.

Chi-square analysis indicated that there was a significant association between parents’ awareness of the AAP screen time guidelines and parents’ adherence to them (172/178, 96.6%;  $\chi^2_1=10.9$ ;  $P<.001$ ; Cramer  $V=0.25$ ). Of the caregivers who were aware of the AAP’s guidelines (107/172, 62.2%), 59.8% (64/107) of them indicated that they adhere to the recommendations. In contrast, of those who were unaware of the AAP’s recommendations (65/172, 37.8%), only 34% (22/65) of the mothers reported that they adhered to the guidelines. This finding on caregiver awareness was further supported by a univariate ANOVA with daily infant screen time as the dependent variable. Results indicated that mothers who were aware of the guidelines allowed significantly less screen time (mean 0.84, SD 0.90 hours/day) than mothers who were not aware of the guidelines (mean 1.13, SD 0.79 hours/day;  $F_{1,169}=4.63$ ;  $P=.03$ ;  $\eta_p^2=0.03$ ).

### RQ 4: Parental Motivation Factors Related to Screen Time Exposure for Infants and Maternal Education

The next RQ explored parental motivation factors for allowing their infant to use screen media in circumstances of nonadherence to the AAP screen time recommendations for young children. In addition, we investigated whether maternal education influences such motives.

Using the subsample of caregivers who reported not adhering to the AAP guidelines (86/172, 50%), descriptive statistics were computed for each of the 5 parental motivation factors developed by Cingel and Krmar [32] in their Parental Motivations Scale (scale of 1-7). A higher score on a specific motivation factor indicated a greater likelihood to allow children to use media based on that reason. The highest rated motivation factor to allow infant screen media use for these mothers was the perceived educational benefits of screen time (mean 4.56, SD 1.56), followed by the child asking for screen time for enjoyment (mean 3.76, SD 1.66), and the mother needing to do chores



(mean 3.62, SD 1.63). Additional motivation factors that ranked lower included giving an infant a screened device as a reward (mean 3.48, SD 1.74) and to help the infant relax (mean 3.47, SD 1.48).

We also sought to explore whether any differences existed in parental motivation factors based on maternal education level. A dichotomous variable for education level was created with two levels (lesser than a bachelor's degree and a bachelor's degree or higher) as an independent variable. There were 62% (53/86) of caregivers in the low education category and 38% (33/86) of caregivers in the high education category. Five dependent variables, consisting of the 5 parental motivation factor subscales, were used in the statistical analysis. There were no outliers in the data based on visual inspection, scores for the factors showed approximately normal distribution based on visual inspection of the Normal QQ Plot, and the assumption of homogeneity of variances was met using Levene test for equality of variances. The significance level for  $P$  was set at .05, and a series of independent sample  $t$  tests (2-tailed) were used to assess whether differences existed for any of the parental motivation factors based on maternal education level. Mothers at low education level (lesser than a bachelor's degree; mean 3.72, SD 1.45) rated the motivation factor *relax* as a rationale for allowing infant screen time higher than mothers at a high education level (mean 3.07, SD 1.46), showing a statistically significant difference of 0.65 (95% CI 0.01-1.29;  $t_{84}=2$ ;  $P=.048$ ;

Cohen  $d=0.44$ ). A second parental motivation construct, reward, was also rated higher as a reason for allowing screen time by mothers with less education (mean 3.73, SD 1.76) as compared with mothers with high education (mean 3.08, SD 1.66), showing a marginally significant difference of 0.65 (95% CI  $-0.11$  to  $1.41$ ;  $t_{84}=1.70$ ;  $P=.09$ ; Cohen  $d=0.38$ ; considering a  $P$  value of .10). None of the other 3 motivation factors differed between the 2 groups by education level, with all  $P>.05$ .

### RQ 5: Parental Motivation Factors and Infant Screen Time Exposure

The final RQ explored the parental motivation factors for allowing an infant to be exposed to screen time and whether any of the factors predict actual screen time exposure for children. Each of the parental motivation factors was identified as an independent variable for this analysis, with the dependent variable being the average hours of screen time exposure per day (128/178, 71.9%).

Regression analyses were conducted to identify whether any of the parental motivation factors were predictive of screen time exposure during infancy. Results including unstandardized coefficients, SEs,  $t$  scores, and  $P$  values are reported in Table 2. None of the motivational factors (ie, educational benefit, chores, reward, relaxation, and asking) predicted daily infant screen time ( $F_{5,123}=0.98$ ;  $P=.43$ ;  $R^2=0.04$ ).

**Table 2.** Linear regressions between average infant screen time per motivational factor.

| Parental motivation factor | B (SE)       | $\beta$ | $t$ test ( $df$ ) | $P$ value |
|----------------------------|--------------|---------|-------------------|-----------|
| Educational benefit        | -0.05 (0.06) | -.10    | -0.94 (123)       | .35       |
| Ask or enjoyment           | 0.07 (0.08)  | .13     | 0.90 (123)        | .37       |
| Chores                     | -0.07 (0.07) | -.14    | -1.04 (123)       | .30       |
| Reward                     | 0.06 (0.05)  | .13     | 1.19 (123)        | .24       |
| Relax                      | 0.03 (0.09)  | .05     | 0.32 (123)        | .75       |

## Discussion

### Principal Findings

The overall goal of this study was to determine the degree to which the parent caregivers were aware of the AAP recommendations regarding screen time exposure to infants and toddlers; their adherence to the guidelines; and, if they did not adhere, their reasons for not following the guidelines and any association with infant screen time use. This information can be used by those involved in pediatric, public health, family support, educational, and other settings supporting children and families.

It is important to note that the COVID-19 pandemic could be amplifying or altering the existing discrepancies between the current screen time recommendations and parental awareness, adherence, and motivations for allowing screen time use for infants. Although these data were gathered before the beginning of the pandemic, the Infant Cognitive Development Lab is preparing a manuscript that explores parental motivations during

the pandemic period (S Lammers, unpublished data, February 2022).

### Awareness of AAP Screen Time Recommendations

Our initial RQ sought to explore the degree to which parents were aware of the AAP's guidelines for no sedentary screen time use by infants younger than 24 months (the AAP recommendations during the period the data were collected) [5]. In our results, we found that approximately 62.2% (107/172) of the participants indicated awareness of the guidelines. Previous research has suggested a wide range in parental awareness levels of screen media recommendations, with Funk et al [29] reporting only 34% of parents who were surveyed had an accurate awareness, whereas Adamiak [30] conversely noted that 76% of parents were aware of age-specific media recommendations. Our finding emerged in the upper level of this range but also illustrated the discrepancy in the suggested parental awareness of screen time guidelines, thus establishing an opportunity for more in-depth investigation through an analysis of open-ended responses.



Upon further investigation of participants' understanding of the AAP guidelines through a qualitative approach, we discovered that only 38.4% (66/172) of mothers were able to accurately state them. However, there were also many mothers who had a general idea that screen time should be limited but were not fully confident of their knowledge (13/172, 7.6%) or aware of the degree to which such restrictions should be applied (17/172, 9.9%). These findings indicate that although most mothers are initially indicating their awareness of the AAP guidelines; a smaller number of them accurately and confidently understand the screen time recommendations for infants younger than 2 years. This pattern suggests the need to reiterate the guidelines in a concise and clear manner with the goal of increasing mothers' comprehension of the guidelines. Moreover, our results further indicate that maternal awareness of such guidelines is not simply an *either-or* situation, but that there is a range in mothers' understanding of AAP recommendations.

It is noteworthy that >2 out of 5 mothers in this sample (52/172, 44.2%) were unaware of the AAP's recommendations, as it suggests there is a continuing lack of awareness about the topic of screen time use during infancy. If we generalize the results regarding maternal awareness from this study to the general adult population of the United States, which has a population of 260 million adults in 2020 [35], we would find that approximately 115 million adults would be unaware of the AAP's recommendation of no screen time for infants aged <2 years. This finding suggests that current methods of conveying important parenting messages can be improved or expanded. Furthermore, mothers' understanding of the AAP's recommendations may also benefit from more elaborate explanations of why screen time should be avoided during infancy rather than simply stating that it should be avoided.

Our study findings also provided insight into how caregivers gain awareness of the AAP guidelines on screen time exposure, with those who were aware of it citing web-based information as a key source (41/172, 23.8%). This is consistent with research suggesting the internet as a common source of parenting information for mothers [25]. This source was closely followed by medical professionals as a primary source of awareness (38/172, 22.1%), a positive finding, as it is consistent with the finding by van der Gugten et al [27] that physician recommendations strongly aid in reducing parental concerns and facilitate the distribution of science-based information to parents in an effective manner [33].

### Adherence to AAP Screen Time Guidelines

This study further explored the level of caregiver adherence to the AAP screen time guidelines for infants, the link between awareness of the guidelines and adherence to them, and whether such adherence influences infant screen time exposure. Although organizations such as the AAP publish such guidelines to encourage best practices in raising children [29], it seems likely that adherence to such recommendations varies widely in actual parental behavior. Findings from the study indicated that approximately half of the parents (86/172, 50%) reported adhering to the recommendations for infants. ANOVA procedures further indicated that adherence to the AAP guidelines resulted in a significant difference in average daily

screen time for infants, with those in the *nonadherent* category reporting approximately twice as much infant screen time per day as mothers who followed the guidelines. This finding suggests the potential value of encouraging and facilitating adherence to the AAP recommendations as a mechanism for improving an infant's well-being. At the same time, as technology is a prominent feature of how contemporary society functions each day, the task of restricting or eliminating access to screens for infants may seem daunting or unrealistic to parents.

In addition, both parent reports of adherence and infant screen time use were related to caregiver awareness of the AAP recommendations. The chi-square analysis indicated that those caregivers who were clearly aware of the AAP recommendations were different in their adherence patterns to screen time recommendations for infants than caregivers who were largely unaware of it. Among caregivers who were aware, approximately 59.8% (64/107) of them adhered to the AAP guidelines with their infant, whereas only approximately 34% (22/65) of mothers who were unaware limited infant screen time exposure. Thus, those who were clearly aware of the guidelines were more likely to restrict screen time for infants. This finding reiterates the need to increase efforts to expand such awareness. Further analysis showed that mothers who were aware of the AAP guidelines allowed significantly less screen time than those who were unaware of the recommendations. However, although awareness seemed to increase compliance with the guidelines, it did not entirely deter parents from allowing some screen time. Our investigation of parental motivations for allowing screen time helped to further explain this finding.

### Parental Motivation Factors and Maternal Education

In circumstances where parents do not adhere to AAP screen time recommendations for infants, we sought to understand the reasons why mothers allow infant screen time exposure and whether maternal education influences these motivations. Previously, research on this topic has suggested a range of parental motivations for allowing screen use by young children [32]. Results of our investigation also revealed that mothers allow screen time for a variety of reasons. Among the 5 parental motivation factors assessed [32], in this study, the highest rated motivation factor was perceived educational benefits for infants (mean 4.56, SD 1.56; on a 7-point scale).

This belief is a moderately troubling misconception. Several studies have demonstrated that infants do not transfer skills they learn on a screened device to the real world, thus furthering the argument for limiting sedentary screen time. In addition, studies with infants show deficits in learning when information is presented in video format rather than from a live individual [1,10]. Hutton et al [3] indicate that instead of providing benefits, infant children exposed to an excess amount of screen time have reduced white matter integrity, which may reduce emerging language skills. However, parents in this instance are giving infants screen time with the belief that they are promoting the well-being of the infant rather than hindering it. Cingel and Krcmar [32] also found that perceived educational benefits was one of the most highly rated motivations for allowing infant screen time in their research, indicating that this belief seems

consistent across different groups of parents. However, current research suggests that the usefulness of engaging in screen time activities for infants younger than 2 years might be compared with watching fireworks. Fireworks are flashy and fun to look at, but infants do not learn fundamental skills from watching them. However, unlike fireworks, the use of screen-based media can occupy a significant amount of time in an infant's life, drawing time away from more worthwhile activities.

In addition, the next two highest parental motivation factors for allowing infant screen time were for infants' enjoyment of the screened device-based activities (mean 3.76, SD 1.66) and the mothers' need to do chores around the house (mean 3.62, SD 1.63). These findings were extremely consistent with those of Cingel and Krmar [32], who also found these 2 motivational factors among the top 3 reasons denoted by parents for allowing infant screen time. When considering such factors, it may be that some parents perceive that they are achieving 2 goals by providing an educational experience for their infants while giving themselves the opportunity to engage in other tasks (eg, cleaning, checking email, and cooking dinner). Similarly, their motivations may encompass multiple reasons at one time, including the factors such as to reward a child or to let a child relax [2,32]. In this study, we added 2 exploratory items that paired with the educational benefits and chores motivational factors, but these additions either did not improve the reliability of the relevant factor or did so only moderately (see *Measures* section).

We also sought to explore whether differences existed among maternal caregivers by education level with regard to how they rated parental motivation factors for allowing infant screen time. Does a mother's level of education shape her attitudes toward allowing infant screen time when such behavior is discouraged by AAP recommendations? In this study, the 3 motivation factors of educational benefits for infants, the infant's enjoyment, and doing parental chores were not statistically different by maternal education level. However, mothers who were less educated endorsed infant screen time to reward a child or to help a child relax significantly more than mothers who were more educated (ie, above vs below a bachelor's degree). This finding may suggest that mothers with a higher education level possess a better understanding of the negative effects associated with screen time exposure during infancy. Therefore, highly educated mothers may be more likely to refrain from using screen time as a tool to calm or reward children, instead using methods that resemble parenting best practices to accomplish these tasks [15,36]. In contrast, the lack of differences in the 3 most highly rated motivational factors seems to indicate that maternal education has a limited influence on mothers' reasons for allowing infant screen time.

### Parental Motivation Factors and Infant Screen Time

The final RQ explored in this study was whether any of the identified parental motivation factors for allowing infant screen time exposure were predictive of screen time use during infancy. Brown and Smolenaers [2] reported a range of motivations that parents provide for allowing infant screen time, including the child's enjoyment or as a tool for calming children. However, this study explored 5 specific motivation factors outlined in a

measure by Cingel and Krmar [32]. The regression analysis indicated that none of these parental motivation factors predicted the average daily screen time exposure for infants. Although these factors provide insight into parent motivations in allowing screen time, it seems that other factors such as sibling's use of a device, number of screens in the household, or other family characteristics will need to be considered to further understand what predicts infant screen time exposure.

### Implications for Education and Policy

The study findings shed light on caregiver awareness of guidelines from the AAP for infant screen time, their adherence to such guidelines, and factors linked with allowing infant screen time exposure. Clearly, the AAP issues such guidelines to educate parents and caregivers, as well as to promote child health and well-being [5]. This study clarifies parental awareness of such information specific to infant screen time, suggesting either a lack of awareness or some level of confusion among many parents regarding the recommended restrictions on screen time for this age group. The fact that many parents knew the guidelines but did not adhere to them is of additional concern.

Among the study findings, it was noted that some parents believe that exposure to screen time before the age of 2 years is actually beneficial to their infant's well-being and development. Perceived educational benefit was rated by parents as the top motivational factor for allowing infants screen time. Thus, some parents incorrectly conclude that screen time provides opportunities to enhance their infant's learning, when instead it often replaces the time spent exploring and interacting with their environment—activities that research shows enhance overall development [3-5,12]. Collectively, these findings about the lack of awareness regarding the AAP guidelines, confusion about it, or the belief that infant screen time can be educational suggest that caregivers may benefit from more thorough explanations about why screen time should be avoided during infancy. The implication for those involved in educating parents is that such an effort must go beyond information transmission and instead consider carefully how parents receive information, how to maximize their learning of research-based knowledge, and ways to elevate the impact of this learning in their parenting practices [26,29,33].

In considering policy implications, it seems important to note that the advertisements for many media companies target children in the infancy age range. Parents and caregivers who are uninformed may assume that their children learn from products that promote the use of devices with screens. In some countries, this type of false advertising is banned. Multiple health organizations have made statements that discourage parents from exposing their children younger than 2 years to screen time, including in the United States, Australia, Canada, and France [5,6,9]. Our findings suggest that substantial effort is required to ensure such information is effectively communicated to parents. Policy statements need to be supported by effective communication strategies. A country that has taken extensive policy measures to ensure the reduction of infant media exposure is France. In 2008, the French High Audiovisual Council made the informed decision to ban their television companies from advertising and airing shows aimed at children

younger than 3 years [4]. Although research suggests that programs delivered via a device with a screen that target young children do not provide educational value, the marketing of such material is influential, and it may override best practice recommendations by the AAP or similar groups in the minds of parents [4,9]. Alternatively, the marketing of material or products that endorse or encourage infant screen time may be done more effectively than the communication of AAP guidelines on the topic. In either case, this topic represents a growing concern in raising young children and needs to be explored further, as empirical research has demonstrated the adverse effects of screen time exposure on an infant's development [3,4].

However, it should also be noted that there are contradictory statements regarding screen time use during infancy that perhaps make the decisions around screen time use for infants more confusing and problematic for parents. For example, the Royal College of Pediatrics and Child Health (RCPCH) in the United Kingdom has made policy statements that counter the guidelines set by the AAP and the World Health Organization. The RCPCH [37] believes that the evidence presented on the adverse effects of screen time exposure for infants and young children is often overstated. Instead, the RCPCH directs parents to make their own decisions regarding screen time use based on each individual child, but acknowledge the expert recommendation of avoiding screens 1 hour before bedtime [37]. Understandably, the contradictory statements made by prestigious entities around the world regarding screen time use for infants can make the choice for parents more challenging. Again, this suggests that institutions promoting child well-being should combine policy recommendations with effective communication strategies for reaching parents and reinforcing their key messages.

### Limitations

A few limitations of this study ought to be considered. First, as participants were recruited using a convenience sample, there were limitations in the representativeness of the data. Information was collected in a limited geographic region with a moderately homogeneous population. Therefore, the results may be less generalizable outside the United States or to other

regions of the United States. In addition, the sample was limited by restricting eligibility to only female primary caregivers. Additional research with an expanded, more diverse population is advisable to strengthen the understanding of the topic beyond this study.

As with all self-report measures, there is also a possibility of social desirability influencing results, particularly relating to reports of adherence to guidelines and use of screen time. We attempted to reduce this bias by asking questions about the AAP guidelines after we asked participants to estimate screen time, rather than priming them with information about the guidelines. Finally, screen time estimates for this age group may benefit from a more fine-grained analysis, perhaps using increments of 15 minutes instead of the 1-hour range that we used here.

### Conclusions

In summary, this study indicates that mothers of infant children have a mixed awareness of AAP guidelines on screen time. Furthermore, half of the caregivers in this study (86/172, 50%) adhered to the guideline in restricting access to screen time, whereas the other half did not and cited multiple parental motivation factors for allowing infant screen time exposure. Both parental awareness of the AAP guideline and adherence to that guideline were linked with greater likelihood of limiting an infant's average daily screen time. More highly educated mothers were less likely to endorse certain reasons for allowing infant screen time, such as to help children relax or to reward them, but otherwise, parental motivations for allowing infant screen time did not differ by level of education. Furthermore, parental motivation factors did not predict the average daily screen time exposure of infant children. The findings suggest the importance of extending beyond policy statements to ensure that parents have a clear and informed understanding of recommendations for child well-being that are provided by groups such as the AAP. In doing so, it is hoped that recommendations based on current research can truly be leveraged to enhance parenting best practices and give infant children greater opportunities for enriched learning and positive developmental growth.

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### Conflicts of Interest

None declared.

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### Multimedia Appendix 1

Added screening and exploratory questions in the parental motivations scale.

[[DOCX File, 13 KB - pediatrics\\_v5i2e29102\\_app1.docx](#)]

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## Abbreviations

**AAP:** American Academy of Pediatrics

**NDSU:** North Dakota State University

**RCPCH:** Royal College of Pediatrics and Child Health

**RQ:** research question

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Original Paper

# Development and Validation of the Adolescent Media Health Literacy Scales: Rasch Measurement Model Approach

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## Abstract

**Background:** High media use has been implicated in negative social and health outcomes among adolescents. Therefore, it is critical that adolescents develop skills to healthily engage with media content. Media health literacy (MHL), skills for assessing and responding to health-related media content, and potentially targetable moderators for the relationship between media use and health-related outcomes are understudied in adolescents. The lack of MHL assessment tools may have contributed to this research gap.

**Objective:** This study aimed to develop and validate test-based scales of adolescents' MHL.

**Methods:** The items developed were vetted iteratively via community reviews and cognitive interviews to establish content and face validity. Adolescents (N=355) completed a questionnaire that included the revised MHL items. The scales (Recognition/Identification, Influence/Critical Analysis, and Action/Reaction) were validated using Rasch measurement models. Convergent validity was assessed by correlating the summed scores of the three scales with existing functional and internet-related health literacy measures. Criterion validity was assessed by modeling logistic regressions for predicting health literacy-related behaviors from each scale after controlling for demographics. Effect sizes were estimated, and a short form was also validated.

**Results:** The final MHL scales (Recognition/Identification, Influence/Critical Analysis, and Action/Reaction) fit their Rasch models. The 9-item Recognition/Identification and 9-item Influence/Critical Analysis scales had good convergent validity with functional and internet-related health literacy measures and were positively related to reading instructions before taking medicines and questioning the truthfulness of health information found online. The 12-item MHL Scales-Short Form also had good convergent and criterion validity. However, convergent and criterion validity were not established for the 3-item Action/Reaction Scale.

**Conclusions:** The Recognition/Identification and Influence/Critical Analysis scales and the MHL Scales-Short Form may be used to determine the impact of MHL on media use and health outcome relationships and ultimately inform the development of interventions and policies to affect these relationships in multiple settings.

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## KEYWORDS

adolescents; health communications; health literacy; measurement; media health literacy; Rasch; mobile phone

## Introduction

### Background

The presence of digital media is evolving as people, especially adolescents, continue to socialize and interact with the world more frequently through this medium [1]. Twenge et al [2] found that the time 12th graders spent online more than doubled

from 2006 to 2016, and 82% of 12th graders used social media daily in 2016. According to a Pew survey (2018), approximately 95% of adolescents own or have access to a smartphone, and almost half of them are online constantly [3]. High levels of media use among adolescents are related to negative outcomes, including poor academic achievement [4], obesogenic behaviors and obesity [5], mental health problems [6], and substance use [7]. Media literacy, and media health literacy (MHL)

specifically, may mitigate these negative relationships. Few studies have explored the effect of media literacy on health beliefs and health outcomes [8-10], and even fewer studies have examined the effect of MHL specifically on these outcomes [11].

Media literacy is the ability to access, understand, evaluate, scrutinize, and create print and electronic media [12,13]. MHL differs from media literacy in that it is more specific to how one engages with health-related media content. Levin-Zamir et al [11] proposed a conceptualization of MHL that was influenced by the functional (reading and writing skills required for everyday situations), communicative or interactive (skills to draw meaning from multiple types of communication and apply to situations), and critical (critical analysis of information and skills to foster sociopolitical action) health literacy (HL) domains proposed by Nutbeam [14,15]. Levin-Zamir et al [11] described MHL as including the following four domains: the identification and recognition of health-related media content, the assessment of health-related media content's intended influence on behavior, the critical analysis of health-related media content, and the declaration of intent to act in response to health-related media content.

The paucity of health behavior research on MHL in comparison with the amount of such research on media literacy is likely due to the lack of measures for assessing adolescents' MHL. Levin-Zamir et al [11] developed a measure of MHL that includes the four domains described in their definition of the concept. However, the items were based on video segments that adolescents viewed, including qualitative and quantitative responses, and the sample was restricted to Jewish adolescents in Israel. Therefore, the measure would be difficult to use in most research and clinical settings, and its applicability and utility outside of a Jewish Israeli population is unclear. There are some measures of media literacy that are specific to health behaviors that are not MHL. For example, Primack et al [16] developed a measure to assess adolescents' smoking content-related media literacy. However, more general measures of adolescents' MHL are necessary to assess these important skills across multiple health behaviors.

### **This Study**

Guided by the definition and measure of MHL provided by Levin-Zamir et al [11], this study aims to develop and validate test-based scales of MHL that could be administered and scored in research and clinical settings. This study used the Rasch measurement model, a probabilistic model that tests data fit against a measurement model rather than a sampled population, as is characteristic of classical test theory [17]. Thus, the resulting fit statistics and validated scales are not sample dependent [18]. In the Rasch measurement model, the probability of a specific person responding in a specific manner to a specific item is calculated, and persons with higher abilities have higher probabilities of endorsing higher items, whereas items with higher difficulties have a lower probability of being endorsed [17,18]. Item difficulty and personal ability are estimated independent of the sample and items in the scale, respectively [18]. This methodology is appropriate for validating the MHL scales, as it identifies the person abilities level and

cutoff scores distinguish between different levels of ability that are informative when trying to assess and intervene on skills. We hypothesized that the final scales would have good convergent validity with previously validated measures of functional and internet-related HL and would also demonstrate good criterion validity with self-reported HL-related behaviors.

## **Methods**

### **Study Design**

A multiphase mixed methods design was used to develop and validate the Adolescent MHL Scales.

### **Ethics Approval**

This study was approved by the Tufts University Social Behavioral and Educational Institutional Review Board (approval number: 1411003). Informed consent was obtained from college students. Parent permission and adolescent assent were obtained for adolescents' participation in data collection.

### **Measures**

#### **Demographics**

Participants self-reported their age, gender (male, female, transgender, nonbinary, and other), ethnicity (Hispanic, Latino or Latina, or Spanish origin), and race (Black or African American, Asian, Native American or Alaskan Native, Native Hawaiian or other Pacific Islander, White, and other). Given the small sample size, Asian, Native American or Alaskan Native, and Native Hawaiian or other Pacific Islander were combined. Participants who selected multiple races were labeled as multiracial. All questions included a "prefer not to answer" option.

#### **Newest Vital Sign**

The Newest Vital Sign (NVS [19]) is a commonly used measure of functional HL and has good internal consistency (Cronbach  $\alpha=.76$ ). The NVS includes 6 reading and numeracy questions related to a provided nutritional facts label. Responses were scored, summed, and categorized as a high likelihood of limited literacy (0-1 correct responses), a possibility of limited literacy (2-3 correct responses), and adequate literacy ( $\geq 4$  correct responses). Summed scores were used to evaluate convergent validity between the functional HL and MHL scales.

#### **eHealth Literacy Scale**

The eHealth Literacy Scale (eHEALS [20]) is a measure of internet-related HL with good internal consistency (Cronbach  $\alpha=.88$ ). The 8-item measure assesses individuals' comfort with, knowledge of, and perceived skills for accessing, evaluating, and using health information found on the internet. Response options were scored on a 5-point Likert scale ranging from strongly disagree to strongly agree. Summed scores were used to evaluate convergent validity between the internet-related HL and MHL scales.

#### **HL Behaviors**

Items that were examples of adolescents' applied use of their HL skills were developed for this study. These items were informed by focus groups where adolescents described how

they used their HL skills [21]. Participants indicated whether they engaged in 2 behaviors indicative of HL—questioning the truthfulness of health information found online and reading instructions before taking medicines. These items were consistent with the scope and reach of the applied use aspect of HL conceptualized by Sørensen et al [22].

### MHL Scales Development

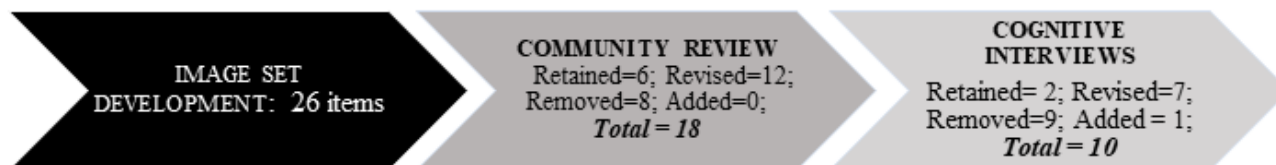
Measurement development involved item bank development, quantitative data collection, and measurement evaluation.

#### Item Bank Development

Using the definition and measure of MHL provided by Levin-Zamir et al [11] as a guide, 26 images were created to assess participants' ability to recognize health messages in media, of which 10 (47%) were intentionally unrelated to health. We chose to use images rather than videos because images are ubiquitous across multiple media outlets, including the social media platforms that adolescents frequent (eg, Instagram), health websites and clinics (via infographics), and in the community (eg, health information posters at school and print advertisements). Images (vs videos) were also chosen because they allowed for self-administration and quick scoring. The 26 images were piloted with undergraduate research assistants who were not involved in this project as a community review step, given this demographic's use of media is similar to that of adolescents. Their feedback was used to revise 12 (46%) images and remove 8 (31%) images. The 18-image measure (including

6 images unrelated to health) was then piloted. In all, 19 cognitive interviews were conducted with college students (age: mean 18.74, SD 0.99 years; women: n=14, 73%; Black participants: n=2, 10%; Asian participants: n=4, 21%) to gather feedback on the appropriateness and relatability of the images, to gather suggestions for modifications, and to qualitatively assess participants' MHL according to the four domains—recognition/identification, influence, critical analysis, and action/reaction—proposed by Levin-Zamir et al [11]. Data collection from the cognitive interviews concluded when saturation was achieved. The qualitative responses were transcribed and content-analyzed. The images were modified based on the content analysis. Specifically, approximately 7 (39%) images were revised (text was removed and images were modified), 3 (17%) health-related images and all 6 (33%) non-health-related images were removed, and 1 (6%) image was added (Figure 1). Non-health-related images were removed, as responses varied in cognitive interviews based on how participants defined health. Qualitative responses were also used to create response options for questions related to influence, critical analysis, and action. It should be noted that only images with consistent responses across interviewees were chosen for these additional questions for the measure. The revised measure contained 10 health-related images. Each image included an accompanying question about health-related message recognition, and 3 (30%) images included 14 questions on influence, critical analysis, and action/reaction.

**Figure 1.** Illustration of iterative image bank revisions before large scale quantitative data collection.



### Quantitative Data Collection and Measurement Evaluation

The revised measure was administered to a convenience sample of adolescents (aged 12-18 years), and Rasch measurement models were used to identify the items that best fit the latent constructs. In coordination with the head health teacher at a local high school, adolescents were recruited via flyers that were posted in school common areas and provided to them, as well as classroom announcements, and they completed the survey during their health class. Data from students whose parents signed permission forms and who signed assent forms were retained and used in this study (N=355). The survey was administered electronically on researcher-provided tablets using the Qualtrics survey platform (Qualtrics International Inc). Students received a US \$15 gift card for their participation.

#### Statistical Analyses

Rasch models were estimated in Winsteps (version 5.1.1) [23], and all other analyses were conducted in SPSS (version 27; IBM Corporation) [24]. The full measure (24 items) was first analyzed using the Rasch Partial Credit Model, as response options were dichotomous and polytomous. The Rasch Partial Credit Model allows each item to have its own rating scale

structure; therefore, not all items have to be on the same rating scale. As anticipated, analyzing the measure as a single latent construct revealed multidimensionality. Separate clustering was observed on the standardized residual contrast plot for action/reaction-oriented items and recognition-oriented items, and the remaining items were clustered together. Given the consistency with the clusters with the a priori content writing of the items (informed by Levin-Zamir et al [11]), the clusters were evaluated as separate scales. Recognition/identification items were analyzed using the Rasch Dichotomous Model, and influence/critical analysis and action/reaction items were analyzed using the Rasch Partial Credit Model, as they included polytomous responses.

The key assumptions of Rasch include unidimensionality (“Do items assess a shared latent construct?”), local independence (“Are the item responses statistically independent of each other?”), and monotonicity of the latent trait (“Are scores monotonically nondecreasing across the latent trait?”). Unidimensionality was evaluated by examining the principal component analysis of the residuals [25] and was confirmed if the eigenvalue of the unexplained variance in the first contrast was  $<2$  [26]. On the basis of the recommendation by Christensen et al [27], the  $Q_{3,*}$  test statistic, which is calculated as  $Q_{3,max}$

(maximum standardized residual correlation between a pair of items) minus the mean of  $Q_3$  (mean of all standardized residual correlations between item pairs), was calculated.  $Q_{3,max}$  and the  $Q_{3,*}$  test statistic were compared with the critical values reported by Christensen et al [27] to determine if there was local independence. Critical values for  $Q_{3,max}$  and the  $Q_{3,*}$  test statistic at the 99th percentile were 0.24 and 0.31, respectively. Monotonically ascending test characteristic curves were indicative of monotonicity [28].

Person and item parameters were estimated using joint maximum likelihood estimation procedures. Outfit mean squares for person and item parameters were examined for good fit (0.5-1.5=good fit; <0.5 or 1.6-2.0=unproductive but not degrading to the measure) [29]. If items had outfit mean squares of >1.5, the standardized statistics were then examined. Items with standardized statistics of >2 were considered for removal. Items with outfit mean squares of <0.5 are less concerning; therefore, they were not considered for removal [30]. The refinement of the measures was performed iteratively. Items with the highest mean square outfit misfit and standardized outfit statistics of >2 were removed first, and the models were re-estimated and re-evaluated after each removal. Regarding person misfit, for each analysis, 1 round of the most misfitting responses was removed (taken from tables of the most misfitting responses), and the models were re-estimated and compared with the original models. If removing these responses did not improve the model fit, the original model was retained, but if the model fit improved, the model with the removed responses was retained for final analyses [29]. Negative point-measure correlations were removed, as these indicated that the items did not belong to the scale [25,31]. Similar to other studies using the Rasch measurement model, final decisions to retain or remove items were based on statistical findings and theoretical reasonings for the items [32]. The key assumptions of the Rasch models were examined at each iteration of model estimation.

Reliability for both items and persons were examined. For items, item separation reliability statistics closer to 1 indicated good item separation (ie, good item difficulty range). Rasch person reliability and classical test theory reliability statistics assume symmetric ability, which is rarely the case in health-related research. To address this, Wright [33] proposed an alternative method of calculating reliability; the Wright sample-independent reliability statistic is computed once measurement calibration is complete [33]. The calculations involve determining the number of strata across the scores and then using this to calculate the sample-independent reliability (ie, number of levels<sup>2</sup>/1 + number of levels<sup>2</sup>). Sample-independent reliability was appropriate for this study because the sample was skewed in terms of ability. Uniform differential item functioning (DIF) for gender, age, and ethnicity was also calculated to determine whether the items performed similarly across subpopulations. Detecting statistically significant DIF that is  $\geq 0.5$  logits requires at least 100 participants per subgroup [34], and significance

thresholds are typically set to  $P < .01$  to account for multiple tests. Given the small sample sizes, age was grouped into early (aged 12-15 years) and late (aged 16-18 years) adolescence to calculate DIF. Sample size requirements were met for all analyses; Rasch model calculations can be estimated with 99% confidence within 0.5 logits with a minimum sample size of 108 to 243 [35], and each response category surpassed the minimum requirement of 10 responses for polytomous items [36].

Descriptive statistics were calculated after the three scales were finalized. Convergent validity (whether 2 measures of constructs that should be related are related [37]) was assessed by correlating the summed scores of the three scales with existing functional and internet-related HL measures. The correlations were expected to be significant but in the low to moderate range, given that functional and internet-related HL are related but have different constructs from those of MHL (ie, hetero-trait). Criterion validity (whether the score on 1 measure is related to a direct outcome of the phenomenon [38]) was assessed by modeling logistic regressions for predicting HL-related behaviors from each scale after controlling for demographics. Effect sizes were also estimated by estimating receiver operating characteristic curves and transforming the areas under the curves to Cohen  $d$  values by using the tables proposed by Salgado [39].

### Unplanned Post Hoc Analyses

Although the initial intent of the measure development process was to develop scales to assess the MHL domains outlined by Levin-Zamir et al [11], the resultant two scales with good validity would likely be difficult to administer in most settings because of the length of the scales. Furthermore, having a single score for MHL may be more useful and easier to interpret in some settings. Therefore, an additional Rasch model was estimated only for images for which all questions were asked (images MHLH6, MHLH7, and MHLH8) in an attempt to create a short form. Items were only included in the short-form estimation if they were included in the final versions of the two validated scales. All of the above outlined procedures were followed to determine the validity of the short form.

## Results

### Overview

A sample of 355 adolescents (age: mean 16, SD 1.34 years; adolescent girls:  $n=165$ , 46.5%) completed the survey. All but 1 participant chose either the male or female option. Approximately 147 (41.8%) adolescents in the sample were non-Hispanic or non-Latinx, and the largest racial group was other (approximately 27.3%), partially owing to Hispanic and Latinx adolescents choosing "other" as their race. A subsample ( $n=200$ ) of adolescents completed the NVS; 70 (35%) of these adolescents had a high likelihood of limited literacy, and 54 (27%) had adequate literacy (see Table 1 for additional descriptive statistics).



**Table 1.** Characteristics of the sample (N=355).

| Variable                            | Values, n (%) | Recognition/ Identification |                     | Influence/ Critical Analysis |                    | Action/ Reaction  |         | Short Form        |                    |
|-------------------------------------|---------------|-----------------------------|---------------------|------------------------------|--------------------|-------------------|---------|-------------------|--------------------|
|                                     |               | Values, mean (SD)           | F value             | Values, mean (SD)            | F value            | Values, mean (SD) | F value | Values, mean (SD) | F value            |
| <b>Gender</b>                       |               |                             | 2.21                |                              | 12.65 <sup>a</sup> |                   | 1.04    |                   | 18.31 <sup>a</sup> |
| Boys                                | 136 (38.3)    | 6.81 (1.98)                 |                     | 11.47 (2.55)                 |                    | 3.55 (2.53)       |         | 13.83 (2.83)      |                    |
| Girls                               | 165 (46.5)    | 7.12 (1.48)                 |                     | 12.49 (2.23)                 |                    | 3.86 (2.57)       |         | 15.18 (2.36)      |                    |
| Missing                             | 54 (15.2)     | — <sup>b</sup>              |                     | —                            |                    | —                 |         | —                 |                    |
| <b>Age (years)</b>                  |               |                             | 0.24                |                              | 0.31               |                   | 1.90    |                   | 0.40               |
| 12-14                               | 57 (16.1)     | 6.89 (1.78)                 |                     | 12.08 (2.75)                 |                    | 4.43 (2.41)       |         | 14.63 (3.01)      |                    |
| 15                                  | 50 (14.1)     | 6.98 (1.49)                 |                     | 11.91 (2.38)                 |                    | 3.79 (2.15)       |         | 14.49 (2.59)      |                    |
| 16                                  | 63 (17.7)     | 7.02 (1.89)                 |                     | 12.24 (2.33)                 |                    | 3.43 (2.79)       |         | 14.81 (2.53)      |                    |
| 17                                  | 101 (28.5)    | 7.09 (1.80)                 |                     | 11.91 (2.35)                 |                    | 3.35 (2.59)       |         | 14.42 (2.66)      |                    |
| 18                                  | 34 (9.6)      | 6.77 (1.54)                 |                     | 11.70 (2.78)                 |                    | 4.03 (2.61)       |         | 14.10 (2.79)      |                    |
| Missing                             | 50 (16.1)     | —                           |                     | —                            |                    | —                 |         | —                 |                    |
| <b>Hispanic or Latinx</b>           |               |                             | 0.30                |                              | 1.26               |                   | 0.02    |                   | 0.47               |
| Yes                                 | 150 (42.3)    | 6.98 (1.67)                 |                     | 11.81 (2.44)                 |                    | 3.68 (2.57)       |         | 14.40 (2.68)      |                    |
| No                                  | 147 (41.4)    | 7.09 (1.67)                 |                     | 12.14 (2.50)                 |                    | 3.72 (2.52)       |         | 14.62 (2.73)      |                    |
| Missing                             | 58 (16.3)     | —                           |                     | —                            |                    | —                 |         | —                 |                    |
| <b>Race</b>                         |               |                             | 1.71                |                              | 2.10 <sup>c</sup>  |                   | 1.23    |                   | 2.56 <sup>d</sup>  |
| ANAANNHOPI <sup>e</sup>             | 24 (6.8)      | 6.38 (2.32)                 |                     | 10.86 (3.30)                 |                    | 2.79 (2.34)       |         | 13.14 (3.52)      |                    |
| Black                               | 61 (17.2)     | 6.87 (1.68)                 |                     | 11.91 (2.76)                 |                    | 3.74 (2.57)       |         | 14.27 (2.96)      |                    |
| White                               | 66 (18.6)     | 7.37 (1.56)                 |                     | 12.34 (2.10)                 |                    | 3.79 (2.73)       |         | 15.03 (2.37)      |                    |
| Multiracial                         | 31 (8.7)      | 6.97 (1.71)                 |                     | 12.67 (2.25)                 |                    | 3.37 (2.28)       |         | 15.03 (2.53)      |                    |
| Other <sup>f</sup>                  | 97 (27.3)     | 7.08 (1.54)                 |                     | 12.00 (2.14)                 |                    | 4.01 (2.58)       |         | 14.69 (2.32)      |                    |
| Missing                             | 76 (21.4)     | —                           |                     | —                            |                    | —                 |         | —                 |                    |
| <b>Newest Vital Sign</b>            |               |                             | 11.13 <sup>a</sup>  |                              | 31.93 <sup>a</sup> |                   | 0.65    |                   | 29.33 <sup>a</sup> |
| High likelihood of limited literacy | 70 (19.7)     | 6.47 (1.98)                 |                     | 10.24 (2.60)                 |                    | 3.94 (2.33)       |         | 12.68 (3.03)      |                    |
| Possibility of limited literacy     | 76 (21.4)     | 6.96 (1.53)                 |                     | 12.28 (2.12)                 |                    | 3.81 (2.75)       |         | 14.75 (2.24)      |                    |
| Adequate literacy                   | 54 (15.2)     | 7.85 (0.92)                 |                     | 13.35 (1.57)                 |                    | 3.41 (2.74)       |         | 16.06 (1.63)      |                    |
| Missing                             | 155 (43.7)    | —                           |                     | —                            |                    | —                 |         | —                 |                    |
| <b>Recognition/Identification</b>   |               |                             | 330.19 <sup>a</sup> |                              | 27.63 <sup>a</sup> |                   | 1.83    |                   | 53.72 <sup>a</sup> |



| Variable                           | Values, n (%) | Recognition/ Identification |                    | Influence/ Critical Analysis |                     | Action/ Reaction  |                     | Short Form        |                     |
|------------------------------------|---------------|-----------------------------|--------------------|------------------------------|---------------------|-------------------|---------------------|-------------------|---------------------|
|                                    |               | Values, mean (SD)           | F value            | Values, mean (SD)            | F value             | Values, mean (SD) | F value             | Values, mean (SD) | F value             |
| Emerging                           | 26 (7.3)      | 3.00 (1.23)                 |                    | 9.43 (2.66)                  |                     | 2.96 (2.18)       |                     | 10.76 (3.00)      |                     |
| Expanding                          | 257 (72.4)    | 7.38 (1.17)                 |                    | 12.23 (2.32)                 |                     | 3.71 (2.60)       |                     | 14.87 (2.42)      |                     |
| Missing                            | 72 (20.3)     | —                           |                    | —                            |                     | —                 |                     | —                 |                     |
| <b>Influence/Critical Analysis</b> |               |                             | 9.66 <sup>a</sup>  |                              | 336.96 <sup>a</sup> |                   | 3.45 <sup>d</sup>   |                   | 283.96 <sup>a</sup> |
| Emerging                           | 20 (5.6)      | 5.82 (2.65)                 |                    | 6.10 (1.25)                  |                     | 3.25 (2.36)       |                     | 8.00 (1.71)       |                     |
| Expanding                          | 184 (51.8)    | 6.96 (1.61)                 |                    | 11.42 (1.64)                 |                     | 3.46 (2.43)       |                     | 13.93 (1.81)      |                     |
| Bridging                           | 89 (25.1)     | 7.55 (1.14)                 |                    | 14.37 (0.49)                 |                     | 4.28 (2.77)       |                     | 17.06 (0.74)      |                     |
| Missing                            | 62 (17.5)     | —                           |                    | —                            |                     | —                 |                     | —                 |                     |
| <b>Action/Reaction</b>             |               |                             | 3.31 <sup>c</sup>  |                              | 8.76 <sup>g</sup>   |                   | 670.44 <sup>a</sup> |                   | 10.16 <sup>g</sup>  |
| Emerging                           | 193 (54.4)    | 6.91 (1.70)                 |                    | 11.65 (2.62)                 |                     | 2.11 (1.43)       |                     | 14.15 (2.87)      |                     |
| Expanding                          | 106 (29.9)    | 7.29 (1.59)                 |                    | 12.54 (2.11)                 |                     | 6.52 (1.35)       |                     | 15.20 (2.19)      |                     |
| Missing                            | 56 (15.8)     | —                           |                    | —                            |                     | —                 |                     | —                 |                     |
| <b>Short Form</b>                  |               |                             | 17.15 <sup>a</sup> |                              | 219.50 <sup>a</sup> |                   | 1.35                |                   | 277.97 <sup>a</sup> |
| Emerging                           | 6 (1.7)       | 4.67 (2.58)                 |                    | 4.67 (1.21)                  |                     | 2.00 (1.67)       |                     | 6.00 (1.10)       |                     |
| Expanding                          | 157 (44.2)    | 6.75 (1.76)                 |                    | 10.72 (1.95)                 |                     | 3.75 (2.45)       |                     | 13.08 (1.99)      |                     |
| Bridging                           | 122 (34.4)    | 7.58 (1.12)                 |                    | 13.95 (0.75)                 |                     | 3.72 (2.74)       |                     | 16.75 (0.77)      |                     |
| Missing                            | 70 (19.7)     | —                           |                    | —                            |                     | —                 |                     | —                 |                     |

<sup>a</sup> $P < .001$ .

<sup>b</sup>Not available (missing data).

<sup>c</sup> $P < .10$ .

<sup>d</sup> $P < .05$ .

<sup>e</sup>ANAANNHOPI: Asian, Native American/Alaskan Native, Native Hawaiian/other Pacific Islander.

<sup>f</sup>In all, 70 adolescents who identified as other indicated that they were Hispanic/Latinx.

<sup>g</sup> $P < .01$ .

## Recognition/Identification

The Recognition/Identification item bank contained 10 items, and 9 (90%) items were retained for the final scale (Multimedia Appendix 1). The final scale assessed adolescents' ability to identify health-related messages in images. One item was removed because of high outfit statistics. The removal of the most misfitting person responses improved the model and item fit; therefore, the final model was estimated after removing these misfitting responses. Point-measure correlations for the final

scales were between 0.45 and 0.61, suggesting high correlations with person abilities. The assumptions of unidimensionality (eigenvalue=1.5), local independence ( $Q_{3,max}=0.17$ ;  $Q_{3,*}$  test statistic=0.27), and monotonicity were met. No DIF was detected for gender, age, or ethnicity. Item separation reliability (0.98) was acceptable. The Wright sample-independent reliability statistic was 0.80, and the scores differentiated 2 distinct levels of performances—emerging (scores of 0-4) and expanding (scores of 5-9). The Kuder-Richardson Formula 20 (KR-20)  $\alpha$  was .74 (see Table 2 for the fit statistics).

**Table 2.** Rasch item difficulties and fit statistics ordered from the most to least difficult item on each individual scale.

| Item                               | Media health literacy individual scales |      |                          |                          |                  |
|------------------------------------|---|------|--------------------------|--------------------------|------------------|
|                                    | Difficulty                              | SE   | Outfit MNSQ <sup>a</sup> | Outfit ZSTD <sup>b</sup> | PMC <sup>c</sup> |
| <b>Recognition/Identification</b>  |   |      |                          |                          |                  |
| MHLH1REC                           | 3.09                                    | 0.16 | 1.16                     | 0.85                     | 0.58             |
| MHLH10REC                          | 1.53                                    | 0.15 | 0.92                     | -0.68                    | 0.61             |
| MHLH8REC                           | 1.47                                    | 0.15 | 1.22                     | 1.88                     | 0.51             |
| MHLH9REC                           | 0.34                                    | 0.17 | 0.87                     | -0.78                    | 0.57             |
| MHLH3REC                           | -0.04                                   | 0.18 | 1.01                     | 0.10                     | 0.52             |
| MHLH4REC                           | -0.49                                   | 0.20 | 0.72                     | -1.18                    | 0.54             |
| MHLH2REC                           | -1.84                                   | 0.30 | 0.39                     | -1.46                    | 0.51             |
| MHLH7REC                           | -2.02                                   | 0.32 | 0.55                     | -0.79                    | 0.45             |
| MHLH6REC                           | -2.05                                   | 0.32 | 0.28                     | -1.68                    | 0.51             |
| <b>Influence/Critical Analysis</b> |   |      |                          |                          |                  |
| MHLH7AGR                           | 1.42                                    | 0.07 | 0.90                     | -1.08                    | 0.68             |
| MHLH6AGR                           | 1.05                                    | 0.07 | 0.98                     | -0.22                    | 0.73             |
| MHLH7INT                           | 0.79                                    | 0.15 | 1.15                     | 1.28                     | 0.39             |
| MHLH6CON                           | 0.12                                    | 0.16 | 1.20                     | 1.15                     | 0.36             |
| MHLH8INF                           | -0.39                                   | 0.20 | 1.08                     | 0.39                     | 0.29             |
| MHLH7CON                           | -0.51                                   | 0.20 | 0.72                     | -1.16                    | 0.65             |
| MHLH7INF                           | -0.57                                   | 0.20 | 1.16                     | 0.68                     | 0.26             |
| MHLH6INT                           | -0.86                                   | 0.22 | 0.64                     | -1.26                    | 0.33             |
| MHLH6INF                           | -1.05                                   | 0.24 | 0.55                     | -1.49                    | 0.35             |
| <b>Action/Reaction</b>             |   |      |                          |                          |                  |
| MHLH7ACT                           | 0.21                                    | 0.09 | 0.86                     | -1.72                    | 0.79             |
| MHLH8ACT                           | 0.09                                    | 0.09 | 1.12                     | 1.33                     | 0.79             |
| MHLH6ACT                           | -0.30                                   | 0.09 | 0.97                     | -0.31                    | 0.81             |

<sup>a</sup>MNSQ: mean square.

<sup>b</sup>ZSTD: standardized statistic.

<sup>c</sup>PMC: point-measure correlation.

Recognition/Identification scores (mean 6.99, SD 1.73) differed significantly by NVS category. Specifically, adolescents who had adequate literacy on the NVS had higher Recognition/Identification scores than those who had a high likelihood of limited literacy (mean difference=1.38;  $P<.001$ ) or the possibility of limited literacy (mean difference=0.89;  $P=.006$ ). The scale had convergent validity with the NVS ( $r=0.30$ ;  $P<.001$ ) and eHEALS ( $r=0.22$ ;  $P=.001$ ). Regarding criterion validity, the scale was positively related to adolescents questioning the truthfulness of health information found online (odds ratio [OR] 1.40, 95% CI 1.17-1.66;  $P<.001$ ; Cohen  $d=0.47$ ) and reading instructions before taking medicines (OR 1.34, 95% CI 1.09-1.66;  $P=.006$ ; Cohen  $d=0.34$ ).

### Influence/Critical Analysis

The Influence/Critical Analysis item bank contained 11 items, and 9 (89%) items were retained for the final scale (Multimedia Appendix 2). The final scale assessed adolescents' ability to

correctly identify the content and intent of the messages and their critical analyses on the intended influences of the messages. In all, 2 (11%) items were removed because of high outfit statistics. The removal of the most misfitting person responses did not improve the model fit. The point-measure correlations for the final scale were between 0.26 and 0.73. The assumptions of unidimensionality (eigenvalue=1.6), local independence ( $Q_{3,max}=0.15$ ;  $Q_{3,*}$  test statistic=0.23), and monotonicity were met. No DIF was detected for gender, age, or ethnicity. Item separation reliability (0.96) was acceptable. The Wright sample-independent reliability statistic was 0.90, and the scores differentiated 3 distinct levels of performances—emerging (scores of 0-7), expanding (scores of 8-13), and bridging (scores of 14-15). The KR-20  $\alpha$  was .91. The possible scores ranged from 0 to 15 rather than 0 to 9 because this scale included dichotomous and polytomous items and, for the Rasch Partial Credit Model, each polytomous response option has a unique

score that corresponds to the degree of correctness (see [Table 2](#) for fit statistics).

Influence/Critical Analysis scores (mean 11.95, SD 2.48) differed by gender and NVS category. Adolescent girls scored significantly higher than adolescent boys (mean difference=1.02;  $P=.001$ ), and adolescents who had adequate literacy on the NVS had higher Influence/Critical Analysis scores than those who had a high likelihood of limited literacy (mean difference=0.60;  $P<.001$ ) or the possibility of limited literacy (mean difference=0.25;  $P=.029$ ). Convergent validity with the NVS ( $r=0.49$ ;  $P<.001$ ) and eHEALS ( $r=0.22$ ;  $P=.001$ ) was established. Regarding criterion validity, the scale was positively related to questioning the truthfulness of health information found online (OR 1.34, 95% CI 1.18-1.52; Cohen  $d=0.69$ ) and reading instructions before taking medicines (OR 1.31, 95% CI 1.11-1.54; Cohen  $d=0.86$ ).

### Action/Reaction

The Action/Reaction item bank contained 3 items that assessed adolescents' intention to take personal or social action in reaction to health-related content in the media image. The response options were ranked from no action to public and personal action intended/planned. All items were retained for the final scale ([Multimedia Appendix 3](#)). There were no misfitting items, and the removal of the most misfitting person responses did not improve the model fit; therefore, all items and responses were retained. Point-measure correlations for the final scale were between 0.79 and 0.81. The assumptions of unidimensionality (eigenvalue=1.6), local independence

( $Q_{3,max}=-0.60$ ;  $Q_{3,*}$  test statistic=-1.10), and monotonicity were met. No DIF was detected for gender, age, or ethnicity. Item separation reliability was low (0.82). The Wright sample-independent reliability statistic was 0.80, with the scores differentiating 2 distinct levels of performances—emerging (scores of 0-4) and expanding (scores of 5-9). The KR-20  $\alpha$  value was .71 (see [Table 2](#) for fit statistics).

Action/Reaction scores (mean 3.68, SD 2.53) did not differ according to demographic characteristics or the NVS category. The scale was significantly positively correlated with the NVS ( $r=0.24$ ;  $P=.002$ ) but not significantly correlated with eHEALS scores; therefore, convergent validity was established only for functional HL. Regarding criterion validity, Action/Reaction scores were not significantly related to measured HL-related behaviors.

### MHL Scales-Short Form

All 12 items of the MHL Scales-Short Form comprised 1 dimension, and all items fit the Rasch Partial Credit Model ([Multimedia Appendix 4](#)). Point-measure correlations were between 0.26 and 0.67. The assumptions of unidimensionality (eigenvalue=1.72), local independence ( $Q_{3,max}=0.14$ ;  $Q_{3,*}$  test statistic=0.20), and monotonicity were met. No DIF was detected for gender, age, or ethnicity. Item separation reliability (0.96) was acceptable. The Wright sample-independent reliability statistic was 0.90, with the scores differentiating 3 distinct levels of performances—emerging (scores of 0-7), expanding (scores of 8-15), and bridging (scores of 16-18). The KR-20  $\alpha$  value was .93 (see [Table 3](#) for fit statistics).

**Table 3.** Rasch item difficulties and fit statistics ordered from most to least difficult item on the Media Health Literacy Scales-Short Form.

| Item     | Media Health Literacy Scales-Short Form |      |                          |                          |                  |
|----------|---|------|--------------------------|--------------------------|------------------|
|          | Difficulty                              | SE   | Outfit MNSQ <sup>a</sup> | Outfit ZSTD <sup>b</sup> | PMC <sup>c</sup> |
| MHLH8REC | 1.48                                    | 0.14 | 1.19                     | 2.21                     | 0.36             |
| MHLH7AGR | 1.44                                    | 0.07 | 1.04                     | 0.44                     | 0.64             |
| MHLH6AGR | 1.16                                    | 0.06 | 0.83                     | -1.52                    | 0.67             |
| MHLH7INT | 0.80                                    | 0.15 | 1.09                     | 0.73                     | 0.39             |
| MHLH6CON | 0.16                                    | 0.16 | 1.08                     | 0.53                     | 0.35             |
| MHLH8INF | -0.35                                   | 0.20 | 0.94                     | -0.18                    | 0.28             |
| MHLH7CON | -0.45                                   | 0.19 | 0.65                     | -1.58                    | 0.64             |
| MHLH7INF | -0.53                                   | 0.20 | 1.13                     | 0.55                     | 0.26             |
| MHLH7REC | -0.79                                   | 0.22 | 0.98                     | 0.03                     | 0.28             |
| MHLH6INT | -0.81                                   | 0.22 | 0.65                     | -1.25                    | 0.31             |
| MHLH6INF | -1.00                                   | 0.24 | 0.53                     | -1.60                    | 0.34             |
| MHLH6REC | -1.13                                   | 0.24 | 0.57                     | -1.32                    | 0.32             |

<sup>a</sup>MNSQ: mean square.

<sup>b</sup>ZSTD: standardized statistic.

<sup>c</sup>PMC: point-measure correlation.

The MHL Scales-Short Form scores (mean 14.50, SD 2.70) differed by gender, race, and NVS category. Adolescent girls scored higher than adolescent boys (mean difference 1.34;  $P<.001$ ), and White adolescents had higher scores than

adolescents in the Asian, Native American or Alaskan Native, and Native Hawaiian or other Pacific Islander cluster. For the NVS categories, adolescents who had adequate literacy had higher MHL scores than those who had a high likelihood of

limited literacy (mean difference=3.38;  $P<.001$ ) or the possibility of limited literacy (mean difference=1.31;  $P=.008$ ). Convergent validity with the NVS ( $r=0.48$ ;  $P<.001$ ) and eHEALS ( $r=0.21$ ;  $P=.002$ ) was established. Regarding criterion validity, the scale was positively related to questioning the truthfulness of health information found online (OR 1.31, 95% CI 1.16-1.47; Cohen  $d=0.68$ ) and reading instructions before taking medicines (OR 1.32, 95% CI 1.13-1.53; Cohen  $d=0.91$ ). Tables showing  $Q_3$ , matrices and reliability statistics for all scales are included in [Multimedia Appendix 5](#).

## Discussion

### Principal Findings

This study developed and validated test-based scales of adolescents' MHL. Face and initial content validity were established using community reviews and cognitive interviews. The final scales fit their respective Rasch models and met the assumptions of unidimensionality, local independence, and monotonicity required for Rasch models. Criterion and convergent validity were established for the Recognition/Identification and Influence/Critical Analysis scales and their combined short form (MHL Scales-Short Form). For Action/Reaction, only convergent validity with functional HL was established.

The questions on the Recognition/Identification scale tested adolescents' ability to recognize that the image was health-related but did not address a more nuanced interpretation of the images. Conversely, the more specific questions on the Influence/Critical Analysis scale focused on the complexity of engaging with health-related media messages, namely the initial interpretation of the content (content question), followed by understanding the purpose behind the message (intent or influence) and the adolescents' level of agreement with the message (agreement). Given that HL is developmental [22], responses to these items will be strongly influenced by adolescents' experiences with media and health content as well as their capacity for critical thought, drawing on previous knowledge and integrating multiple sources of information. Therefore, although all responses for some items (eg, influence items) may seem plausible based on an adolescent's background, adolescents whose responses reflect more critical thought and/or the integration of multiple sources of information would have higher influence/critical analysis skills and are more likely to choose responses that are scored higher on the scale.

Although the Action/Reaction scale was validated using the Rasch Partial Credit Model, convergent validity was only established with functional HL, and criterion validity was not established. The items in this scale are qualitatively different from the other items, as this scale attempts to assess intended personal and community advocacy in reaction to health-related media content. Our scoring system ranked individuals' responses from no action to personal and community action. It is possible that our criterion validity items were not sufficiently sensitive or specific to detect the validity of this scale. It is also possible that the items may not adequately assess the Action/Reaction construct as intended. Furthermore, asking adolescents to predict what they may do might be too abstract, and this approach might

be highly susceptible to social desirability responses based on what is the *right thing to do*. Alternative items or methods for assessing this concept (eg, more detailed scenarios for the media content) should be explored, and the expansion of the items (eg, more empowerment-related HL behaviors) should also be considered to improve the validity of this scale for measuring this construct. This scale should not be used until further refinement and evaluation of the psychometric properties are performed.

The items were originally written to align with the definition and measure of MHL provided by Levin-Zamir et al [11]. However, the measure resulted in 3 scales rather than 4. Levin-Zamir et al [11] conceptualized the domains of recognition/identification and influence as being similar to the functional HL proposed by Nutbeam [14]. They also equated their critical analysis domain (agreement with content) with the critical HL proposed by Nutbeam [14]. However, Nutbeam [14] described interactive HL as skills that can be used "to extract information and derive meaning from different forms of communication"; therefore, both the influence and critical analysis domains in the definition given by Levin-Zamir [11] are better aligned with interactive HL. Consistent with the definition of interactive HL by Nutbeam [14], the influence and critical analysis items in our item bank formed 1 dimension that may be better explained as interactive MHL, and the recognition items formed a separate dimension that may be better explained as functional MHL. Relatedly, Nutbeam [14] described the goal of critical HL as personal and community empowerment. The domain of action/reaction proposed by Levin-Zamir et al [11] focuses on the intent to engage in action as a result of the health message and equates this to the interactive HL proposed by Nutbeam [14], but the definition and question items are arguably better aligned with the critical HL proposed by Nutbeam [14].

It is possible that the use of images rather than videos, all close-ended responses rather than open- and close-ended responses, and the Rasch measurement for analyses rather than the Guttman scale may have contributed to differences in the final MHL scales when compared with the Levin-Zamir et al [11] measure. However, conceptually, the items on each scale are what would be expected if the definitions of functional, interactive, and critical HL proposed by Nutbeam [14] were applied to MHL, and the same item bank was used. Furthermore, the use of images rather than videos has practical implications for how the scales may be used. The capability for self-administration in multiple modalities (eg, online and on paper) means that the scales would have higher utility in research and practice settings. In addition, images such as those used in the MHL scales are familiar to adolescents and are present in multiple types of media that adolescents frequent for health and non-health-related content (eg, websites, health clinics, school hallways, and social media).

The effect sizes for predicting HL-related behaviors from the Recognition/Identification and Influence/Critical Analysis scales ranged from small to large (Cohen  $d=0.34-0.86$ ), suggesting that the final scales are useful in predicting HL-related behavior and for assessing the MHL skills necessary for engaging in applied HL behaviors. The smallest effect sizes were noted for Recognition/Identification; however, this is not surprising, given

that this domain is similar to functional HL and is a more basic skill set than interactive HL. If both scales cannot be used, the MHL Scales-Short Form should be used, as it includes both recognition/identification and influence/critical analysis items. Furthermore, given that the effect sizes for predicting HL-related behaviors from the short form ranged from medium to large, the short form is as good an indicator as or a better indicator of HL-related behaviors than either scale alone.

### Limitations

This study has several limitations. The sample comprised adolescents enrolled in health classes, with some having an interest in health careers; therefore, their MHL ability might be higher than the average adolescent. However, to account for the skewed sample, sample-independent reliability was used instead of person reliability statistics that assume a normal distribution of ability. Future studies with normally distributed ability levels should continue to assess the validity of the scales. Another limitation was the insufficient age and race subgroup sample sizes for calculating DIF for each age and racial group. Despite the insufficient subgroup samples for calculating DIF, Rasch analyses were conducted with an adequate sample, and the racial diversity of the participants throughout each phase of the study is a significant strength of this study. Future studies should include appropriate sample sizes to determine measurement invariance for multiple demographic variables related to MHL, including parent education, household income, and chronic disease status. Longitudinal designs are also required to assess the predictive validity and the sensitivity and specificity of the scales to detect changes over time. An important future consideration is the validation of these MHL scales or the development of similar scales for assessing MHL in adults. The infiltration and expansion of fake news and misinformation on media platforms, especially those related to health, have led to poor and misinformed health decision-making with potentially grave consequences. Although MHL has been implicated in individuals using and sharing health misinformation, there are no measures of adult MHL for assessing this implication or

identifying individuals who may benefit from an MHL intervention.

### Conclusions

This study developed test-based scales of adolescents' MHL that may be self-administered. The Rasch measurement model supported a 9-item Recognition/Identification scale, a 9-item Influence/Critical Analysis scale, a 3-item Action/Reaction scale, and a 12-item Short-Form including items from the Recognition/Identification and Influence/Critical Analysis scales. Although all scales met the assumptions of the Rasch measurement model, the Action/Reaction scale did not have good convergent and criterion validity; therefore, this scale should not be used until more research is done on its psychometric properties. The Recognition/Identification and Influence/Critical Analysis scales and the MHL Scales-Short Form had good criterion and convergent validity. These scales could be used in clinical and research settings to inform interventions, policies, and programs to improve adolescents' MHL and health decision-making.

### Practical Implications

The development of MHL scales is a critical step in determining the impact of MHL on the relationship between media use and health outcomes and ultimately informing the development of programs, interventions, and policies to reduce the negative effect of media use on adolescents' health outcomes. The Recognition/Identification and Influence/Critical Analysis scales and their combined short form are useful in multiple settings. For example, health teachers may use the scales as a pretest to assess their students' abilities and to plan and implement curricula for improving students' MHL accordingly. Researchers and practitioners may also use the scales to identify MHL intervention needs for adolescents. Furthermore, the scales may be used to collect data to establish a baseline understanding of adolescents' MHL skills, which may inform health-related media content developed for adolescents.

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### Conflicts of Interest

None declared.

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#### Multimedia Appendix 1

Final Recognition/Identification Scale.

[[DOCX File , 467 KB - pediatrics\\_v5i2e35067\\_app1.docx](#) ]

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#### Multimedia Appendix 2

Final Influence/Critical Analysis Scale.

[[DOCX File , 193 KB - pediatrics\\_v5i2e35067\\_app2.docx](#) ]



## Multimedia Appendix 3

Final Action/Reaction Scale.

[\[DOCX File , 192 KB - pediatrics\\_v5i2e35067\\_app3.docx \]](#)

## Multimedia Appendix 4

Media Health Literacy Scales-Short Form.

[\[DOCX File , 194 KB - pediatrics\\_v5i2e35067\\_app4.docx \]](#)

## Multimedia Appendix 5

Tables of standardized residual correlations and reliability statistics of all media health literacy (MHL) scales.

[\[DOCX File , 17 KB - pediatrics\\_v5i2e35067\\_app5.docx \]](#)**References**

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## Abbreviations

- DIF:** differential item functioning
- eHEALS:** eHealth Literacy Scale
- HL:** health literacy
- KR-20:** Kuder-Richardson Formula 20
- MHL:** media health literacy
- NVS:** Newest Vital Sign
- OR:** odds ratio

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Original Paper

# Contrasting Social Media Use Between Young Adults With Inflammatory Bowel Disease and Type 1 Diabetes: Cross-sectional Study

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## Abstract

**Background:** Social media is used by young adult patients for social connection and self-identification.

**Objective:** This study aims to compare the social media habits of young adults with inflammatory bowel disease (IBD) and type 1 diabetes (T1D).

**Methods:** This is a cross-sectional study of subjects from Boston Children's Hospital outpatient IBD and diabetes clinics. Patients above 18 years of age were invited to complete a brief anonymous survey, which asked about the various ways they use several social media platforms.

**Results:** Responses were received from 108 patients (92.5% response rate), evenly split across disease type. We found that 83% of participants spent at least 30 minutes per day on social media, most commonly on Instagram and Facebook. Although the content varied based on the platform, patients with IBD posted or shared content related to their disease significantly less than those with T1D (23% vs 38%,  $P=.02$ ). Among Instagram users, patients with IBD were less likely to engage with support groups (22% vs 56%,  $P=.04$ ). Among Twitter users, patients with IBD were less likely to seek disease information (77% vs 29%,  $P=.005$ ). Among Facebook users, patients with IBD were less likely to post about research and clinical trials (31% vs 65%,  $P=.04$ ) or for information seeking (49% vs 87%,  $P=.003$ ). Patients with IBD were also less likely to share their diagnosis with friends or family in person.

**Conclusions:** Young adults with IBD were less willing to share their diagnosis and post about or explore the disease on social media compared to those with T1D. This could lead to a sense of isolation and should be further explored.

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## KEYWORDS

social media; inflammatory bowel disease; type 1 diabetes; internet; young adult; children; Instagram; Facebook; type 1; diabetes

## Introduction

Inflammatory bowel disease (IBD) and type 1 diabetes (T1D) are both prevalent chronic diseases with significant impact on health and quality of life [1,2]. Young adults in particular are

affected by the social and interpersonal impact of these conditions [3] at a time when social interaction with peers is often central. Young adults may face loss of other familiar social structures at this time such as moving away from the family

home, starting college, starting a job, and transitioning their medical care to new providers [4,5].

Social media consists of a rapidly changing collection of internet tools and phone apps. However, literature has consistently shown that adolescents and young adults use social media to make social connections, seek support, explore self-identity, and learn self-presentation and disclosure [6]. Prior to the COVID-19 pandemic, 76% of American teenagers used at least one form of social media, with an average daily usage of 1 hour and 11 minutes [6], and this likely increased with the onset of the pandemic. Social media is a commonly used tool that may provide clues about how young adults are feeling through their self-disclosures, discussion of their condition, searches for information, or avoidance of the topic.

Young adults with IBD and T1D are useful comparisons as these conditions vary in public familiarity and stigma. IBD has been reported to have very poor public familiarity and was ranked in one study as having higher social stigma than genital herpes, alcoholism, and obesity [7]. Diabetes is more common in the general population and better recognized. Some studies have evaluated social media use by a cohort of patients with a single condition such as IBD, but there is limited literature about social media patterns of patients with contrasting conditions [8]. Specifically, to our knowledge, no prior study has explored and compared social media usage of adolescents with IBD and those with T1D. This comparison can be used to help begin to tease out which factors influence how young adults use social media with respect to their medical condition. We hypothesize that patients with T1D will know others with the condition and will be more inclined to share health information. In contrast, we wonder if patients with IBD will share less as the condition is less well known and has more associated stigma [9].

## Methods

### Participants and Data Collection

This cross-sectional pilot study included 108 young adult patients who presented to outpatient Boston Children's Hospital IBD and diabetes clinics from October 2019 to January 2020. Patients were given an envelope with the invitation letter and the survey and could return the envelope with the survey blank or filled out. Of the 126 patients given envelopes, 108 filled in answers. Information for the study was collected in an anonymous paper-based survey. Those who were younger than 18 years old or who were not proficient in English were excluded. Eligible patients were informed about the study and that submission of the anonymous survey would imply consent to use their answers for research.

The survey was created to explore specific issues not found in validated instruments. One round of pilot testing was done with a group of 4 patients. Further iterations were done with providers knowledgeable about surveys and these conditions and young adults with other conditions. The instrument has not yet been validated.

The patient survey collected demographics, including participants' age, gender, race, diagnosis (Crohn disease or ulcerative colitis, for the IBD group only), time since diagnosis,

and self-reported disease severity on a scale of 1-5, with 5 being most severe. The survey explored participants' social media usage and posting patterns, along with in-person habits such as how often and with whom they discuss their diagnoses.

### Ethics Approval

This study was approved by the Boston Children's Hospital Institutional Review Board (IRB-P00032571).

### Statistical Analysis

Patient age and disease severity are described with mean (SD) and all other patient characteristics with frequency (percentage). Patient characteristics were compared between the T1D and IBD groups using the standardized difference to assess balance. To do this, propensity scores ( $P_i$ ) were obtained from a logistic regression model using Firth penalized maximum likelihood estimation to reduce bias in the parameter estimates due to low prevalence of some predictors. A total of 3 indicator variables for disease history (1-2, 3-5, or 6 or more years ago; referencing <1 year ago) and 5 indicator variables for disease severity (1=mild, 5=most severe; referencing unknown severity) were included in the model. Inverse probability of treatment weights (IPTW) were calculated as  $1/P_i$  for the  $i^{th}$  observation in the T1D group, and as  $1/(1-P_i)$  for the  $i^{th}$  observation in the IBD group. Standardized differences were calculated for each patient characteristic  $X$  as  $\frac{\bar{X} - \bar{X}_{pooled}}{SD_{pooled}}$ , where  $\bar{X}$  = mean of patient characteristic  $X$  and  $SD_{pooled}$  = standard deviation pooled over the two groups. Absolute standardized differences <0.25 were deemed negligible [10]. The overlap of the distributions of estimated propensity score by disease type (common support) was assessed graphically (Multimedia Appendix 1).

Respondent characteristics (age, sex, race, ethnicity) as well as disease severity and time since diagnosis are described with unweighted summary statistics. Survey questions regarding how much patients thought about their disease and how much they discussed their disease were reverse coded so that higher scale numbers were associated with higher frequency of behavior. Categories of questionnaire (Likert scale) items are reported as weighted (IPTW) percentages and summarized by weighted median and IQR for each disease group. To avoid confusion, the frequencies corresponding to weighted percentages are not shown since the weighting resulted in fractional quantities that were not directly comparable to the observed sample sizes. For categorical (nonordered) survey questions, comparisons between disease groups were made with the Rao-Scott chi-square statistic. For Likert scale items, the nonparametric Jonckheere-Terpstra test for ordered categories was used to compare groups; it has greater power for ordered categories than the Wilcoxon rank-sum test. All comparisons are unadjusted for other covariates with statistical tests ( $P$  values) based on the propensity score weighted (IPTW) data. All tests of significance were 2-sided, with  $P < .05$  considered statistically significant. Analysis was performed with SAS (version 9.4; SAS Institute).



## Results

A total of 108 patients completed the study questionnaire and they were evenly split across disease type. Participants consisted of 59 male patients and 49 female patients, and 11% (12/108) were Hispanic or Latino. Mean age was 20.3 (SD 2.1) years (range 18-25), and median self-reported disease severity was 3 (IQR 2-3; range 1-5, from mild to most severe). The majority of participants (68/108, 63%) were diagnosed more than 5 years ago. Absolute standardized differences were beyond the negligible threshold of >0.25 for age (0.35) and disease severity ratings 1 (mild; 0.57), 2 (0.33), and 3 (0.62). After applying inverse probability of treatment weights, all patient characteristics had absolute standardized differences <0.25 (range 0.00-0.12; Table 1), considered negligible.

Overall, patients with IBD and T1D appear to have different patterns of in-person interactions regarding their diagnoses

(Figure 1). Patients with T1D reported thinking about their disease and discussing their disease with others more often when compared to patients with IBD (thinking: median 6, IQR 5-6 vs median 5, IQR 4-5,  $P<.001$ ; discussing: median 4, IQR 2-5 vs median 3, IQR 1-4,  $P<.001$ ). Those with T1D were also quicker (lower score) to share their diagnosis with others than patients with IBD (median 1, IQR 1-2 vs median 2, IQR 1-4,  $P<.001$ ). Compared to patients with IBD, those with T1D were more likely to discuss their disease with friends (87% vs 69%,  $P=.001$ ), their significant other (66% vs 41%,  $P<.001$ ), and colleagues (35% vs 12%,  $P<.001$ ; Figure 1). There was no correlation between time since diagnosis and how often patients thought about ( $P=.86$ ) or discussed their disease with others ( $P=.26$ ; Figure 2). Finally, compared to patients with IBD, those with T1D were more likely to report knowing family/friends (62% vs 38%,  $P=.002$ ) or celebrities with their diagnosis (71% vs 29%,  $P=.01$ ; data not shown).

**Table 1.** Patient characteristics (N=108).

| Characteristics                            | Unweighted              |            |            | Absolute difference (T1D-IBD) | Standardized difference (T1D-IBD) <sup>a,b</sup> |           |
|--|-------------------------|------------|------------|-------------------------------|--|-----------|
|  | All respondents (N=108) | IBD (n=54) | T1D (n=54) |                               | Unweighted                                       | Weighted  |
| Age (years), mean (SD)                     | 20.3 (2.1)              | 20.6 (2.2) | 19.9 (1.9) | -0.7 (2.1)                    | -0.35  | 0.12      |
| <b>Sex, n (%)</b>                          |                         |            |            |                               |  |           |
| Male                                       | 59 (55)                 | 32 (59)    | 27 (50)    | -5 (8)                        | -0.19  | 0.08      |
| Female                                     | 49 (45)                 | 22 (41)    | 27 (50)    | 5 (8)                         | 0.19   | -0.08     |
| Hispanic or Latino, n (%)                  | 12 (11)                 | 4 (7)      | 8 (15)     | 4 (8)                         | 0.24   | 0.03      |
| White <sup>c</sup> , n (%)                 | 89 (87)                 | 45 (88)    | 44 (86)    | -1 (2)                        | -0.05  | 0.00      |
| <b>Disease severity<sup>d</sup>, n (%)</b> |                         |            |            |                               |  |           |
| 1 (mild)                                   | 11 (11)                 | 10 (19)    | 1 (2)      | -9 (17)                       | -0.57  | 0.08      |
| 2  | 30 (29)                 | 19 (37)    | 11 (21)    | -8 (16)                       | -0.33  | -0.05     |
| 3  | 46 (45)                 | 15 (29)    | 31 (61)    | 16 (32)                       | 0.62   | 0.02      |
| 4  | 12 (12)                 | 7 (13)     | 5 (10)     | -2 (3)                        | -0.12  | -0.10     |
| 5 (most severe)                            | 4 (4)                   | 1 (2)      | 3 (6)      | 2 (4)                         | 0.20   | 0.06      |
| <b>Years since diagnosed, n (%)</b>        |                         |            |            |                               |  |           |
| <1   | 6 (6)                   | 3 (6)      | 3 (6)      | 0 (0)                         | Reference  | Reference |
| 1-2  | 9 (8)                   | 6 (11)     | 3 (6)      | -3 (5)                        | -0.20  | -0.06     |
| 3-5  | 25 (23)                 | 14 (26)    | 11 (20)    | -3 (6)                        | -0.13  | -0.01     |
| >5   | 68 (63)                 | 31 (57)    | 37 (68)    | 6 (11)                        | 0.23   | 0.06      |

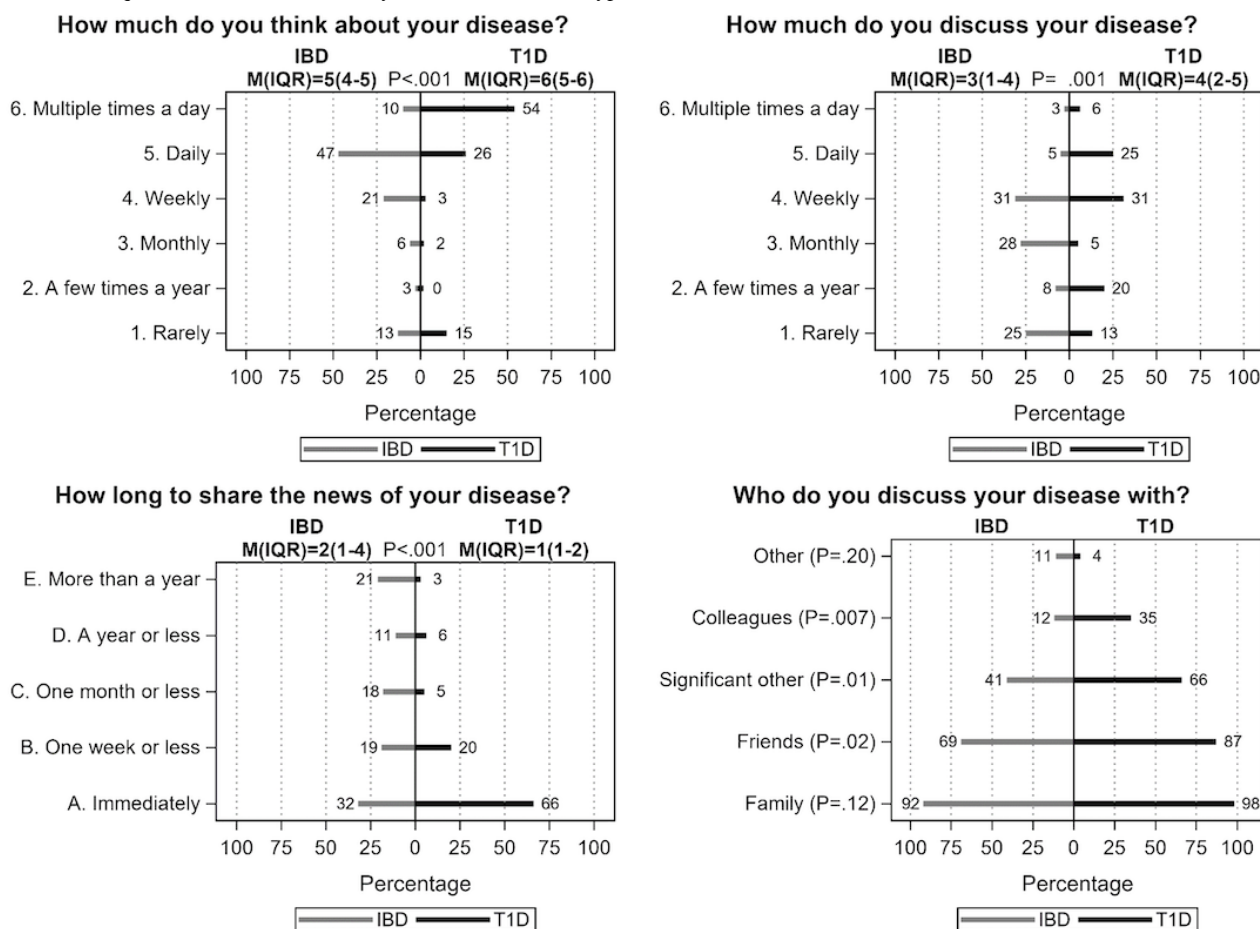
<sup>a</sup>T1D: type 1 diabetes.

<sup>b</sup>IBD: inflammatory bowel disease, including Crohn disease (n=38), ulcerative colitis (n=15), and indeterminate colitis (n=1).

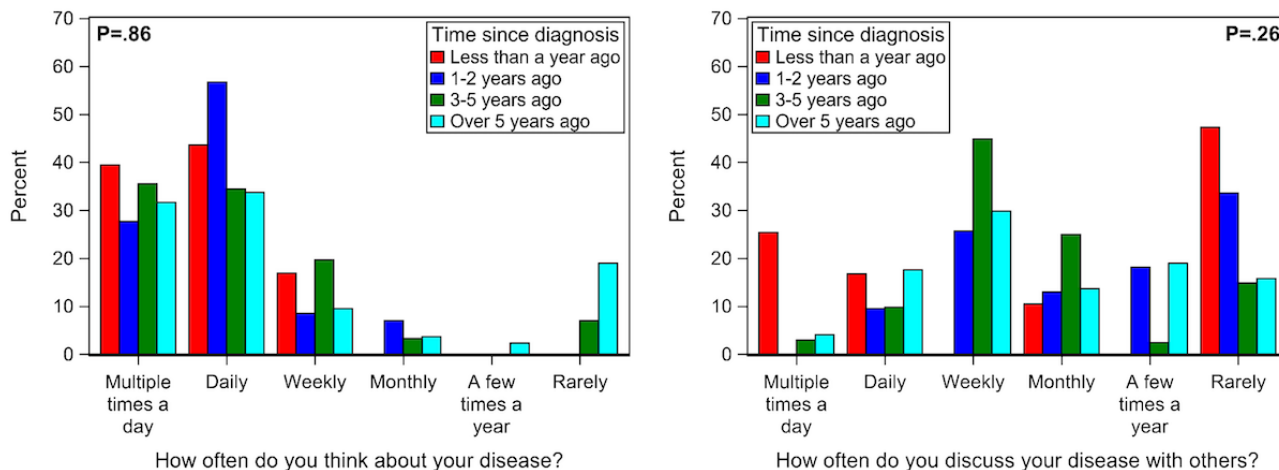
<sup>c</sup>N=6 (3 IBD, 3 T1D) unknown. Non-White races were African American (n=5), Asian (n=4), Cape Verdean (n=1), Haitian American (n=1), Native American (n=1), and unspecified other (n=1).

<sup>d</sup>N=5 (2 IBD, 3 T1D) declined to answer. Indicator variables were used to assess balance across the groups.

**Figure 1.** Comparison of in-person interactions by disease type. Weighted percentage and median (IQR) are shown for "select one response" questions with 2-group comparison by Jonckheere-Terpstra test, and weighted percentage for "check all that apply" questions compared with 2-group comparison by Rao-Scott chi-square test. IBD: inflammatory bowel disease; T1D: type 1 diabetes.



**Figure 2.** Association of time since disease diagnosis by (A) how often you think about your disease and (B) how often you discussed your disease with others. P value from Rao-Scott chi-square test after combining (1) weekly and rarely categories, and (2) <1 year, 1-2 years, and 3-5 years ago, to avoid table cells containing zeros.



Almost all patients (99%) reported actively using social media, and most (84%) spent at least 30 minutes per day on social media. Instagram was the most common platform (40% of users), followed by Facebook (38%) and Twitter (25%; Figure 3). There was no difference by disease group for amount of time spent on social media; however, Facebook users were more likely to be patients with T1D than IBD (49% vs 26%, P=.03; Figure 3). Overall, 73% of patients with T1D vs 51% of patients

with IBD (P=.03) reported disease-specific social media usage on one or more of these platforms (including searching, reading posts, following other accounts, posting or sharing content) from time of diagnosis until the time of the survey. The most frequent activity related to their personal experiences with their disease (60% posted to at least one platform), ranging from following "new developments or funny moments" or "profiles of others" to posting about one's disease. The least commonly

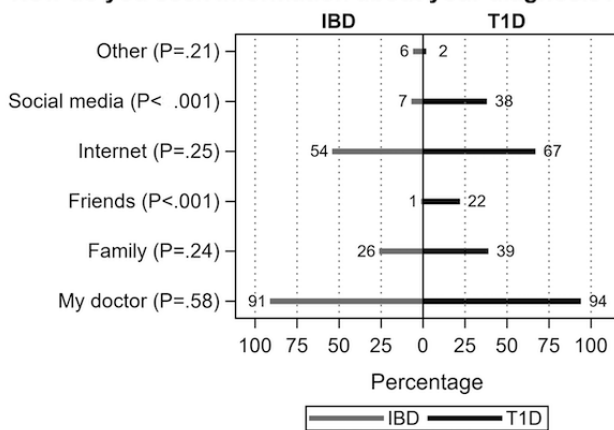
reported platformwide uses included drugs or therapeutics and research or clinical trials (Figure 4).

Overall, disease-specific social media activity differed by platform. Among Instagram users, patients with T1D were more likely to engage with support groups (56% vs 22%,  $P=.04$ ). Among Twitter users, patients with T1D were more likely to post/share about disease-related events (80% vs 27%,  $P=.003$ ) and for information seeking (77% vs 29%,  $P=.005$ ). Finally, among Facebook users, patients with T1D were more likely to

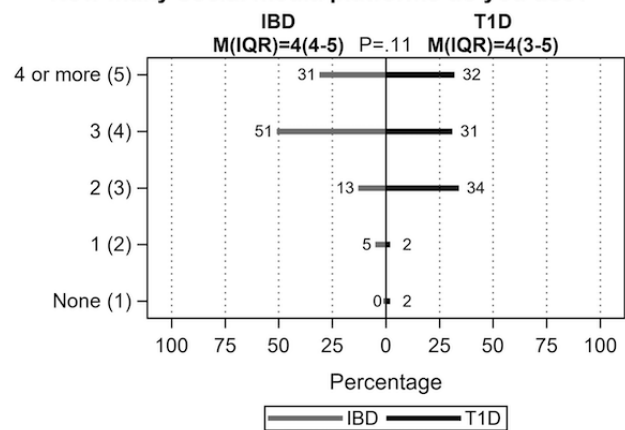
post about research and clinical trials (65% vs 31%,  $P=.04$ ) and for information seeking (87% vs 49%,  $P=.003$ ), while patients with IBD were more likely to post about fundraising (85% vs 40%,  $P<.001$ ; Figure 4). In contrast to high usage rates, only 31% of patients had specifically posted or shared content about their condition across any of these platforms from the time of diagnosis to enrollment date, with 38% of patients with T1D posting or sharing compared to 23% patients with IBD ( $P=.02$ ; data not shown).

**Figure 3.** Patient information seeking. Weighted percentage and median (IQR) shown for "select one response" questions with 2-group comparison by Jonckheere-Terpstra test, and weighted percentage for "check all that apply" questions compared with 2-group comparison by Rao-Scott chi-square test. IBD: inflammatory bowel disease; T1D: type 1 diabetes.

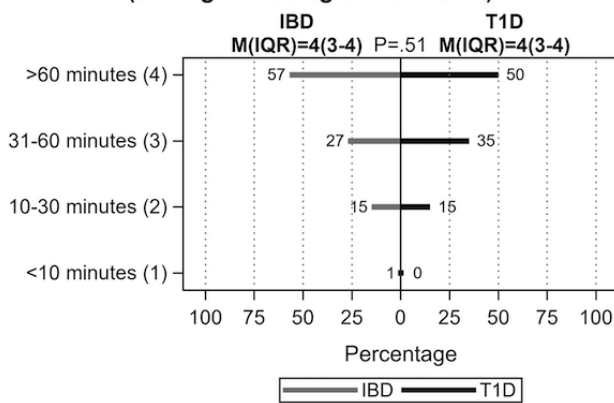
**How do you seek information about your diagnosis?**



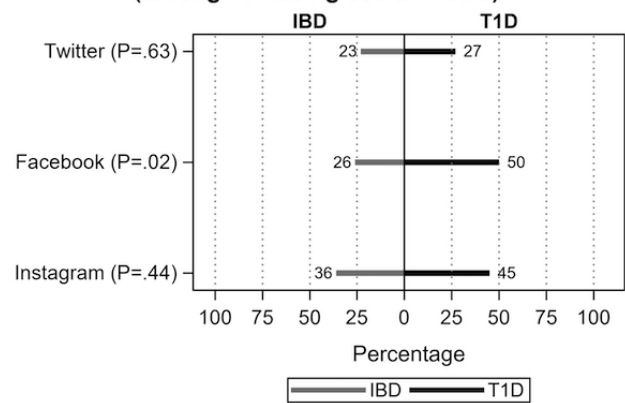
**How many social media platforms do you use?**



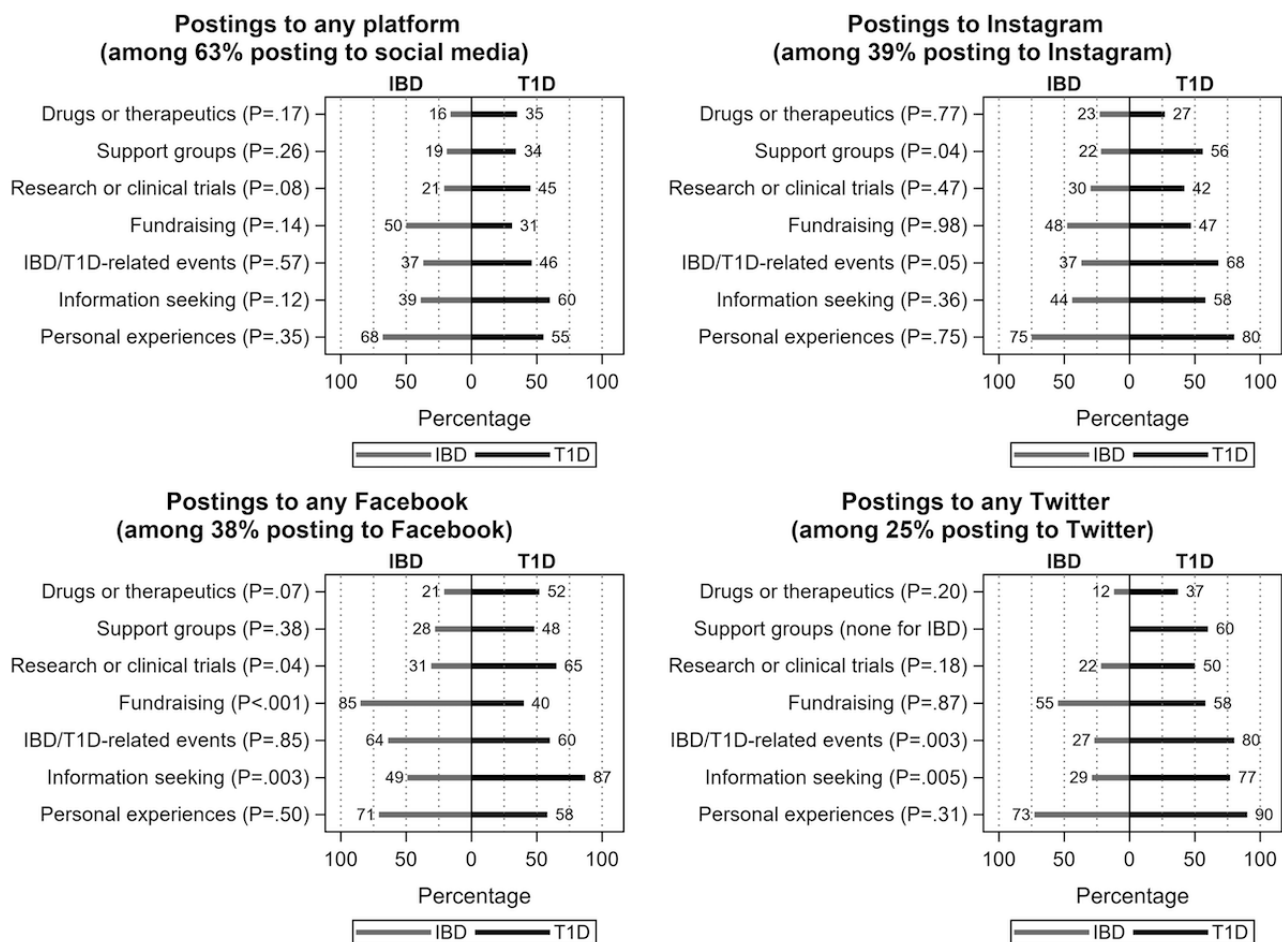
**How long do you spend on social media per day? (among 107 using social media)**



**Social media platforms used (among 107 using social media)**



**Figure 4.** Comparison of information seeking by disease type. Reported are the weighted percentages and Rao-Scott chi-square test results. IBD: inflammatory bowel disease; T1D: type 1 diabetes.



## Discussion

### Overview

Our study explores the social media practices of young adult patients with two very different chronic diseases, IBD and T1D. The use of social media was almost universal, and the time spent on social media did not differ by diagnosis. Researchers such as Uhls and Moreno and colleagues [6,11] would argue this is typical for all adolescents and that social media can enable the important developmental tasks of connecting with peers and exploration of identity.

### Disclosing or Sharing

We found that patients with T1D were far more likely than those with IBD (38% vs 23%) to specifically post about their condition on social media. Patients with T1D discussed their diagnosis with others more often and sooner after their diagnosis, with a majority of respondents sharing their diagnosis immediately. Patients with T1D may be more likely to share or discuss their diagnosis as it is more visible in the community and mainstream media, and a feeling of social belonging is important for adolescents [12]. Those with T1D more frequently reported knowing both family/friends and celebrities (eg, singer Nick Jonas) with their disease compared to patients with IBD. In comparison, it has been shown that public familiarity with IBD is poor and comprehension of this disease is limited [7]. Patients

with IBD may thus fear that disclosure would not be met with understanding and acceptance. Studies have found that adolescents with IBD preferred not to reveal their condition and cited negative reactions as a major factor [13] and those experiencing stigma had more health communication difficulties. There is a wide range of disclosure by patients.

One Italian study that studied patients with 4 conditions, including IBD and T1D, found that 98% expressed a need to share their medical condition on social media [14]. However, another study of patients with connective tissue disorders noted only 17% revealed their condition on social media [15]. These studies can be used to put the disclosure rate of young adults with IBD and T1D in context.

Those with T1D also thought about their disease more often than patients with IBD, with a majority of participants choosing “multiple times a day,” whereas patients with IBD most often reported “daily” or “weekly.” This is understandable given that patients with diabetes are often on multiple-dose insulin regimens and must carefully consider their diets and adjust dosing for changes such as physical activity or illness [16]. On the other hand, many IBD treatment options are dosed on a biweekly or monthly basis, though some medications must still be taken daily [17].



## Information Gathering

Social media is less commonly used for information gathering than internet sites. Patients with T1D always reported more information gathering than those patients with IBD, although the exact percent varied by platform. This discrepancy is echoed in the literature. One study of the adolescent diabetes population suggested growing interest in using social media to find information [18]. In contrast, a study found that youth with IBD were rarely using social media as an information source [19]. This represents a new avenue for physicians to engage with their patients in an accessible manner. It is also important to educate patients to be critical of the accuracy and quality of health-related information posted on social media, especially if it is used to inform health or treatment-based decisions.

## Community or Connection

Social media can be a powerful tool for creating friendships and connections, particularly among those with similar experiences. We found that, overall, 34% of patients with T1D used social media for support groups compared with 19% of patients with IBD. It is difficult to directly compare one study to another in the literature as the platforms included in the term social media keep shifting. Facebook is one social media platform that has been popular for support groups, particularly for those with rare or embarrassing conditions. The use of private groups on Facebook helps assuage some concerns about privacy. A large number of patients used Facebook to search for friends with the same disease or community support groups to find others who were going through the same thing and could understand their feelings [14]. These online social connections might be particularly important for patients with IBD as some researchers have postulated that the embarrassment of frequent bathroom trips or diarrhea might lead to perceived stigma and social withdrawal [12]. One program used Instagram to augment the social supports for adolescents with T1D to avoid the barriers of travel and time required to attend in person [20]. Online diabetes communities have been shown to be important for peer support as well as problem solving [21].

Another common theme of social media posts for both groups was humor, especially on Twitter. An analysis of humor in the chronic care setting showed patient-initiated humor was most commonly used to deal with negative emotions [22]. Therefore, including this sentiment in social media posts may be an important coping strategy for young adults. Overall, despite low disease-specific posting and sharing rates, young adults in both groups engage with social media in a variety of ways. These platforms can still be an important tool for understanding

how young adults feel about and cope with their chronic disease, and may also represent an avenue for providers to interact with their patients.

There are some limitations to this study. This is a single-center study and thus the patient population may not be generalizable. We sought to decrease selection bias by inviting every eligible patient in a consecutive manner and offering a nonconfrontational way to refuse participation, by turning in a black survey inside the envelope. However, selection bias is always present. Young adult responses may be affected by embarrassment or social desirability. The survey instrument also did not ask specifically about Snapchat or TikTok (though some participants did mention Snapchat in the written portion of the survey), which are also popular among this age group. These platforms typically encourage more spontaneous posting or usage, and could represent an important contrast to the other platforms investigated in our study [23,24]. In addition, young adults may have multiple accounts on a single social media platform—for instance, auxiliary accounts on Instagram are colloquially referred to as “finsta,” a portmanteau of “fake” and “Instagram.” These accounts are often less curated and again consist of more spontaneous posting and could also be a key tool for patients to share about or cope with their disease [25]. TikTok has become much more popular even in the time since the study was conducted, and the absence of this platform does limit more current assessment of social media use. Lastly, this study aims to compare social media usage among only two specific patient populations; therefore, it would be advantageous for future research to investigate this topic across institutions and among diverse illnesses.

## Conclusion

Overall, this study expands our understanding of social media use among young adults with chronic disease. To our knowledge, there is limited understanding of how specific chronic conditions impact the use of social media. This study hints at familiarity of disease and stigma around a condition as factors that affect engagement. The more that is known about how patients use these various forms of social media, the more impact providers can have. Patients with IBD seem to communicate far less about their disease compared to patients with T1D in almost all realms across various social media platforms, which has significant implications for education, sense of community, and self-acceptance. Future research is needed for deeper explorations of even more media platforms and a wide array of chronic conditions.

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## Conflicts of Interest

None declared.

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Multimedia Appendix 1

Supplemental figure.

[[DOCX File, 21 KB - pediatrics\\_v5i2e34466\\_app1.docx](#)]

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## Abbreviations

**IBD:** inflammatory bowel disease

**IPTW:** inverse probability of treatment weights

**T1D:** type 1 diabetes

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Original Paper

# Social Media and Online Digital Technology Use Among Muslim Young People and Parents: Qualitative Focus Group Study

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## Abstract

**Background:** Digital technology and social media use are common among young people in Australia and worldwide. Research suggests that young people have both positive and negative experiences online, but we know little about the experiences of Muslim communities.

**Objective:** This study aims to explore the positive and negative experiences of digital technology and social media use among young people and parents from Muslim backgrounds in Melbourne, Victoria, Australia.

**Methods:** This study involved a partnership between researchers and a not-for-profit organization that work with culturally and linguistically diverse communities. We adopted a participatory and qualitative approach and designed the research in consultation with young people from Muslim backgrounds. Data were collected through in-person and online focus groups with 33 young people aged 16-22 years and 15 parents aged 40-57 years. Data were thematically analyzed.

**Results:** We generated 3 themes: (1) maintaining local and global connections, (2) a paradoxical space: identity, belonging and discrimination, and (3) the digital divide between young Muslims and parents. Results highlighted that social media was an important extension of social and cultural connections, particularly during COVID-19, when people were unable to connect through school or places of worship. Young participants perceived social media as a space where they could establish their identity and feel a sense of belonging. However, participants were also at risk of being exposed to discrimination and unrealistic standards of beauty and success. Although parents and young people shared some similar concerns, there was a large digital divide in online experiences. Both groups implemented strategies to reduce social media use, with young people believing that having short technology-free breaks during prayer and quality family time was beneficial for their mental well-being.

**Conclusions:** Programs that address technology-related harms must acknowledge the benefits of social media for young Muslims across identity, belonging, representation, and social connection. Further research is required to understand how parents and young people can create environments that foster technology-free breaks to support mental well-being.

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**KEYWORDS**

Muslim; social media; young adult; qualitative research; social connection; parenting; pediatrics; digital health; youth; adolescent; parent; digital technology; user experience; mental health; psychological effect; diverse population; COVID-19

## Introduction

Digital technology and social media have changed how people interact and build social connections [1]. Social media sites, such as Instagram, Facebook, SnapChat, YouTube, and TikTok, have become increasingly popular and enable young people to relax, seek information, and construct and maintain their social networks [2,3]. Since the COVID-19 pandemic, social media use among young people has increased, particularly during lockdown periods, when socializing outside of the home was heavily restricted [4,5]. Although routine social media use has been associated with higher levels of social well-being and positive mental health [6], emotional connection to social media, excessive use, and passive browsing have been associated with decreased social well-being and poorer mental health outcomes [7-9]. However, these findings are heterogenous, and few studies have adopted longitudinal designs; thus, it is unclear whether social media has negative effects on well-being [10,11]. Although these quantitative data are important, they do not provide insight into the experiences that young people have online.

Qualitative research has explored young people's use of digital technology and social media to access news, develop relationships, and form their identity [12-15]. Parents have also documented their concerns about their children spending time online, fearing they will be exposed to online bullying, isolation from the outside world, and negative mental health outcomes [16,17]. However, few studies have focused on the online experiences of young people and parents from cultural and ethnic minority groups. Minority populations have experienced racism and discrimination online, including Islamophobic hate speech, targeted bullying, and threats of offline violence for people from Muslim backgrounds [18-20]. Importantly, young people from cultural and ethnic minority groups also use social media to access social support and connect with family who live overseas [21,22]. Young people from Muslim backgrounds have also described how online environments promote agency, social connection, inclusion, and expression of identity and religion [23-27]. Few qualitative studies have recruited both young people and parents from cultural and ethnic minority groups; thus, further research is required to better understand their experiences on social media, particularly during the COVID-19 pandemic.

In Australia, the 2016 census reported that 3% of the population identified as Muslim [28]. Approximately 37% of this group were born in Australia and 63% were born overseas across countries in North Africa, the Middle East, and South and Central Asia [29]. In 2019, Green Crescent Australia, a not-for-profit organization that works closely with Muslim community members in Melbourne, Victoria, Australia, approached researchers and indicated that community members had expressed concern about technology dependence among young people. These concerns were predominantly from parents and older community members; however, it was unclear whether concerns reflected the experiences of young people from Muslim backgrounds. To develop recommendations, programs, and policies that are relevant for families, it is essential to listen to both young people and parents from Muslim backgrounds and

promote their voices and experiences [30,31]. In this exploratory study, we aim to understand the positive and negative experiences of digital technology and social media use from the perspective of young people and parents from Muslim backgrounds.

## Methods

### Partnership

This exploratory study involved a partnership between Green Crescent Australia, the Burnet Institute, and La Trobe University. Green Crescent Australia is a not-for-profit organization that provides culturally intelligent education and awareness programs for substance and behavioral dependencies in culturally and linguistically diverse communities. The Burnet Institute is a not-for-profit medical research organization with experience in exploring social media use of young people. La Trobe University has research programs exploring diverse public health issues. Each partner brought unique skillsets to the study, including community connections, cultural knowledge, and youth-friendly research skills.

### Study Design and Development

Green Crescent Australia approached the researchers to develop a study exploring technology dependence among young Muslims based on concerns from parents that arose during regular community meetings. We developed the study design and research questions through face-to-face and phone meetings between the study partners. Based on the researchers' experience of conducting studies with young people and reading background literature, we suggested exploring both negative and positive experiences of social and digital media from the perspective of young people and parents from Muslim backgrounds. Overall, we adopted a participatory and qualitative approach that was appropriate for the study aim of understanding participant experiences with social media. The research team held 2 sessions with Green Crescent Australia representatives (4 adults and 10 young people) to present ideas, pilot-test activities, and obtain feedback on the study design. Overall, the representatives believed their peers would be comfortable discussing digital technology and social media in small groups with people of similar age and gender, thus leading to the use of focus groups. Focus groups were deemed appropriate because interactions between participants can provide further insight into their experiences with social media [32]. Both adult and youth volunteers suggested to make the focus groups culturally appropriate by including halal food options, dressing appropriately, building in time for prayer breaks, and holding the focus groups at venues familiar to participants (eg, mosques, schools).

### Ethics Approval

The La Trobe University Human Research Ethics Committee approved the study (#HED 19458).

### Participants and Recruitment

Young people were eligible to participate in the study if they were aged between 16 and 22 years and identified as Muslim. This age range was selected to account for the researchers' past



experiences where wide age gaps between participants limited the ability of younger participants to contribute to the discussion. Parents were eligible if they identified as Muslim and had children aged 13-22 years; this age range was chosen as we anticipated some shared concerns from parents of teenagers and young adults. Parents did not have to be related to a young person in the study to be eligible. Because the Green Crescent Australia representatives were part of the Muslim community, they assisted in participant recruitment. We used purposive sampling to ensure that we recruited participants who represented different genders, age groups, and ethnicities and were able to provide relevant information about the topic. Determining our sample size was a pragmatic exercise [33]; we aimed to recruit between 40 and 50 participants based on the study time frame and budget and to collect data from a diverse sample. Green Crescent Australia representatives contacted Muslim youth organizations, Islamic schools, and their social networks to describe the study's purpose. Those who were interested were sent a copy of the participant information sheet and consent form prior to the focus group.

### Data Collection

We held 7 focus groups of 90 minutes each between November 2019 and September 2020, including 4 with only young people, 2 with only parents, and 1 with both young people and parents. The first 4 focus groups were in person at local mosques and community-based venues in the cities of Melbourne and Hume. Most participants who attended the focus groups knew one another beforehand. During data collection, Melbourne went into 112 days of COVID-19 lockdown; thus, we submitted an ethics amendment so that the 3 remaining focus groups could occur online through the videoconferencing platform Zoom [34]. Researchers facilitated the focus groups in English, with support from a Green Crescent Australia representative who could speak Arabic. A female researcher facilitated the female focus groups, and 2 male researchers facilitated the male focus groups. One exception was 1 male participant who attended a predominantly female focus group with a relative and friends. Prior to the focus group starting, the researchers verbally explained the study and provided an opportunity for questions. Participants were invited to provide written informed consent for in-person focus groups and verbal consent for online focus groups.

The focus groups began with an icebreaker activity, where participants and facilitators shared the meaning of their name. We asked young people and parents to list how they or their children used digital technology throughout the day (eg, what devices, programs, websites, social media sites, and apps). This activity generated discussion between participants and was followed up with the prompt "What are the positive and negative impacts of digital technology or social media on your or your children's lives?" After the first 2 focus groups, the researcher adapted the focus group guide to include additional prompts about strategies to reduce technology use, as participants brought this up of their own accord in the first 2 focus groups. When focus groups were in person, participants recorded their responses on sticky notes and added them on to a whiteboard compared to Zoom focus groups where we used an interactive online whiteboard. Written responses were used to generate

discussion, and participants could elaborate on their answers. Upon completion, participants received AU \$40 (US \$28.44) in cash or were sent an AU \$40 (US \$28.44) voucher if they attended online focus groups.

### Data Analysis

Focus groups were audio-recorded and transcribed verbatim. Personal identifying information was removed from the transcripts. We coded and analyzed the data thematically using a descriptive approach [35]. This process involved reading the transcripts multiple times and reviewing the written and electronic material produced by the participants. Transcripts were coded in NVivo (QSR International) [36]. We adopted an inductive approach to coding and generated ideas from the raw data rather than using a codebook. Coding focused on understanding the meanings and experiences that participants ascribed to digital technology and social media. We also noted where there were key differences between participant groups (eg, gender, parents/young people, before or during COVID-19). In total, 6 preliminary themes were summarized and presented verbally to coauthors for feedback. Discussions indicated that although preliminary themes were relevant to the research question, there was some overlap between ideas. Consequently, the first author placed all codes into a mind map, reviewed the transcripts, and rearranged the data into 3 key themes. Coauthors provided additional feedback on the content included in each theme.

### Researcher Positionality

In this study, the research team consisted of 2 Muslim and 4 non-Muslim researchers. The Green Crescent Australia representatives involved in study development, participant recruitment, and data collection and interpretation also identified as Muslim. Data analysis was led by a non-Muslim researcher; thus, obtaining feedback from the broader research team was essential to ensure we considered religious and cultural factors that may have been missed. In addition, 2 researchers were under 30 years old, 2 were parents, and all used social media; thus, each individual brought a unique perspective to data interpretation.

## Results

### Participants

Overall, we conducted 7 focus groups with 48 participants, including 33 (69%) young people and 15 (31%) parents. Most of the young participants were female ( $n=25$ , 76%) and born in Australia ( $n=28$ , 85%), whereas most of the parent participants were male ( $n=10$ , 67%) and born overseas ( $n=9$ , 60%). Participants identified with a range of ethnicities, including Turkish, Australian, Somali, Albanian, Ethiopian, Bosnian, Lebanese, Palestinian, Pakistani, African, Yemeni, South Asian, Eritrean, Egyptian, and Jordanian. From these focus groups, we generated 3 key themes to showcase the positive and negative impacts of digital technology and social media from the perspective of young Muslims and parents: maintaining global and local connections, a paradoxical space: identity, belonging and discrimination, and the digital divide between young Muslims and parents.



## Maintaining Global and Local Connections

Theme 1 highlighted how participants perceived online technology as an important environment for social connection both before and during the COVID-19 pandemic. Participants described how social media acted as a space for developing and maintaining social connections in Australia and across national boundaries. Young people described how their online interactions were typically extensions of their friendships from real life; they could spend most of the day with their peers at school or university and then continue interacting online to strengthen their relationships. For both young Muslims and parents, social media and group messaging platforms were seen as practical tools that enabled them to overcome distance and connect with their friends and family who lived overseas.

*Now we can instantly message someone. You used to have to send a letter to someone on the other side of the world. You save a lot of time, you know?* [Young male, online focus group]

Having access to a phone and being constantly contactable by friends and family increased social security for young male and female participants. Although this was not apparent in the parent focus groups, researchers noted that almost all participants checked their phones at least once during the in-person focus groups. Young participants also described being frequently called and messaged by their parents and other family members to ensure they knew their whereabouts. Young participants rarely left home without their phones, expressing an anxiety that they may miss key events or updates in their friendship groups, demonstrating that access to technology is tied to social connection. When asked how they felt when they did not have their phone, a common response was:

*Definitely separated, like, left out, you know? Disconnected in a sense.* [Young male, online focus group]

Among female participants, always carrying a phone and being able to contact people they trusted represented an increased sense of safety. For example, some female participants felt that carrying their phone was responsible and a mechanism for protecting themselves. This topic did not come up during male focus group discussions.

*My phone...if I press the trigger lots of times, it sends an SOS. So, it will send my location to specific people that I want to send it through. So, I have it on for my cousins and my close friends.* [Young female, in-person focus group 1]

Online focus groups held during the Melbourne lockdown period drew attention to the isolation that people experienced. Although participants used social media to connect with friends and family who were outside of their households, both young people and parents felt disconnected during the lockdown that coincided with Eid, a significant religious festival where Muslim community members typically gather for prayer and share food, gifts, and donations. One parent described Islam as a “social religion”; therefore, being unable to connect in person at places of worship was highly difficult. Young people also expressed

missing their routine, in-person social connections that would typically occur through school, work, or university.

*For the past 6 months have not being able to go to the mosque. We can't go. If you go to the mosque, you see people, you say hello, you find out who is suffering, who has problems, you attempt to resolve them. We help each other out as a community. Technology has not reached that point yet.* [Father, online focus group 7]

Overall, prior to the pandemic, it was essential for young people to physically have their phones to feel a sense of social security and physical safety, particularly among young females. After COVID-19 caused long periods of lockdown and physical distancing, having access to technology and social media became essential for both young people and parents to socially connect with the outside world; however, some parents felt that technology was insufficient to generate the sense of community they felt when they attended mosque.

## A Paradoxical Space: Identity, Belonging, and Discrimination

Theme 2 captured how online environments were paradoxical spaces where young Muslims could establish their identity and belonging while also being exposed to discrimination. Young female participants described how online spaces, such as Instagram and TikTok, allowed them to curate communities where they felt comfortable and safe. Young male participants did not discuss comfort and safety; however, they appreciated being able to express their opinions and follow people they admired online. Parents, particularly mothers, also recognized that using social media was considered “normal” for young people and a tool for “fitting in.” When female participants followed accounts that they considered positive, they felt a sense of creativity, inspiration and belonging.

*I feel like it curates, like you have your own little community. Like, um, with my social media, most of my followers, they're all, like, Muslim, so I feel like I know all of them and I feel comfortable with them, so it's having that support from them.* [Young female, online focus group 6]

*I definitely do try and follow more pages of people that look like me and have the same interests as me. I follow pages that are, like, pro-African, pro-Black, like, pro-Islam, [because] that's [the] kind of the thing that we don't get to see anywhere else.* [Young female, focus group 4]

Young people also felt that social media enabled them to see their culture, religion, and minority groups represented. Multiple participants felt this representation and diversity was lacking in mainstream media, which was perceived as biased and one-dimensional. Although mainstream media was seen as an exclusive environment that promoted the agendas of powerful and privileged groups, social media was seen as more inclusive for minority groups. Female participants in the online focus group were particularly passionate about this topic, which coincided with global news about the murder of George Floyd and widespread advocacy on social media.

*Often with regular news, you'll only get a single perspective. With the internet and talking to other people, you get a different understanding or a different point of view rather than what has just been given to you. [Young male, online focus group 5]*

*We were stuck in lockdown during Eid. On social media, you can see, like, everyone...like posting about it. Even, like, when the Black Lives Matter everything happening, you see videos and photos from, like, people that went to protests, people advocating for Black Lives Matter, and as a Black person, you know you feel like you've got support, you've got representation. [Young female, online focus group 6]*

Despite positive experiences, both young people and parents recognized that digital technology has the potential to perpetuate discrimination, exclusion, and unrealistic standards around beauty and success. Parent participants had concerns about online bullying among young people, with mothers expressing fears about the nonconsensual sharing of sexually explicit images. A small number of young female participants echoed these concerns; however, most of the discussion centered on receiving negative comments on social media profiles. Other young people had seen more “passive” acts of discrimination, such as friends sharing, liking, or commenting on racist or Islamophobic posts or videos. Young participants believed the anonymity of the internet allows people to be discriminatory without consequences.

*You can stay somewhat anonymous. With certain individuals, they go around spewing hate...They can speak in the world how they want, and they can get away with certain things. Things that they would not get away with in real life. [Young male, online focus group 5]*

Although social media could be a positive space, most young people compared their lives to the ideals portrayed online by celebrities and influencers. Female participants were frequently exposed to unrealistic beauty standards, which created self-doubt about their own appearance. Young female participants also expressed concern for future generations of young Muslim women who were exposed to social media earlier in life; they recognized that although they could curate their own online spaces, there was still limited beauty coverage inclusive of Muslim women and hijabs.

*Little girls that are growing up now, they're having these, like, expectations to dress in a certain way. Even with social media sometimes, there's not a lot of coverage on females that wear scarves, and if a young child sees that, they just don't feel like they have a place in society. [Young female, online focus group 6]*

*I think it's creating a lot of anxiety, too. My daughter recently went off TikTok because she said, “Everyone on there is so beautiful. They make me feel ugly.” Well, I said, you know, that's probably a good time to get off it. [Father, in-person focus group 3]*

Although parents believed these online pressures were worse for young females, the young male participants also described seeing unrealistic standards of success that made them question their own goals and achievements. Although young male participants recognized that social media showed only the best parts of people's lives, they still questioned their self-worth.

*I think going off that also the fact that people hold certain ideal standards. For social media, for example, someone will only post the really great moments or those really perfect pictures. And they're setting a standard that in reality is not achievable. [Young male, online focus group 5]*

*Seeing people that are successful and all that on social media all the time, it kind of affects you because you think that you need to be there right now. You sit down and compare your life to other people's lives...they don't show their real lives...they're just showing the highlights, the best parts. [Young male, in-person focus group 4]*

These experiences highlight how digital technology can boost the identity and belonging of young Muslims while still being a risk environment for discrimination, self-doubt, and negative self-esteem. Importantly, being able to curate personal online spaces increased the representation of minority groups, which was perceived as lacking on other mainstream channels.

### **The Digital Divide Between Young Muslims and Parents**

Theme 3 outlined the distinctions between how young Muslims and parents defined legitimate and productive forms of technology use and appropriate strategies for reducing time spent online. Importantly, young participants focused on social media sites being mostly positive environments where negative events could occur. In contrast, parents focused on social media sites as negative and potentially dangerous spaces where positive connection was possible. Young people and parents recognized that their generations had been introduced to technology at different life stages, thus creating a major divide in their experiences. Parents perceived that spending time online robbed young people of the opportunity to exist in the “real world” that they had grown up in when they were children/adolescents. They discussed how young people were unaware of their prolonged use and could not see the negative impact it was having on their lives.

*When we were young, we were always outside. Every day. We come home from school, always outside. Now, you look on the street and there is no one outside. My kids, I've got 2 younger boys, they're always on YouTube watching other people play. I'm, like, go and do it yourself! [Father, in-person focus group 3]*

*In these teen years, I feel that they're missing out on, like, actually life, like doing things, seeing things, and they have no interests, like, my kids, like, even holiday destinations...it's like, “Oh, but don't you wanna see this and this,” “Nup, like, just Google it,” you know. [Mother, in-person focus group 2]*

In contrast, young people were cognizant of the large amounts of time that they spent online and the potentially negative outcomes. They perceived that increased screen time was a consequence of technology being embedded in their social, school, and work lives rather than a conscious choice. When technology was used for a clear purpose, such as learning, consuming news, exploring interests, expressing oneself, working, relaxing, or communicating, young people felt that this use was legitimate and acceptable. Although parents believed that online learning, exploring interests, and consuming news were productive forms of technology use for young people, they could not personally relate to social media being a place for identity and belonging.

*When I was in high school, I was really depressed, and I had Tumblr. And for me, that was my way of, like, you share posts and quotes. And I remember my parents were, like, to me, "You can't use Tumblr anymore." And, I was so upset, I was, like, you don't understand how I express myself. [Young female, in-person focus group 1]*

For both young people and parents, certain activities were associated with time wasting and productivity guilt. For young people, these activities included scrolling through apps, such as Instagram, without realizing how much time was passing; watching short videos on TikTok and YouTube for hours; constantly checking social media for no specific reason; and using their phones when they needed to concentrate on a different task. A minority of parents also described how they personally used social media in these nonproductive ways; however, this was perceived as far more common among their children.

*I was getting really agitated when I couldn't check it. I reckon everyone here does it. I'd go into Instagram...no updates. I'd go into Snapchat...no updates, and then by the time I've gone to Snapchat, I'll be back on Instagram. And I'll be, like, Oh, I just got out of it. So, I was going constantly back and forth. [Young female, in-person focus group 1]*

*There's so many different platforms to keep them entertained, and then having said that, I know myself, I'm on Insta so much, the time I waste on that I could be doing a lot! [Mother, focus group 2]*

Both young people and parents agreed that reducing technology use was extremely difficult. Parents felt a sense of responsibility to protect their children from online harms and spending excessive amounts of time online. Often, their attempts to reduce technology use were punitive, for example, confiscating phones as punishment or turning off the Wi-Fi to enforce family time. Some parents felt compelled to monitor what their children were doing online by checking their personal profiles to see who they followed and what they shared. Some parents adopted a more hands-off approach, where they allowed their children to have freedom online but ensured they had regular conversations about what they were doing and the potential risks. Despite these attempts, parents recognized that their efforts were hindered because their children had greater digital literacy and could easily hide their history. At the end of the focus groups, parents

commented how they had learned about new social media platforms from the other parents who attended the session and reflected on how they generally relied on their children to educate them about digital technology.

*You keep tabs on them so much more like you've gotta be involved in their life and what's actually going on. [Mother, in-person focus group 2]*

*I know, but, you know that, they're so, they'll only let you see what they want you to see. [Mother, in-person focus group 2]*

*But, you know, my kids are on a lot of that social media stuff, and it makes me crazy. Every 2 seconds, you know? I'll be sitting there talking to them, and there will be a beep, and they'll grab their phone. Give me that bloody phone! If you take it off them, they become normal human beings. [Father, in-person focus group 3]*

For young people being told to "get off their phones" was unrealistic because their school, work, and social lives depended on their online presence. Although some young people had tried to cut back their screen time by turning off notifications, deleting apps, and setting time limits, these efforts were largely unsuccessful. However, there were certain times when young people were motivated to have short technology breaks, generally when they had a goal or activity that required them to focus or be present. For example, young people described having technology breaks when they were praying, spending quality time with close friends, or having meals with their families. During this technology-free time, young people would generally create physical distance from their phone so they did not feel obliged to check it. For young people, it was important that they were doing something enjoyable in a safe space when they did not have their phones, otherwise the separation led to anxiety.

*If I'm praying...I realize that if my phone is in the room while I'm praying, as soon as I hear it ringing, I want to look at my phone. I make the effort to take time while I'm praying...whereas if it's not there, I'm, like, I'll stay an extra few minutes, do extra, take some more time. [Young female, in-person focus group 1]*

Although both young Muslim and parent participants reported using digital technology and social media, their perceptions of productive use differed. Participants recognized the difficulties of reducing screen time; however, capitalizing on the desire for technology-free breaks during prayer and family time warrants further investigation.

## Discussion

### Principal Findings

Our study highlights how digital technology and social media are ingrained into the routines and social worlds of young people and parents from Muslim backgrounds. Our results demonstrate that parents and young participants share some similar concerns about digital technology and social media; however, they have different online experiences, particularly around identity and belonging. Young people and parents considered digital



technology and social media use as acceptable when they were used for a specific purpose. However, activities considered mindless, such as scrolling and constantly checking notifications, were associated with productivity guilt. Not surprisingly, young people felt their social media use increased during the COVID-19 lockdown period and valued having technology-free breaks while praying or spending quality time with family.

Participants acknowledged that technology has a myriad of benefits, including connecting with friends and family, facilitating online work and study, and providing spaces for identity and belonging. Social media allows young Muslims to explore their interests, express themselves, and create virtual social worlds where they feel safe and included [25]. Non-Muslim young people and parents have reported similar benefits of connection, participating in work and study and identity formation [37,38]. Our participants also described social media as more diverse than mainstream media; however, they hoped to see more positive representation of Muslim communities in the future. On a practical level, young people from Muslim backgrounds should be supported to participate in online environments where they feel connected, represented, and comfortable to explore their identity.

Importantly, our study also found that young people and parents have experienced and observed harms from digital technology and social media, including exposure to discrimination. Islamophobic hate speech on social media is a major concern and creates fear and exclusion among Muslim communities [20]. Social media platforms have a responsibility to identify and remove hate speech from their platforms; however, perpetrators rarely face consequences [39]. Our study showed that young Muslims are exposed to unrealistic standards on social media and often compare themselves to others, contributing to self-doubt and negative self-esteem. Building young people's social media literacy to analyze and evaluate online content may protect against some of these harms; however, further research is needed [40].

Our study suggests there is a large divide in parents' and young people's online experiences. Parents believe that their children's preference for technology-based leisure is inferior to the leisure activities they valued during their childhood and adolescence. These results are similar to studies with non-Muslim young people and parents that have reported that intergenerational differences in technology use can create family tension [1,37]. Some parents attempted to monitor their children's use; however, their limited digital literacy made it difficult. Similarly, an online survey reported over a quarter of parents felt they lacked the computer skills to protect their children from technology-based harms [2]. Parents may benefit from digital literacy training so that they can support their children to participate in online environments while also mitigating potential harms [41]. Although most participants had implemented various strategies to reduce young people's screen time, efforts had largely been ineffective. This finding reflects the broader literature that suggests that reducing recreational screen time among adolescents is difficult; results from a cluster-randomized controlled trial indicated that a 6-month intervention with reminder messages and education targeting both young people and parents had no significant impact on screen time [42].

Although reducing screen time was difficult, our participants valued having short technology breaks when they had a goal or activity where they wanted to feel present. Key activities that facilitated these breaks included prayer times and activities shared with family and friends where they felt safe and positive. In the Muslim community, prayer occurs 5 times per day and is considered a pillar of Islam; thus, integrating technology breaks around times of worship may be feasible. Further research is needed to determine whether reducing time spent on social media has a positive effect on mental health and well-being [43,44].

Since COVID-19, participants reported an increase in digital technology and social media use. This finding is similar to results from a survey with mostly non-Muslim young people, with 74% reporting that their social media use had increased during the pandemic and that it was the main way they stayed connected [45]. In our study, participants reflected that digital technology became the only place to work, study, and socialize during the lockdown. This shared experience meant that parents became more understanding of the time that young people spent online. Although young people acknowledged that social media enabled them to stay in touch with their friends, they missed human interaction. Parents also missed their routine social connections, as they were no longer able to attend the mosque during the lockdown. Qualitative research in the United Kingdom highlighted that although mosque closures were an important public health measure to reduce the spread of COVID-19, many Muslim community members lost their usual channels of communication [46]. Social media is an important extension of social connection; however, this medium does not replace the need for face-to-face interactions that occur in structured environments, such as school and places of worship. Further research on how faith groups can be supported to maintain a sense of community during COVID-19 lockdowns is warranted.

### Strengths and Limitations

This study had some limitations. Participants were recruited through the networks of the researchers and Green Crescent Australia and were often connected with mosques, Islamic schools, or youth groups. Most of the participants knew each other; thus, it is unlikely that we reached young people and parents who were socially isolated and those who did not attend the mosque. Most of the young participants were born in Australia and identified as female. In contrast, most of the parent participants were male; this likely occurred because we conducted a focus group with fathers on Zoom during the COVID-19 lockdown in Melbourne, which may have been more convenient to attend than the mothers' focus group, which occurred in person prepandemic.

Our ability to adapt the mode of data collection was a strength of our research and enabled us to explore social media use among young Muslims and parents in a COVID-19-safe way. Although we anticipated it would be difficult to run online focus groups after participants had likely spent extended periods online, participants appeared to enjoy discussing and reflecting on their experiences. Additionally, a community organization drove this research, enabling us to establish strong links with

the Muslim community, incorporate feedback, and increase the study's cultural appropriateness by holding focus groups at local mosques, providing halal food, having prayer breaks, and being mindful of the gender of participants and facilitators. We were also able to communicate the findings with Green Crescent Australia to share with their community.

## Conclusion

This study provided insight into digital technology and social media use from the perspective of young people and parents from Muslim backgrounds. Programs that aim to address

technology-related harms must acknowledge the benefits of digital technology and social media for young people for their identity, belonging, representation, and social connection, particularly during the COVID-19 pandemic. Young people and parents should be supported in developing digital literacy skills to enable participation in online environments, while mitigating potential harms. Further research is required to understand how parents and young people can create environments that foster technology-free breaks and the effect on mental well-being.

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## Conflicts of Interest

None declared.

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Viewpoint

# Lessons Learned Recruiting and Retaining Pregnant and Postpartum Individuals in Digital Trials: Viewpoint

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## Abstract

In an increasingly connected world and in the midst of a global pandemic, digital trials offer numerous advantages over traditional trials that rely on physical study sites. Digital trials have the potential to improve access to research and clinical treatments for the most vulnerable and minoritized, including pregnant and postpartum individuals. However, digital trials are underutilized in maternal and child health research, and there is limited evidence to inform the design and conduct of digital trials. Our research collaborative, consisting of 5 research teams in the U.S. and Australia, aimed to address this gap. We collaborated to share lessons learned from our experiences recruiting and retaining pregnant and postpartum individuals in digital trials of social and behavioral interventions. We first discuss the promise of digital trials in improving participation in research during the perinatal period, as well as the unique challenges they pose. Second, we present lessons learned from 12 completed and ongoing digital trials that have used platforms such as Ovia, Facebook, and Instagram for recruitment. Our trials evaluated interventions for breastfeeding, prenatal and postpartum depression, insomnia, decision making, and chronic pain. We focus on challenges and lessons learned in 3 key areas: (1) rapid recruitment of large samples with a diversity of minoritized identities, (2) retention of study participants in longitudinal studies, and (3) prevention of fraudulent enrollment. We offer concrete strategies that we pilot-tested to address these challenges. Strategies presented in this commentary can be incorporated, as well as formally evaluated, in future studies.

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**KEYWORDS**

digital trials; maternal and child health; pregnant and postpartum individuals; fraudulent enrollment; retention and recruitment; pediatrics; parenting; pregnant women; COVID-19; pandemic; postpartum; digital health

## Introduction

### Background

Although they have numerous benefits, digital trials are underutilized in maternal and child health research. Digital trials, sometimes referred to as internet, virtual, siteless, or decentralized trials, leverage technology to engage participants outside of physical sites, from recruitment through outcome assessment. Although digital trials first appeared in 2002, the COVID-19 pandemic and the need to protect research participants from exposure further spurred their growth. At present, digital trials are increasingly being used for clinical research, including drug trials and trials of social and behavioral interventions [1,2].

Although trials that are fully digital or incorporate digital elements can overcome some of the key limitations of traditional trials that rely on physical study sites, they also pose unique challenges for researchers and participants. Common concerns about digital trials include high attrition rates and the inability to reach research subjects with low digital literacy. Further, although methods have been developed for digital trials of drugs and devices [3], there is far less evidence to inform the design

and conduct of digital trials of social and behavioral interventions among pregnant and postpartum individuals.

To address this evidence gap, a group of 5 research teams in the U.S. and Australia collaborated to share lessons learned conducting innovative digital trials with pregnant and postpartum individuals. Across our research collaborative, we recruited participants using multiple digital platforms, including platforms used by the general public (eg, Facebook, Instagram, Twitter) and those specifically targeting individuals in the perinatal period (eg, Ovia, BabyCenter). We conducted fully digital trials without any human interaction, as well as digital trials with some in-person or face-to-face synchronous interaction (eg, video visit to complete informed consent). In this commentary, we present lessons learned from 12 different completed and ongoing digital trials (Table 1) that evaluated interventions for breastfeeding, prenatal and postpartum depression, insomnia, decision making, and chronic pain. We focus on challenges and lessons learned in 3 key areas: (1) rapid recruitment of large samples with a diversity of minoritized identities, (2) retention of study participants in longitudinal studies, and (3) prevention of fraudulent enrollment. We offer concrete strategies in each of these areas through which we experimented. These strategies can be incorporated into as well as formally evaluated in future studies.

**Table 1.** Description of studies in the research collaborative.

| Name of study, principal investigator(s)   | Study status as of September 2021 | Sample size, n | Completed studies: minoritized demographics, %  | Ongoing studies: recruited and minoritized demographics as of January 1, 2022, n (%)  | Study topic  | Length of follow-up for longitudinal studies  | Digital/social media platform used for recruitment   | Retention, %        |
|--|-----------------------------------|----------------|---|---|--|---|--|---------------------|
| Prevention of Perinatal Depression, Dr Felder  | Ongoing                           | Goal of 300    | N/A <sup>a</sup>  | Total: 280<br>Black: 27 (9.69); Asian/Pacific Islander: 26 (9.34); multiracial: 14 (4.84); other: 2 (0.69); Latinx/Hispanic: 35 (12.46)           | Survey of pregnant adult women at risk for depression to evaluate the extent to which they are identified and referred for preventive intervention | N/A   | Ovia   | N/A                 |
| REST <sup>b</sup> study, Dr Felder   | Completed                         | 208            | Black, Asian/Pacific Islander, multiracial, other: 33.75; Latinx/Hispanic: 7.25; low income (<US \$10,000/year): 32.2 | N/A   | Evaluation of digital CBT <sup>c</sup> for insomnia among pregnant women   | Enrolled up to 28 weeks gestation, followed until 6 months postpartum   | Facebook, flyers, Research Match, word of mouth, University of California San Francisco (UCSF) electronic health record messages and patient letters | 89                  |
| Beating the Blues before Birth, Drs Milgrom, Skouteris, Galbally, East, and Glover (Australia) | Ongoing                           | Goal of 230    | N/A   | Total: 63<br>Australia: 42 (66.67); New Zealand & Oceania: 4 (6.35); Europe: 7 (11.11); Africa: 2 (3.17); Asia: 2 (9.52); North America: 2 (3.17) | Evaluation of an antenatal depression treatment (CBT) on child neurodevelopment.   | Mothers and children followed up to 24 months postbirth, additional follow-ups conducted at 10-week postrandomization, 3 months and 12 months postbirth | Ovia, Facebook, Parent Infant Research Institute Website   | To be decided (TBD) |
| Sunnyside, Drs Duffecy and O'Hara  | Completed                         | 210            | Black: 3.33; multiracial: 8.57; Asian: 2.86; Native Hawaiian/Pacific Islander: 0.95; Hispanic/Latinx: 11.90           | N/A   | Evaluation of digital intervention to prevent postpartum depression  | Participants recruited at 20-28 weeks pregnant, remained in the trial until 12 weeks postpartum   | Ovia, university email list (University of Illinois Chicago (UIC) and U of Iowa), Research Match   | 72                  |
| Sunnyside+, Drs Duffecy and Pezley   | Completed                         | 22             | Black: 100; Latinx/Hispanic: 0.5; low income (<US \$51,000/year): 54.5  | N/A   | Evaluation of digital intervention to prevent postpartum depression and improve breast feeding outcomes in Black women                             | Participants recruited at 20-28 weeks pregnant, remained in the trial until 12 weeks postpartum   | Ovia   | 73                  |
| Sunnyside for prevention and treatment, Drs Duffecy and Maki                                   | Ongoing                           | Goal of 90     | N/A   | Total: 48<br>Black: 3 (6.4); Asian: 2 (4.1); Native American: 2 (4.1); White: 36 (75); Latinx/Hispanic: 5 (10.4)                                  | 6-week digital intervention to prevent postpartum depression   | 6 weeks   | Ovia, UIC clinic recruitment   | TBD                 |



| Name of study, principal investigator(s)                | Study status as of September 2021 | Sample size, n | Completed studies: minoritized demographics, %  | Ongoing studies: recruited and minoritized demographics as of January 1, 2022, n (%)   | Study topic  | Length of follow-up for longitudinal studies  | Digital/social media platform used for recruitment | Retention, % |
|---|-----------------------------------|----------------|---|--|--|---|--|--------------|
| Tele-MILC <sup>d</sup> , Dr Uscher-Pines                | Ongoing                           | Goal of 2400   | N/A   | Total: 422<br>Black: 37 (8.77);<br>Latinx/Hispanic: 72 (17.1); other minoritized race: 40 (9.48)   | Evaluation of a breastfeeding support app  | Participants recruited in their third trimester of pregnancy, remained in trial until infant 6 months old | Ovia   | TBD          |
| EPIC <sup>e</sup> Survey, Dr McCabe                     | Ongoing                           | Goal of 150    | N/A   | Total: 106<br>Black: 13 (12.26); Native American: 2 (1.89); Asian/Pacific Islander: 9 (8.5); multiracial: 6 (5.66); Latinx/Hispanic: 12 (11.3) | Association between prenatal stressors during COVID-19 and subsequent child development  | Wave 1 data at third trimester, wave 2 data at 6 weeks postpartum, wave 3 data at 16 weeks postpartum     | Ovia, Facebook                                     | TBD          |
| Birth and Postpartum Care During COVID-19, Dr Breman    | Completed                         | 388            | Asian/Pacific Islander: 3.2;<br>Black: 7.1;<br>mixed: 3.8; Latinx/Hispanic: 11.6; low income (<US \$50,000/year): 16  | N/A  | Experience of giving birth and postpartum care during the first wave of the COVID-19 pandemic  | N/A   | Ovia   | N/A          |
| Shared Decision-Making During Hospital Birth, Dr Breman | Completed                         | 1173           | Asian/Pacific Islander: 6; Black: 10.4; mixed: 5.4; Latinx/Hispanic: 13; low income (<US \$50,000/year): 26   | N/A  | Assessment of shared decision making during hospital birth in the U.S.   | N/A   | Ovia, Pacify, Facebook/Instagram, YouTube          | N/A          |
| BetterLife, Drs Vignato and Segre                       | Completed                         | 158            | Black: 10.76; Native American: 1.27; Latinx/Hispanic: 13.29; Asian/Pacific Islander: 1.90; other/2 or more races: 3.80; low income (Medicaid eligible): 32.28 |  | Assessment of the relationship between low back and pelvic pain, depression symptoms, and quality of life in pregnant women in their third trimester | N/A   | Ovia   | N/A          |

| Name of study, principal investigator(s)                 | Study status as of September 2021 | Sample size, n | Completed studies: minoritized demographics, % | Ongoing studies: recruited and minoritized demographics as of January 1, 2022, n (%) | Study topic   | Length of follow-up for longitudinal studies                 | Digital/social media platform used for recruitment | Retention, % |
|--|-----------------------------------|----------------|--|--|---|--|--|--------------|
| Listening Visits for NICU <sup>f</sup> mothers, Dr Segre | Ongoing                           | 29             | N/A  | Total: 4; no racially or ethnically minoritized participants                         | Evaluation of listening visits delivered via Zoom by NICU nurses to emotionally distressed mothers of hospitalized newborns | Participants recruited while their newborns are hospitalized | Ovia   | TBD          |

<sup>a</sup>N/A: not applicable.

<sup>b</sup>REST: Research on Expecting Moms and Sleep Therapy.

<sup>c</sup>CBT: cognitive behavioral therapy.

<sup>d</sup>Tele-MILC: Telehealth to Increase Mothers' Lactation Confidence.

<sup>e</sup>EPIC: Experiences of Pregnancy and Isolation during COVID-19.

<sup>f</sup>NICU: neonatal intensive care unit.

## The Promise of Digital Trials for Pregnant and Postpartum Individuals

Digital trials have numerous benefits. First, they offer an alternative to costly and inconvenient traditional trials [4,5]. Traditional trials, with their multiple limitations, have dominated the landscape since the 1940s but needed disruptive innovation [6]. Participants in traditional trials must be located near physical study sites, restricting access for many. Further, it is well documented that most traditional trials fail to meet their recruitment targets [7,8]. Traditional trials are also expensive [4,5].

In the area of access and participation, digital trials can support rapid recruitment of large samples [1]. Because participants do not need to be near a study site, these trials can serve hard-to-reach and diverse populations [1,9]. Further, because digital trials offer participants greater autonomy, convenience, and privacy, they may be more appealing to certain participants who would not otherwise engage [10]. Researchers at Harvard and the Massachusetts Institute of Technology (MIT) demonstrated that digital trials may improve access to studies for women and racially and ethnically minoritized populations, who are significantly underrepresented in clinical trials [11,12].

With regard to costs, digital trials are also likely to be more efficient because they require smaller teams of investigators [2] and avoid power reduction due to clustering, which is an issue when recruiting from multiple sites [13]. Further, digital technologies, which allow for continuous data collection or data collection at more time points, can reduce costs related to clinical assessments [14].

Furthermore, digital trials introduce a host of methodological advantages. For example, with electronic consent (eConsent) procedures, multimedia web tools (eg, videos, animation) can be used to enhance understanding [15], and randomization has the potential to be more secure [2,16].

Although many populations can benefit from digital trials, they may be particularly suited for pregnant and postpartum individuals. First, demands of infant care can make travel challenging, and studies have demonstrated that young parents find it difficult to visit clinical sites to participate in research [17]. Second, the perinatal period is one that is rife with distress, with approximately 20% of childbearing women exhibiting symptoms of anxiety and depression [18,19]. The significant responsibilities and physical and emotional changes that occur in the perinatal period often impede individuals from engaging in healthy behaviors and participating in research that may benefit themselves or science in general [17]. Third, women of childbearing age exhibit the highest rates of smartphone ownership [20]. As such, the historic criticism that requiring internet use may lead to less representative samples in digital trials may not be applicable to this population [2,16,21].

Although many of these advantages were clear prior to the COVID-19 pandemic, the pandemic revealed additional benefits with great urgency and led to the rapid adoption of digital engagement strategies. The social distancing orders in March 2020 led the US Food and Drug Administration to issue guidance on the safety risks of proceeding with traditional trials and urged researchers to develop safer alternatives for data collection [10]. Shortly thereafter, a review by ClinicalTrials.gov revealed that patient interactions in ongoing trials, including some focused on pregnant and postpartum populations, began to predominantly occur remotely [22]. This shift to digital engagement is expected to persist. Most clinical trial investigators expect a threefold increase in digital patient interactions 6 months postpandemic [22,23].

## Digital Trials and Tribulations

Digital trials of social and behavioral interventions, while innovative, also face unique challenges. First, a key concern is that because these studies leverage technology, they cannot engage individuals without mobile devices or access to the internet. Further, participants must have digital literacy (eg, to

complete online assessments, download a study app). These requirements may lead to a lack of representation and may perpetuate health disparities, as minoritized and underserved populations have reduced broadband access and subsequently less health and digital literacy [23]. For example, as of April 2021, 80% of White Americans had home internet access compared to 71% of Black and 65% of Latinx Americans [20]. Second, attrition in longitudinal studies remains a serious concern. Research has shown that digital trials have higher attrition rates, in part, because research subjects are not as invested or activated. In addition, the personal, human touch that occurs during in-person interactions with members of the study team, lacking with digital trials, may be a key ingredient for retention. Lastly, although privacy has been noted to be a strength of digital trials, it can also be a limitation. Although digital trials allow a certain level of anonymity, trials that occur in a participant's home over the internet may face challenges with data security. In sum, securing participant data and ensuring privacy are challenges, and researchers must continue to develop methods to monitor and evaluate data from health technologies [24].

## Key Challenges and Useful Strategies

### Background

In the past 5 years, our research teams have launched numerous digital trials as well as modified existing traditional trials among pregnant and postpartum individuals to incorporate digital trial elements. We have used several social media platforms and pregnancy and parenting apps for recruitment, with the most common being Facebook and Ovia. Facebook is the most popular social media platform among American adults, with 69% reporting that they use Facebook [20]. Facebook is popular across all demographic groups; however, some adults access it more often. Specifically, 77% of women use Facebook daily compared to 61% of men, and 74% of Black Americans use Facebook daily compared to 67% of White and 72% of Latinx users. Ovia is 1 of the most popular pregnancy apps available for free download [25]. Used by over 2 million people in the U.S. each month (email communication with Ovia staff, August 10, 2021), it provides educational content, conducts health assessments, and uses proprietary algorithms and machine learning to provide user-specific support, advice, and resources [25].

Although we confronted numerous challenges in designing and executing our digital trials, we found 3 areas to be particularly daunting: rapid recruitment of large, diverse samples; retention; and fraudulent enrollment monitoring. We explain each of these areas next, as well as promising strategies to overcome the challenges.

### Challenge #1: Rapid Recruitment of Large, Diverse Samples

Across all the social media platforms and apps, our studies were typically featured in a paid ad. Potentially interested participants saw the ad, clicked on it, and were routed to a study web page or screening survey. Although the steps varied by study, many participants then completed an eligibility screening survey,

completed an informed consent process, and were enrolled. In this recruitment process, we struggled with recruiting minoritized individuals and routing eligible participants through the enrollment process.

### Minoritized Participants

None of the platforms we used for recruitment allowed us to target ads to users of a particular race or ethnicity. However, it was possible to target based on geography (eg, state or zip code), and in the case of Ovia, the stage of pregnancy and parity. In August 2020, after several lawsuits and scandals surrounding housing discrimination by advertisers, Facebook no longer permitted targeting based on race [26,27]. Given this new policy, researchers in our collaborative were unable to use ads to directly oversample minoritized groups. To overcome this constraint, the Research on Expecting Moms and Sleep Therapy (REST) study, a longitudinal study that examined the effectiveness of digital cognitive behavioral therapy (CBT) for insomnia for pregnant women, used the Facebook audience tool to advertise to certain zip codes that have a high proportion of Black and Latinx populations.

Further, even in cases where a platform's user base is nationally representative and ads go out to users of all races and ethnicities, we learned that we may fail to generate interest among minoritized groups. For example, in several studies, we found that highly educated, White participants were more likely to click on study ads and were disproportionately represented. As a result, our teams worried that we may be perpetuating the systemic barriers that minoritized and marginalized groups face in accessing clinical research and care. To combat this, we experimented with the following strategies:

- Strategy 1: Expand beyond paid ads. Although researchers can pay platforms to advertise, there are other ways to reach minoritized populations on social media. Members of our collaborative used social media platforms to join online pregnancy support groups (eg, Black Mamas Matter, Black Families Do Breastfeed) and promote the study if given approval. For example, members of the CHOICE for Birth study team used professional and personal networks to contact and collaborate with an influencer to promote their study. Further, the team used a recruitment firm to connect them with accounts on social media that were specifically tailored to minoritized groups. Through this connection, the team was able to have a paid ad on Instagram and successfully recruited more Asian pregnant people.
- Strategy 2: Run ads that feature images of racially or ethnically minoritized pregnant people and explicitly state in the materials that the research team is recruiting minoritized populations. This strategy falls under the category of surface structure adaptations (vs deep adaptations, which demonstrate the salience of the intervention for the target population) [28]. Here, visual modifications to the materials and intervention content are implemented based on more superficial characteristics (eg, locations, language, food) of or preferred by the target group. These strategies demonstrate how the research program or materials fit with the culture and may increase acceptance of the materials [28]. Most researchers in our collaborative utilized these

types of strategies. The Telehealth to Increase Mothers' Lactation Confidence (Tele-MILC) study, a National Institutes of Health (NIH)-funded trial to assess the impact of a breastfeeding app, utilizes this strategy, among others. Although the study continues to recruit, as of September 2021, two-fifths (n=80, 40%) of the 200 enrolled participants identified as Latinx or Black.

- Strategy 3: Partner with community members to develop culturally concordant recruitment materials. For example, 1 of our research teams is planning to partner with a participant recruitment program that has services to support enrollment of underrepresented populations. The program will collaborate with community members, who will provide feedback on recruitment materials. They will then offer consulting services to ensure materials are in plain language.

### ***Sustaining Interest Through the Informed Consent Process***

Some of our digital trials lost large numbers of eligible individuals during the recruitment process because of the time-consuming, intimidating, and non-user-friendly nature of the informed consent process. For example, in a trial focused on parents of hospitalized newborns that used Ovia for recruitment, 40% (n=72) of individuals who viewed the study ad were eligible to complete the eligibility screening survey, and 33% (n=24) completed the eligibility screening survey. However, only two individuals (18% of those who were deemed eligible to enroll in open trial) completed the eConsent form over the entire recruitment period for Ovia. The research team attributed this low enrollment to the use of a long and legalistic informed consent form typically used for face-to-face recruitment. Although our teams seldom received direct, formal feedback from participants initially, several teams that changed their consent processes to be more streamlined saw immediate results.

Our teams implemented several strategies to improve the eConsent experience for participants. First, 1 team had initially included a 2-part consent process, where potential participants had to consent to the screening survey and then, if eligible, the full study. In the streamlined version, the team is planning to have a single consent task that occurs following screening.

Another team with challenges enrolling participants revised the look and content of the eConsent form. Members of the Encouraging Mothers and Babies Everywhere - Research Center (EMBERcenter) [29] revised their eConsent process after consulting with a marketing strategist. They inferred that the original consent process was problematic, given the limited number of eligible participants who successfully completed the full consent process. Progress of potential participants was tracked using Qualtrics. After consultation with the marketing strategist, the EMBERcenter team modified the informed consent document to be a letter from the principal investigator and included emojis, a picture of the principal investigator, and bullet points in place of some paragraphs. They also cut some material so that the final version read more like a description a participant might hear from a research coordinator enrolling participants in person.

The goal of many of these strategies is to provide a seamless experience for the participant as they leave the social media or app platform and enter the virtual study environment. If the social media platform is informal and has limited text, then the study environment should mirror that as much as possible. We recommend that researchers conducting lower-risk digital trials work with their institutional review board (IRB) to amend the consent length and requirements. The goal is to utilize as few words as possible to ensure that participants understand the risks and benefits and to avoid creating consent materials that look like a technology company's terms of service, given many users are accustomed to signing these without reading them. Because many guidelines and templated consent documents are based on traditional in-person trials, research teams may need to work with and educate their IRBs about adaptations for digital trials.

### **Challenge #2: Retention**

Once participants are successfully enrolled, it can be difficult to retain them. In many of our studies, we required participants to respond to online surveys over months or years, and we were concerned that high attrition rates would pose a threat to validity. As previously stated, attrition is a well-documented problem in digital trials, with most participants dropping out within the first week of the study [30]. Fortunately, robust engagement strategies can have a significant impact on retention. Several digital trials across our study teams had above-average retention rates [31,32].

Our study teams implemented several novel retention strategies beyond providing incentives and sending reminders to reduce attrition. One effective strategy for traditional trials is a 30-minute orientation to the study prior to randomization [33]. During the interactive orientation, motivational interviewing techniques can be used to process feelings and ambivalence about the intervention and the different groups participants could be assigned (ie, control vs experimental) [33]. In the REST study [34], these orientations were conducted by a study coordinator via phone. In the Sunnyside study, an evaluation of a longitudinal digital intervention using CBT to prevent the development of postpartum depression, an initial engagement call was completed to introduce participants to the program and ensure ability to access study materials [35].

Another strategy 1 of our teams used was to include escalating incentives based on the proportion of online surveys that the participants completed. Further, some study teams sent gifts to participants to demonstrate the importance and value of the participants' information and participation. For example, in the Experiences of Pregnancy and Isolation during COVID-19 (EPIC) Survey, the research team mailed baby wipes along with a letter to congratulate participants on the birth of their baby. The Tele-MILC study engaged participants by having monthly contests that were announced in the study's newsletter; specifically, participants could create memes, send in a baby photo, or answer a trivia question to receive additional incentives.

Other strategies to improve engagement focused on creating a community among participants and eliciting altruism. The study team for the EPIC Survey implemented a few strategies to create

a community feeling. First, they gave a group name to their participants so that a more personal feeling was elicited. Further, study staff generated a map of all zip codes where participants lived in order to show the reach of the study and proximity to other participants. The team placed a dot near each zip code where a participant lived in order to ensure privacy and confidentiality. Members of the Tele-MILC study team made a “Thank You” video, which appeared at the end of the enrollment process. In the video, the principal investigator and members of the research team conveyed their appreciation of the participants, the importance of the study, and the role that participants were playing in contributing to science. The video was designed both to tap into the participants’ altruism and to show the real humans behind the digital trial.

### **Challenge #3: Fraudulent Enrollment**

Fraudulent enrollment is a common problem in digital trials, particularly trials that utilize social media for recruitment, and can introduce threats to data integrity and sample validity [36]. Fraudulent enrollment can occur in several ways. First, ineligible individuals can misrepresent themselves as eligible. In some of our studies, we were concerned that men or women who were not pregnant at the time of recruitment would attempt to enroll despite ads clearly describing the target population. We were also concerned that certain individuals would continue to edit their responses to the screening survey until the instrument declared that they were eligible. Second, participants who are eligible can attempt to enroll in a study more than once to obtain

additional incentives. Lastly, software applications that run automated tasks, known as bots, can pose as participants to receive incentives [37]. Several of our study teams have monitored for fraudulent enrollment and detected bots. We found that an advantage of Ovia, and other platforms that target pregnant and postpartum people, is that there are fewer instances of ineligible individuals trying to enroll.

Research teams that used social media platforms that were not used exclusively by pregnant and postpartum individuals developed methods to verify pregnancy and identify bots. Some teams requested photos of a recent ultrasound or required that the participants upload a birth certificate. One team included an “insider” question (ie, a question that only an eligible participant is likely to answer correctly) in an early survey, asking each participant to enter the name of their obstetrician.

Additional strategies that our digital trials used to detect fraud included consistency checks (eg, Does “weeks pregnant” match the baby’s due date?) and open-ended survey questions. Open-ended questions are useful because the study team can assess whether answers are coherent. The Tele-MILC study combined 2 fraud detection strategies (insider and open ended) in 1 survey question. In the first survey, we asked individuals what they liked most about the Ovia app. We reviewed responses to this question to ensure that participants were in fact Ovia users (and that off-platform recruitment was not taking place) and were actual humans versus bots with incoherent answers. Additional strategies are included in [Table 2](#).



**Table 2.** Concrete strategies for improving recruitment, retention, and fraud monitoring.

| Strategy  | Description   |
|---|---|
| <b>Recruitment</b>                                      |   |
| Expand beyond paid ads.                                 | <ul style="list-style-type: none"> <li>Utilize social media influencers to promote your study. Join groups that are dedicated to your population (eg, Black Mamas Matter) and ask permission to promote the study.</li> </ul>   |
| Run targeted ads.                                       | <ul style="list-style-type: none"> <li>Create ads that feature images of racially or ethnically minoritized individuals or your targeted population of interest to improve acceptability and signal that your study is interested in their experiences.</li> </ul>  |
| Develop culturally concordant materials.                | <ul style="list-style-type: none"> <li>Utilize university or external programs that have services to support enrollment of underrepresented populations that partner with community members to create or contribute to materials.</li> <li>Employ and collaborate with community members.</li> <li>Before enrollment or conceptualization of your study, engage with your community of interest and develop a relationship. Understand their needs and wants in advance and reflect on your positionality and privilege as a researcher before undertaking the research study.</li> </ul> |
| Improve the eConsent <sup>a</sup> process.              | <ul style="list-style-type: none"> <li>Condense the consent process into 1 step.</li> <li>Edit the consent form to include more visual elements and highlighted bulleted points.</li> <li>Streamline the process from the ad to the study landing page. Ensure that your website matches the style and language of the social media platform as much as possible.</li> <li>Meet with your IRB<sup>b</sup> to amend the requirements on length and detail.</li> </ul>  |
| Utilize experts from other disciplines (eg, marketing). | <ul style="list-style-type: none"> <li>Hire marketing strategists or other communications experts to review and edit your study materials, particularly consent and assent documents, to ensure they are digestible and inviting</li> </ul>   |
| <b>Retention</b>  |   |
| Collect secondary contacts.                             | <ul style="list-style-type: none"> <li>Collect a friend or relative's contact information in case the research team loses touch with the participant.</li> </ul>  |
| Send birthday congratulations.                          | <ul style="list-style-type: none"> <li>Email or mail birthday cards and other postcards for important milestones.</li> </ul>  |
| Send monthly newsletters.                               | <ul style="list-style-type: none"> <li>Send participants a monthly newsletter that contains descriptions or interviews with a member of the research team and other helpful resources related to the study topic (eg, ideas for self-care, fun facts about pregnancy).</li> </ul>   |
| Share positive quotes.                                  | <ul style="list-style-type: none"> <li>Ask participants to share quotes about their experiences in the study to share widely with other participants.</li> </ul>  |
| Send reminders.   | <ul style="list-style-type: none"> <li>Utilize an automated service to send reminders to participants about their upcoming assessments or have a research team member text, call, or email personalized reminders.</li> </ul>   |
| Provide escalating incentives.                          | <ul style="list-style-type: none"> <li>Provide different levels of incentives/compensation based on how many follow-up surveys the participant completes. Make the final assessment worth more than prior assessments.</li> </ul>   |
| Utilize games/contests.                                 | <ul style="list-style-type: none"> <li>Create contests wherein participants can be compensated or entered into a raffle to win a gift card or other incentive. Contests such as "best caption for a meme or gif" and solving riddles have been engaging.</li> </ul>   |
| Send gifts.   | <ul style="list-style-type: none"> <li>Send participants items (eg, coffee mugs, pens, notebooks, baby wipe case, hand sanitizer) with the study name or logo on it.</li> </ul>   |
| Develop a video from the study team.                    | <ul style="list-style-type: none"> <li>Create a thank-you video to appear at the end of a survey or on your study website, featuring the research team and positive messages or stories to elicit altruism.</li> </ul>  |
| Create opportunities for networking/interaction.        | <ul style="list-style-type: none"> <li>Create a visual map of participants' locations.</li> <li>Create a social media page where study participants can interact; host virtual meetings for participants to facilitate interactions among them.</li> </ul>  |
| <b>Fraudulent enrolment</b>                             |   |

| Strategy  | Description  |
|---|--|
| Check internet protocol (IP) addresses or latitude and longitude. | <ul style="list-style-type: none"> <li>Review IP addresses (unique addresses that identify devices on the internet or on a local network) to ensure that the same individual is not attempting to enroll more than once.</li> </ul>  |
| Add reCAPTCHA (Google).   | <ul style="list-style-type: none"> <li>Add reCAPTCHA, a tool that uses advanced risk analysis techniques, to distinguish between humans and bots.</li> </ul>   |
| Require face-to-face meetings or emailing back and forth.         | <ul style="list-style-type: none"> <li>Require that potential participants engage with the study team (either in a synchronous meeting or via asynchronous communication) prior to dispensing incentives.</li> </ul>   |
| Only dispense incentives after eligibility is confirmed.          | <ul style="list-style-type: none"> <li>Do not automatically dispense incentives; ensure fraudulent enrollment monitoring is completed before participants are official enrolled in order to keep bots and ineligible participants from depleting your incentives.</li> </ul> |
| Include honeypot questions.                                       | <ul style="list-style-type: none"> <li>Include a survey question that is invisible to humans but visible to bots. If it is answered, this suggests bot activity.</li> </ul>  |
| Perform consistency checks.                                       | <ul style="list-style-type: none"> <li>Include 2 or more survey questions that ask the same question in different ways (eg, age and date of birth); check for consistent responses.</li> </ul>   |
| Include insider questions.  | <ul style="list-style-type: none"> <li>Include a question that only an eligible participant is likely to answer correctly/know the answer. A common example is to ask members of the military a question about their rank.</li> </ul>  |
| Include time stamps/time to complete survey.                      | <ul style="list-style-type: none"> <li>Include time stamps and review how long it takes for a participant to complete a survey. For example, flag if the participant completes a long survey in less than 5 minutes.</li> </ul>  |
| Create a duplicate email flag.                                    | <ul style="list-style-type: none"> <li>Flag if the same email is entered in the enrollment records of multiple participants.</li> </ul>  |
| Control survey navigation.  | <ul style="list-style-type: none"> <li>Do not enable a back button in screening surveys. Including a back button may enable participants to change prior answers to meet eligibility criteria.</li> </ul>  |

<sup>a</sup>eConsent: electronic consent.

<sup>b</sup>IRB: institutional review board.

## Conclusions

Despite the demonstrated need and utility of digital trials for pregnant and postpartum individuals, the guidance on methodology remains limited. Methods are needed for the recruitment and retention of large, diverse samples, particularly minoritized populations, given the systemic barriers these communities face in participating in research. As such, our collaborative aimed to begin a dialogue and generate

recommendations for researchers as well as reviewers of digital trial protocols. Although the strategies we presented in this commentary have been pilot-tested in 1 or more trials, future research should formally test their effectiveness with different populations and study types. Given the rapid growth and important advantages of digital trials, strong study designs that help to overcome their weaknesses are needed to advance the science and spur ongoing innovation in the field of maternal and child health.

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## Conflicts of Interest

None declared.

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## Abbreviations

**CBT:** cognitive behavioral therapy

**eConsent:** electronic consent

**EMBERcenter:** Encouraging Mothers and Babies Everywhere - Research Center

**EPIC:** Experiences of Pregnancy and Isolation during COVID-19

**IRB:** institutional review board

**REST:** Research on Expecting Moms and Sleep Therapy

**Tele-MILC:** Telehealth to Increase Mothers' Lactation Confidence

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Original Paper

# Experience of Pediatricians and Pediatric Surgeons With Virtual Care During the COVID-19 Pandemic: Descriptive Study

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## Abstract

**Background:** Prior to the COVID-19 pandemic, in-clinic visits were the standard of care for pediatric physicians and surgeons at our center. At the pandemic onset, web-based care was adopted at an unprecedented scale and pace.

**Objective:** This descriptive study explores the web-based care experience of pediatric physicians and surgeons during the pandemic by determining factors that supported and challenged web-based care adoption.

**Methods:** This study took place at the Children's Hospital at London Health Sciences Centre, a children's hospital in London, Ontario, Canada, which provides pediatric care for patients from the London metropolitan area and the rest of Southwestern Ontario. The Donabedian model was used to structure a web-based survey evaluating web-based care experience, which was distributed to 121 department-affiliated pediatric physicians (including generalists and subspecialists in surgery and medicine). Recruitment occurred via department listserv email. Qualitative data were collected through discrete and free-text survey responses.

**Results:** Survey response rate was 52.1% (63/121). Before the pandemic, few physicians within the Department of Paediatrics used web-based care, and physicians saw <10% of patients digitally. During March-May 2020, the majority transitioned to web-based care, seeing >50% of patients digitally. Web-based care use in our sample fell from June to September 2020, with the majority seeing <50% of patients digitally. Telephone and Ontario Telemedicine Network were the platforms most used from March to September 2020. Web-based care was rated to be convenient for most providers and their patients, despite the presence of technical difficulties. Challenges included lack of physical exam, lower patient volumes, and poor patient digital care etiquette. Regardless of demographics, 96.4% (116/121) would continue web-based care, ideally for patients who live far away and for follow-ups or established diagnoses.

**Conclusions:** Transition to web-based care during COVID-19 was associated with challenges but also positive experiences. Willingness among pediatricians and pediatric surgeons to continue web-based care was high. Web-based care experiences at our center could be improved with patient education and targeting select populations. Future research is needed to improve practice efficiency and to inform regulatory guidelines for web-based care.

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**KEYWORDS**

virtual care; web-based care; COVID-19; pediatrics; pandemic; physicians; digital health; pediatricians; telehealth



## Introduction

Web-based care has been defined as any interaction between patients or members of their circle of care, occurring remotely, using any forms of communication or information technologies, with the aim of facilitating or maximizing the quality and effectiveness of patient care [1]. Though Canadian physicians have been using technologies for delivery of web-based care as early as the 1970's [2], prior to the COVID-19 pandemic, there remained significant barriers to widespread delivery of web-based care across the country [3]. Although web-based care has demonstrated utility in several pediatric subspecialties [4], before March 2020, the standard of care for pediatricians affiliated with our center was in-clinic visits, with web-based visits limited to the Ontario Telemedicine Network for select patients in remote locations. Additionally, given the sparse uptake of web-based care across pediatric subspecialties at our center, little was known about local web-based care practice patterns before the pandemic.

With the onset of the COVID-19 pandemic, web-based care was adopted at an unprecedented scale and pace to mitigate and manage the risk of spread of the disease [5]. Regardless of previous experience with web-based care, physicians of nearly all specialties and disciplines were required to adopt some proportion of digital practice as a means of maintaining a continuum of patient care [6]. Despite initial positive feedback, the sudden rush to web-based systems carried the risk of diminishing quality of clinical care [7]. At the time of our study, little was known of the impact of this shift for providers, particularly pediatricians. Therefore, this descriptive study sought to qualify the web-based care experiences of local pediatricians during the early stages of the COVID-19 pandemic (March to September 2020), with the intention of implementing web-based care clinical practice changes at the department level.

## Methods

### Study Design

The Donabedian model for health care quality improvement was used to guide questions within the survey on the Qualtrics platform ([Multimedia Appendix 1](#)). This survey was then used to evaluate the web-based care experience of staff pediatric physicians and surgeons through their responses. In this survey, web-based care was defined as any interaction between patients or members of their circle of care, occurring remotely, using any forms of communication or information technologies [1]. Within the Donabedian model, "structure" refers to assessment of health care settings, qualifications of providers, and administrative systems through which care is provided. In our survey, this was assessed with demographic questions, web-based care settings, start-up costs, and platforms used. "Process" refers to the elements of care delivered within clinician-technical and clinician-interpersonal relationships. This was addressed in our survey with questions about percentage of care provided virtually, as well as free text responses related to patient care. Finally, "outcome" refers to achievement of goals of care, with indicators such as

satisfaction, safety, and good use of resources. In our survey, our primary outcome was physician experience with web-based care, measured by positive experience with web-based care, negative experience with web-based care, and willingness to continue to provide web-based care in the future. Phrasing of survey questions was balanced to include positive and negative options to avoid leading questions, and the survey was pilot tested by a non-London Health Sciences Centre (LHSC)-affiliated pediatrician for readability and content.

### Ethics Approval

Research ethics exemption was granted by the Office of Human Research Ethics on behalf of Western University's Research Ethics Board. As this study is a part of a larger quality improvement initiative, this was granted under the Quality Assurance/Quality Improvement/Program Evaluation classification.

### Study Setting

This study took place at LHSC, a children's hospital in London, Ontario, Canada, which provides pediatric care for patients from the London metropolitan area and the rest of Southwestern Ontario. This survey was introduced to the Department of Paediatrics in September 2020 to assess web-based practice patterns from March 2020 to September 2020.

### Recruitment and Data Collection

Recruitment for the study occurred via email in September 2020 to all LHSC-affiliated pediatric physicians and surgeons within the department's listserv email database. The Department of Paediatrics email listserv comprises 121 staff physicians, including generalists, subspecialists, pediatric surgeons, as well as academic and community physicians. A follow-up email was sent through the same listserv 2, 4, and 6 weeks after the initial email to prompt further response, with a deadline of 6 weeks total to complete the survey.

### Data Analysis

The web-based survey was analyzed through the QualtricsXM platform and Microsoft Excel (version 16.16.5). The results were collated, and descriptive statistics for numerical data were calculated. Partially completed responses to the survey were excluded from analysis, noted as "no response" in [Tables 1-5](#). Free text responses were reviewed by the research team to identify themes and provide further support to numerical data ([Multimedia Appendix 2](#)).

## Results

### Survey Response

Of the 121 pediatric physicians, 63 (52.1%) responded. Demographic information of the respondents may be viewed in [Table 1](#). The respondents were primarily subspecialists working at an academic institution. This is consistent with the demographics of the total listserv database, which comprises 19 (15.7%) community generalists and 102 (84.3%) academic subspecialists in both pediatric surgery and medicine.

**Table 1.** Demographic characteristics of the survey respondents.

| Characteristics                  | Values, n (%) |
|----------------------------------|---------------|
| <b>Primary practice location</b> |               |
| Academic Children's Hospital     | 56 (88.9)     |
| Community Hospital               | 0 (0)         |
| Community Clinic                 | 5 (7.9)       |
| Other                            | 2 (3.2)       |
| <b>Practice type</b>             |               |
| General                          | 10 (15.9)     |
| Subspecialist                    | 53 (84.1)     |
| <b>Years in practice</b>         |               |
| ≤5                               | 17 (27.0)     |
| 6-10                             | 9 (14.3)      |
| 11-20                            | 20 (31.7)     |
| ≥21                              | 17 (27.0)     |

### Adoption of Web-Based Care During the COVID-19 Pandemic

While the majority of respondents had no prior web-based care experience (Table 2) during the first wave of the pandemic (March-May 2020), almost all respondents transitioned to web-based care, with the majority seeing more than half of their patients digitally. By summer (May-September 2020) web-based care use declined, with the majority of physicians seeing less

than 25% of their patients digitally. Reported percentages of web-based care are based on physician estimates.

Respondents were more likely to use synchronous web-based care methods with live audio or video feedback over asynchronous methods such as email or secure messaging software (Table 3). The most commonly used web-based care platforms in our sample were telephone and the Ontario Telemedicine Network, which were also selected as the most popular platforms ideally used in the future.

**Table 2.** Web-based care practice patterns.

| Characteristics  | Values, n (%) |
|--|---------------|
| <b>Prior web-based care experience</b>                                 |               |
| Yes  | 19 (30.2)     |
| No   | 44 (69.8)     |
| <b>Adopted web-based care during pandemic</b>                          |               |
| Yes  | 59 (93.7)     |
| No   | 4 (6.3)       |
| <b>Percentage of practice via web-based care (March-May 2020)</b>      |               |
| Closed practice  | 1 (1.6)       |
| 0%   | 4 (6.3)       |
| 1%-10%   | 8 (12.7)      |
| 11%-25%  | 6 (9.5)       |
| 26%-50%  | 3 (4.8)       |
| 51%-75%  | 6 (9.5)       |
| 75%-100%   | 28 (44.4)     |
| No response  | 6 (9.5)       |
| <b>Percentage of practice via web-based care (June-September 2020)</b> |               |
| Closed practice  | 0 (0)         |
| 0%   | 2 (3.2)       |
| 1%-10%   | 15 (23.8)     |
| 11%-25%  | 15 (23.8)     |
| 26%-50%  | 8 (12.7)      |
| 51%-75%  | 12 (19.0)     |
| 75%-100%   | 4 (6.3)       |
| No response  | 6 (9.5)       |

**Table 3.** Physician platform use.

| Characteristics  | Values, n (%) |
|--|---------------|
| <b>Platforms used to provide care (March-September 2020)</b> |               |
| <b>Synchronous</b>   |               |
| Doxy   | 4 (6.3)       |
| Cisco Webex  | 17 (27.0)     |
| Zoom   | 16 (25.4)     |
| OTN <sup>a</sup>   | 35 (55.6)     |
| Facetime   | 7 (11.1)      |
| Telephone  | 41 (65.1)     |
| Microsoft Teams  | 1 (1.0)       |
| <b>Asynchronous</b>  |               |
| Secure messaging   | 3 (4.8)       |
| Email  | 18 (28.6)     |
| No response  | 10 (15.9)     |
| <b>Anticipated platform use (September 2020 onward)</b>      |               |
| <b>Synchronous</b>   |               |
| Doxy   | 4 (7.4)       |
| Cisco Webex  | 12 (22.2)     |
| Zoom   | 10 (18.5)     |
| OTN  | 39 (72.2)     |
| Facetime   | 1 (1.9)       |
| Telephone  | 34 (63.0)     |
| Microsoft Teams  | 2 (1.0)       |
| <b>Asynchronous</b>  |               |
| Secure messaging   | 3 (3.7)       |
| Email  | 18 (33.3)     |
| No response  | 9 (14.3)      |

<sup>a</sup>OTN: Ontario Telemedicine Network.

### Challenges of Web-Based Care Use

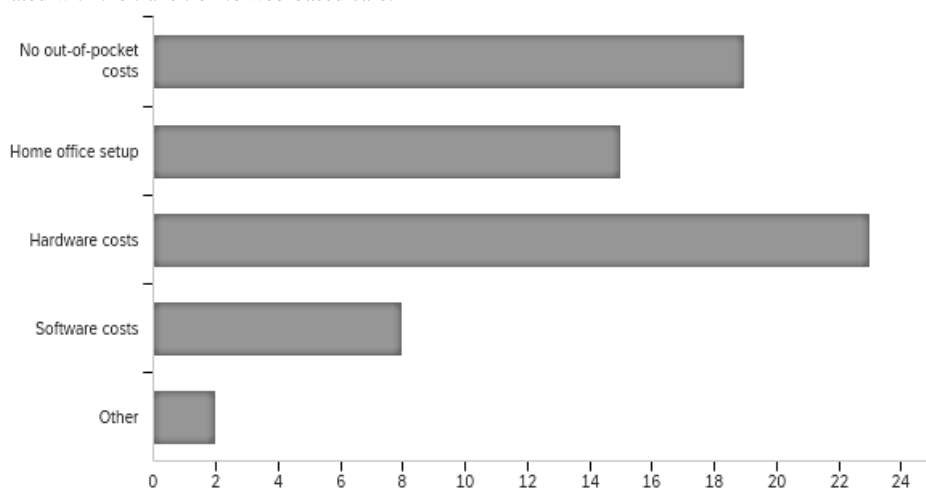
Free text responses by survey respondents provided insight into challenges during their adoption of web-based care from March 2020 onward ([Multimedia Appendix 2](#)). Those who felt web-based care did not work well for their patients frequently cited the inability to perform a physical examination and the associated diagnostic uncertainty as challenges. The respondents reported disappointment with a lack of respect of the web-based encounter, citing examples of patients answering digital calls

in shopping malls or poolside. The majority of physicians did not feel they could see a higher volume of patients digitally ([Table 4](#)). Technical difficulties and lack of adequate compensation were additional challenges.

With the transition to web-based care, out-of-pocket costs were encountered by 64% (34/63) of the respondents ([Figure 1](#)). While the exact cost associated was not quantified in our study, these tended to be one-time start-up costs (ie, web camera) versus recurring fees.

**Table 4.** Provider opinions on web-based care, March 2020 to September 2020.

| Question  | Strongly agree, n (%) | Somewhat agree, n (%) | Neither agree nor disagree, n (%) | Somewhat disagree, n (%) | Strongly disagree, n (%) | No response, n (%) |
|---|-----------------------|-----------------------|-----------------------------------|--------------------------|--------------------------|--------------------|
| Virtual care does not work well for my patient population.            | 4 (7.7)               | 16 (30.8)             | 11 (21.2)                         | 12 (23.1)                | 9 (17.3)                 | 11 (17.4)          |
| Technical difficulties are a challenge for me in my virtual practice. | 3 (5.8)               | 19 (36.5)             | 14 (26.9)                         | 14 (26.9)                | 2 (3.8)                  | 11 (17.4)          |
| I am compensated adequately for the virtual care I provide.           | 7 (13.5)              | 12 (23.1)             | 14 (26.9)                         | 7 (13.5)                 | 12 (23.1)                | 11 (17.4)          |
| I see a higher volume of patients virtually.                          | 4 (7.7)               | 6 (11.5)              | 10 (19.2)                         | 15 (28.8)                | 17 (32.7)                | 11 (17.4)          |
| I find it difficult to use virtual care platforms.                    | 1 (1.9)               | 9 (17.0)              | 13 (24.5)                         | 13 (24.5)                | 17 (32.1)                | 10 (15.9)          |
| Virtual care is convenient for me.                                    | 13 (24.5)             | 26 (49.1)             | 5 (9.4)                           | 6 (11.3)                 | 17 (5.7)                 | 10 (15.9)          |
| Patients find it difficult to use virtual care platforms.             | 4 (7.7)               | 15 (28.8)             | 15 (28.8)                         | 15 (28.8)                | 3 (5.8)                  | 11 (17.5)          |
| My patients are safer as a result of virtual care.                    | 8 (15.4)              | 16 (30.8)             | 20 (38.5)                         | 6 (11.5)                 | 2 (3.8)                  | 11 (17.5)          |
| Technical difficulties are a challenge for my patients.               | 9 (17.3)              | 23 (44.2)             | 11 (21.2)                         | 7 (13.5)                 | 2 (3.8)                  | 11 (17.5)          |
| Patients are satisfied with the transition to virtual care.           | 12 (23.1)             | 32 (61.5)             | 6 (11.5)                          | 2 (3.8)                  | 0 (0)                    | 11 (17.5)          |
| Patients are compliant with virtual care visits.                      | 4 (7.7)               | 31 (59.6)             | 10 (19.2)                         | 7 (13.5)                 | 0 (0)                    | 11 (17.5)          |
| Virtual care is convenient for my patients.                           | 19 (36.5)             | 30 (57.7)             | 3 (5.8)                           | 0 (0)                    | 0 (0)                    | 11 (17.5)          |

**Figure 1.** Costs associated with the transition to web-based care.

### Facilitators of Web-Based Care Use

Web-based care was rated as convenient for both physicians and patients, despite the presence of technical difficulties (Table 4). Based on free text feedback (Multimedia Appendix 2), the physicians who viewed web-based care as appropriate for their patient populations were typically those with a primary focus on history and less reliance on a physical exam.

### Future Use

Regardless of practice location, specialty, years in practice, or prior experience with web-based care, 96.4% (n=54) of the survey respondents would continue to provide web-based care in the future (Table 5). The majority of respondents would ideally see less than half of their patients digitally moving forward and identified patients who live far away and follow-ups or established diagnoses as ideal populations to serve digitally. Patient satisfaction, improved technology, and provincial or national policies are top motivating factors for continued web-based care use.



**Table 5.** Provider opinions on web-based care use from September 2020 onward.

| Characteristics  | Values, n (%) |
|--|---------------|
| <b>Plans to continue to provide web-based care</b>                 |               |
| Yes  | 54 (96.4)     |
| No   | 2 (3.6)       |
| No response  | 7 (11.1)      |
| <b>Ideal percentage of future web-based patient interactions</b>   |               |
| 0%   | 3 (5.4)       |
| 1%-10%   | 17 (30.4)     |
| 11%-25%  | 20 (35.7)     |
| 26%-50%  | 12 (21.4)     |
| 51%-75%  | 3 (5.4)       |
| 75%-100%   | 1 (1.8)       |
| No response  | 7 (11.1)      |
| <b>Patients best served virtually</b>                              |               |
| Nonacute   | 21 (51.2)     |
| New consults   | 9 (22.0)      |
| Follow-ups or established diagnosis                                | 30 (73.2)     |
| Patients who live far away   | 37 (90.2)     |
| Immunocompromised patients   | 21 (51.2)     |
| Patient preference   | 22 (53.7)     |
| No response  | 22 (34.9)     |
| <b>Motivating factors for continued web-based care integration</b> |               |
| Department-wide policy   | 23 (42.6)     |
| Financial incentive  | 29 (53.7)     |
| Patient satisfaction   | 36 (66.7)     |
| Better technology  | 33 (61.1)     |
| Other (please specify)   | 9 (16.7)      |
| Provincial or national policy                                      | 32 (59.3)     |
| LHSC <sup>a</sup> endorsement of a specific platform               | 14 (25.9)     |
| Training sessions for how to optimize web-based care               | 11 (20.4)     |
| Ability to incorporate trainees into web-based care                | 28 (51.9)     |
| No response  | 9 (14.3)      |

<sup>a</sup>LHSC: London Health Sciences Centre.

## Discussion

### Principal Results

Our study provides a unique insight into how pediatric physicians and surgeons at our center adjusted to a sudden virtualization of health care and their attitudes toward integration of web-based clinical practice in the future. With the onset of the COVID-19 pandemic, web-based care was adopted swiftly, exemplified by its almost-unanimous adoption by pediatric physicians and surgeons at our center, over half of whom provided the majority of their care digitally. Interestingly, months later, in the summer of 2020, practice patterns changed

to reduce the percentage of web-based visits, with over half of physicians and surgeons seeing less than 50% of their patients virtually. Those who were the most enthusiastic about web-based care were academic subspecialists who spend a greater proportion of their visits taking history, see patients with less acuity, and do not rely heavily on a physical examination. Looking to the future, buy-in for web-based care was high, with almost all survey respondents willing to continue to provide web-based care in the future, regardless of demographic factors and prior experience with web-based care.

## Comparison With Prior Work

Our results contribute to the existing literature demonstrating increased prevalence of web-based care visits during the COVID-19 pandemic, through examination of patterns of pediatric physician and surgeon provision. As evidenced by Bhatia and colleagues, prior to the pandemic, the delivery of care through web-based means was limited, with only a small number of Ontario physicians offering visits. However, during the first 6 months of 2020, the majority of Ontario residents had used web-based care for at least one appointment [8]. Furthermore, those who had connected with their doctor digitally during that time reported a 91% satisfaction rate [9]. Similar to provincial patterns, within our cohort, telephone visits were the primary method of contact during the first wave of the pandemic [8]. Interestingly, previous studies reporting on physician preference report that although audio or video visits represent the closest substitute to in-person visits, they are less convenient for providers when compared to asynchronous messaging, which allows time to review patient cases and respond when available [10,11]. In our study, asynchronous messaging represented a smaller proportion of web-based care visits, perhaps due to lack of familiarity, lack of department endorsement of these platforms, and perhaps poorer financial incentives. However, asynchronous delivery of care does offer the potential to reduce issues identified by our respondents, such as reduced web-based care patient volumes and poor patient etiquette.

Throughout the literature, it has been determined that web-based care works well in populations where a significant portion of the visit is spent taking history, with less reliance on a physical exam, which was supported by free text responses from our sample [12]. The challenges identified in our study, including lack of physical examination and poor patient etiquette, were supported by other studies of web-based care during the pandemic [4,13]. In addition to factors challenging physician adoption of web-based care, certain patient-level factors were identified as prohibitive to widespread use of web-based care. At our center specifically, which sees a high volume of Amish and Mennonite populations, accessibility in terms of equipment availability, technological literacy, and patient engagement are concerns. These barriers may be experienced by additional patient groups, such as newcomers, patients experiencing poverty and homelessness, and those with physical or intellectual disabilities.

Issues with web-based care etiquette were not unique to our center, as evidenced by a recent article outlining the experiences of physicians across the country renegotiating the rules of engagement in their web-based practices [14]. Physicians felt that, without better patient education, conducting a detailed interview, passive evaluation, or facilitated evaluation necessary to create a thorough assessment and treatment plan would be extremely difficult. While there is a wealth of patient

information tools for web-based care readiness available, we found that standardization of pediatric-specific, web-based care patient education tools was lacking in our center. Furthermore, while physician education on web-based care has been well documented in the literature [6,15,16], further research is needed to explore the impact of patient education. Based on survey responses and lack of available data on the topic, our department plans to create a pediatric-specific web-based etiquette tool, with the goal of measuring the impact of web-based care on physician experience.

## Limitations

Our study is limited by our response rate, with only 52.1% (63/121) of pediatric physicians and surgeons at our center having completed the survey. Though our convenience sample was representative of all durations of practice and included those with and without previous experience in web-based care, sampling method and response rate limit the generalizability of data across the Department of Paediatrics as a whole, and selection bias may have occurred. Given the small number of participants, we were unable to provide any subanalysis. Furthermore, only a small number of community pediatricians (7.9%) offered responses, with no response provided by those working in community hospitals. Further research is needed to explore the needs of community pediatricians and how the provision of web-based care may differ between academic and community practices. It should be noted that this study is only representative of a short period of time, March 2020 to September 2020. Additionally, during this period, we were unable to validate true percentages of web-based care used, and recall bias may have influenced responses to these questions. As COVID-19 continues to challenge the provision of in-person care, further research is needed to better understand current practice patterns and how they have changed over the last 2 years to improve practice efficiency and to inform regulatory guidelines for web-based care.

## Conclusion

In conclusion, the transition to web-based care during the early COVID-19 pandemic period at our center was associated with challenges, but also with positive experiences. Willingness to continue web-based care among pediatric physicians and surgeons is high. It was determined that select populations, particularly follow-ups and established diagnoses, may benefit more from web-based care compared with other groups such as new consults and higher acuity cases. Pediatric physicians' web-based care experiences at our center could be improved with greater patient education, improved technology, and provincial or national policies to guide web-based practice. Future directions include the development of a web-based care patient education tool to improve patient and provider experience.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Survey questions.

[\[DOCX File , 23 KB - pediatrics\\_v5i2e34115\\_app1.docx \]](#)

## Multimedia Appendix 2

Themes and illustrative quotes.

[\[DOCX File , 22 KB - pediatrics\\_v5i2e34115\\_app2.docx \]](#)**References**

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Letter to the Editor

# Empowering Without Misinforming Adolescents and Young Adults with Cystic Fibrosis. Comment on “Perceptions of Social Media Use to Augment Health Care Among Adolescents and Young Adults With Cystic Fibrosis: Survey Study”

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**KEYWORDS**

cystic fibrosis; social media; mobile health; adherence; adolescents; young adults; medical misinformation

We would like to thank the authors of the original research published in *JMIR Pediatrics and Parenting* [1] for exploring the attitudes toward social media and the capacity in which it can serve to enhance health care delivery for patients with cystic fibrosis (CF). Despite how far we have come in our understanding of the disease and the significant improvement in the care and overall prognosis of this cohort of patients, studies have shown that adolescents and young adults with CF continue to face significant barriers in their care concerning increasing CF complications, issues with medication compliance, and notably increased isolation and mental health vulnerabilities [1]. This article highlights thoughtful avenues in which social media may play a role in addressing some of these issues, such as access to medical information and education and the creation of online patient forums for peer social support. As the COVID-19 pandemic has forced us away from traditional face-to-face practice of medicine and further toward the realm of telemedicine and the digital world, this article is even more pertinent in its notes on the interplay between social media and health care today.

However, the pandemic has also exposed the uncapped danger that social media poses in the form of medical misinformation.

One aspect that this article could have considered is the prevalence of medical misinformation and how this may limit the role of social media in aiding health care services for patients with CF.

The spread of false medical information has become a public health crisis in recent years [2]. A study examining the spread of misinformation of the Zika virus showed misinformation was three times more likely to be shared on social media than verified stories [3]. This study found that, of the 50 adolescents and young adults with CF who participated in the survey study and reviewed CF-related information online, 55% rarely or never checked to ensure the source of the medical content they consumed was accurate [1]. Not only does misinformation dilute factual content [4], it also has the potential to severely impact a patient's quality of life and risk of mortality [3]. Vosoughi et al [5] hypothesized that false information spreads faster than facts because users identify more with its content, as it often elicits a strong emotional response. Considering patients with CF are a much younger demographic, it should be considered whether these patients are more vulnerable to misinformation.



If we, as health care professionals, advocate social media to our patients, we should also consider our role in ensuring they are being exposed to the correct information and sources. However, the practicalities of this can be argued: how can we ensure patients view only credible sources or whether individuals can evaluate the validity of such sources? Moving forward, further

research must be conducted to ensure how we can, practically and safely, implement social media guidelines for these patients, to empower adolescents and young adults with CF and provide them with a safe space to access information related to their condition.

## Conflicts of Interest

None declared.

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## Abbreviations

CF: cystic fibrosis.

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Letter to the Editor

# Author Reply to: Empowering Without Misinforming Adolescents and Young Adults with Cystic Fibrosis. Comment on “Perceptions of Social Media Use to Augment Health Care Among Adolescents and Young Adults With Cystic Fibrosis: Survey Study”

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**KEYWORDS**

Cystic fibrosis; Social media; mobile health; adherence; adolescents; young adults; Medical misinformation

We would like to thank the authors for their thoughtful comments on our study [1]. The COVID-19 pandemic has forced us to consider the incorporation of alternative models of care delivery. As noted in our study [2], social media is a model with potential to address compliance, social support, reduce isolation, and other vulnerabilities. The authors raise the question about medical misinformation and the potential adverse implications it may impart in care delivery. The COVID-19 pandemic has illuminated these potential perils, as evidenced by the dissemination of invalid therapeutic and preventative medications to combat the SARS-CoV-2 virus [3].

With regard to cystic fibrosis, the authors highlight that 55% of respondents rarely or never checked the accuracy of medical information, suggesting a potential vulnerability of the population to medical misinformation. Although not directly assessed in our study, an underlying theme of concern regarding medical misinformation does exist. For example, 92% of respondents suggested it was important that medical information comes from well-known sources. Additionally, 92% strongly agreed or agreed that medical information should come from a trusted source like the CF Foundation and 90% strongly agreed or agreed that it should come from a physician. These findings suggest respondents did have some degree of concern

surrounding misinformation although additional exploration is warranted.

The authors suggest that patients with cystic fibrosis may be more vulnerable to misinformation depending on their age. Considering the implications of age on vulnerability to misinformation is also very important. Although this population may be younger than other chronic disease cohorts [4-6], patients with CF are aging (mean age in the United States: 23.3 years) and over half of the population (57% in the United States and the United Kingdom) are older than 18 years [7,8]. It should be considered that many of these patients grew up during the rise of social media popularity. These experiences may allow for improved digital literacy and for misinformation to be more readily identified. Fake news and misinformation target consumers from all age groups; however, older adults have been noted to share more misinformation than younger users [9]. The implications of age and prior digital media experience with respect to misinformation warrants further investigation.

We agree that the voice of health care professionals will play an important role in ensuring that our patients receive accurate medical information. Although some suggestions for combating medical information have been previously proposed [10,11], it will be important as a medical community to develop

frameworks for addressing misinformation. Further in the future. investigations are needed to better characterize such activities

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## Abbreviations

**CF:** cystic fibrosis

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Original Paper

# The Sign 4 Big Feelings Intervention to Improve Early Years Outcomes in Preschool Children: Outcome Evaluation

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## Abstract

**Background:** Any delays in language development may affect learning, profoundly influencing personal, social, and professional trajectories. The effectiveness of the Sign 4 Big Feelings (S4BF) intervention was investigated by measuring changes in early years outcomes (EYOs) after a 3-month period.

**Objective:** This study aims to determine whether children's well-being and EYOs significantly improve (beyond typical, expected development) after the S4BF intervention period and whether there are differences between boys and girls in progress achieved.

**Methods:** An evaluation of the S4BF intervention was conducted with 111 preschool-age children in early years settings in Luton, United Kingdom. Listening, speaking, understanding, and managing feelings and behavior, in addition to the Leuven well-being scale, were assessed in a quasi-experimental study design to measure pre- and postintervention outcomes.

**Results:** Statistically and clinically significant differences were found for each of the 7 pre- and postmeasures evaluated: words understood and spoken, well-being scores, and the 4 EYO domains. Gender differences were negligible in all analyses.

**Conclusions:** Children of all abilities may benefit considerably from S4BF, but a language-based intervention of this nature may be transformational for children who are behind developmentally, with English as an additional language, or of lower socioeconomic status.

**Trial Registration:** ISRCTN Registry ISRCTN42025531; <https://doi.org/10.1186/ISRCTN42025531>

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## KEYWORDS

language development; sign language; early years outcomes; well-being

## Introduction

### Background

Any delays in language development may affect speech and learning, profoundly influencing personal, social, and professional trajectories. The role of social interaction and gesturing in cognitive development is paramount [1]. Socioemotional development is increasingly acknowledged as important for future life opportunities. *Effective mastery* of social and emotional skills supports the attainment of key life outcomes such as good health and social well-being, educational attainment and employment, and the avoidance of behavioral

and social difficulties [2], especially in the context of increasing concern about children's mental health and well-being [3,4]. Gesturing has been proposed as a *therapeutic communication tool* to help children express emotions and construct an understanding of their own internal states [5].

Goodman et al [6] linked social, emotional, and cognitive skills recorded in the British Cohort Study from children born in 1970 aged 10 years with their experiences 32 years later. Developing a good range of cognitive, social, and emotional skills—including good emotional well-being, self-regulation, and a sense of self-efficacy—in childhood is important for success in adult life. Moreover, psychological problems

experienced in childhood affect the ability to work in adulthood and impair earning power, marital stability, and intergenerational and within-generation social mobility [7]. In terms of ensuring school readiness, it is argued that developing preschool children's socioemotional skills as well as language skills help them adjust to primary school. This is argued as particularly important for at-risk children as a way of ensuring school readiness [8].

### Evidence for Effectiveness of Sign Language and Gesturing in Children

Research on the benefits of sign language for hearing children spans a range of ages. Góngora and Farkas [9] reported how an infant sign-language program with babies aged between 5 and 9 months increased visual and tactile interactions and the likelihood of vocal interactions compared with mother-infant dyad control groups. However, this was a small sample of 14 children with mothers from middle to higher socioeconomic status. Children as young as 12 months were reported to be able to comprehend communicative intentions behind gestures [10], and Vigliocco et al [11] found that preverbal children who have an understanding of both gesture and word combinations then go on to acquire the equivalent word combinations. In other words, gestures come before verbal speech. This is also argued in research investigating the relationship between motor and language development, in that infants practice with motor skills first—gestures—as a precursor to using new vocabulary [12]. In the late 1990s, Felzer [13] reported that hearing preschool children retained far more words and phonetic sounds using a multisensory approach by learning to read by seeing, hearing, saying, and signing words. Gesturing in particular was tested by Cook and Goldin-Meadow [14] during teaching, which in turn encouraged children to mirror gestures, increasing engagement and interaction, thereby enhancing learning.

School-based research has shown that teachers who use sign language with young hearing children significantly increased their vocabularies compared with children taught conventionally. These positive effects were sustained through the following kindergarten year [15]. A later study by the same researcher used American Sign Language with hearing children and reported that they had made significant progress in vocabulary [16]. In terms of specific academic subjects, children who observed gestures while learning mathematics performed better than a matched control group who received verbal instruction only [17]. In terms of longitudinal evidence, Rowe and Goldin-Meadow [18] reported that the gestures children make at 18 months can predict later language learning. They found that gestures used at 18 months predicted vocabulary at 42 months, and gestures and speech combinations conveying sentence-like constructs at 18 months predicted sentence complexity at 42 months.

With respect to the neuroscientific evidence, brain scanning studies have shown that the same areas of the brain are activated for symbolic gestures, signs, and words, and gestures conveying meaning will activate these parts of the brain, thus making learning new words easier [19,20]. The sensorimotor stage—birth to 2 years—extends from birth to early language development [21]. Children gradually construct knowledge by

coordinating their vision and hearing with physical interactions. In the preoperational stage (2-7 years), children can think symbolically, and a gesture can stand for something other than simply moving hands. As the understanding of brain function has advanced through theories such as embodied cognition [22], cognitive processes have been linked to our physical interactions with the world and the idea that signing and gestures may facilitate learning.

Although there is a great deal of research on the positive effects of signing and gesturing, there is also evidence to the contrary. A randomized controlled trial on the effects of signing on infant language reported no acceleration in linguistic development; however, mothers were more responsive to their child's nonverbal cues [23]. Concerns have also been raised about whether gesturing actually hampers language development in preverbal children. However, Goodwyn et al [24] reported that symbolic gesturing does not hamper verbal development and may encourage it.

### Sign 4 Program, Luton, United Kingdom

Luton is a large town situated in the county of Bedfordshire and 50 km northwest of London. It is 1 of 3 White British minority towns in the United Kingdom, extremely ethnically diverse because of high rates of international immigration and a greater number of people moving from London boroughs to Luton because of changes in benefit entitlements. Nearly one-third of children in Luton live in poverty (28.5%) [25]. More than a quarter of children are classified as obese (25.9%), and levels of General Certificate of Secondary Education (GCSE) attainment are worse than average for England overall. The dental decay rates in 5-year-olds in Luton (36.8%) are significantly higher than the England average [26]. Luton has a sizable transient, vulnerable population, with many families living in temporary accommodation. It is estimated that between 30% and 50% of the population were either not born or not living in Luton at the time of the 2011 census [27].

Consequently, multiple languages are spoken, and the number of primary school pupils with English as an additional language (EAL) now outnumbers English-speaking pupils [28]. To meet these challenges, Luton Borough Council (LBC) formulated an early help strategy to support stakeholders in a coordinated way [28]. LBC funds Flying Start, an organization dedicated to improving early years outcomes (EYOs) through support, programs, and services [29]. Sign 4 Big Feelings (S4BF) is one of many interventions funded by Flying Start [30].

This study investigates the effectiveness of the S4BF intervention following initial pilot data reporting accelerated progress in preschool children. Four interventions have been identified for evaluation, of which S4BF is one [31-36]. We examine its impact with an analysis of pre- and postoutcome data collected from Luton settings. The aims of this study are as follows:

- Do EYOs significantly improve (beyond typical, expected development) after using the S4BF program?
- Is there a statistically significant relationship between EYO domains (listening and attention, feelings and behavior,



speaking, and understanding), EYO domains and children's age, and the Leuven well-being scale?

- Does children's well-being improve after the S4BF intervention period?
- To what extent does gender play a role in any progress made?

## Methods

### Ethics Approval and Consent to Participate

This study was approved by the University of Bedfordshire research ethics committee (UREC104) on April 10, 2017. Written consent was obtained from the parents.

### Availability of Data and Materials

The data sets used and analyzed during this study are available from the corresponding author upon reasonable request.

### Participants

Data from 111 children were collected. Boys outnumbered girls (60/111, 54% and 48/111, 43.2%, respectively; 3/111, 3% unknown), just over a third of children had English as a second language (37/111, 33.3%), and just over one-fifth had funded preschool places (25/111, 22.5%; Table 1). At the start of the study, the mean age of the children was 39 (SD 10.81) months, but the ages ranged from 21 to 71 months. A total of 110 wordlists (words understood and spoken pre- and postintervention), 91 EYO assessments (pre- and postintervention), and 48 Leuven well-being scales (pre- and postintervention) were completed.

**Table 1.** Children by age, gender, English as an additional language, and funded 2 status (N=111).

| Characteristics                       | Values               |
|---------------------------------------|----------------------|
| <b>Gender, n (%)</b>                  |                      |
| Male                                  | 60 (54.1)            |
| Female                                | 48 (43.2)            |
| Unknown                               | 3 (2.7)              |
| <b>EAL<sup>a</sup> status, n (%)</b>  |                      |
| EAL-yes                               | 37 (33.3)            |
| EAL-no                                | 45 (40.5)            |
| Unknown                               | 28 (25.2)            |
| <b>Funding status, n (%)</b>          |                      |
| Funded 2 yes                          | 25 (22.5)            |
| Funded 2 no                           | 82 (73.9)            |
| Unknown                               | 3 (3.6)              |
| <b>Age (months), mean (SD; range)</b> |                      |
| January                               | 39.44 (10.81; 21-71) |
| March                                 | 42.65 (11.11; 44-75) |

<sup>a</sup>EAL: English as an additional language.

The S4BF intervention was delivered by childminders or early years practitioners trained as designated safeguarding officers (DSOs) overseeing preschool-age children in early years settings across Luton. Registered childminders provide childcare to young children in their own homes and must meet a range of statutory requirements set out by the Office for Standards in Education, Children's Services and Skills and LBC, such as safety standards and rules regarding care. DSOs are early years practitioners working in private, voluntary, or independent nursery settings. Their role is to keep abreast of relevant legislation, remain up-to-date with training related to safeguarding issues, and consequently be able to identify any sign of abuse, maltreatment, neglect, or distress in preschool children.

### Recruitment

Childminders and DSOs attend termly meetings held by LBC for briefings and changes in legislation and training. A slot was organized for the head of S4BF and the sign language trainer to give a presentation on S4BF, followed by a demonstration, hand out of S4BF books and dolls, and time for childminders and DSOs to practice the stories and sign among themselves. If childminders and DSOs were responsible for children aged 2 to 5 years and happy to participate, a memorandum of understanding was given with instructions on how to complete forms to monitor progress before and 3 months after S4BF, when outcome forms would be returned for analysis. Forms required childminders and DSOs to record EYOs in listening and attention, understanding, speaking, and managing feelings and behavior.

## Data Collection

Childminders and DSOs were asked to choose 2 children to monitor for the study period and collect and submit data at the beginning and end of the term. Where possible, these children were to have lower levels of expected development in communication and language and concerns about well-being as they were viewed as able to benefit most from the S4BF intervention. Part of the data collection was a statutory requirement, that is, the submission of EYO scores to monitor development and 2 additional forms per child completed as part of the evaluation: the number of words understood and spoken and the Leuven well-being scale. As DSOs work in nursery settings, they have a number of children of varying abilities and circumstances to monitor. However, childminders have a more limited scope as they usually care for between 1 and 3 children. Childminders and DSOs were briefed on how to complete and submit the forms as part of the termly meetings (see the *Recruitment* section above). As forms were submitted to the research project, they were checked to ensure that any queries could be addressed by settings and resolved as quickly as possible.

## Outcome Measures

Practitioners were already familiar with EYO scales to monitor early years' progress as they typically record this information every term. Children are assigned to age bands (ie, 24-30 months and 32-40 months), which are then subdivided into c=low, b=secure, and a=high to rate the level of attainment within each age band. Practitioners rate children on their ability; therefore, a child's chronological age may not reflect where they are placed on the EYO scale. Children are expected to move up 1 level per term; for example, 16-22c (low) to 16-22b (secure), which represents expected progress.

Two further measures were collected: the number of words (1) understood and (2) spoken out of 16 keywords featured in the S4BF storybook (happy, sad, why, because, quiet, hiding, crying, excited, frightened, dangerous, safe, worried, secret, shouting, noisy, and proud) and the Leuven well-being scale (for childminders and DSOs to fill in if they were trained to do so). A total of 2 Leuven scales exist for well-being and involvement, respectively. For the purpose of this study, the Leuven well-being scale was used [37,38] because it is commonly used by early years professionals in Luton. The Leuven scales were developed in part because it was hypothesized that where there are consistently low levels of well-being and involvement, it is likely that a child's development will be compromised [39,40]. The Leuven scale allows early years practitioners to place each child on a 5-point well-being scale ranging from 1 (extremely low) to 5 (extremely high), with clear definitions at each point for practitioners to judge against; training in the use of the scales is also routinely provided for Luton's early years' workforce.

Further information was collected on children's gender, age in months, whether EAL, and whether they have funded early years status (funded 2), which was used as a marker of deprivation.

## Research Design

A quasi-experimental design was used in this study. Data were collected pre- and postintervention from childminders and DSOs in Luton. Where possible, the children assessed were those with lower levels of expected development in communication and language and those subject to concerns about well-being because they would benefit the most from the S4BF intervention.

## Statistical Tests

A paired sample 2-tailed *t* test was used to measure the progress made by children, comparing EYO scores collected at the beginning and end of the school term, to determine whether the progress was significant. A correlation analysis was performed to determine any positive and statistically significant relationships between the variables under study. An analysis of covariance (ANCOVA) was conducted on the mean EYO scores to determine the level of progress achieved by preschool children when controlling for age.

## Sign 4 Big Feelings Intervention

The S4BF intervention was developed to address gaps of attainment in preschool children. Such gaps were identified by looking at routinely collected early years data to monitor the progress of children across Luton. S4BF uses books depicting children experiencing different emotions and accompanying dolls to *act out* how the characters feel. Early years practitioners read books to children regularly at storytimes using simple sign language to convey the emotions of the characters in the story and encourage children to copy the signs and repeat the words the signs convey ("Ishan feels really safe. Why does he feel safe? Because he's having a bedtime story;" "Izzy is sad. Why is she sad? Because the television is broken").

The intervention was designed to help preschool children to communicate more effectively, express emotions constructively, and learn linking words such as *because* and *why* to use complex sentences to explain the reasons behind behaviors. S4BF was designed to provide young children with a range of vocabulary to convey how they feel and an opportunity to talk with a trusted adult about events they may find frightening or difficult, such as family conflict or domestic abuse. The intervention was intended to help children 3-fold: improve speech and vocabulary with stories and accompanying sign language, help them *name and tame* their emotions rather than act out with difficult or destructive behavior, and help early years practitioners in identifying any safeguarding issues that may arise by talking about the emotions depicted in the S4BF book. [Textbox 1](#) shows the theory of change to illustrate the progression from S4BF outputs and activities to short- and long-term outcomes.

**Textbox 1.** Theory of change: use of a sign-language intervention to improve early years outcomes in preschool children.

|   |
|---|
| <p>Outputs</p> <ul style="list-style-type: none"> <li>• Funding (by local government) and development of sign-language program to improve communication via speech and language development through:             <ul style="list-style-type: none"> <li>• Sign language to reinforce keywords with accompanying gestures and facial expressions</li> <li>• Stories to reflect different social situations</li> <li>• Repetition of stories and use of signs during interactions during the school day</li> <li>• Production of Sign 4 Big Feelings books and dolls</li> </ul> </li> </ul> <p>Activities</p> <ul style="list-style-type: none"> <li>• Training sessions with early years practitioners in the Sign 4 Big Feelings program</li> <li>• Early years practitioners read Sign 4 Big Feelings books and used dolls with children at regular story times throughout the week</li> <li>• Recording and monitoring of early years outcomes over time to ensure disadvantaged children keep up with national average development and attainment goals</li> </ul> <p>Short-term outcomes</p> <ul style="list-style-type: none"> <li>• Early years practitioners are trained in key sign-language skills</li> <li>• Accelerated improvements in key early years outcomes:             <ul style="list-style-type: none"> <li>• Listening and attention</li> <li>• Understanding</li> <li>• Speaking</li> <li>• Managing feelings and behavior</li> </ul> </li> <li>• Significant improvements in:             <ul style="list-style-type: none"> <li>• Number of words spoken and understood</li> <li>• Well-being</li> </ul> </li> <li>• Narrowing the gap in attainment with peers before starting primary school for those children who are developmentally behind</li> </ul> <p>Longer-term outcomes</p> <ul style="list-style-type: none"> <li>• Early years practitioners can use their sign-language skills with future cohorts of children</li> <li>• Early years settings appreciate long-term benefits of the use of sign-language intervention to improve early years outcomes and embed as part of long-term provision</li> <li>• Improved educational attainment, social skills, and employment prospects, leading to a better quality of adult life and better health</li> </ul> |
|---|

## Results

### Overview

**Table 2** summarizes the S4BF data set. Although 111 children took part in the evaluation of S4BFs, some measures were incomplete.

In total, 48 Leuven Scales (pre- and postintervention), 91 EYO assessments (pre- and postintervention), and 110 word lists (words understood and spoken pre- and postintervention) were completed. Baseline data were collected in November 2016, and follow-up data were collected 3 months later, from February to March 2017.

**Table 2.** Summary of the Sign 4 Big Feelings data set (N=111).

| Outcome                                  | Valid, n (%) | Missing, n (%) | Mean (SD)    | Range | Minimum | Maximum |
|--|--------------|----------------|--------------|-------|---------|---------|
| <b>January</b>                           |              |                |              |       |         |         |
| Words understood                         | 110 (99.1)   | 1 (0.9)        | 6.30 (4.04)  | 16    | 0       | 16      |
| Words said                               | 110 (99.1)   | 1 (0.9)        | 4.10 (3.93)  | 16    | 0       | 16      |
| Leuven                                   | 48 (43)      | 63 (57)        | 2.89 (1.05)  | 4     | 1       | 5       |
| EYO <sup>a</sup> listening and attention | 91 (82)      | 20 (18)        | 9.06 (2.45)  | 11    | 4       | 15      |
| EYO understanding                        | 91 (82)      | 20 (18)        | 8.83 (2.62)  | 13    | 2       | 15      |
| EYO speaking                             | 91 (82)      | 20 (18)        | 7.94 (2.96)  | 14    | 1       | 15      |
| EYO feelings and behavior                | 91 (82)      | 20 (18)        | 8.71 (2.31)  | 10    | 4       | 14      |
| <b>March</b>                             |              |                |              |       |         |         |
| Words understood                         | 110 (99.1)   | 1 (0.9)        | 11.41 (3.57) | 13    | 3       | 16      |
| Words said                               | 110 (99.1)   | 1 (0.9)        | 9.60 (4.44)  | 16    | 0       | 16      |
| Leuven                                   | 48 (43)      | 63 (57)        | 3.97 (0.73)  | 3     | 2       | 5       |
| EYO listening and attention              | 91 (82)      | 20 (18)        | 11.02 (2.44) | 12    | 6       | 18      |
| EYO understanding                        | 91 (82)      | 20 (18)        | 10.77 (2.45) | 13    | 5       | 18      |
| EYO speaking                             | 91 (82)      | 20 (18)        | 10.25 (2.69) | 14    | 4       | 18      |
| EYO feelings and behavior                | 91 (82)      | 20 (18)        | 10.69 (2.27) | 11    | 6       | 17      |

<sup>a</sup>EYO: early years outcome.

## Analysis

In addition to descriptive statistics, a number of tests were used: a within samples *t* test, correlations, ANCOVAs, and multivariate analysis of covariance.

### Paired Sample *t* Test

A paired sample *t* test was conducted to establish any statistically significant difference between the pre- and post-S4BF intervention after checking that the data were within the normal distribution (Table 3). There was a statistically significant difference in the mean scores for each of the 7 pre- and postpairs tested. For mean words understood by children, a paired-samples *t* test indicated that scores were significantly higher in March (mean 11.41, SD 3.57) than in January (mean 6.3, SD 4.04;  $t_{109}=16.4$ ;  $P<.001$ ; Cohen  $d=1.56$ ). Mean words spoken were significantly higher in March (mean 9.6, SD 4.44)

than in January (mean 4.11, SD 3.93;  $t_{109}=15.55$ ;  $P<.001$ ; Cohen  $d=1.38$ ). The Leuven well-being scores were significantly higher in March (mean 3.98, SD 0.73) than in January (mean 2.89, SD 1.05;  $t_{47}=9.78$ ;  $P<.001$ ; Cohen  $d=1.42$ ). The EYO listening and attention was significantly higher in March (mean 11.0, SD 2.45) than in January (mean 9.06, SD 2.45;  $t_{90}=12.46$ ;  $P<.001$ ; Cohen  $d=1.3$ ).

The EYO understanding was significantly higher in March (mean 10.75, SD 2.45) than in January (mean 8.83, SD 2.62;  $t_{90}=11.64$ ;  $P<.001$ ; Cohen  $d=1.2$ ). The EYO speaking was significantly higher in March (mean 10.25, SD 2.69) than in January (mean 7.94, SD 2.96;  $t_{90}=11.27$ ;  $P<.001$ ; Cohen  $d=1.17$ ). The EYO feelings and behavior were significantly higher in March (mean 10.69, SD 2.27) than in January (mean 8.71, SD 2.31;  $t_{90}=11.9$ ;  $P<.001$ ; Cohen  $d=1.24$ ).

**Table 3.** Paired-samples *t* test results.

| Pairs   | Paired differences |         |                          | <i>t</i> test ( <i>df</i> ) | <i>P</i> values (2-tailed) |
|---|--------------------|---------|--------------------------|-----------------------------|----------------------------|
|   | Mean (SD)          | SE mean | 95% CI of the difference |                             |                            |
| 1. Words Jan under–words Mar under                        | –5.11 (3.26)       | 0.31    | –5.73 to –4.50           | –16.43 (109)                | <.001                      |
| 2. Words Jan say–words Mar say                            | –5.49 (3.70)       | 0.35    | –6.19 to –4.79           | –15.55 (109)                | <.001                      |
| 3. Leuven Jan–Leuven Mar                                  | –1.08 (0.76)       | 0.11    | –1.30 to –0.86           | –9.78 (47)                  | <.001                      |
| 4. EYO <sup>a</sup> Jan list and att–EYO Mar list and att | –1.95 (1.49)       | 0.15    | –2.26 to –1.64           | –12.46 (90)                 | <.001                      |
| 5. EYO Jan under–EYO Mar under                            | –1.92 (1.60)       | 0.16    | –2.25 to –1.59           | –11.46 (90)                 | <.001                      |
| 6. EYO Jan speak–EYO Mar speak                            | –2.30 (1.95)       | 0.20    | –2.71 to –1.90           | –11.27 (90)                 | <.001                      |
| 7. EYO Jan feel and beh–EYO Mar feel and beh              | –1.97 (1.58)       | 0.16    | –2.30 to –1.64           | –11.91 (90)                 | <.001                      |

<sup>a</sup>EYO: early years outcome.

### Correlations

A correlation analysis was undertaken for children's age, EYOs, and Leuven well-being scales (Table 4). There was a positive, statistically significant relationship between age and the EYO of listening and attention Pearson  $r_{91}=0.56$ ,  $P<.001$ ; age and EYO for understanding, Pearson  $r_{91}=0.57$ ,  $P<.001$ ; age and EYO for speaking, Pearson  $r_{91}=0.49$ ,  $P<.001$ ; and age and EYO for feelings and behavior, Pearson  $r_{91}=0.51$ ,  $P<.001$ . A strong

positive, statistically significant relationship was also found between each of the EYOs; for example, EYOs for listening and attention and understanding, Pearson  $r_{91}=0.90$ ,  $P<.001$ , and between feelings and behavior and speaking, Pearson  $r_{91}=0.83$ ,  $P<.001$ . A positive, statistically significant relationship was found between the Leuven well-being scores and all the EYO domains, the strongest of which was with speaking, Pearson  $r_{44}=0.51$ ,  $P<.001$ .

**Table 4.** Correlations between age, early years outcomes, and Leuven scales.

|  | Age March        | EYO <sup>a</sup> March listening and attention | EYO March understanding | EYO March speaking | EYO March feelings and behavior |
|--|------------------|--|-------------------------|--------------------|---------------------------------|
| <b>Age March</b>                         |                  |  |                         |                    |                                 |
| Pearson correlation                      | 1                | 0.56 <sup>b</sup>                              | 0.57 <sup>b</sup>       | 0.49 <sup>b</sup>  | 0.51 <sup>b</sup>               |
| Significance (2-tailed)                  | N/A <sup>c</sup> | 0.00   | 0.00                    | 0.00               | 0.00                            |
| n  | 110              | 91   | 91                      | 91                 | 91                              |
| <b>EYO March listening and attention</b> |                  |  |                         |                    |                                 |
| Pearson correlation                      | N/A              | N/A  | 0.90 <sup>b</sup>       | 0.87 <sup>b</sup>  | 0.87 <sup>b</sup>               |
| Significance (2-tailed)                  | N/A              | N/A  | 0.00                    | 0.00               | 0.00                            |
| n  | N/A              | N/A  | 91                      | 91                 | 91                              |
| <b>EYO March understanding</b>           |                  |  |                         |                    |                                 |
| Pearson correlation                      | N/A              | N/A  | N/A                     | 0.85 <sup>b</sup>  | 0.82 <sup>b</sup>               |
| Significance (2-tailed)                  | N/A              | N/A  | N/A                     | 0.00               | 0.00                            |
| n  | N/A              | N/A  | N/A                     | 91                 | 91                              |
| <b>EYO March speaking</b>                |                  |  |                         |                    |                                 |
| Pearson correlation                      | N/A              | N/A  | N/A                     | N/A                | 0.83 <sup>b</sup>               |
| Significance (2-tailed)                  | N/A              | N/A  | N/A                     | N/A                | 0.00                            |
| n  | N/A              | N/A  | N/A                     | N/A                | 91                              |
| <b>Leuven March</b>                      |                  |  |                         |                    |                                 |
| Pearson correlation                      | N/A              | 0.48 <sup>b</sup>                              | 0.52 <sup>b</sup>       | 0.58 <sup>b</sup>  | 0.50 <sup>b</sup>               |
| Significance (2-tailed)                  | N/A              | 0.00   | 0.00                    | 0.00               | 0.00                            |
| n  | N/A              | 44   | N/A                     | N/A                | N/A                             |

<sup>a</sup>EYO: early years outcome.

<sup>b</sup>Correlation significant at the 0.01 level (2-tailed).

<sup>c</sup>N/A: not applicable.

### EYO Progress, Gender, English as an Additional Language, Funded 2 Status, and Well-being

Although there was no difference in gender in terms of progress, children with EAL accomplished nearly 4 steps in EYO stages (boys 3.7 steps, girls 3.8), whereas non-EAL children accomplished 2 steps (both boys and girls progressed 2.2 steps). Expected progress per term (3 months) is one step.

Gender differences were marginal, with funded 2 girls making slightly more progress than boys (girls 4.4 steps and boys 3.9) and nonfunded boys making slightly more progress than nonfunded girls (boys 2.6 steps, girls 2.4 steps). Overall, children who had funded 2 status progressed just over 4 steps

(4.15) compared with nonfunded children who progressed 2.5 steps. In terms of well-being, children were assessed on the Leuven scale pre- and postintervention in January and March. At baseline, most children were put at level 3 (moderate, 46%), and at level 4 (high, 54%) postintervention, showing an overall shift of the sample higher up the Leuven well-being scale.

### Analysis of Variance

An analysis of variance was conducted on the S4BF data set (Table 5). A 3×2 within-group ANCOVA was run on the means of the EYO scores as the scores correlated with one another. The ANCOVA conducted with mean EYO scores (mean 10.73, SD 2.33) showed that the main effect of EYOs was statistically



significant throughout time when controlling for age ( $F_{1,89}=4.89$ ,  $P=.03$ ; partial  $\eta$  0.58; 39.33, SD 10.81). There was a statistically significant interaction between EYOs (mean 10.73, SD 2.33) and age ( $F_{1,89}=6.18$ ,  $P=.01$ ; partial  $\eta$  0.72; mean 39.33, SD 10.81). There was a statistically significant interaction between EYOs (mean 10.73, SD 2.33) and EAL ( $F_{1,89}=8.48$ ,  $P=.005$ ;

partial  $\eta$  0.09; mean 4.33, SD 2.29). There was another statistically significant interaction in the ANCOVA test between EYOs (mean 10.73, SD 2.33) and funded 2 status ( $F_{1,89}=10.65$ ,  $P=.002$ ; partial  $\eta$  0.11; mean 10.84, SD 2.29). No statistically significant interaction was found between EYOs and gender or between combinations of the aforementioned variables.

**Table 5.** Analysis of covariance with mean EYO<sup>a</sup> scores.

| Tests of within-subjects effects | Type III sum of squares | Mean square | F (df)     | Significance | Partial $\eta$ squared |
|----------------------------------|-------------------------|-------------|------------|--------------|------------------------|
| EYO                              | 4.011                   | 4.011       | 4.895 (1)  | 0.030        | 0.058                  |
| EYO×age_Jan                      | 5.066                   | 5.066       | 6.183 (1)  | 0.015        | 0.072                  |
| EYO×gender                       | 0.011                   | 0.011       | 0.014 (1)  | 0.907        | 0.000                  |
| EYO×EAL <sup>b</sup>             | 6.955                   | 6.955       | 8.488 (1)  | 0.005        | 0.096                  |
| EYO×funded 2                     | 8.726                   | 8.726       | 10.651 (1) | 0.002        | 0.117                  |
| EYO×gender×EAL                   | 0.008                   | 0.008       | 0.010 (1)  | 0.922        | 0.000                  |
| EYO×gender×funded 2              | 0.209                   | 0.209       | 0.255 (1)  | 0.615        | 0.003                  |
| EYO×EAL×funded 2                 | 0.000                   | 0.000       | 0.000 (1)  | 0.997        | 0.000                  |
| EYO×gender×EAL×funded 2          | 0.016                   | 0.016       | 0.019 (1)  | 0.891        | 0.000                  |

<sup>a</sup>EYO: early years outcome.

<sup>b</sup>EAL: English as an additional language.

### Statistical Significance and Clinical Significance: EYO Scores

The previous section has shown that children made statistically significant progress in their EYO scores. Children are expected to progress by 1 EYO level per term, but to what extent have children progressed further than this? Further inspection of the data showed that children cared for by childminders showed considerably less progress (1.4 steps) compared with the EYO results reported by DSOs (3.6 steps).

### Control Data

Control data collected from the same academic year records average progress of preschool children throughout 2 terms. Table 6 shows that children made 1 or 2 steps progress in each EYO domain. Children are expected to progress 1 step in each term. Therefore, data collected from these settings show that below-expected progress was made in listening and attention and speaking (1 step throughout 2 terms), and expected progress was made in understanding and managing feelings and behavior (2 steps throughout 2 terms).

**Table 6.** Control data: average steps progress of children throughout 2 school terms.

| EYO <sup>a</sup> domain        | Autumn term 1, n (%) |            |            |           | Spring term 2, n (%) |            |            |            | Steps progress |
|--------------------------------|----------------------|------------|------------|-----------|----------------------|------------|------------|------------|----------------|
|                                | Total pupils         | Below      | At         | Above     | Total pupils         | Below      | At         | Above      |                |
| Listening and attention        | 413 (100)            | 140 (33.9) | 190 (46)   | 82 (19.9) | 498 (100)            | 130 (26.1) | 189 (38)   | 179 (35.9) | 1              |
| Understanding                  | 413 (100)            | 169 (40.9) | 169 (40.9) | 75 (18)   | 498 (100)            | 179 (35.9) | 169 (33.9) | 150 (30.1) | 2              |
| Speaking                       | 404 (100)            | 186 (46)   | 162 (40)   | 56 (13.9) | 498 (100)            | 220 (44.2) | 150 (30.1) | 130 (26.1) | 1              |
| Managing feelings and behavior | 394 (100)            | 158 (40.1) | 189 (47.9) | 47 (11.9) | 498 (100)            | 189 (38)   | 189 (38)   | 120 (24.1) | 2              |

<sup>a</sup>EYO: early years outcome.

## Discussion

### Principal Findings

Statistically significant differences were found for each of the seven pre- and postmeasures taken: words understood and spoken, well-being scores, and the 4 EYO domains. Therefore,

children achieved better than expected progress when assessed at the end of the intervention. Most children in the sample achieved better than expected progress, with many progressing multiple steps in EYO attainment.

Positive correlations were found between age and the EYOs of listening and attention, understanding, speaking, and feelings

and behavior. A strong, statistically significant relationship was found between each EYO domain. Therefore, having a high EYO in one domain was positively associated with having a high score in another. This is corroborated by early years professionals, in that one EYO domain underpins another. For example, if a child is assessed as low in understanding or speaking, they are unlikely to manage their feelings and behavior as that involves speaking. A positive, statistically significant relationship was found between the Leuven well-being scores and all the EYO domains, the strongest of which was with speaking. In other words, there was a positive relationship between well-being and higher EYO scores. Children with EAL made more progress than native speakers, and those with funded places made more progress than nonfunded children.

As age was positively correlated with all EYO domains, an ANCOVA was run with age as a covariate. This showed that EYO as a main effect was statistically significant throughout time when controlling for age. There was a statistically significant interaction between EYO and EAL and between EYO and funded 2 status. No statistically significant interaction was found between EYO and gender. Gender differences were negligible in all analyses undertaken. Considerable variations in progress were evident when comparing data reported by childminders and DSOs.

Clinically significant results in EYO scores were shown by documenting the stages of progress made by children in the sample. Whereas more than one-quarter of children made expected progress (by progressing up 1 level), most progressed more than expected (by 2 stages or more). Although children reported as having progressed by multiple stages should be treated with caution, overall, most children in the sample made better than expected progress in terms of these 4 EYO domains. Indeed, in the early years, professionals reported seeing rapid progress in children if they were engaged in learning.

In summary, the statistical tests show us that the children made significant progress in terms of EYOs and words understood and spoken, even when controlling for the effect of age. By looking at the number of stages of progress made, we know that a large proportion of the sample made clinically significant progress.

### Limitations

There was a clear divide in the level of progress reported by childminders and DSOs. Childminders are likely to care for children on a part-time basis, which means less contact and therefore less time to read stories and sign consistently with children. Childminders seem less supported in that they work from home compared with DSOs who work within an institution and consequently have support and input from colleagues. They also care for smaller groups of children, some of whom may not have met the study criteria of being below the level of expected development. A number of childminder forms were excluded from the sample as insufficient detail was provided on the EYOs (eg, the age range in months was given, but not an a-c rating to indicate proficiency within that band or only an a-c rating without an age band given in months). Childminders may be less supported as independent businesses than as part of institutions, and although they were provided training and

guidance on how to use the EYO bands, a proportion were still unable or unsure how to report them fully. Conversely, there may have been a positive bias in the results reported by DSOs, as the progress made by some children seemed so great, moving many EYO bands further ahead.

A relatively small sample size was achieved; however, we were interested in studying a subsection of that population, specifically children below the expected levels of development. On the basis of the local authority tracking system for EYOs, a step up the scale per term is judged as typical progress; however, there is no such thing as the *typical* child. In fact, funded 2 children are expected to accelerate progress to catch up. Early years settings in Luton report that they are getting better at identifying children who require additional help and are modifying their approach to better meet educational needs with interventions such as S4BF. For those children who were reported to have made less than expected progress, there may be an undiagnosed special educational need, inconsistent attendance (2-year-olds are nonstatutory), or change in key workers as possible explanations. Data on well-being as measured on the Leuven scale were particularly restricted, as not all early years practitioners were trained to use them. Scales are an indicator of progress, but they do not consider each child as a whole and their personal circumstances.

Childminders and DSOs were asked to incorporate the S4BF book and doll into their daily routines; however, there were variations between practitioners and settings regarding the frequency of use. In particular, childminders commented that the intervention period was too short to allow for any substantive change in children. Future studies would benefit from running across more than 1 term and having larger sample sizes.

An independent assessment of child outcomes would have strengthened the results. However, staff in early years settings routinely assess children in terms of EYO progress as an integral part of their role. Furthermore, it could be argued that staff working with children on a daily basis would be best placed to judge the rate, extent, and nuances of children's progress than an external assessor.

This study has been defined by the progress made by children rather than final attainment. Further work is required to ascertain whether the considerable progress that most children in this sample have made has allowed them to catch up with their peers, although this approach would benefit from a study tracking children for longer than 3 months. A longer-term, longitudinal study tracking children's educational outcomes up to secondary school may help understand critical points in development and where gender differences start to be apparent. It is hoped that the positive effects reported here will be sustained throughout time, as with Daniels [15], and have a profound and long-lasting impact [18].

### Previous Research and Theory

Overall, the results reported here contribute to research on the positive effects of sign language and gesturing for preschool children [11,12]. Effects of low income on educational outcomes [41,42] have been reported. The results presented here suggest that children receiving funding (funded 2) made considerable

progress. At the very least, interventions such as S4BF encourage children and early years practitioners to engage with each other through gestures, eye contact, and facial expressions, fostering receptive, word-rich environments [43]. It could be argued that the benefits of interventions successful in promoting speech, sentences, and acquisition of vocabulary are difficult to quantify in the sense that children are given the tools to quickly build upon iteratively, influencing more than educational attainment. The UK Government has expanded funded preschool places in recent years, and it is an area where inequalities in longer-term outcomes can be tackled early on [44].

Children learning a foreign language also face greater challenges in attainment than their peers [45,46]. The results presented here from the S4BF intervention suggest that EAL children can make significant progress beyond expected levels of attainment, thereby helping them catch up with their peers. Gender did not appear to have any significant effect on EYOs, wordlists, or well-being. Any differences between boys and girls are perhaps less pronounced in the early years in terms of educational outcomes; however, we know that they become stark by the time children reach early adulthood [47]. The statutory data collected in Luton suggest that the gap becomes apparent at reception age when children are required to write and therefore have fine motor skills.

Working with Flying Start, LBC, and early years practitioners to evaluate S4BF has facilitated the cooperation of people working in settings with the expertise to work closely with young children. Progress has been measured in multiple

domains: EYOs, word knowledge, and Leuven well-being scales. EYOs, in particular, are established measures in early years education and widely used across Luton, allowing professionals to place children on a reasonably finely grained scale to monitor their progress on a range of key developmental domains.

## Conclusions

S4BF was designed in part to help children express difficult emotions, thereby reducing destructive behavior. Most children in this sample made significant progress in all EYO domains, not least managing feelings and behavior. This element needs to be explored further in the forthcoming process study of S4BF. The wider evaluation of the Sign 4 Program will include the views of parents [48] and in-depth interviews with early years professionals. It will also be possible to see if there has been an increase in safeguarding referrals since the introduction of S4BF. The evidence presented here suggests that interventions such as S4BF can benefit preschool children but are particularly important for children who experience multiple disadvantages. S4BF was developed because of the worrying gaps in the attainment of young children in Luton. Such children are starting at a disadvantage and appear to benefit greatly from this additional support. Children of all abilities may benefit considerably from S4BF. However, the intervention may be transformational for children who are behind developmentally, with EAL needs or of lower socioeconomic status, and who require additional support to catch up with their peers to realize their potential in later life.

## Conflicts of Interest

None declared.

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## Abbreviations

- DSO:** designated safeguarding officer
- EAL:** English as an additional language
- EYO:** early years outcomes
- LBC:** Luton Borough Council
- S4BF:** Sign 4 Big Feelings

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Original Paper

# Apps for Promoting Children's Oral Health: Systematic Search in App Stores and Quality Evaluation

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## Abstract

**Background:** Increasingly, mobile apps are being used to promote oral care. Many of them are aimed at children.

**Objective:** This study aimed to systematically search and evaluate apps that promote oral care and hygiene for children.

**Methods:** A broad search strategy (13 keywords) was developed to identify apps from Apple's App Store and the Google Play Store in April 2019. After reviewing the apps' titles and summaries, potentially relevant apps were downloaded for viewing. The quality of the apps that met the inclusion criteria was assessed by the Health on the Net Foundation Code of Conduct (HONcode) criteria for medical and health websites and the Scientific Basis of Oral Self-care (SBOSC).

**Results:** More than 3000 Apps were identified and 54 relevant apps informed the review. The quality of the apps according to the HONcode criteria was generally low. The mean HONcode score was 1.8/8.0. One-quarter of the apps had a HONcode score of 0 (14/54, 26%). The SBOSC score of the apps was evaluated based on a 6-point scale. The mean SBOSC score was 1.5/6.0; 19% (10/54) of the apps had a score of 0. There was a significant and positive correlation between HONcode and SBOSC scores ( $r=0.37$ ;  $P<.01$ ). More recently uploaded apps had significantly higher HONcode scores ( $P<.05$ ).

**Conclusions:** There are many apps aiming to promote oral self-care among children. The quality and scientific basis of these apps are low. Newer apps are of higher quality in terms of scientific basis. There is a need to ensure high-quality and evidence-based apps are available. The effectiveness of apps in terms of oral care and clinical outcomes among children needs to be evaluated.

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**KEYWORDS**

apps; oral health; evidence-based; oral hygiene; children

## Introduction

Among all health problems that may be experienced during childhood, oral disease remains the most common [1]. A systematic analysis of the global burden of oral diseases has identified that untreated dental caries (tooth decay) among young children can cause considerable pain and suffering and impacts

their quality of life, families, and communities [2]. Oral diseases are multifactorial infectious diseases and dental plaque (bacteria) plays a key role in their pathogenesis [3]. Thus, in preventing oral disease, a key focus has been on controlling dental plaque by improving oral hygiene (ie, toothbrushing) [4]. Cochrane systematic reviews are leading sources of scientific evidence to help people (both patients and clinicians) make

better-informed decisions about their oral care. Several Cochrane systematic reviews have identified that toothbrushing with fluoridated toothpaste is the mainstay to prevent dental caries among children [5,6] and has minimal side effects [7].

Not surprisingly, the practice of toothbrushing is a cornerstone of oral health promotion activities, particularly among children [8]. Traditionally, toothbrushing has been promoted through conventional education programs (eg, lectures, leaflets, and posters). However, evidence of their effectiveness is questionable, particularly for long-term behavioral change and clinical outcomes [9]. Apps are increasingly used in health care and health informatics in recent years [10-12]. Promising results have been generated from narrative and systematic searches and reviews of apps for promoting mental health, physical health, and lifestyle behaviors [13-16]. In more recent times, there has been growing recognition of the potential use of apps for oral health, especially in promoting oral hygiene, and among children [17,18]. Web-based health information may not be reliable, and the quality of the knowledge delivered is not guaranteed to be high. Fallacious information could have a harmful effect on children using the apps. To date, a systematic search and review of apps for oral care is lacking, and the quality and scientific basis of such apps has not been considered. This study aimed to systematically search for and review apps for oral care aimed at young children to determine their profile

characteristics, quality, and scientific basis. In addition, this study aimed to determine the relationship between the quality and scientific basis of the apps and the association between app characteristics with quality and scientific basis.

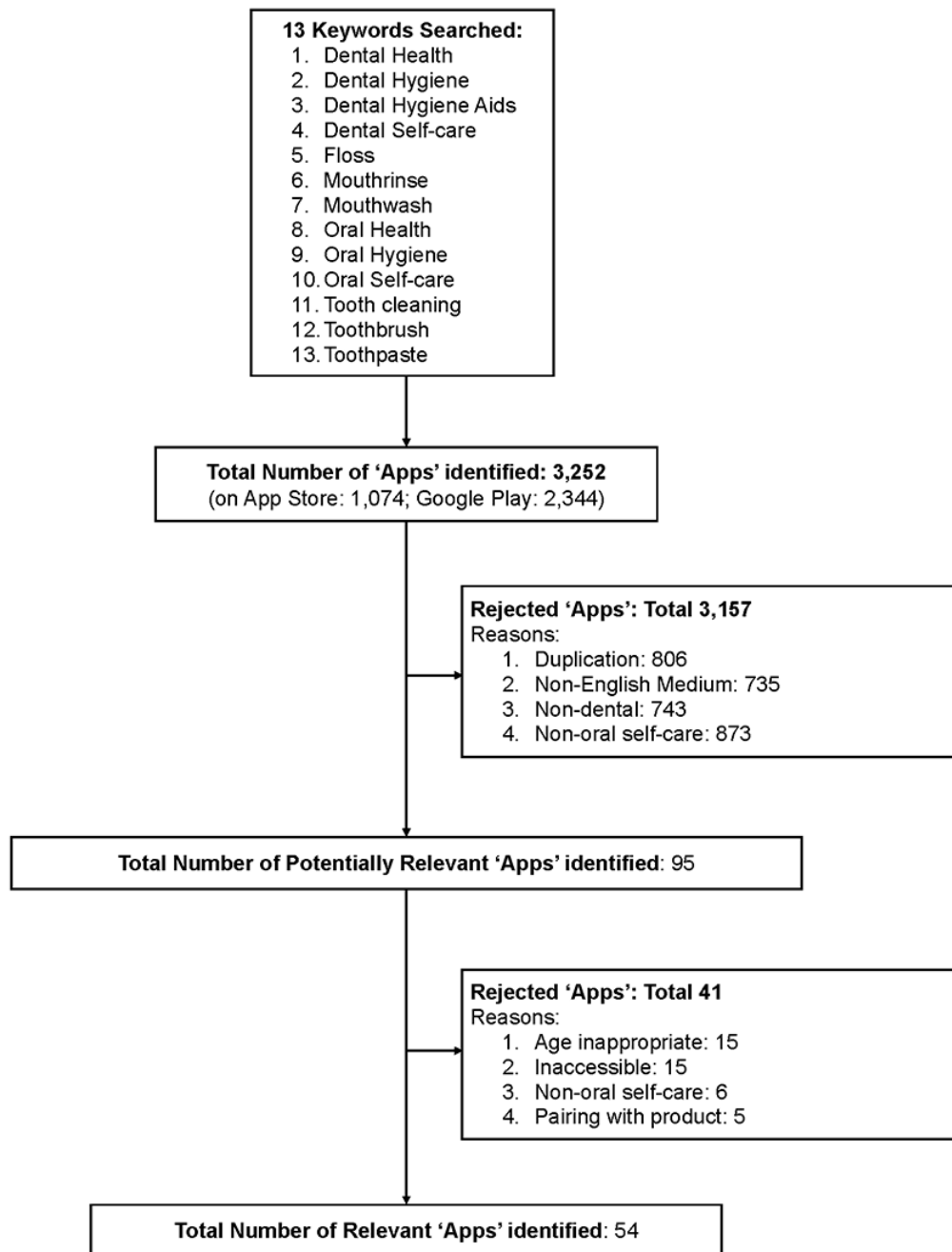
## Methods

### Data Search Strategy and Identification of Apps

A search of the Apple App Store and Google Play Store was conducted in April 2019 to identify apps designed for promoting oral self-care among children. A total of 13 oral self-care-related keywords were chosen for the search (Table 1). Screenshots of the titles and descriptions of the apps were obtained and reviewed to identify potentially relevant apps (first screening). Criteria for rejection included (1) duplicated apps, (2) non-English-language apps, (3) non-dental-related and non-oral health-related apps, and (4) non-oral self-care-related apps (Figure 1). Potentially relevant apps were downloaded and reviewed to identify relevant apps to inform the review. Criteria for rejection include (1) age-inappropriate apps (ie, age not rated as 3+ or 4+ years), (2) inaccessible apps, (3) apps requiring pairing with products to use, and (4) non-oral self-care-related apps (Figure 1). A total of 2 independent assessors conducted the search and assessments, and agreement was determined using the Cohen kappa statistic ( $\kappa=0.836$ ). Where disagreement occurred, it was resolved with a third rater.

**Table 1.** Descriptive information on the apps reviewed (N=54).

| Category of information     | Apps, n (%) |
|-----------------------------|-------------|
| <b>Age rating in years</b>  |             |
| 3+                          | 18 (33)     |
| 4+                          | 36 (67)     |
| <b>Compatibility</b>        |             |
| Android only                | 18 (33)     |
| Apple                       | 36 (67)     |
| <b>Price</b>                |             |
| Free                        | 42 (78)     |
| Not free                    | 12 (22)     |
| <b>Star rating</b>          |             |
| ≥4                          | 40 (74)     |
| <3                          | 14 (26)     |
| <b>Last upload in years</b> |             |
| ≤2                          | 41 (76)     |
| >2                          | 13 (24)     |
| <b>Developer</b>            |             |
| Company                     | 26 (48)     |
| Individual                  | 28 (52)     |

**Figure 1.** Flowchart for the Apps selection process.

### Assessment of Apps (Data Collection)

Profile information (descriptive) on the apps was obtained, including (1) age rating, (2) compatibility, (3) price, (4) star rating (rating on app platforms), (4) period of last update, and (5) developer.

All identified relevant apps were assessed for (1) Health on the Net Foundation Code of Conduct (HONcode) and (2) Scientific Basis of Oral Self-care (SBOSC) scores. The HONcode assesses the reliability and credibility (validity) of medical and health information on the internet and social media [19]. The 8 criteria of the HONcode are (1) authority (author credentials and qualifications), (2) complementarity (information supporting, but not replacing, patient–health care professional relationships), (3) privacy (anonymous and confidential use of users’ personal

data), (4) attribution (references to the sources of published information and when they were last updated), (5) justifiability (balanced claims supported with references to scientific information), (6) transparency (contact information of authors provided), (7) financial disclosure (identifiable funding source), and (8) advertising policy (details about advertising on the site and distinction from editorial content). A score for each app was derived based on the 8 criteria of HONcode (with information absent scoring 0 and information present scoring 1 for each attribute). HONcode scores could range from 0-8.

The SBOSC was derived from the guidelines of the Childsmile program for oral self-care [20]. The program was based on the scientific basis of dental health education. The following 6 factors were considered: (1) choice of toothbrush (size and bristle), (2) use of fluoride toothpaste (fluoride concentration

and amount), (3) brushing time (frequency, timing, and duration), (4) adult supervision, (5) brushing techniques, and (6) other advice for the prevention of caries. A score for each app was derived based on the 6 criteria of SBOSC; a score of 0 is assigned when information is absent and a score of 1 is assigned when information is present. SBOSC scores could range from 0-6.

### Data Analyses

Descriptive statistics were calculated for the app features (percentage and number). HONcode scores were derived by summing scores across the 8 criteria, and descriptive statistics were produced (range, mean, SD, median, and IQR). Likewise, SBOSC scores were derived by summing scores across the 6 criteria, and descriptive statistics were produced (range, mean, SD, median, and IQR).

Pearson correlation values between HONcode and SBOSC scores were determined. Variations in HONcode and SBOSC scores with respect to app profile characteristics were determined using the *t* test for independent samples where applicable, using SPSS (version 25.0; IBM Corp).

## Results

The initial search identified 3252 Apps (1074 from the Apple App Store and 2344 from the Google Play Store). Among those identified, approximately one-quarter were duplicates (806/3252, 24.8%), duplicated either within search terms or between platforms. Also excluded were non-English-language (735), non-dental-related (743) and non-oral self-care-related (873) apps. A total of 95 apps were identified as potentially relevant to inform the review and were downloaded (Figure 1). Following the review of the downloaded apps, 54 Apps were identified as relevant to inform the review. Reasons for exclusion included

non-age-specific apps (15), inaccessible (after 3 attempts to download) apps (15), non-oral self-care-related apps (6), and apps requiring a product to pair with them (5). A total of 2 independent assessors carried out the search and assessments, and agreement was determined ( $\kappa=0.836$ ).

The profile characteristics of the 54 relevant apps are presented in Table 1. Approximately two-thirds of the apps were designed for or targeted children ages 4 years and older (36/54, 67%). Most apps were available on the Apple platform (34/54, 63%) and were free of charge ( $n=42$ , 78%). Many of the apps were last updated within the previous 2 years (41/54, 76%) and had a 4-star rating or higher ( $n=40$ , 74%). Approximately one-half of the apps were uploaded or developed by a company (26/54, 48%).

HONcode scores ranged from 0-8; approximately one-quarter of apps had a HONcode score of 0 (14/54, 26%) and 4% ( $n=2$ ) had the maximum score of 8. The mean HONcode score was 1.8 (SD 2.0) and the median score was 1.0 (IQR 0-2.25). SBOSC scores ranged from 0-6; 10 (19%) of the 54 apps had a score of 0 and 2 (4%) had the maximum score of 6. The mean SBOSC score was 1.5 (SD 1.4) and the median score was 1.0 (IQR 1.0-2.0). A summary of HONcode and SBOSC scores is presented in Table 2. There was a significant and positive correlation between HONcode scores and SBOSC scores ( $r=0.37$ ;  $P=.006$ ).

Associations of app profile characteristics with both HONcode and SBOSC scores are presented in Table 3. The target age, platform compatibility, price (payment), and star rating were not significantly associated with HONcode scores ( $P>.05$ ), nor SBOSC scores ( $P>.05$ ). The time since the last update was significantly associated with HONcode scores ( $P=.04$ ), but not SBOSC scores ( $P=.11$ ).

**Table 2.** The number of apps meeting the Health on the Net Foundation Code of Conduct (HONcode) and Scientific Basis of Oral Self-care (SBOSC) criteria (N=54).

| Assessment tool and criteria   | Apps, n (%) |
|--------------------------------|-------------|
| <b>HONcode<sup>a</sup></b>     |             |
| Authority                      | 4 (7)       |
| Complementarity                | 5 (9)       |
| Privacy                        | 11 (20)     |
| Attribution                    | 5 (9)       |
| Justifiability                 | 13 (24)     |
| Transparency                   | 40 (74)     |
| Financial disclosure           | 10 (19)     |
| Advertising policy             | 8 (15)      |
| <b>SBOSC<sup>b</sup></b>       |             |
| Choice of toothbrush           | 6 (11)      |
| Use of fluoride toothpaste     | 7 (13)      |
| Brushing time                  | 15 (28)     |
| Adult supervision              | 2 (4)       |
| Brushing technique             | 44 (81)     |
| Other caries prevention advice | 5 (9)       |

<sup>a</sup>HONcode: Health on the Net Foundation Code of Conduct.

<sup>b</sup>SBOSC: Scientific Basis of Oral Self-care.



**Table 3.** Variation in the mean Health on the Net Foundation Code of Conduct (HONcode) and Scientific Basis of Oral Self-care (SBOSC) scores with respect to app features (N=54).

| Category                    | HONcode <sup>a</sup> score, mean (SD) | <i>P</i> value <sup>b</sup> | SBOSC <sup>c</sup> score, mean (SD) | <i>P</i> value |
|-----------------------------|---------------------------------------|-----------------------------|-------------------------------------|----------------|
| <b>Age rating in years</b>  |                                       |                             |                                     |                |
| 3+                          | 1.3 (1.4)                             | .79                         | 1.4 (0.9)                           | .26            |
| 4+                          | 2.0 (2.2)                             |                             | 1.5 (1.6)                           |                |
| <b>Compatibility</b>        |                                       |                             |                                     |                |
| Android only                | 1.5 (1.6)                             | .52                         | 1.3 (0.9)                           | .44            |
| Apple                       | 1.9 (2.2)                             |                             | 1.6 (1.6)                           |                |
| <b>Price</b>                |                                       |                             |                                     |                |
| Free                        | 1.9 (2.2)                             | .30                         | 1.4 (1.2)                           | .39            |
| Not free                    | 1.3 (1.3)                             |                             | 1.8 (1.9)                           |                |
| <b>Star rating</b>          |                                       |                             |                                     |                |
| ≥4                          | 1.6 (2.0)                             | .32                         | 1.6 (1.5)                           | .44            |
| <3                          | 2.1 (2.1)                             |                             | 1.1 (0.9)                           |                |
| <b>Last update in years</b> |                                       |                             |                                     |                |
| ≤2                          | 2.3 (0.4)                             | .04                         | 1.5 (1.5)                           | .11            |
| >2                          | 1.1 (0.5)                             |                             | 1.5 (1.1)                           |                |
| <b>Producer</b>             |                                       |                             |                                     |                |
| Company                     | 1.4 (1.2)                             | .70                         | 1.8 (1.9)                           | .92            |
| Individual                  | 1.5 (1.6)                             |                             | 1.8 (2.2)                           |                |

<sup>a</sup>HONcode: Health on the Net Foundation Code of Conduct.

<sup>b</sup>*P* values are derived from *t* tests for independent samples.

<sup>c</sup>Scientific Basis of Oral Self-care.

## Discussion

### Principal Findings

Over 3000 apps designed for oral self-care among children were identified, and 52 relevant apps informed this review. The quality and scientific basis of these apps were low. More of the new apps were of high quality in terms of scientific basis than older apps.

There has been growing interest in apps promoting general health care and oral health [12-14,17,18]. To follow a systematic approach, the search and identification strategy followed PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines as they are widely used in systematic reviews in the field of dentistry [21]. A broad search strategy was adopted using a wide range of terms for oral hygiene performance. This was also employed in previous systematic reviews, including Cochrane reviews [5-7]. The search was limited to the main mobile app distribution platforms, the Apple App Store and Google Play store (Android), but it is acknowledged that there are other platforms. It was not surprising to have many duplications among search results between platforms as the search strategy had overlapping terms for oral hygiene. Agreement between the 2 independent assessors was high, and where a disagreement occurred, it was resolved through discussion among the supervisors. Thus, there was uniformity in app selection to inform this review.

Most apps were designed for children ages 4 years and older. The current guidelines recommend toothbrushing as soon as the first tooth erupts. There is a need for apps to be developed for a younger age group [20]. It is acknowledged that younger children may not be able to fully comprehend the content of the apps. Nonetheless, the apps can familiarize them and introduce them to the concept of early toothbrushing, as in many other childhood learning apps. Most apps were available on the Apple platform. It was a welcome finding to observe that these apps were mostly free of charge; thus, the potential to use the apps in health promotion and clinical practice is widespread. The majority (approximately three-quarters) of apps were rated 4-stars or above, highlighting the positive feedback from app users.

As previously mentioned, the HONcode is a code of conduct for medical and health websites (including apps). The criteria promote the dissemination of accurate health information through technology and cover 8 principles [19]. In this review, the HONcode scores of the apps varied considerably, with approximately one-quarter having a score of 0 (ie, not following any of the recommendations or guidelines). The overall mean and median HONcode scores were around one-quarter of the total possible score, suggesting that there is room for improvement in enhancing the reliability of app content. The identified apps, in general, had good transparency (40/54, 74%, ie, availability of app developer's contact information).

However, they had low scores for the following criteria: authority (4/54, 7%, ie, having credentialed medical or dental professionals as authors), complementarity (5/54, 9%, ie, stating information to support, not replace, patient–health care professional relationships), and attribution (5/54, 9%, ie, using clear reference sources and indicating when they were last updated). Among the various app profile characteristics, only the time of last update was significantly associated with HONcode scores, in that apps that were uploaded or updated in the past 2 years had higher HONcode scores than those that were uploaded or updated more than 2 years ago. A greater understanding of the need to follow codes of conduct such as the HONcode when publishing health information on websites and social media must be advocated for [19].

For rating the scientific basis of the apps in providing oral health information, the SBOSC, a standardized scale based on 6 criteria for toothbrushing, was used [20]. The 6 criteria were choice of toothbrush, use of fluoride toothpaste, brushing time, adult supervision, brushing technique, and other prevention advice. The SBOSC scores of the apps also varied considerably, with nearly 1 in 5 scoring 0 and few fulfilling all the 6 criteria (less than 1 in 20). The mean and median SBOSC scores were around one-third of the maximum score. This again highlights the need for a massive improvement in the scientific basis of the information provided in apps for oral hygiene.

Interestingly, SBOSC scores and HONcode scores were significantly and positively correlated, although the strength of the correlation could best be interpreted as weak to moderate ( $r < 0.5$ ). Thus, apps with high SBOSC and HONcode scores should be promoted. Apps should also be evaluated for their efficacy in enhancing oral hygiene behavior and clinical outcomes related to oral hygiene. In the future, app platforms may consider requesting mHONcode certification (which is HONcode certification specifically for apps) before publishing health care apps to ensure the dissemination of accurate health information. Health care authorities should be encouraged to provide support and funding to professional bodies for developing high-quality oral self-care apps.

## Conclusions

Many apps are available to assist children in adopting oral hygiene practices. The quality and scientific basis of these apps are low. App quality is correlated with its scientific basis, though the strength of the correlation is weak to moderate. Apps updated or developed in the past 2 years are of higher quality than older apps, but there is no evidence that the scientific basis of the apps has improved. There is a need to ensure high-quality and evidence-based apps are available. Their effectiveness in terms of promoting proper oral hygiene behaviors and improving oral health among children should be evaluated.

## Authors' Contributions

CM devised the idea for the study. CM, CKYY, and GHML designed the study and supervised TCYH, who collected the data and performed the statistical analysis. All authors discussed the results and contributed to the final manuscript.

## Conflicts of Interest

None declared.

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## Abbreviations

**HONcode:** Health on the Net Foundation Code of Conduct

**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses

**SBOSC:** Scientific Basis of Oral Self-care

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Corrigenda and Addenda

# Correction: Effectiveness of Pediatric Teleconsultation to Prevent Skin Conditions in Infants and Reduce Parenting Stress in Mothers: Randomized Controlled Trial

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In “Effectiveness of Pediatric Teleconsultation to Prevent Skin Conditions in Infants and Reduce Parenting Stress in Mothers: Randomized Controlled Trial” [*JMIR Pediatr Parent* 2022;5(1):e27615] the authors noted two errors.

First, in the Abstract; Results section of the originally published article the significant difference was reported as follows:

20% vs 33%,  $P=.03$ ; relative risk ratio, 0.614 [95% CI 0.406-0.927]

This has been corrected as follows:

20% vs 33%,  $P=.02$ ; relative risk ratio, 0.709 [95% CI 0.519-0.969]

Second, in Table 2 of the originally published article the  $P$  value for “Atopic dermatitis” was reported as follows:

$P=.03$

This has been corrected as follows:

$P=.02$

The correction will appear in the online version of the paper on the JMIR Publications website on April 12, 2022, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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Corrigenda and Addenda

# Correction: Multimedia Knowledge Translation Tools for Parents About Childhood Heart Failure: Environmental Scan

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In “Multimedia Knowledge Translation Tools for Parents About Childhood Heart Failure: Environmental Scan” (*JMIR Pediatr Parent* 2022;5(1):e34166) the authors noted one error.

In the originally published paper, Multimedia Appendix 1 contained one incorrect value. In the “Duplicate apps removed before screening” box, the value was listed as “6”.

In the corrected version of the paper, [Multimedia Appendix 1](#) has been revised as follows:

In the “Duplicate apps removed before screening” box, the value is listed as “5”. The updated version of Multimedia Appendix 1 is available below.

The correction will appear in the online version of the paper on the JMIR Publications website on June 21, 2022, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

**Multimedia Appendix 1**

Corrected version of Multimedia Appendix 1: Screening of apps and web-based tools.

[[DOCX File , 40 KB - pediatrics\\_v5i2e39049\\_app1.docx](#) ]

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