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Contents

Original Papers

Original Paper

Identification of Requirements for a Postoperative Pediatric Pain Risk Communication Tool: Focus Group Study With Clinicians and Family Members

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Abstract

Background: Pediatric surgery is associated with a risk of postoperative pain that can impact the family’s quality of life. Although some risk factors for postoperative pain are known, these are often not consistently communicated to families. In addition, although tools for risk communication exist in other domains, none are tailored to pediatric surgery.

Objective: As part of a larger project to develop pain risk prediction tools, we aimed to design an easy-to-use tool to effectively communicate a child’s risk of postoperative pain to both clinicians and family members.

Methods: With research ethics board approval, we conducted virtual focus groups (~1 hour each) comprising clinicians and family members (people with lived surgical experience and parents of children who had recently undergone surgery/medical procedures) at a tertiary pediatric hospital to understand and evaluate potential design approaches and strategies for effectively communicating and visualizing postoperative pain risk. Data were analyzed thematically to generate design requirements and to inform iterative prototype development.

Results: In total, 19 participants (clinicians: n=10, 53%; family members: n=9, 47%) attended 6 focus group sessions. Participants indicated that risk was typically communicated verbally by clinicians to patients and their families, with severity indicated using a descriptive or a numerical representation or both, which would only occasionally be contextualized. Participants indicated that risk communication tools were seldom used but that families would benefit from risk information, time to reflect on the information, and follow-up with questions. In addition, 9 key design requirements and feature considerations for effective risk communication were identified: (1) present risk information clearly and with contextualization, (2) quantify the risk and contextualize it, (3) include checklists for preoperative family preparation, (4) provide risk information digitally to facilitate recall and sharing, (5) query the family’s understanding to ensure comprehension of risk, (6) present the risk score using multimodal formats, (7) use color coding that is nonthreatening and avoids limitations with color blindness, (8) present the most significant factors contributing to the risk prediction, and (9) provide risk mitigation strategies to potentially decrease the patient’s level of risk.

Conclusions: Key design requirements for a pediatric postoperative pain risk visualization tool were established and guided the development of an initial prototype. Implementing a risk communication tool into clinical practice has the potential to bridge existing gaps in the accessibility, utilization, and comprehension of personalized risk information between health care professionals and family members. Future iterative codesign and clinical evaluation of this risk communication tool are needed to confirm its utility in practice.

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KEYWORDS

eHealth; risk communication; risk; decision aid; pain; individualized risk; surgery; anesthesia; anesthetic; anesthesiology; focus group; requirement definition; prototyping; prototype; pediatrics; pediatric; child; postoperative; prediction; digital health; development; user feedback; patient feedback; user-centered design

Introduction

Background

Approximately 1 in 5 children experiences persistent postoperative pain at 12 months following surgery [1], which can substantially impact their quality of life, opioid consumption, frequency of hospital visits, and overall trust in the health care system [2]. Thus, improving pediatric pain management [3] using a patient-centered approach [4] has become a strategic priority at BC Children's Hospital (BCCH, where BC stands for British Columbia). Some risk factors for pediatric postoperative pain have been previously identified (eg, anxiety, poor pain coping skills, and pain catastrophizing) [1,5-7]. In contrast, providing prehabilitation plans outlining patient-specific interventions (eg, diet and nutritional supplementation [8,9] and improving physical function and exercise capacity [9-12]) have resulted in improved postoperative outcomes (eg, decreased length of stay [13] and reduced pain [14]). Combining identified risk factors for postoperative pain and tailored interventions provides opportunities to improve pediatric pain management to optimize postoperative outcomes.

The use of risk communication tools prior to surgery can be engaging and may result in the majority of patients understanding their surgery-associated risks well [15,16]. Several surgical risk stratification scores/tools have been developed to provide risk estimates with the goal of informing and improving care [17]. Although preliminary, these tools have enhanced patient risk comprehension, perceived quality of preoperative clinical conversations, and physician prognostic accuracy, and there is evidence they can decrease length of hospital stay [18]. However, a recent scoping review identified that only 7 (<1%) of 796 screened studies both described the methods used to calculate personalized risk and communicated these findings directly to the patient or health care professional or both [18], and many tools have failed to include patient-centered design principles [15,19]. Finally, risk communication tools should apply best practices when communicating information to patients, including the use of plain language and pictographs to present information visually [20].

Currently, there are no best practices for designing risk communication technologies for use within complex clinical settings. As such, tool/score development would benefit from applying patient-oriented research methods [21-23], user-centered design principles [24], and human factor engineering methods [24-27] to elicit design requirements that effectively communicate procedure-associated risks to both families and clinicians.

Objectives

Our long-term goal is to reduce the incidence of postoperative pain and long-term opioid use by developing a risk prediction tool, which will generate risk scores from health care data using machine learning techniques, to guide clinicians and family members in informed and collaborative decision-making to reduce these risks or mitigate their effects. The purpose of this study is to define the requirements and features for a potential prototype risk visualization and communication tool by conducting focus groups with our expected end users (ie, parents and clinicians) and to apply human-centered design principles to generate an initial prototype.

Methods

Study Design

We conducted a semistructured qualitative study with a convenience sample comprising parents of children who had previously undergone surgery, adults with lived pediatric surgical experience, and clinicians (ie, attending physicians and nurse practitioners) who work at the BCCH.

Ethical Considerations

Ethical approval was obtained from the Children's & Women's Health Centre of British Columbia Research Ethics Board, University of British Columbia (H20-00613; date of approval October 20, 2020; principal investigator [PI] M. Görges). Our findings are reported in accordance with the Consolidated Criteria for Reporting Qualitative Research [28].

Participants

Clinicians were approached via departmental email distribution lists. Parents were recruited through email lists obtained from the BCCH patient experience office, as well as in person in the Anesthetic Care Unit during their child's hospital visit. Adults with previous childhood surgery were recruited via provincial research networks (ie, Reach BC and the BCCH patient experience office e-network). After a trained research team member described the study in detail, informed consent was obtained by research staff in person or virtually, with electronic consent documented using Research Electronic Data Capture (REDCap, Vanderbilt University, Nashville, TN, USA) [29,30]. In our reporting, parents and participants with pediatric lived experience are not distinguished and are collectively referred to as family members in the results to protect their privacy.

Due to the focus groups being conducted virtually, participants were required to have an internet connection, have access to an electronic device with a camera, and be proficient in English. To encourage participation in the study, participants were remunerated CA $25 (US $19.39) per hour for their expertise and time. Panels of approximately 3-5 family members or 3-5 clinicians were targeted for each focus group.

Data Collection

A brief prestudy questionnaire, administered via REDCap [30], collected participants' demographic information. Next, 2 research team members with expertise in qualitative methods conducted 6 virtual focus groups between December 2020 and August 2021 using Zoom videoconferencing software (Zoom Video Communications, San Jose, CA, USA); 1 researcher facilitated the sessions (author MG or MDW), while another research team member took notes and relayed additional prompts for consideration by the facilitator (author MDW or KC); only the 2 research team members and recruited participants attended each session. Due to potential power dynamics, these sessions were conducted using separate groups for clinicians and family members. At the start of each focus group, each study team member introduced themselves, described their role in the study, and had participants introduce themselves in a similar manner. Next, the facilitator provided a brief overview of our research program, including some background on the use of machine learning in health care and difficulties in communicating procedure-associated risk.

Each focus group session had 2 parts. First, open-ended discussion was structured around 4 themes: (1) how procedure-associated risks (in general) were communicated to families, (2) whether this risk information was clearly understood by families, (3) what tools/methods were typically used to illustrate these risks during the clinical consultation, and (4) whether participants currently used any digital health tools. Second, participants were shown examples of existing risk communication tools [31,32] to elicit preliminary design requirements and visualization preferences to inform prototype development. While viewing examples, participants were prompted to tell researchers their general thoughts on the designs (eg, whether they liked/disliked the design and how these designs could be improved). No repeat interviews were conducted, but we invited participants back for future codesign sessions at the end of each session. Sessions lasted approximately 1 hour, were audio-recorded, and then were digitally transcribed. Participant names were replaced by sequential identifiers, and transcripts were verified by a research team member (KC) rather than participants due to the practicality of conducting sessions online.

Data Analysis

Focus group transcripts were analyzed using NVivo (QSR International, Melbourne, Australia), and results were summarized using thematic analysis [33]. Two research team members (MDW and KC) independently reviewed 2 transcripts and used inductive coding [34] to organize transcript text by theme, subtheme, and participant type [35]. These researchers then compared interpretations and developed consistent codes. This coding framework was then applied to the remaining 4 transcripts (ie, deductive coding) [34]; however, the 2 researchers discussed any additional themes that emerged after coding these remaining transcripts, resolving any further discrepancies, and inductively modified the coding framework to ensure that key concepts were not missed. Due to the qualitative nature of the study, we did not estimate a target sample size. Alternatively, we implemented a saturation criterion (ie, additional data collection and analysis lead to informational redundancy) [36]; specifically, 2 research team members (MDW and KC) determined that similar comments and concerns were repeatedly discussed across focus groups and that data saturation had occurred.

Finally, prominent themes that emerged from focus groups (see the Results section) were used to generate design requirements for a prototype risk communication tool. Participant responses to the open-ended questions defined when and how our tool would be used and suggested points in the clinical process that need to be addressed and potentially improved, whereas feedback on the sample visualizations provided information to design the prototype for desirability and accessibility. Our prototype was developed using an iterative process in which the research team created, discussed, and revised a preliminary prototype using Figma (Figma Inc, San Francisco, CA, USA) to serve as the baseline for future codesign and pilot evaluation sessions, which may include mixed sessions with clinicians, people with lived surgical experience, and various family members (ie, parents, children, or adolescents).

Results

Demographics and Questionnaire Results

In total, 19 participants, including 10 (53%) clinicians (4, 40%, nurse practitioners, 6, 60%, physicians) and 9 (47%) family members, attended 6 focus group sessions with 2-4 participants per session; 4 family members could not be contacted after consenting, 1 declined due to lack of interest and availability, and 1 clinician refused while being approached, due to limited availability. Participants included 15 (79%) females, and 13 (68%) of 19 participants were under 49 years of age. Clinicians worked in anesthesiology and pain management, or surgical/perioperative nursing. Family members included 7 (78%) with either a certificate (university/nonuniversity) or university degree and 2 (22%) with a high school diploma (or equivalent).

Procedure-Associated Risk Communication in Practice: Key Themes

Risk Communication Process Overview

Clinicians indicated they consider risk based on both the patient's medical history and the specific procedure. Next, they approach family members with a preformulated care plan, which entails discussing the typical patient postoperative experience and any specific concerns that might contribute to increased risk of pain. Clinicians believed it was their responsibility "to try and be unbiased" (clinician 1) and ensure that they "have an honest conversation" (clinician 2) with families to ensure that procedural consent is "not forced upon them in any way" (clinician 2). Clinicians largely did not "mention any of the more severe [or] scary risks that could lead to poor outcomes" (clinician 3) unless it had a high probability of occurrence, it was related to a specific procedure with well-established risks (eg, epidural catheter insertion), or the family had specifically requested further information.

Most family members described a similar risk communication process, felt that the procedure's associated risks were effectively described, and felt that they were adequately prepared. However, some family members indicated that risk had not been adequately described, for example, in the context of emergency surgery, and 1 indicated that "there's a very standard list of the risks associated with the surgeries that clinicians go through, including pain, but very little discussion around contextualization of these risks" (family member 1).

Hence, we identified a design criterion that risk information should be presented clearly and with appropriate contextualization (requirement R1.1; see Table 1).

Table 1. Procedure-associated risk communication in practice and identified design and feature requirements from focus groups with clinicians and family members.

Requirement	Description
R1.1	The risk information should be presented clearly and with appropriate contextualization.
R1.2	Risk information should include a numeric risk score that is contextualized.
R1.3	Preoperative family preparation for their surgical visit should be facilitated by presenting risk information with appropriate checklists.
R1.4	Risk information should be provided using a digital tool to facilitate recall and sharing with other family members.
R1.5	The risk tool should include specific prompts to ensure family member comprehension of the risk information presented.

Generalized Risk Statements Used for Clarification

Clinicians explained that they typically describe the severity of a procedure-associated risk descriptively (eg "low," "moderate," or "high") but may provide a numerical representation with a comparative example for contextualization, such as "There is an approximately 1 in 10,000 risk of [a] motor vehicle accident on the way to the hospital, which is similar to the risk of a significant issue or complication with the anesthetic, and that makes it very rare" (clinician 4).

Although families generally agreed that risk was communicated effectively, most had difficulty recalling how risk was specifically conveyed: "I believe [in our initial consultation] the clinician was giving numbers…He may have added, like, a comparison, or an anecdote, but I don't recall any specifics of that" (family member 2). Participants suggested that providing a real-life comparative scenario, such as "winning the CA $2 million jackpot," would contextualize risk statements and "be easier to remember" (family member 3).

Thus, we identified a design criterion that risk information should include a numeric risk score that is contextualized (requirement R1.2).

Methods Used to Communicate Risk in Clinics

Clinicians said that although risk was most frequently explained verbally, some clinicians used whiteboard or paper-and-pencil illustrations, checklists of risks/complications for procedures, existing clinical tools (eg, the Faces Pain Scale), or medical equipment (eg, an epidural catheter) as educational adjuncts to explain aspects of the procedure. When discussing a complex surgical procedure (scoliosis correction), a clinician used "a preprinted list of risks that I go through for every spine patient, which I tick off when I'm seeing the family…I then give the risk checklist to the family, which has the percentage of risk at the top" (clinician 4).

Family members agreed that risk was predominantly communicated verbally and that educational material, such as pamphlets and checklists, provided during the preoperative consultation were informative and, if not lost, could help preparation and stress reduction for the surgical visit.

We identified a design criterion that risk information should provide a preoperative opportunity to help family members prepare for their surgical visit (requirement R1.3).

Experience with Health Technology to Communicate Risk

Clinicians stated that they typically do not use health technology to communicate risk information to patients, though some use it for their own learning or when teaching trainees and others. Clinicians also provide preoperative education via locally developed or curated videos about what to expect on the day of surgery. Some family members believed digital communication was "a little bit easier to find, maintain, and store" (family member 2) and reported using smartphone calendars and reminders for appointments and medication adherence.

We identified a design criterion that risk information should be provided as a digital tool (with the option of a hard copy) to facilitate recall and sharing with other family members (requirement R1.4).

Family Member Comprehension of Risk

Despite clinicians' insistence that family members are informed of the risks associated with a procedure, most participants recognized that they were not asked whether they specifically comprehended the risk information presented. As a clinician indicated regarding risk comprehension, "I do not routinely ask patients to repeat back to me what I've said" (clinician 5). Clinicians generally indicated that the last question is always "Do you have any questions?" and that one would assume "if something wasn't understandable to the family, then they would ask at that time" (clinician 4); if there are no further questions, it is assumed that family members adequately understand the given risk(s). As outpatient surgery is common in pediatrics and perioperative discussions are particularly time limited, clinicians highlighted that day surgery visits allow little opportunity to elaborate on risks and resolve questions and indicated that risk communication should ideally occur at a preoperative consultation.

Family members further indicated that contacting staff to answer questions was difficult and often resulted in them using the internet for answers instead; for example, "I was trying to reach the nurses and the hospital clinic and there was no answer, and after 3 days, a nurse called me and then she explained [the discharge instructions]. Other than that, my only help was Google" (family member 4). As the consultation is "meant to inform the patient's decision of what to expect from the surgery and whether or not to have it" (family member 5), assessing comprehension would allow clinicians "to very quickly help educate and correct any misconceptions [or] to readjust the patient's understanding of what those risks are" (clinician 6).

We identified a design criterion that the risk tool should include specific prompts for use by both clinicians and family members to ensure comprehension of the risk information presented (requirement R1.5).

Additional Feature Considerations Indicated from Critically Reviewing Risk Communication Tool Examples

Multimodal Presentation of the Risk Score

Participants suggested that risk information should be presented in a multimodal format; this finding was succinctly indicated by a participant that the risk communication tool needs to "maximize the likelihood of finding an approach that any given viewer is going to be able to effectively comprehend" and "accessible and diverse enough in its application to be easy for the clinicians to use as well" (family member 5).

We identified a design criterion that presentation of the risk score should be multimodal and include a simple graphical visualization and that the score should be contextualized with text indicating the percentage and a descriptive risk severity (ie, mild, moderate, or severe) (requirement R2.1; see Table 2).

Table 2. Additional design and feature considerations indicated from viewing risk communication tool examples with clinicians and family members.

Requirement	Description
R2.1	Presentation of the risk score should be multimodal and include a simple graphical visualization, contextualized with text, and a descriptive risk severity (ie, mild, moderate, or severe).
R2.2	Color coding should be based on nonthreatening and a color-blindness-friendly palette (ie, shades of blue) to represent severity.
R2.3	Information should be provided about how the risk prediction score was derived by including the most significant factors that contribute to that patient's level of risk.
R2.4	Risk mitigation strategies should be provided to help family members potentially decrease the patient's level of risk.

Appropriate Color Coding of Risk Visualization

Participants recognized that color coding the score may be problematic for users who are color blind and that, for example, using red may indicate danger/harm to the reader, which might contradict the clinician's responsibility to communicate "risk in a nonthreatening, nonfrightening way to the family" (clinician 2). However, some clinicians felt that a color, such as red, could be immediately illustrative and attract their attention to modify a patient's care plan.

Hence, we identified a design criterion that color coding should be based on a nonthreatening and color-blindness-friendly palette (ie, shades of blue) to represent severity as 1 mode of risk presentation (requirement R2.2).

Provide Patient Risk Factors and Mitigation Strategies to Allow Agency Over Care

Participants indicated that they would want to see information indicating "what the risk factors actually are and why that patient is high risk" (clinician 7). Clinicians anticipated that clearly identifying these patient risk factors and providing appropriate risk mitigation strategies would give family members "a sense of control, a sense of something to work on to improve their postsurgical outcomes" (clinician 7). Family members acknowledged that having accurate information prior to surgery would make them feel more prepared and would be better than potentially unreliable online resources. Participants suggested that sharing this resource digitally or giving family members a hard copy to take home would improve information accessibility and retention.

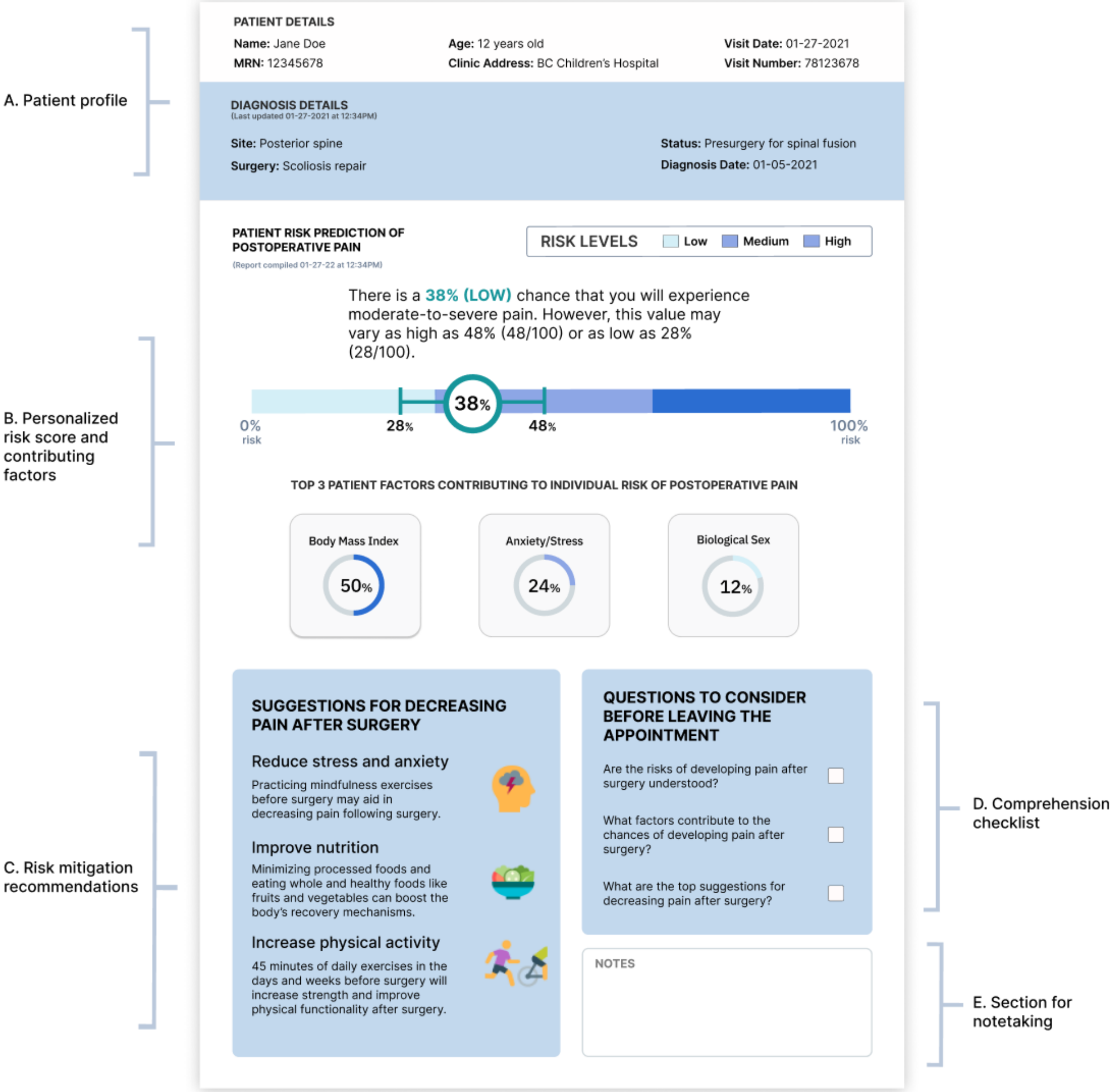
We identified a design criterion that the most significant factors that contribute to that patient's current level of risk should be presented (requirement R2.3). We also identified that risk mitigation strategies should be provided to potentially decrease the patient's level of risk (requirement R2.4).

Identified and Implemented Design Requirements Resulting in Prototype Generation

Prominent design and feature requirements that informed the development for our prototype risk communication tool (Figure 1) are summarized in Tables 1 and 2. The initial prototype had 5 sections: (A) demographics and clinical characteristics (not a requirement from the focus groups but included practically to facilitate future implementation in a clinical setting), (B) a color-coded risk scale with a textual statement and plots to present the individual's level of risk and the top factors contributing to the score (requirements R1.1, R1.2, R2.1, R2.2, and R2.3), (C) mitigation strategies that patients could follow to reduce their risk of postoperative pain (requirements R1.3

and R2.4), (D) a checklist of questions that family members or clinicians can use to ensure that risk information is understood (requirements R1.3 and R1.5), and (E) a section for users to take notes during the consultation to facilitate recall and sharing with other family members (requirement R1.4). The design fits on a traditional 8.5- × 11-inch letter paper for printing but is also suitable for a web-based application and could be adapted for tablets/smartphones (requirement R1.4).

Figure 1. Initial prototype of a potential risk communication tool. (A) Indicates patient demographics and clinical characteristics. (B) Provides a low-medium-high color-coded risk scale with a textual statement and plots to represent the individual's level of risk and the top factors contributing to the score. (C) Provides mitigation strategies for patients to decrease their chance of pain after surgery. (D) Provides a checklist of questions for patients to consider before leaving their appointment. (E) Provides a blank box for clinicians or family members to take notes during the clinical consultation. BC: British Columbia.



PATIENT DETAILS

Name: Jane Doe
MRN: 12345678
Age: 12 years old
Clinic Address: BC Children's Hospital
Visit Date: 01-27-2021
Visit Number: 78123678

DIAGNOSIS DETAILS
(Last updated 01-27-2021 at 12:34PM)

Site: Posterior spine
Surgery: Scoliosis repair
Status: Presurgery for spinal fusion
Diagnosis Date: 01-05-2021

PATIENT RISK PREDICTION OF POSTOPERATIVE PAIN
(Report compiled 01-27-22 at 12:34PM)

RISK LEVELS ▢ Low ▢ Medium ▢ High

There is a **38% (LOW)** chance that you will experience moderate-to-severe pain. However, this value may vary as high as 48% (48/100) or as low as 28% (28/100).

TOP 3 PATIENT FACTORS CONTRIBUTING TO INDIVIDUAL RISK OF POSTOPERATIVE PAIN

Body Mass Index 50%
Anxiety/Stress 24%
Biological Sex 12%

SUGGESTIONS FOR DECREASING PAIN AFTER SURGERY

Reduce stress and anxiety
Practicing mindfulness exercises before surgery may aid in decreasing pain following surgery.

Improve nutrition
Minimizing processed foods and eating whole and healthy foods like fruits and vegetables can boost the body's recovery mechanisms.

Increase physical activity
45 minutes of daily exercises in the days and weeks before surgery will increase strength and improve physical functionality after surgery.

QUESTIONS TO CONSIDER BEFORE LEAVING THE APPOINTMENT

Are the risks of developing pain after surgery understood? ☐
What factors contribute to the chances of developing pain after surgery? ☐
What are the top suggestions for decreasing pain after surgery? ☐

NOTES

Discussion

Principal Findings

Participants indicated that anesthetic and pain risk is typically communicated verbally to patients and their family members, with its severity expressed descriptively or numerically or both ways, which may be expanded upon with a comparative example for contextualization. It was deemed imperative that family members be provided with risk information and then allowed time to reflect and follow up with questions or concerns. Participants specified the following key design requirements and feature considerations: (1) present risk information clearly and with contextualization, (2) quantify the risk and contextualize it, (3) include checklists for preoperative family member preparation, (4) provide risk information digitally to facilitate recall and sharing, (5) query the family member's understanding to ensure comprehension of risk, (6) present the risk score using multimodal formats, (7) use color coding that is nonthreatening and avoids limitations with color blindness, (8) present the most significant factors contributing to the risk prediction score, and (9) provide risk mitigation strategies to potentially decrease the patient's level of risk. Our initial risk communication tool prototype embodies all identified requirements and features.

Comparison With Prior Work

Using iterative feedback from patient partners and a multidisciplinary team of clinicians, researchers at the Ottawa Hospital developed the Personalized Risk Evaluation and Decision Making in Preoperative Clinical Assessment (PREDICT) risk score [37]; this tool generates a multimodal risk analysis composed of numerical absolute risks, a pictograph, brief contextual statements, and guiding questions to encourage discussion of their care and facilitate shared decision-making [37]. Importantly, participants using the PREDICT app had significantly better knowledge of their risk profile, reported lower anxiety, and reported higher satisfaction scores relative to the standard of care, and no surgeries were cancelled as a result of exposure to the risk score [37]. This suggests that communicating individualized risk in a clear and concise multimodal format has the potential to improve clinically relevant outcomes and ensure that patients are informed of procedure-associated risks. Although the PREDICT app had substantially different outcome assessments (ie, morbidity, mortality, and expected length of stay) and targeted adults, compared to our proposed pediatric risk score (ie, postoperative pain), focus group participants indicated similar design requirements. The PREDICT app communicated risks as population-informed personalized risks (eg, "For people like you who had this surgery, 10 of 100 had a serious complication postsurgery.") [37], whereas our prototype indicates the individual's risk (ie, "There is a 38% chance your child will experience moderate-to-severe postoperative pain."). As such, future iterations of our prototype may need to assess which phrasing choices end users prefer to effectively indicate their level of risk.

A study from the University of Toronto used semistructured interviews with end users and key stakeholders to establish design requirements for a risk communication tool to predict radiation toxicity risk for patient with cancer using machine learning [32]. Their user interface requirements included patient information, variables associated with risk prediction, prediction accuracy, integration of user feedback into the tool, links to validation studies, the outcome's expected time frame (eg, risk in the next 30 days), and a graph of risk over time [32]. Our prototype includes similar design requirements; yet, the Toronto team identified 2 additional requirements to consider: (1) indicating changes in the predicted risk over time and overlaying this information with clinical events, which has the potential to both illustrate the clinical impact that tailored risk reduction strategies have on a patient's level of risk and provide insight into why that risk increased/decreased, and (2) including a feedback mechanism in the application's user interface to assess the agreement between clinical judgment and tool prediction/recommendation (ie, "Do you agree with this prediction? Did you follow the recommendation?") [32]. This feature may enable early assessment of any discrepancies between our model's prediction and the clinical utility of resulting recommendations and, hence, may be a useful addition to our risk communication tool.

A recent study surveyed communication needs and preferences of pediatric patient families and indicated that their primary preoperative concern was complications/risks associated with the procedure/treatment, which highlights the importance of effective risk communication [38]. Verbal communication was the preferred modality, but many families indicated that a list of complications, percentages, and diagrams were also desirable [38]. Although our prototype includes a multimodal risk score, clinicians should present the risk score to patients and their family members. Families also prefer to resolve queries following discharge over the telephone, a short message service app, or email, and the most important element of a "good" perioperative experience is effective communication with the health care team [38]. Thus, implementing communication features in our risk tool may be necessary for successful implementation.

Finally, pain risk communication may have significant nocebo effects (ie, where unintended negative suggestions/phrasing about a treatment/procedure result in increased adverse events) [39], such as loss of appetite, nausea, itching, and stomach pain [40]. Phraseology is important [39], and framing an opportunity to improve future patient comfort by identifying relevant and modifiable risk factors, instead of highlighting risks of pain and unmodifiable risk factors, might reduce these potential nocebo effects. As 1 of the design requirements of our prototype is to present risk in a nonthreatening manner, we may wish to limit the use of the initial prototype to clinicians, while developing a version that focuses on "optimizing comfort" rather than "reducing pain" for sharing with family members. Similar to the PREDICT app [37], we should consider tracking child and parent anxiety levels, user satisfaction, and surgery cancelations when our tool is used to confirm that its presentation does not result in unintended consequences that could impede recovery following surgery.

Limitations

Our clinician participants comprised a relatively small cohort of anesthesiologists and nurse practitioners, which represents a sampling bias [41] that may limit the transferability (ie, external validity) [42] of our findings to other hospital sites and settings, as well as to other health care professions. As such, a larger and more diverse cohort of health care team members (eg, surgeons, physiotherapists, psychologists, and medical office assistants), and family members, may be desirable in future studies; we plan to recruit a wider range of health care workers for our codesign and pilot evaluation sessions. As children have the right to acquire information pertinent to their health and well-being [43], it may also be imperative to include children over 7 years old in future sessions to facilitate future implementation in pediatric care. Next, our focus groups comprised only English-speaking participants, which may have further limited transferability; language interpretation services and closed captioning (when virtual) were offered during recruitment but will be highlighted for future sessions. Although focus groups were conducted virtually, our sample may not be representative of harder-to-reach communities, and our tool may lack some requirements for effectively communicating risk with them. Furthermore, our focus groups comprised separate cohorts of clinicians in one set of meetings and family members in another set, which limited interactions among participants. Due to the potential power imbalance between family members and clinicians, we decided to conduct these initial focus groups separately. Given the users' previous education level, the risk score may be difficult to interpret and may not clearly guide clinical decision-making, but this was beyond the scope of our current study. Lastly, our risk score prediction statements and interpretations (eg, 38% chance of moderate-to-severe pain following surgery) were generated by the research team from the identified requirements as examples and do not represent definitive interpretations of these concepts. Although participants did not provide feedback on our current findings, we plan to conduct mixed group codesign workshops to further develop the prototype and obtain qualitative feedback on the tool prior to usability evaluation.

Conclusion

Our study identified several design requirements for personalized risk communication, such as presenting risk in a nonthreatening/nonfrightening manner; providing a comprehensive multimodal format, including top contributing variables to the pain risk score; providing a comprehension checklist; and providing potential risk reduction strategies. Although further family-centered design and clinical evaluation are needed, we envision that implementing a risk communication tool into clinical practice has the potential to bridge existing gaps in the accessibility, utilization, and comprehension of personalized risk information between health care professionals and family members of pediatric surgical patients.

Acknowledgments

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Authors' Contributions

MDW and KC participated in study design, data collection, qualitative analysis, designing of the prototype, and drafting and editing of the manuscript. PD, RS, EPC, KCL, IJ, and SW participated in study design, designing of the prototype, and drafting and editing of the manuscript. NW participated in study design, and drafting and editing of the manuscript. MG participated in study design, data collection, designing of the prototype, and drafting and editing of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

BCCH: British Columbia Children’s Hospital
PREDICT: Personalized Risk Evaluation and Decision Making in Preoperative Clinical Assessment
REDCap: Research Electronic Data Capture

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Original Paper

Dose-Response Relationship of a Blended In-Person and Online Family-Based Childhood Obesity Management Program: Secondary Analysis of a Behavior Intervention

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Abstract

Background: The Early Intervention Program (EIP) was a 10-week, blended, in-person and online lifestyle intervention for families with children who were off the healthy weight trajectory. The engagement pattern and the dose response of EIP have not been examined.

Objective: The aims of this paper are to examine families' engagement patterns with the EIP and to evaluate the dose-response relationship between EIP engagement patterns and physical activity and healthy eating–related outcomes at 10 weeks.

Methods: Families with children (8-12 years old) who are off the healthy weight trajectory (child BMI ≥85th percentile for age and sex) were recruited. Pre- and postintervention questionnaires assessed child lifestyle behaviors, parental support behaviors, family lifestyle habits, as well as parental physical activity and healthy-eating identity. Hierarchical cluster analysis of both in-person and online components was used to classify engagement patterns. Regression analysis assessed differences in outcomes by engagement groups.

Results: Two distinct clusters of engagement groups were identified (N=66), which were in-person (IP; n=40, 61%) and in-person + online (IP+; n=26, 39%) engagement. Relative to the IP group at week 10, IP+ showed a greater child moderate-to-vigorous physical activity level (1.53, SD 0.56; *P*=.008), child physical activity confidence (1.04, SD 0.37; *P*=.007), parental support for child physical activity (5.54, SD 2.57; *P*=.04) and healthy eating (2.43, SD 1.16; *P*=.04), family habits for physical activity (3.02, SD 1.50; *P*=.049) and healthy eating (3.95, SD 1.84; *P*=.04), and parental identity for physical activity (2.82, SD 1.19; *P*=.02).

Conclusions: The online EIP portal complemented the in-person sessions. Additional engagement with the portal was associated with greater improvements in child physical activity and parental support behaviors, habits, and identity for physical activity.

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KEYWORDS

engagement; dose response; childhood obesity; web-based intervention; child; obesity; weight; web based; intervention; family; families; lifestyle; parent; parental support; healthy eating; family support; physical activity; diet; exercise; fitness; online portal

Introduction

The rising prevalence of childhood obesity worldwide is a major public health concern. In Canada, the combined prevalence of overweight and obesity among children and adolescents increased from 23% in 1978-1979 to 35% in 2004 [1]. Recent data suggest that the prevalence of childhood overweight and obesity has stabilized in the last decade; however, over 31% of children and adolescents (aged 6-17 years old) are still overweight (18%) or obese (13%) in Canada [1]. In 2017-2018, the prevalence of obesity among children and adolescents aged 2-19 years was 19.3% in the United States [2]. The latest data from England suggest that 25.5% of the children between the ages of 10 and 11 years were obese, and 15.4% were overweight [3]. The rising prevalence of being overweight and obesity among children in these counties has been associated with several lifestyle factors including physical inactivity, unhealthy eating patterns, and insufficient sleep [4].

Childhood obesity has been linked to several physiological and psychological consequences throughout childhood [5,6]. For example, children with obesity are more likely to be diagnosed with chronic conditions such as heart disease, which were once only identified in adults [7]. Further, obesity that develops during childhood often continues into adulthood and is associated with shorter lifespans and lower quality of life [6]. Consequently, the development of lifestyle interventions for childhood obesity treatment and prevention have become a priority for public health agencies globally.

Family-focused behavioral interventions aimed to promote a healthy lifestyle, such as regular physical activity and a healthy diet, are one of the principal approaches for the management of obesity among children [8,9]. Parental involvement is a key component in family-based interventions since parents provide their children with the necessary support for adopting a healthy lifestyle in the home environment [10,11]. Family-based interventions targeting children aged 8-12 years can be particularly effective in managing childhood obesity. Prepuberty children have potential to grow in height, which can enable them to return to healthy growth parameters in the normal course of growth if their weight is controlled [12,13]. Children in this age group can be more flexible than adults in their ability to change behaviors, because they are just beginning to develop self-regulation skills for healthy living [12]. Several randomized controlled trials have demonstrated that family-focused behavior interventions delivered in person can be effective strategies to manage childhood obesity [8,9]. However, due to the requirements of in-person interventions such as travel to a location or missing work responsibilities, their structures are often limited in flexibility and scalability [14]. Emerging evidence has indicated the inclusion of digital technologies (eg, smartphones, tablets, computers, and wearables) in conjunction with in-person, family-based interventions, which may allow researchers to increase both program outreach and provide flexibility for families [15,16].

The Early Intervention Program (EIP) implemented a blended design including both in-person and online components to promote healthy lifestyle intervention for off-trajectory children (ages 8-12 years with a BMI ≥85th percentile) and their families in British Columbia (BC), Canada. The blended intervention design can help improve program delivery flexibility [16]. The EIP curriculum integrated the Multi-Process Action Control (M-PAC) framework, and emphasized behavior change techniques such as goal setting, self-monitoring and feedback, as well as social support [17]. Intervention activities focused on behavior change skills that enabled children and their families to develop regular physical activity and healthy dietary behaviors. Our team recently evaluated the effectiveness of the EIP. Our results suggested that children in the EIP blended intervention, relative to control, significantly improved in moderate-to-vigorous physical activity (MVPA), as did parental support for healthy eating and physical activity [18].

Currently, families' engagement patterns with the EIP program have not been examined. Both the online and in-person intervention components may influence participants' ability to achieve the desired behavior outcomes. The relationship between intervention engagement (dose) and intervention outcome (response) is an important outcome for digital health intervention [19]. Previous studies have shown that intervention engagement was associated with improvements in physical activity and health-related outcomes [14,19]. Currently, there is a lack of studies examining the dose-response relationship for blended family-based healthy lifestyle interventions for off-trajectory children.

Thus, the study objectives were as follows: (1) to examine families' engagement patterns with the EIP; and (2) to evaluate the dose-response relationship between EIP engagement patterns and physical activity and healthy eating–related outcomes at 10 weeks. We hypothesized that there were distinct patterns of program engagements, and participants who demonstrated a greater engagement with the intervention would show greater improvements in lifestyle behavior outcomes.

Methods

Study Design

This study was a secondary analysis of data from a trial evaluating the effectiveness of EIP (October 2018 to March 2019) [18] and EIP scale-up evaluation (April 2019 to September 2019). All participants enrolled in the EIP intervention during October 2018 to September 2019 were included in this study. EIP was delivered at one of the following local community centers in BC, Canada: Prince George (YMCA of Northern BC); Kelowna (YMCA of the Okanagan); Surrey (Tong Louie YMCA); Surrey (City of Surrey); Burnaby (City of Burnaby); and Greater Victoria (Westshore Recreation and Parks Society). Recruitment strategies included the following: newspaper advertisements, letters, and email blasts to provincial networks and organizations; posters and rack cards displayed in recreation centers, public community spaces, medical offices, and schools; and social media advertisements.

Ethics Approval

Informed consent was obtained from all parents, and children were asked to complete an ascent form confirming that they understood the terms of participating in the study. Participant confidentiality was maintained throughout the study by having no participant names on any of the data. This study was approved by the University of Victoria and University of British Columbia Research Ethics Boards (BC18-024).

Participants

The inclusion criteria were children between the ages of 8 and 12 years who are ≥85th percentile BMI for age and sex [20]. The program required the participation of at least one parent, caregiver, or legal guardian along with the children. The exclusion criteria were children with known health issues such as cardiovascular disease, mental health issues, or eating disorders; children who had a BMI of <85th percentile; and if the parent and child were unable to communicate in English.

Early Intervention Program

EIP represents a community-based delivery model that was theoretically informed by the M-PAC framework, which emphasizes social cognitive approaches to facilitate intention formation and the adoption of action control through self-regulation, including an action control maintenance phase where a behavior becomes habitual and self-identified [17]. EIP was developed to complement the existing childhood obesity management program in BC, Canada (HealthLink BC Eating and Activity Programme for Kids: telephone-based support program for children who were overweight; Shapedown: a clinical-based program for children with BMI ≥97th percentile for age and sex).

Intervention activities were designed to instruct and support children and parents in learning about and experiencing supportive lifestyle behaviors (eg, increased physical activity), positive mental health strategies (eg, gratitude and appreciation circles), and behavior change techniques (eg, goal setting, feedback, and monitoring).

The 10-week EIP included weekly interactive in-person group sessions and online activities. A minimum of 5 families were needed to run the intervention at each program site. Group sessions were held once a week for 90 minutes and included family physical activity; child-only physical activity aiming at improving enjoyment, confidence, motivation, and fundamental movement skills; and parent-only group discussion to identify barriers and strategies for promoting healthy lifestyle behaviors. Following the in-person sessions, 10 weekly online interactive lessons were made available to the families using a web portal. The weekly online lessons complemented the in-person sessions by offering additional resources about healthy living, weekly physical activity challenges, family recipes ideas, personal diaries for family goal setting and monitoring, and an online discussion forum. Families were encouraged to complete weekly self-directed online portal activities. The in-person group session content was also made available on the portal in case families were not able to attend the weekly sessions.

Study Procedure

Study data were collected by a research assistant at baseline and 10-week follow-up at each study site. The parents and children completed a survey prior to attending their first session and final program sessions. Demographic information (ie, ethnicity, parent education, and annual household income) was collected at baseline.

EIP Engagement Metrics

In-Person Engagement

This was calculated using the total number of in-person sessions attended over the 10 possible occasions a family could attend the in-person component of the intervention. Session attendance was recorded by site facilitators if the participant was present for the entire in-person session.

Web Portal Log-in Frequency

The total number of log-ins consisted of the number of times the families logged onto the online EIP portal throughout the EIP program. All modules could be completed during a single log-in occasion; however, the participants were allowed to log in as many times as they wished.

Weekly Online Minutes

The average minutes per week a family spent logged into the portal was recorded. The average weekly time was calculated by dividing the total time by 10 (the length in weeks of the EIP program).

Percentage of Online Content Accessed

Data were captured for each distinct weekly lesson webpage a family accessed. A total of 111 webpages contained content regarding behavior improvements, such as strategies to improve physical activity, different healthy recipes, as well as family physical activity and healthy eating challenges.

Child Measures

Physical Activity

Weekly MVPA was assessed using a child physical activity questionnaire that was based on the guidelines provided by the Physical Activity Questionnaire for Older Children (=.79) [21]. In order to determine the days per week of MVPA, children were asked to indicate how many days over the course of the previous week they were physically active for a total of at least 60 minutes, including all the time they spent doing activities that increase their heart rate or made them breathe hard.

Physical Activity Confidence

Physical activity confidence was measured using the Patient-centered Assessment and Counselling for Exercise questionnaire (=.75) [22]. This questionnaire included a 5-point Likert scale that assessed if a child felt confident preforming physical activity when they felt sad; whether they dedicated time to preform physical activity; whether they could maintain a commitment to physical activity when their family wanted to do another activity; whether they woke up early to perform physical activity; whether they continued to perform physical activity when they had school work; and if they still preformed physical activity despite poor weather conditions (ie, rainy or humid days).

Dietary Behaviors

Fruit, vegetable, and sugary sweetened beverages intake were assessed using questions from the Centre for Disease Control and Prevention Behavioral Risk Factor Surveillance System 7-day recall (intraclass correlation coefficient=0.50) [23].

Parental Measures

Parental Support for Healthy Eating and Physical Activity

Three items were adapted from previous research [24,25]. The eating items were scored on a 1 (not at all) to 4 (every day), which began with the following stem: “During a typical week, how often have you or a member of your household.” The items were as follows: “Encouraged your child to eat more fruit,” “Encouraged your child to eat more vegetables,” and “Bought fruit or vegetables that you know your child likes.” The physical activity items were scores on a scale of 1 (strongly disagree) to 5 (strongly agree) and were as follows: “I watch my child play sports or participate in other activities such as martial arts or dance," "I enroll my child in sports teams and clubs such as soccer, basketball, and dance," and "I take my child to places where he/she can be active."

Family Habits for Eating and Physical Activity

Family healthy eating and physical activity habits were measured using The Self-Report Index of Habit Strength, which included a 5-point Likert scale and questions such as the following: "preparing and eating healthy meals and snacks is something I do automatically…" and "participating in physical activity as a family is something we do without thinking" [26].

Parental Identity for Healthy Eating and Physical Activity

Three items, adapted from the role identity subscale of the Exercise Identity Scale measured identity for eating (α=.82) and physical activity (α=.88) [27]. The eating items were as follows: "I consider myself an individual who prepares healthy food and beverage choices;" "When I describe myself to others, I usually include my commitment to eating healthy;" and "Others see me as someone who regularly eats healthy." The physical activity items were as follows: "I consider myself an exerciser;" "When I describe our family to others, I usually include something about our physical activities;" and "Others see us as a family that is regularly active." Each item was scored on a scale that ranged from 1 (strongly disagree) to 5 (strongly agree).

Data Analysis

Patterns in missing data were examined for each of the behavior outcomes separately to ensure that the data were missing completely at random. Missing data were imputed using the data using baseline observations carried forward. Hierarchical cluster analysis by means of the Ward method was used to explore EIP engagement patterns [28]. The engagement data (ie, weekly in-person attendance, frequency of online log-ins, percentage of online portal content accessed, and average weekly time spent engaging with the online EIP portal) were converted into z-scores and included in the cluster analysis. The hierarchical cluster identified the two following clusters: (1) families that mostly engaged with in-person (IP) sessions; and (2) families that engaged with both in-person and online (IP+) sessions.

Independent *t* tests were used to explore whether the baseline family characteristics differed between the patterns of engagements for continuous variables (eg, child and parent outcome measures). Chi-squared tests were used to explore differences between the engagement groups for categorical variables (eg, child ethnicity, family income, and parent education).

Linear regressions were used to compare whether child and parent outcome measures differed at follow-up between the 2 engagement groups. Each regression model was adjusted for baseline values of our dependent variable. Data were analyzed using SPSS V26.0 (IBM Corp). The statistical significance criterion was set to $P<.05$.

Results

EIP Engagement Patterns

The cluster analysis revealed 2 distinct engagement clusters, which were families that engaged mostly with the IP sessions (n=40) and families that engaged with the IP+ sessions (n=26). We did not observe significant baseline differences between the groups (IP vs IP+) for parent education, child ethnicity, child physical activity, child dietary behaviors, parental support for child physical activity and healthy eating, as well as physical activity and healthy eating identity and habits ($P>.05$; Table 1). However, we observed a significant difference for family income between the groups (N=55, $X^2_2=6.2$; $P=.02$). Specifically, families with higher income (more than CAD $59,000 [US $45,000]) were more likely to engage with both in-person and the online portal compared with families with lower income (less than CAD $59,000 [US $45,000]).

Over the 10-week period, the mean in-person session attendance percentage for both groups was 8.1, 81.03% (SD 1.54). The mean EIP online portal engagement for both groups for log-in frequency was 3.29 (SD 2.98) times, mean weekly portal engagement minutes was 14.57 (SD 13.47) minutes, and families accessed on average 22.19% (SD 21.74) of the online portal content. The number of in-person sessions attended did not vary significantly between these 2 groups ($P>.05$). However, engagement of the online portal did vary significantly between the groups ($P<.05$). The IP+ group showed a greater number of online portal log-ins, weekly engagement minutes, and percentage of content accessed (Table 2).

Table 1. Baseline characteristics by EIP[a] engagement patterns (N=66).

Characteristics	Engaged with in-person sessions (n=40)	Engaged with both in-person and online sessions (n=26)	*P* value
Ethnicity, n (%)			.63
White	17 (42)	14 (54)	
Indigenous	3 (8)	3 (12)	
Asian[b]	8 (20)	4 (15)	
Other[c]	2 (5)	2 (7)	
Multi-ethnicities[d]	10 (25)	3 (12)	
Parent education, n (%)			.30
High school diploma	5 (14)	6 (25)	
2-year college	16 (43)	12 (52)	
University	7 (19)	3 (14)	
Graduate degree	9 (24)	2 (9)	
Household income[e] (US $), n (%)			.01
<45,000	18 (53)	4 (19)[f]	
>45,000	16 (47)	17 (81)[f]	
60 min of MVPA[g] (days per week)	3.28 (2.28)	3.58 (2.41)	.61
Child physical activity confidence[h]	2.62 (1.34)	3.08 (1.27)	.17
Child fruit intake, times per day in a typical week (SD)	2.10 (1.17)	2.58 (1.31)	.34
Child vegetable intake, times per day in a typical week (SD)	1.82 (1.42)	2.01 (1.30)	.88
Child sugary drink intake, times per day in a typical week (SD)	1.47 (1.03)	1.75 (1.25)	.34
Parental physical activity support[i]	21.07 (5.90)	21.61 (3.38)	.76
Parental support for healthy eating[j]	10.49 (2.03)	9.93 (1.13)	.20
Family healthy eating habit[k]	11.85 (5.17)	12.58 (3.18)	.52
Family physical activity habit[l]	9.70 (4.90)	10.88 (4.24)	.32
Parental healthy eating identity[m]	10.17 (3.30)	10.07 (2.30)	.89
Parental physical activity identity[n]	7.78 (3.3)	8.67 (2.68)	.30

[a] EIP: Early Intervention Program.

[b] Asian: South Asian, East Asian, Chinese, and Southeast Asian.

[c] Other: Black and Latin American.

[d] prefer not to answer, n=6.

[e] prefer not to answer, n=11.

[f] Post-hoc chi-square significant group difference (*P*<.05).

[g] MVPA: moderate-to-vigorous physical activity.

[h] Higher value represents higher physical activity confidence (scale: 1-5).

[i] Higher value represents higher parental physical activity support (scale: 5-25).

[j] Higher value represents higher parental support for healthy eating (scale: 4-12).

[k] Higher value represents higher family health eating habit (scale: 5-15).

[l] Higher value represents higher family physical activity habit (scale: 5-15).

[m] Higher value represents higher parental healthy eating identity (scale: 0-12).

[n] Higher value represents higher parental physical activity identity (scale: 0-12).

Table 2. EIP[a] engagement profile (N=66).

EIP engagement metrics	Engaged with in-person sessions (n=40)	Engaged with both in-person and online sessions (n=26)	*P* value
Percent of in-person attendance, n (%, SD)	7.9 (79.8, 1.60)	8.5 (84.54, 1.32)	.13
Online engagement			
Total number of log-ins, mean (SD)	1.37 (1.12)	6.23 (2.45)	<.001
Average weekly time spent online, min (SD)	6.23 (2.49)	26.85 (13.16)	<.001
Core webpages accessed, % (SD)	7.26 (6.24)	45.16 (16.22)	<.001

[a] EIP: Early Intervention Program.

The Relationship Between EIP Engagement and Intervention Outcomes

Child physical activity (MVPA), and physical activity confidence at follow-up were significantly higher in the IP+ group than in the IP group (*P*<.05). We did not observe a significant between-group difference in dietary behaviors (Table 3). Parental support for child physical activity and healthy eating, as well as family habits for healthy eating and physical activity were significantly higher in the IP+ than the IP group (*P*<.05). Family physical activity identity was also significantly higher in the IP+ group than in the IP group (*P*<.05). No significant difference between the groups was observed for family healthy eating identity (Table 3).

Table 3. Comparison of family behavior outcomes in the EIP[a] engagement patterns follow-up.

EIP outcomes	In-person + online vs in-person sessions, B[b] (SE)	*P* value
Child physical activity (days per week reaching 60 min of MVPA[c])	1.53 (0.56)	.008
Child physical activity confidence	1.04 (0.37)	.007
Child fruit intake (times per day in a typical week)	0.73 (0.45)	.11
Child vegetable intake (times per day in a typical week)	0.05 (0.36)	.88
Child sugary drink intake (times per day in a typical week)	–0.26 (0.25)	.16
Parental physical activity support	5.54 (2.57)	.04
Parental support for healthy eating	2.43 (1.16)	.04
Family healthy eating habit	3.95 (1.84)	.04
Family physical activity habit	3.02 (1.50)	.049
Parental healthy eating identity	2.19 (1.30)	.1
Parental physical activity identity	2.82 (1.19)	.02

[a] EIP: Early Intervention Program.

[b] B: linear regression models adjusted for baseline variable.

[c] MVPA: moderate-to-vigorous physical activity.

Discussion

Principal Findings

Family-based lifestyle interventions can be an effective way to promote regular physical activity and healthy eating among families with children who are off the healthy weight trajectory. The blended in-person and online delivery model can help further improve program flexibility and scalability. This is one of the first studies to explore engagement patterns and the dose-response relationship of a blended family-based lifestyle intervention designed for families who are off the healthy weight trajectory. Our findings assist in understanding the impact of program engagement on intervention outcome and ways to improve intervention engagement.

Our results suggested that engagement with the in-person component of the EIP was high among both groups (IP and IP+). Engagement with the online component of the intervention was the distinguishing factor between the 2 groups. The additional online engagement (IP+) resulted in greater improvements than the IP group in child physical activity behaviors, parental support for child physical activity and dietary behaviors, as well as family physical activity and dietary habits and identity. This observed dose-response relationship between intervention usage and outcomes was reported in previous online studies among children and adolescents [19,29]. Our results contribute to this field by demonstrating the potential complementary effects of online intervention with in-person intervention for family-based lifestyle programs.

Families that engaged with both the online portal and the in-person EIP (IP+) added almost 1.5 days per week of at least 60 minutes of child MVPA compared with families who mostly engaged with the in-person group (IP). A number of studies have reported that child physical activity level is associated with parental support behaviors, family physical activity habits, and parental exercise identity [10,30]. Thus, it is not surprising that compared to the IP group, the IP+ group showed a greater improvement in parental support for child physical activity, family habits, and parental physical activity habits. The EIP was designed based on the M-PAC framework to strengthen behavior intention formation (eg, the physical and mental health benefits of physical activity as well as parental support behaviors) and promote behavior maintenance (restructuring the physical and social environment to create opportunities for physical activity, habit formation, and identity formation). The online component of the EIP offered families additional opportunities to engage in physical activity together through various challenges and activities in their local community (eg, outdoor games and geotagging). Some studies indicate that parents' opportunity to coparticipate in physical activity with their children is associated with an increase in parental support [31]. We speculate, then, that the suggestions provided for family physical activity in the EIP online portal influenced parent support for physical activity.

Furthermore, according to the M-PAC framework, the improvements in physical activity identity are related to physical activity participation. Specifically, repeated participation in physical activity may improve the perception of the ability to engage in the behavior and enhance the participant's perception of their commitment to the behavior [32]. Both of these constructs support continued participation in physical activity, which, in turn, promotes increased physical activity identity. Similarly, in the early stages of physical activity engagement, repeated participation builds habit formation, which then increases the probability of repeated engagement [29]. Since the EIP program's online component provided resources and opportunities for at-home family physical activity, the families were able to review those resources and actively engage in the behavior. As such, we associate the increases in parental identity and habit with family physical activity engagement at home.

We found that increased online portal engagement was not associated with improvements in child dietary outcomes, but we did detect an increase in parental support for healthy eating and habit and parental identity for healthy eating. As with the physical activity psychological constructs, we associate these increases with the additional portal resources engagement such as family nutrition challenges and recipes. We also anticipate that the lack of significant change in actual child-eating behavior may be due to ceiling and floor effects, whereby children were consuming an adequate level of fruit and vegetables and few sugary drinks (ie, none to 1-3 sugary drinks in the past 7 days) at baseline, thus reporting minimal change at follow-up [33].

Additionally, we found that baseline family income was significantly associated with online portal engagement. Sociodemographic characteristics such as socioeconomic status were associated with lower computer literacy skills and access, resulting in lower engagement with digital health interventions [34]. According to the Digital Health Engagement Model, there are several potential ways to improve engagement with the digital interventions [35]. For example, providing tutorials on how to use the online portal during the first in-person session may help families familiarize themselves with the available online tools and the additional resources. Furthermore, ensuring the web portal is accessible to mobile phones can help provide additional ways to access the program when a computer is not available. These changes to the EIP may further improve the scalability and flexibility of EIP delivery.

Limitations

There are several limitations to this study. First, our findings may have limited generalizability due to the small sample size. Additionally, the portal usage metrics reported may not accurately reflect the participants' actual usage within the portal. For example, weekly portal minutes are reflective of the number of minutes the participants view the portal, but it does not show whether the participants were viewing the portal, or it may also be possible that the page was left open on the desktop. The long-term effect of the program remains unclear. Lastly, the quality of interaction the participants had with the in-person sessions was not monitored.

Conclusion

We identified 2 main types of engagement patterns (IP and IP+) with the blended family-based healthy lifestyle intervention for children who are off the healthy weight trajectory. Engagement level with the in-person component of the program remained high in both groups. However, relative to the in-person engagement group (IP), families that engaged with both in-person and online (IP+) improved child physical activity level, child MVPA, child physical activity confidence, parental support for child physical activity and healthy eating, family habits for physical activity and healthy eating, as well as parental identity for physical activity. There were no significant changes between the groups for child dietary outcomes, which may be attributed to a ceiling effect in fruits and vegetable consumption and a floor effect in sugary drink consumption. This study suggests the benefit of adding an online component to an in-person family-based childhood obesity intervention.

Conflicts of Interest

None declared.

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Abbreviations

BC: British Columbia
EIP: Early Intervention Program
IP+: in-person + online
IP: in-person
M-PAC: Multi-Process Action Control
MVPA: moderate-to-vigorous physical activity

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Original Paper

Measuring and Enhancing Initial Parent Engagement in Parenting Education: Experiment and Psychometric Analysis

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Abstract

Background: Prevention efforts focused on parenting can prevent and reduce the rates of child internalizing and externalizing problems, and positive changes in parenting skills have been shown to mediate improvements in child behavioral problems. However, parent skills training programs remain underused, with estimates that under half of eligible parents complete treatment and even lower rates engage in preventive interventions. Moreover, there is no validated measure to assess initial engagement in parent education or skills training, which is an understudied stage of parent engagement.

Objective: We aimed to test a novel engagement strategy, exploring whether including information pertaining to the neuroscience of child development and parent skills training enhanced parental intent to enroll. In addition, a novel self-report measure, the 18-item Parenting Resources Acceptability Measure (PRAM), was developed and validated.

Methods: In a group of 166 parents of children aged 5 to 12 years, using an engagement strategy based on the *Seductive Allure of Neuroscience Explanations*, we conducted a web-based experiment to assess whether the inclusion of neuroscience information related to higher levels of engagement via self-report and behavioral measures. The PRAM was subjected to an exploratory factor analysis and examined against relevant validity measures and acceptability measurement criteria.

Results: Three PRAM factors emerged ("Acceptability of Parenting Resources," "Interest in Learning Parenting Strategies," and "Acceptability of Parenting Websites"), which explained 68.4% of the total variance. Internal consistency among the factors and the total score ranged from good to excellent. The PRAM was correlated with other relevant measures (Parental Locus of Control, Parenting Sense of Competence, Strengths and Difficulties Questionnaire, Parent Engagement in Evidence-Based Services, and behavioral outcomes) and demonstrated good criterion validity and responsiveness. Regarding the engagement manipulation, parents who did not receive the neuroscience explanation self-reported lower interest in learning new parenting skills after watching an informational video compared with parents who did receive a neuroscience explanation. However, there were no significant differences between conditions in behavioral measures of intent to enroll, including the number of mouse clicks, amount of time spent on a page of parenting resources, and requests to receive parenting resources. The effects did not persist at the 1-month follow-up, suggesting that the effects on engagement may be time-limited.

Conclusions: The findings provide preliminary evidence for the utility of theory-driven strategies to enhance initial parental engagement in parent skills training, specifically parental interest in learning new parenting skills. In addition, the study findings demonstrate the good initial psychometric properties of the PRAM, a tool to assess parental intent to enroll, which is an early stage of engagement.

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KEYWORDS

parental engagement; parenting intervention; parenting education; intent to enroll; measure development

Introduction

Parent Engagement in Parenting Education and Skill Training

Promoting child mental health has been identified as a key public health issue [1-3]. Most forms of child mental health treatment involve parents, with many efficacious interventions even focusing exclusively on parents, most commonly in the form of parent skills training [4,5]. Parent-based skill training, or parenting education, can take the form of parenting groups, individual treatment, self-help (such as parenting books), and web-based programs. A wealth of evidence suggests that parent skills training programs are effective in reducing child internalizing and externalizing symptoms [6-9]. In addition, parenting education with a *prevention* focus has been shown to reduce the risk of a wide range of youth emotional and behavioral problems over follow-up periods of up to 20 years [10]. Thus, parent skills training programs are clearly an effective way to treat and prevent child mental health problems.

Despite the demonstrated efficacy of parenting education programs, low parental engagement in these programs has been recognized as a significant barrier to improving child mental health [11]. A systematic review of parental engagement found that 25% of parents who met the criteria for behavioral parent training interventions did not enroll in treatment, and an additional 26% dropped out before the end of treatment, leading to 51% of identified eligible parents not completing treatment [12]. Thus, most families who may stand to benefit from parent training services do not receive a full dose of treatment. Engagement rates in preventive parenting interventions have been found to be similarly low or even lower than those in standard interventions [13,14].

Unfortunately, limited engagement can compromise the ability of parenting education programs to provide desired outcomes for children and families and can temper conclusions drawn from parent skills training research [15]. Moreover, programs with underenrollment are less cost-effective, limiting the effectiveness and disseminability of parenting intervention programs [16]. A host of parent-level, community-level, and programmatic factors have been associated with lower levels of engagement in prevention programs, including socioeconomic disadvantage, lack of social support, single parent status, and minority status [13]; younger parental age and neighborhood disadvantage [11]; parental attributions (eg, external locus of control regarding child behaviors) [17,18]; and limited parental knowledge of efficacious child treatments [19]. A recent study also examined factors that positively influence intent to engage in a parenting intervention in a very large web-based sample (N=6733). Parent behaviors (ie, more coercive parenting, lower consistency, greater use of positive encouragement, and more help-seeking behaviors) and parent cognitions (ie, lower sense of parental self-efficacy, greater psychological distress, and lower perceived quality of parent-child relationship) emerged as significant positive predictors of intent to engage in a parenting program [18].

Methods to Enhance Engagement

Piotrowska et al [20] outlined a model of parent engagement with 4 stages: connection, attendance, participation, and enactment. Connection, the earliest stage of engagement, occurs when parents decide to enroll. Importantly, intent to enroll significantly predicts subsequent enrollment and is a moderate-strength predictor of first-session attendance [21,22]. However, despite the underenrollment of parents in prevention and intervention programs to promote child mental health, few studies have experimentally investigated methods to increase program engagement, with only a handful of methods demonstrating efficacy in the early stages of parent engagement. These have included a promotion-focused advertisement [23], a comprehensive "engagement package" (ie, a testimonial flyer, teacher endorsement, and extra calls from group leaders) [24,25], and monetary incentives [26,27].

Overall, few experimental studies have attempted to increase initial engagement. Furthermore, studies have used inconsistent operationalizations of the different aspects of engagement, experimental studies tend to have low methodological quality, and the diversity of methods to enhance engagement makes generalizations difficult [28,29]. Moreover, most initial engagement knowledge comes from intervention research that examined recruitment and enrollment factors post hoc. In these designs, only information from parents who were interested in enrolling is accessible, which precludes identifying the factors associated with parents who choose *not* to enroll. Taken together, these reviews suggest that there is a need to test novel methods to promote initial parental engagement in preventive interventions.

A separate line of work suggests that including neuroscience explanations can increase subjective credibility and favorability ratings of written information; this phenomenon is known as the "Seductive Allure of Neuroscience Explanations" (SANE) [30,31]. For example, explanations are viewed as more compelling if they include statements such as "brain scans show that..." or "frontal lobe brain circuitry is known to be involved in..." [30,31]. Some researchers have found that this effect is driven by mere conceptual inclusion of neuroscience information [32], whereas others have found this effect only when superfluous neuroscience text *and* images are included [33]. A review of the neuroimage bias literature concluded that the effects of including these superfluous images may vary according to contextual characteristics [34]. Furthermore, it has been proposed that using optimistic neuroscience explanations that characterize the brain as neuroplastic may enhance the credibility of the information and promote positive social-emotional responses within an intervention [35]. Although it has been suggested that neuroscience explanations may increase engagement with treatment, to our knowledge, this has not been demonstrated experimentally.

In this study, considering the potential utility of preventive parent training, we examined whether a neuroscience-enhanced video presentation about child development and parent skills training enhanced parental intent to enroll more than a program description without neuroscience (standard video). Focusing on the initial stage of engagement, *connection* [20], we directly compared 2 different methods of advertising a preventive parent skills training program, maximizing the data collected from both interested *and* uninterested parents. Our model integrates 2 separate lines of work: one on the impact of neuroscience explanations on credibility and the other on parent intervention engagement. We used a framework consistent with the SANE aiming to expand the menu of engagement strategies. Moreover, this study examined the initial stages of engagement in depth, collecting information on self-reported interest in addition to capturing behavioral proxies of intent to enroll.

Measuring Initial Engagement

Beyond the limitations of using self-selected samples of caregivers in initial engagement research, there is a lack of measures of engagement at this earliest stage. In the context of parents already enrolled in a behavioral parent training program, the Parent Motivation Inventory [36] assesses parent desire for child change along with readiness and perceived ability to change parenting behaviors. Other measures have been developed to assess conceptually related constructs, such as the Parental Attitudes Toward Psychological Services Inventory [37] and the Parent Engagement in Evidence-Based Services (PEEBS) questionnaire [38,39], both of which assess parental attitudes toward mental health services. Importantly, these measures assess parental openness to engaging their child in treatment rather than the acceptability of *parent-focused* training.

In light of this measurement gap and the goal of this study to examine the impact of neuroscience information on parent willingness to engage with parenting education materials, we developed and validated a measure to assess parental intent to enroll, part of the *connection* stage of engagement [20]. The Parenting Resources Acceptability Measure (PRAM; Multimedia Appendix 1) was created based on a measure of acceptability of positive parenting strategies [40] and on previous work examining consumer preferences for parenting support delivery methods [41]. This measure was developed and evaluated according to a set of established criteria for acceptability measures [42]. Following the development of the 18 items, the measure validation proceeded in 3 phases. First, the measure was subject to an exploratory factor analysis (EFA), and the factors and total scores were correlated with established measures of other relevant constructs. Validity measures were selected based on published measures assessing conceptually related constructs [38,39] along with constructs that have been shown to relate to parent engagement, including child problems [43,44], social support [13], parental locus of control [17], and parental self-efficacy [18]. Next, this measure was used in the experimental study outlined previously. Finally, a subsample of parents was assessed 1 month following the baseline battery administration, and the PRAM was correlated with self-reported engagement in parenting education resources in the previous month. These findings represent the initial validation of this novel measure of the acceptability of parenting education resources.

We hypothesized that the PRAM would demonstrate strong psychometric properties and relate to theoretically relevant measures. We further hypothesized that a neuroscience-enhanced video presentation about child development and parent skills training would enhance parental intent to enroll, as measured by the PRAM, compared with a presentation without neuroscience information. We also hypothesized that this group would display behavior consistent with higher intent to enroll, operationalized as more mouse clicks and time spent on a page of parenting resources, along with a greater likelihood of requesting parenting resources following the presentation.

Methods

Participants and Procedure

Recruitment and Study Completion

Participants were drawn from a registry of families previously recruited for research by the Center for Developmental Science of the Psychology Department at Florida State University. Potential participants were not selected based on pre-existing traits or risk factors; thus, this study is consistent with a *universal prevention* approach [45]. Caregivers were called and asked to participate in a study examining attitudes, interests, and the impact of COVID-19 on Tallahassee families. Participants were compensated with a US $10 Amazon gift card for participating in the baseline survey and entered to win a US $150 gift card for completing the 1-month follow-up survey. The eligibility criteria were as follows: (1) being a parent or legal guardian, and primary caregiver, of at least one child aged 5 to 12 years; (2) having access to a computer; (3) currently living in Tallahassee; and (4) being able to respond to questions in English. Though the term “parent” is used throughout this paper, this term includes nonparent legal guardians.

Participants were then randomly assigned to one of two conditions, with an equal chance of being in either condition, and emailed a link to an approximately 1-hour–long survey (Qualtrics XM Platform; Qualtrics International Inc), which they were instructed to complete in a single sitting and within 1 week. However, survey responses collected beyond the 1-week time limit were included; the purpose of stating a time limit was to increase participation rates. Reminder emails or calls were sent or given 5 days after the initial enrollment and every 1 to 2 weeks thereafter. The purpose of instructing parents to complete the survey in a single sitting was to reduce the likelihood of a disruption occurring during the video manipulation. At the end of the survey, participants were asked about any interruptions. Although 31.2% (53/170) of parents indicated that they experienced a disruption during the survey, participants were only excluded if the disruption occurred during the video manipulation (4/170, 2.4%). Finally, a list of parenting resources was sent in a follow-up email upon request (ie, “Would you like to be emailed a list of parenting resources after this survey?”).

Follow-up surveys were emailed to caregivers approximately 1 month after completion of the baseline survey. In this survey, participants were readministered a subset of measures included in the baseline survey, and they were asked whether they had engaged with any of the services or resources provided after the baseline survey.

Final Sample

A total of 590 family registry phone numbers were called. Of these 590 phone numbers, 108 (18.3%) were deemed ineligible (eg, had moved away or had no children in the age range) or were unable to be contacted (eg, phone number disconnected), 164 (27.8%) were left voicemails that were never returned, 32 (5.4%) were reached but unwilling or unable to speak in the moment and not reached again later, and 58 (9.8%) expressed that they were not interested. A total of 228 parents agreed by phone to participate in the study and were emailed a link to the survey. Of these parents, 76.3% (174/228) completed the entire baseline survey, 6.6% (15/228) partially completed the survey, 0.9% (2/228) unenrolled from the study (1/2, 50% lost access to a computer and 1/2, 50% unenrolled for medical reasons), and 16.2% (37/228) never started the survey. Of the 174 parents who completed the survey, 4 (2.3%) reported experiencing a disruption during the video presentation and were excluded. Finally, all parents who reported being nonprimary caregivers (4/174, 2.3%) were excluded. Thus, the final sample consisted of 166 parents, with equal numbers per condition (83/166, 50%).

Of the 166 parents who completed the baseline survey, 128 (77.1%) completed the follow-up survey regarding past-month use of parenting resources, completing it an average of 38 (SD 21) days after the baseline survey. Follow-up completers did not differ from the noncompleters in any demographic characteristic or PRAM scores at baseline (P>.05 in all cases).

Owing to an early administrative error, 34% (28/83) of parents who had been randomly assigned to the standard video were erroneously sent the neuroscience-enhanced video survey link, leading to an imbalance of numbers per condition. Recruitment goals were extended to balance condition assignment and, thus, the conditions were pseudorandomized. However, the timing of enrollment did not relate to any study variables, suggesting that the groups likely did not differ systematically as a result of this error. Moreover, follow-up survey completion rates did not differ between participants who were truly randomized and those who were pseudorandomized to either the standard video or neuroscience-enhanced video.

Manipulation Materials

The baseline Qualtrics survey included a number of questionnaires presented in a randomized order, followed by an experimental manipulation; a page of parenting resources with which parents could interact; and, finally, the postmanipulation repeated measure.

Video Presentations

The experimental manipulation consisted of a simple, narrated slideshow video presentation with textual captions on-screen. The video presentation came in 2 formats: standard video (60 seconds) and neuroscience-enhanced video (97 seconds). These conditions were identical besides the additional content in the neuroscience-enhanced video focused on the effect of parenting on child brain development. To avoid the confound of adding extraneous content to the standard video condition, video length was confounded with video content (video links are available in Multimedia Appendix 2 [46-55]).

The videos were designed to be similar in language to what is advertised in currently available positive parenting resources, as determined by the first author’s informal survey of popular web-based parenting resource web pages and course offerings. Video content was developed following stakeholder input from a parent of 2 young children who also directed a nonprofit organization providing parenting resources and education. Consultation focused on identifying appropriate and compelling terminology (eg, “effective parenting” and “supporting child development”). Additional input was solicited from a panel of psychologists, many of whom specialized in child development and were themselves parents of young children. On the basis of previous research that favors a health *promotion* focus over a problematic behavior *prevention* focus, the videos emphasized health promotion [23]. The lead author’s voice was used for the slideshow narration.

The standard video design included general information about parent skills training programs and resources and how they can be helpful for promoting healthy child development and effective and positive parenting, addressing behavioral or emotional problems, decreasing parenting stress, and increasing feelings of parenting efficacy. It included descriptions of raising children along with images of happy families.

The neuroscience-enhanced video design included identical content to the standard video, with 2 additional slides of general information about how children’s development can be mapped out in the brain and how parenting behaviors, and parent skills training in particular, can affect neurodevelopmental trajectories. It also featured 2 images depicting children’s brains.

Immediately after viewing the video (standard video or neuroscience-enhanced video), participants were asked the following: “Would you like to learn more about resources for parents on positive parenting practices?” Regardless of the response, all parents were then taken to the resource page within the survey.

Resources and Program Links

A page with 8 parenting resource websites was displayed. Resources included web-based parent skills training courses (a free, 4-week, web-based parenting course [*Everyday Parenting* by Kazdin] and a US $80 web-based parenting skills class), in-person or local parenting resources (a parenting resource page from a local Early Learning Coalition and a community resource directory page from a pediatric health organization), self-help written parenting resources [46,47], and web pages with evidence-based parenting information (*Positive Parenting Tips* from the Centers for Disease Control and Prevention and *Resources for Families* from the Child Mind Institute). Multimedia Appendix 2 contains further details on these resource pages. The purpose of providing these web pages was to measure parents’ behavioral engagement, including mouse clicks and time spent on the resource page. Each resource was an embedded web page (ie, an inline frame or “iframe”) within the Qualtrics survey. Only the front page or cover of each resource was shown so that participants remained in the Qualtrics survey while navigating the resource page. However, participants were able to click and scroll within the embedded web pages. After spending as much time as desired on the resource page, participants completed the postmanipulation survey questions.

Measures

Engagement Measure: PRAM

Parents completed a measure designed to assess their openness to, interest in, and likelihood of engaging in parent training (Multimedia Appendix 1). This measure was created because no measure for this construct currently exists. It was modeled after the Parenting Strategies Questionnaire, which examines parents' rated acceptability and usefulness of and behavioral intention to engage in parenting strategies learned in a positive parenting training program for children diagnosed with autism spectrum disorder [40]. This questionnaire was chosen as the model for measuring development because of its high topical relevance and because it showed strong psychometric properties and achieved a high rating on a set of established criteria for measures of acceptability and appropriateness [42]. The PRAM has 6 general statements about parent attitudes toward receiving resources to increase knowledge of effective parenting skills and strategies, half of which are reverse-scored. In addition, consistent with the 3 proposed subscales of the Parenting Strategies Questionnaire, the PRAM contains statements about parents' (1) rated acceptability (openness); (2) rated usefulness (interest); and (3) self-assessed behavioral intent (likelihood) to participate in specific types of parenting interventions, including a web-based parenting program, websites with information about positive parenting, local resources for parents, and books about parenting. These 4 domains mapped onto the types of resources provided to parents following completion of the PRAM. Respondents could also write other unlisted resources that they would find acceptable. All items were measured on a 5-point Likert scale (1=*strongly disagree*, 2=*disagree*, 3=*neither agree nor disagree*, 4=*agree*, and 5=*strongly agree*). The measure was subjected to an EFA and internal consistency analysis. A total mean score was also computed. Parents completed this measure at baseline, again after viewing the video manipulation, and again at the 1-month follow-up.

Demographics

Demographic information included the following: parent gender identity, age, education level, single or dual parent status, marital status, race or ethnicity, and income bracket; percentage of time providing childcare; number and ages of children; and previous participation in parenting classes or use of parenting self-help resources.

Convergent Validity

These measures were completed at baseline.

Child Behavioral and Internalizing Problems

Parents were given the Strengths and Difficulties Questionnaire (SDQ) to self-report their child's internalizing and externalizing problems [56]. The SDQ is a 25-question, widely used measure of internalizing, externalizing, and prosocial behaviors, and it has satisfactory psychometric properties [57]. A 3-factor solution has been shown to be appropriate for community samples, consisting of a total difficulties score along with externalizing and internalizing subscales [58]. In addition, the total difficulties score of the SDQ has been validated as a dimensional measure of child mental health [59]. Parents were told to answer these questions as they pertained to their child with the most behavioral or emotional problems within the age range of 5 to 12 years. Higher scores reflect greater problems.

Perceived Social Support

The 23-item Social Support Appraisals Scale measures perceived social support on a 4-point Likert scale (1=*strongly agree* to 4=*strongly disagree*) with good reliability and adequate validity [60]. Higher scores reflect lower perceived social support. It indexes subjective experience of support from family and friends, with items such as "My family cares for me very much" and "My friends and I have done a lot for one another." In a previous study, parent-perceived social support predicted a higher likelihood of enrollment in a prevention program but did not further distinguish families who attended at least one session [13]. Thus, social support may have the strongest predictive power in the very early stages of parent engagement.

Perceived Parenting Self-efficacy

The 17-item Parenting Sense of Competence (PSOC) scale [61] is measured on a 6-point Likert scale (1=*strongly agree* to 6=*strongly disagree*). It has a 3-factor structure (ie, Satisfaction [eg, "Being a parent makes me tense and anxious"], Efficacy [eg, "If anyone can find the answer to what is troubling my child, I am the one"], and Interest [eg, "My talents and interests are in other areas, not in being a parent"]), each with acceptable internal consistency in both mothers and fathers [62]. Higher scores reflect lower levels of satisfaction, efficacy, and interest. The PSOC is one of the most widely used assessments of perceived parenting self-efficacy [63].

Parental Knowledge and Attitudes Toward Evidence-Based Care

The PEEBS measure was developed based on the theory of planned behavior [64] and assesses parental attitudes toward and knowledge of how to engage in evidence-based care [38,39]. It is rated on a 5-point Likert scale (1=*strongly disagree* to 5=*strongly agree*). A total of 12 items comprising 2 subscales of a revised version of the PEEBS were administered, which were previously found to have acceptable reliability: Subjective Norms (Cronbach α=.76) and Knowledge (Cronbach α=.73) [39]. The Knowledge scale reflects parents' knowledge of child-focused mental health treatments and how to access them (eg, "I know how to access treatments for my child"). The Subjective Norms scale reflects the degree to which parents generally value the endorsements of others (including from a therapist, school staff, pediatricians, psychiatrists, the web, other families, and parent advocates) in selecting a treatment for their child (eg, "Treatments endorsed by a therapist are important to me"). Higher scores reflect greater knowledge and valuation of subjective norms.

Parental Locus of Control

Parents completed a 36-item measure on a 5-point Likert scale (1=*strongly disagree* to 5=*strongly agree*) assessing locus of control with respect to parenting skills and behavior (Parental Locus of Control [PLOC]) [65]. This measure yields 4 factors with acceptable to good internal consistency (Parental Efficacy, where higher values reflect feeling *ineffective* in the parenting role; Parental Responsibility, where higher values reflect parents who *do not* feel responsible for their child's behavior; Child Control, where higher scores reflect parents' belief that their child's needs dominate their life; and Parental Control, where higher values reflect parents who believe they are *unable* to control their child's behavior). Example items include "I always feel in control when it comes to my child" and "I am responsible for my child's behavior."

Behavioral Measures: Additional Convergent Validity

Behavioral outcomes were used as measures of convergent validity for the PRAM as well as outcome measures for the experimental manipulation. All behavioral measures except for the 1-month follow-up retrospective report were administered immediately following the experimental manipulation within the baseline survey.

Request for Additional Information

The groups were examined for differences in whether they requested additional information on positive parenting resources immediately following the video presentation.

Mouse Clicks and Time Spent on Resource Pages

The total elapsed time, along with the number of mouse clicks, viewing the resource page within Qualtrics was recorded.

Predictive Validity: Follow-up Report of Behavioral Engagement

At the approximately 1-month follow-up survey, participants were asked whether they had engaged with any parenting resources in the previous month in the form of books, websites, courses, or local resources. The variable of interest was whether parents endorsed having engaged in *any* form of parenting education in the previous month.

Statistical Analyses

To determine the validity and factor structure of the PRAM (Multimedia Appendix 1), the measure was subjected to an EFA and internal reliability analysis (ie, the Cronbach α). A 3-factor solution was expected, comprising one factor of acceptability (openness), one factor of rated usefulness (interest), and another factor measuring behavioral intent (likelihood).

Pearson product-moment correlations (*r*) were used to determine the strength of the relationships among PRAM factors, validity measures, and behavioral outcomes, including retrospective reports of engagement at the 1-month follow-up.

Regarding group differences based on manipulation, chi-square tests examined group differences in whether participants responded "yes" to the question, "Would you like to learn more about resources for parents on positive parenting practices?"

To test for differences in engagement between groups immediately following the manipulation within the baseline survey, a negative binomial regression compared the number of total mouse clicks between groups (neuroscience-enhanced video and standard video), and a one-way ANOVA compared the total time spent on the resource page between the 2 groups (neuroscience-enhanced video and standard video). In addition, repeated-measure (RM) ANOVAs assessed differences in acceptability before and after viewing the videos. One evaluated the pre-post differences in total PRAM scores, and 3 additional RM ANOVAs were conducted on the subfactors of this scale based on the results of the EFA.

Finally, univariate RM ANOVAs using all 3 time points of the PRAM were conducted on the subset of participants who completed the 1-month follow-up survey to assess the prospective differences between the standard video and neuroscience-enhanced video groups.

Ethics Approval

The Florida State University Institutional Review Board exempted this study on February 26, 2020 (reference STUDY00001059).

Results

Preliminary Analysis

Chi-square tests and one-way ANOVAs revealed no differences in demographic variables per condition (standard version and neuroscience-enhanced version; *P*>.05 in all cases). Pre-existing differences between groups on the outcome and validity variables at baseline were ruled out using 2-tailed independent-sample *t* tests (*P*>.05). The descriptive statistics for the study participants and baseline measures are reported in Table 1 and Table 2, respectively.

Internal consistency analysis was conducted for all variables. To reduce the total number of statistics, increase the reliability of the results, and simplify interpretation, scales with poor internal consistency (ie, SDQ Internalizing Problems, PLOC Child Control, PLOC Parental Efficacy, and PSOC Interest) were omitted from further correlational analyses. Table 3 presents a bivariate correlation matrix of the important study variables.

Table 1. Participant demographics (N=166).

Variable	Values
Parent demographics	
Age (years), mean (SD; range)	38.93 (6.38; 24-61)
Number of children, mean (SD; range)	2.45 (1.13; 1-8)
Education level, n (%)	
High school diploma or equivalent	2 (1.2)
Some college	17 (10.2)
Associate degree or vocational degree	13 (7.8)
Bachelor’s degree	56 (33.7)
Master’s degree	57 (34.3)
Doctorate or professional degree	21 (12.7)
Current employment, n (%)	
Unemployed	46 (27.7)
Employed part time	21 (12.7)
Employed full time	99 (59.6)
Annual household income (US $), n (%)	
10,000 to 39,999	14 (8.4)
40,000 to 69,000	40 (24.1)
70,000 to 99,000	40 (24.1)
100,000 to 149,000	46 (27.7)
≥150,000	26 (15.7)
Household structure, n (%)	
Dual parent	150 (90.4)
Single parent	16 (9.6)
Gender, n (%)	
Cisgender female	153 (92.2)
Cisgender male	11 (6.6)
Transgender female	2 (1.2)
Race, n (%)	
White	133 (80.1)
Black or African American	16 (9.6)
Asian	10 (6)
Multiracial[a]	5 (3)
Middle Eastern or North African	1 (0.6)
No response	1 (0.6)
Ethnicity, n (%)	
Hispanic or Latino	8 (4.8)
Not Hispanic or Latino	158 (95.2)
Previous use of parenting resources[b], n (%)	
Yes	110 (66.3)
No	56 (33.7)
Marital status, n (%)	

Variable	Values
Married	141 (84.9)
Single or never married	11 (6.6)
Divorced	10 (6)
Separated	3 (1.8)
Widowed	1 (0.6)
Child demographics[c]	
Age of child (years), mean (SD; range)	8.32 (2.21; 5-12)
Sex of child, n (%)	
Male	88 (53)
Female	77 (46.4)
Missing	1 (0.6)
Schooling, n (%)	
Public school	118 (71.1)
Private school	34 (20.5)
Homeschooled	14 (8.4)

[a] Participants were able to select multiple races; thus, “multiracial” reflects participants who selected more than one race.

[b] This question explicitly excluded parenting resources related only to *childbirth*.

[c] Parents were asked to report information for their child aged 5 to 12 years with the most significant behavioral or emotional problems.

Table 2. Descriptives of validity measures (N=166).

Validity variable	Cronbach α[a]	Value, mean (SD; range)
SDQ[b]		
Total difficulties	.81	11.76 (5.74; 2-28)
Externalizing symptoms	.81	7.54 (3.92; 0-20)
Internalizing symptoms	.67	4.22 (2.96; 0-12)
Prosocial scale	.77	7.43 (2.12; 1-10)
Parent-reported impact	—[c]	1.32 (2.10; 0-10)
PLOC[d]		
Parent control	.82	2.63 (0.73; 1.2-4.5)
Parental responsibility	.84	3.02 (0.64; 1.7-4.9)
Child control	.66	2.07 (0.57; 1-3.7)
Parental efficacy	.54	1.67 (0.41; 1-2.8)
Perceived social support (SS-A[e]; total)	.95	37.41 (9.78; 23-67)
Perceived parenting self-efficacy (PSOC[f])		
Satisfaction	.77	23.86 (5.44; 10-36)
Efficacy	.79	22.22 (4.07; 7-30)
Interest	.63	15.69 (1.95; 6-18)
PEEBS[g]		
Subjective norms	.79	3.78 (0.50; 1.4-5)
Knowledge	.83	3.45 (0.83; 1-5)

[a] Cronbach α, a measure of internal consistency.
[b] SDQ: Strengths and Difficulties Questionnaire.
[c] Cronbach α not computed for the Impact scale.
[d] PLOC: Parental Locus of Control.
[e] SS-A: Social Support Appraisals Scale.
[f] PSOC: Parenting Sense of Competence.
[g] PEEBS: Parent Engagement in Evidence-Based Services.

Table 3. Bivariate correlation matrix of study variables (N=166).

	1	2	3	4	5	6	7	8	9	10	11
1. Request for resources[a]	X[b]	—[c]	—	—	—	—	—	—	—	—	—
2. Mouse clicks	0.28[d]	X	—	—	—	—	—	—	—	—	—
3. Time spent on resource page[e]	0.32[d]	0.55[d]	X	—	—	—	—	—	—	—	—
4. PRAM[f] mean total (baseline)	0.48[d]	0.20[d]	0.24[d]	X	—	—	—	—	—	—	—
5. Lack of parental responsibility[g]	0.06	−0.01	0.03	0.07	X	—	—	—	—	—	—
6. Lack of parent control[g]	0.31[d]	0.15[h]	0.23[h]	0.19[d]	0.23[d]	X	—	—	—	—	—
7. Dissatisfaction[i]	−0.25[d]	−0.10	−0.12	−0.26[d]	−0.14	−0.58[d]	X	—	—	—	—
8. Inefficacy[i]	−0.29[d]	−0.13	−0.27[d]	−0.22[d]	−0.20[h]	−0.52[d]	0.48[d]	X	—	—	—
9. Lack of perceived social support[j]	−0.03	−0.04	0.04	−0.09	−0.02	0.32[d]	−0.31[d]	−0.43[d]	X	—	—
10. Subjective norms[k]	0.18[h]	0.09	0.28[d]	0.22[d]	0.03	0.13	−0.07	−0.05	−0.23[d]	X	—
11. Knowledge[k]	−0.10	−0.07	−0.17[h]	0.13	0.05	−0.15	0.06	0.24[d]	−0.10	−0.01	X
12. SDQ[l] total difficulties	0.30[c]	0.16[h]	0.14	0.22[d]	0.24[d]	0.56[d]	−0.41[d]	−0.33[d]	0.23[d]	0.03	−0.02

[a] Request for resources: 1=yes and 0=no.

[b] *r*=1.

[c] Not applicable.

[d] *P*<.01.

[e] A transformation was applied with log base-10.

[f] PRAM: Parenting Resources Acceptability Measure.

[g] Scales from the Parental Locus of Control measure; higher scores reflect a lower sense of responsibility for and control of the child's behavior.

[h] *P*<.05.

[i] Scales from the Parenting Sense of Competence scale; higher scores reflect a lower sense of parental satisfaction and efficacy.

[j] Social Support Appraisals Scale total score; higher scores reflect lower perceived social support.

[k] Scales from the Parent Engagement in Evidence-Based Services questionnaire.

[l] SDQ: Strengths and Difficulties Questionnaire.

Part 1: PRAM and Baseline Validity Measures

After subscale scores were derived for the PRAM based on the EFA, between 1 and 2 low outliers (ie, SD ≥3) were identified for each factor and the total score on both the pre- and postvideo scores and brought to the lower fence. Skewness and kurtosis for each of these scales before and after were within acceptable ranges (<|1.0|).

Results of the Factor Analysis

An EFA was conducted using all 18 items; 3 factors emerged with eigenvalues >1. A 3-factor solution was then forced, and the 18 items were subject to principal component analysis with a promax (oblique) rotation. Loadings from the pattern matrix are displayed in Table 4. Factor 1 (9 items) was deemed "Acceptability of Parenting Resources." Factor 2 consisted of the first 6 items and was deemed "Interest in Learning Parenting Strategies." Factor 3 (3 items) was deemed "Acceptability of Parenting Websites." These 3 factors explained 68.4% of the total variance in the measure (factor 1: 51%; factor 2: 9%; factor 3: 8%). Internal consistency of the PRAM scales ranged from good (Cronbach α=.89) to excellent (Cronbach α=.94). Table 5 contains item and scale descriptives.

Given the small number of items in factor 3, we also examined the reliability of the PRAM with the 3 items from factor 3 omitted and found it to be excellent (Cronbach α=.94).

Table 4. Parenting Resources Acceptability Measure (PRAM) rotated pattern matrix factor loadings (N=166)[a].

PRAM item	Factor 1: "Acceptability of Parenting Resources"	Factor 2: "Interest in Learning Parenting Strategies"	Factor 3: "Acceptability of Parenting Websites"
1	0.115	*0.841* [b]	−0.064
2 (R[c])	0.181	*0.736*	−0.243
3	−0.009	*0.790*	0.139
4 (R)	−0.058	*0.839*	0.142
5	0.061	*0.735*	0.127
6 (R)	−0.091	*0.858*	0.168
7a	*0.698*	0.064	0.128
7b	*0.693*	0.088	0.059
7c	−0.074	0.186	*0.843*
7d	*0.878*	0.080	−0.173
8a	*0.544*	−0.131	0.450
8b	*0.715*	−0.078	0.221
8c	0.033	−0.045	*0.949*
8d	*0.819*	−0.226	0.179
9a	*0.583*	0.230	0.037
9b	*0.551*	0.230	−0.061
9c	−0.026	0.065	*0.774*
9d	*0.784*	0.169	−0.282

[a] Values reflect factor loadings from the pattern matrix with a promax (oblique) rotation. A 3-factor solution was chosen based on 3 factors with eigenvalues >1. Refer to Multimedia Appendix 1 for the content of the PRAM items.

[b] Italics reflect items that load onto each respective factor.

[c] R: reverse-scored item.

Table 5. Bivariate correlations between Parenting Resources Acceptability Measure (PRAM) scales and scale descriptives (N=166)[a]

	PRAM total	Factor 1	Factor 2	Factor 3
Factor 1	0.938	—[b]	—	—
Factor 2	0.880	0.700	—	—
Factor 3	0.715	0.553	0.565	—
Number of items	18	9	6	3
Cronbach α	.94	.91	.92	.89
Mean (SD)	3.68 (0.70)	3.54 (0.80)	3.76 (0.78)	3.97 (0.79)
Minimum	1.56	1.12	1.37	1.52
Maximum	5.00	5.00	5.00	5.00

[a] A total of 18 items. All correlations were significant ($P<.001$).

[b] Not applicable.

Validity Measures

Table 6 shows PRAM scales and measures of convergent validity. Broadly, the PRAM total score, factor 1, and factor 2 showed similar correlational patterns, whereas factor 3 diverged somewhat. Child maladjustment assessed via the SDQ total difficulties score was positively associated with PRAM factors 1 and 2, such that higher total difficulties related to greater general acceptability of and interest in learning parenting strategies, but was unassociated with factor 3. With respect to parent-level variables, PRAM factors 1 and 2 were positively associated with parental lack of control over the child's behavior via the PLOC, such that lower perceived control related to greater acceptability of and interest in learning new strategies, but it was unassociated with factor 3. No PRAM scales were associated with parental perceptions of responsibility for their child's behavior via the PLOC. Interestingly, parental dissatisfaction with the parenting role and parental sense of inefficacy assessed via the PSOC were both negatively associated with PRAM factors 1 and 2 such that lower efficacy and lower satisfaction both related to lower acceptability of parenting resources and education. Dissatisfaction and inefficacy were not associated with factor 3. Knowledge of child treatments via the PEEBS was positively associated with factor 1 such that greater knowledge related to greater general acceptability of parenting resources. Knowledge did not relate to factor 2 or 3. Subjective Norms via the PEEBS was positively associated with factors 2 and 3 such that greater valuation of child treatments being endorsed by others was related to greater interest in learning new strategies and greater acceptability of parenting websites. Subjective Norms did not relate to greater general acceptability of parenting resources (factor 1). Finally, perceived social support assessed via the Social Support Appraisals Scale was negatively associated with factor 3 such that less social support related to lower acceptability of parenting websites. Social support did not relate to factor 1 or 2.

Behavioral outcomes were also positively correlated with parent-reported resource acceptability assessed via the PRAM such that self-reported acceptability aligned with all 3 behavioral measures of engagement: PRAM total by request for resources (*r*=0.48; *P*<.001), time spent on resource page (*r*=0.24; *P*=.002), and mouse clicks (*r*=0.20; *P*=.01; Table 6). Behavioral outcomes showed the strongest associations with factor 2.

Table 6. Convergent validity bivariate correlations (N=166).

	PRAM[a] total	Factor 1[b]	Factor 2[c]	Factor 3[d]
Child adjustment (SDQ[e])				
Total difficulties	0.224[f]	0.221[f]	0.251[f]	0.039
Externalizing	0.138	0.143	0.160[g]	0.001
Parent variables				
Lack of parent control (PLOC[h])	0.189[g]	0.171[g]	0.227[f]	0.027
Lack of parental responsibility (PLOC)	0.074	0.030	0.115	0.088
Dissatisfaction (PSOC[i])	−0.262[j]	0.264[j]	−0.280[j]	−0.039
Inefficacy (PSOC)	−0.216[f]	−0.170[g]	−0.307[j]	−0.024
Subjective norms (PEEBS[k])	0.223[f]	0.115	0.269[j]	0.272[j]
Knowledge (PEEBS)	0.134	0.169[g]	0.057	0.095
Lack of social support (SS-A[l])	−0.091	−0.034	−0.049	−0.279[j]
Behavioral measures				
Request for resources	0.476[j]	0.336[j]	0.572[j]	0.374[j]
Mouse click count	0.200[f]	0.152	0.254[j]	0.099
Time spent on resource page[m]	0.242[f]	0.149	0.322[j]	0.190[g]
Prospective resource use[n]	0.359[j]	0.292[j]	0.404[j]	0.223[g]

[a] PRAM: Parenting Resources Acceptability Measure.

[b] Factor 1: "Acceptability of Parenting Resources."

[c] Factor 2: "Interest in Learning Parenting Strategies."

[d] Factor 3: "Acceptability of Parenting Websites."

[e] SDQ: Strengths and Difficulties Questionnaire.

[f] *P*<.01.

[g] *P*<.05.

[h] PLOC: Parental Locus of Control.

[i] PSOC: Parenting Sense of Competence.

[j] *P*<.001.

[k] PEEBS: Parent Engagement in Evidence-Based Services.

[l] SS-A: Social Support Appraisals Scale.

[m] A transformation was applied with log base-10.

[n] One-month follow-up retrospective report on the use of any parenting resources (n=128).

Part 2: Group Differences following Experimental Manipulation

Acceptability Measure

Four 2 (time: before and after)×2 (condition: standard video and neuroscience-enhanced video) RM ANOVAs were conducted for the composite (mean) of each factor as well as the total score on the PRAM to examine differences between groups from before to after the video manipulation. In line with predictions, for the total score, a significant time-by-condition interaction emerged such that the change in reported acceptability from before to after differed by group ($F_{1,164}$=5.202; P=.02; η^2=0.031). Follow-up paired-sample t tests revealed that acceptability ratings significantly decreased in the standard video condition from before (mean 3.67, SD 0.62) to after (mean 3.60, SD 0.61; t_{82}=3.107; P=.003) but did not significantly change in the neuroscience-enhanced video condition from before (mean 3.69, SD 0.77) to after (mean 3.70, SD 0.74; t_{82}=−0.530; P=.60). For factor 2, dubbed “Interest in Learning Parenting Strategies,” there was also a significant time-by-condition interaction ($F_{1,164}$=5.213; P=.02; η^2=0.031), with follow-up paired-sample t tests showing similar findings (standard video: mean before 3.78, SD 0.72; mean after 3.66, SD 0.73; t_{82}=2.914; P=.005; neuroscience-enhanced video: mean before 3.74, SD 0.85; mean after 3.78, SD 0.77; t_{82}=−0.675; P=.50). There was no significant time-by-condition interaction for factor 1 ($F_{1,164}$=2.432; P=.12; η^2=0.015) or factor 3 ($F_{1,164}$=0.003; P=.96; η^2=0.000).

Behavioral Measures

Overview

Table 7 and Table 8 present descriptives for the pre-post outcome variables and behavioral outcomes by condition, respectively. Behavioral outcomes (ie, requests for resources, mouse clicks, and time spent on the resource page) were all positively correlated (Table 3).

Table 7. Descriptives for pre-post outcomes (N=166).

Measure	Standard video (control condition)		Neuroscience-enhanced video (experimental condition)	
	Before[a], mean (SD)	After[b], mean (SD)	Before, mean (SD)	After, mean (SD)
PRAM[c]				
Mean total score[d]	3.67 (0.62)	3.60 (0.61)	3.69 (0.77)	3.71 (0.74)
Factor 1[e]	3.53 (0.73)	3.46 (0.76)	3.55 (0.86)	3.56 (0.87)
Factor 2[f]	3.78 (0.72)	3.66 (0.73)	3.74 (0.85)	3.78 (0.77)
Factor 3[g]	3.91 (0.76)	3.89 (0.61)	4.02 (0.82)	3.99 (0.79)

[a] Before viewing the video manipulation.

[b] After viewing the video manipulation.

[c] PRAM: Parenting Resources Acceptability Measure; mean total=mean acceptability of all items (items 1-18).

[d] PRAM before and after mean total scores were strongly positively correlated (r=0.92).

[e] Factor 1 (9 items): “Acceptability of Parenting Resources.”

[f] Factor 2 (6 items): “Interest in Learning Parenting Strategies.”

[g] Factor 3 (3 items): “Acceptability of Parenting Websites.”

Table 8. Descriptives for behavioral outcome variables (N=166).[a]

Variable	SV[b] (n=83)	NEV[c] (n=83)
Request for parent resources, n (%)		
Yes	56 (67.5)	63 (75.9)
No	27 (32.5)	20 (24.1)
Mouse click count, mean (SD)	4.17 (2.99)	4.82 (4.49)
Time spent on resource page (seconds), mean (SD)	55.39 (113.41)	103.21 (188.52)
Log-transformed time spent on resource page, mean (SD)	1.48 (0.44)	1.59 (0.60)

[a] Log-transformed timing was calculated using a base of 10. The parent resource question was posed immediately after viewing the video manipulation and was phrased as follows: “Would you like to learn more about resources for parents on positive parenting practices?” Mouse clicks were counted while viewing the resource page.

[b] SV: standard video.

[c] NEV: neuroscience-enhanced video.

Number of Mouse Clicks

A negative binomial regression was conducted to examine group differences in the overdispersed mouse click count data. The number of mouse clicks did not differ significantly by condition (standard video mean 4.17, SD 2.99; neuroscience-enhanced video mean 4.81, SD 4.49; β=.145; Wald χ^2_1 [N=166]=1.3; *P*=.26; 95% Wald CI −0.105 to 0.395).

Time Spent on Resource Pages

Owing to high positive skewness and kurtosis, a log transformation (base 10) was applied to this variable. The skewness and kurtosis of the resulting log-transformed variable were acceptable (ie, both <|1|). An independent-sample *t* test was used to test whether the time spent on the resource page differed between groups. There was no significant difference ($t_{150.06}$=−1.396; *P*=.17), indicating that the amount of time spent on the resource page did not differ by condition (standard video mean 1.48, SD 0.44; neuroscience-enhanced video mean 1.59, SD 0.60).

Expressed Interest in Information on Resources for Positive Parenting Practices

To test for group differences in the tendency to request additional information immediately following the viewing of the video, a chi-square test was conducted. No significant difference was found (χ^2_1 [N=166]=1.454; *P*=.23), indicating no group differences in this outcome.

Part 3: PRAM—1-Month Follow-up

Use Descriptives

Regarding the subset of parents assessed at follow-up (128/166, 77.1%), the 1-month retrospective reports of resource use were as follows: 60.9% (78/128) reported accessing parenting information on the web, 25% (32/128) reported engaging with at least one book related to parenting, 14.1% (18/128) accessed local parenting resources, and 5.5% (7/128) enrolled in or completed a parenting course. Of the 83 (83/128, 64.8% of the total) respondents who endorsed having engaged with any of the types of parenting resources, 40 (48%) engaged with only 1 type, 35 (42%) engaged with 2 types, 7 (8%) engaged with 3 types, and 1 (1%) engaged with all 4.

Predictive Validity

The PRAM total score and each factor at baseline related positively to past-month use of any type of listed parenting resource measured at follow-up (PRAM total: *r*=0.36 and *P*<.001; factor 1: *r*=0.29 and *P*<.001; factor 2: *r*=0.40 and *P*<.001; factor 3: *r*=0.22 and *P*=.01; Table 6). Exploratory analyses examining the associations between PRAM scales and past-month use by resource *type* are shown in Multimedia Appendix 2.

To better understand the relationship between behavioral proxies and actual behavior, exploratory bivariate correlations were conducted between past-month use and mouse click count (*r*=0.01; *P*=.87), log of time spent on the resource page (*r*=0.07; *P*=.41), and request for resources (*r*=0.38; *P*<.001), indicating that only expressed interest in receiving more information on parenting resources was prospectively related to resource use.

Group Differences

Within the follow-up completers, RM ANOVAs with Greenhouse-Geisser corrections tested for group differences in change across all 3 time points. There was no significant time-by-condition interaction for PRAM factor 1 ($F_{1.47,185.35}$=0.984; *P*=.35), factor 2 ($F_{1.71,215.46}$=0.753; *P*=.45), factor 3 ($F_{1.62,204.63}$=2.273; *P*=.12), or total ($F_{1.45,182.91}$=1.578; *P*=.21), indicating no group differences at the 1-month follow-up.

Discussion

Principal Findings

We created and tested a novel measure to assess the acceptability of resources for parenting education or parent skills training. The measure showed good psychometric properties and related to several theoretically relevant measures. Using this measure, we examined whether, in the context of a brief presentation on parenting education, the inclusion of neuroscience information on child development affected parental intent to enroll in parent skills training. The first hypothesis was partially supported; that is, from before to after the video manipulation, parents in the neuroscience-enhanced video condition scored higher on rated acceptability than parents in the standard video condition on PRAM factor 2 ("Interest in Learning Parenting Strategies") and on the total PRAM score. By contrast, changes in scores did not significantly differ between conditions on factor 1 or factor 3 ("Acceptability of Parenting Resources" and "Acceptability of Parenting Websites," respectively). Interestingly, the group differences in rated acceptability from before to after were found to be driven by *decreases* in rated acceptability in the standard video condition (in contrast to no significant change from before to after in the neuroscience-enhanced video condition). However, when similar analyses were conducted with the subsample of 1-month follow-up completers, there were no significant group differences across all 3 time points. This may indicate that the impact of neuroscience explanations on acceptability is only short-lived. With respect to behavioral measures (ie, requests for resources, number of mouse clicks, and time spent on the resource page), there were no significant differences by condition. However, all behavioral outcomes indicated levels of engagement in the expected direction, with the neuroscience-enhanced video condition showing nonsignificant higher levels of behavioral engagement. We view the results of this study as a first step toward examining the impact of neuroscience-related information on engagement in prevention and treatment approaches.

The PRAM self-report measure was created for this study to fill the measurement gap in assessing the acceptability of parenting resources or training materials. Three factors emerged, roughly divided in terms of *media format* (ie, *acceptability of parenting resources*, *interest in learning parenting strategies*, and *acceptability of parenting websites*) rather than by facets of *acceptability* (ie, openness, usefulness, and likelihood). It is possible that the differences among various levels of intent to engage are less important than the *ways* in which parents consider engaging. For instance, browsing a website for parenting tips requires very little effort compared with other ways of accessing parenting resources and materials. In line with this, at the 1-month follow-up, most respondents reported having accessed parenting resources in the previous month, and the most commonly accessed resource type was web-based information. Previous studies have shown that most parents find evidence-based parenting information to be acceptable and tend to prefer self-administered formats [41,66]. In this community sample, acceptability ratings appeared favorable across factors and the total score; mean ratings were between *neither agree nor disagree* and *agree*, skewed toward *agree*, and "Acceptability of Parenting Websites" had the highest rated acceptability.

Of note, when the 3 items assessing acceptability of parenting websites (factor 3) were omitted, the PRAM retained excellent internal consistency. Thus, it appears that this measure could be administered as a 15-item measure without a meaningful loss of reliability. However, factor 3 showed multiple unique relations with other variables and, thus, may capture an important swath of parents who have lower levels of interest in information found on mainstream websites. In summary, it is recommended that this measure be modified to include or exclude factor 3 depending on the individual study or intervention purposes.

The PRAM displayed a number of strong psychometric properties. Indeed, the measure earned a passing score on each metric of a set of established criteria [42] used to evaluate measures of acceptability, including reliability, structural validity, criterion (predictive) validity, norms, responsiveness, and usability. Specifically, the PRAM earned ratings of *excellent* on norms (ie, sample size used to establish norms >100), reliability (ie, all Cronbach α values ≥.80), and structural validity (ie, N>100, N>7×the number of items, and an EFA explaining >50% of the variance). It earned a rating of *good* on usability (ie, instrument length; between 10 and 50 items) and ratings of *adequate* on criterion validity (ie, medium correlation between the PRAM and another outcome measured in the future) and *responsiveness* (ie, statistically significant change over time on at least a medium-sized sample; N>50). Importantly, each factor of the PRAM and the total score showed small to moderate–strength positive correlations with behavioral proxies of engagement, including prospective associations with self-reported engagement. Thus, the PRAM has predictive validity as a measure of parental engagement. To further explore the PRAM's responsiveness and criterion validity, it should be used in prospective studies of established interventions that enhance the acceptability of parent skills training.

In our sample, higher ratings of acceptability were associated with greater parent-reported child maladjustment (internalizing and externalizing problems) in addition to greater difficulty in controlling their child's behavior. Interestingly, higher reports of parenting dissatisfaction and greater feelings of parenting inefficacy were related to *lower* acceptability. Although these findings appear to conflict somewhat with those on child behavioral problems, it may be the case that the parental satisfaction and efficacy constructs may better reflect parental stress or psychopathology than actual child behaviors. Future research should test this hypothesis. Furthermore, parental knowledge of effective child treatments, along with the perceived importance of others' opinions on child-focused treatments (ie, subjective norms), was associated with greater acceptability. Taken together, our results provide evidence that parents of children who display more problems may be more open to help seeking related to parenting education or skill training. Furthermore, our findings outline parent characteristics that may relate to acceptability, and further work is needed to assess whether these traits, including parental sense of efficacy, satisfaction, knowledge of treatments, and subjective norms, are suitable targets for interventions aimed at increasing initial engagement. Finally, perceived social support related only to acceptability of parenting *websites*; parents who are less socially connected may also have greater mistrust of or less interest in web-based parenting resources touted by experts (eg, the Centers for Disease Control and Prevention) and may benefit from modified engagement methods.

Regarding the experimental manipulation, we found partial support for the hypothesis that self-reported acceptability differed by condition. Specifically, parents who received additional neuroscience information in the video manipulation (neuroscience-enhanced video) did not change their rated interest in learning new parenting strategies from before to after, whereas those in the control condition (standard video) decreased slightly from before to after. Furthermore, at the 1-month follow-up, there were no group differences. It was expected that ratings of acceptability would increase in both conditions, with greater increases in the neuroscience-enhanced video condition. It is possible that parents across both conditions found the video manipulations uncompelling given that no specific parenting intervention or resource was discussed in the video presentations—both videos discussed parent training generally. In addition, given our sample's skew toward higher educational attainment, it could be that the information presented in the standard video condition was too basic to be of interest, whereas the neuroscience-enhanced video content appealed more to this demographic. It is possible that the pattern of results would differ in a more educationally diverse sample. Despite these unexpected results, this study provides preliminary evidence that the SANE [30,31] can be extended to engage parents—at least initially—in seeking evidence-based parenting resources or education. Interestingly, the only factor of the PRAM that differed between groups was the "Interest in Learning Parenting Strategies" factor and not the 2 factors that included items alluding to specific *media formats* (ie, books, web-based courses, websites, and local resources). Thus, the SANE effect may enhance interest in general parenting education by increasing beliefs that parents can benefit from parenting education or resources but not with respect to specific media formats. Although additional research is needed to test models of parent engagement with and without neuroscience information, findings suggest that including information about the child brain and the effects of parent training on child brain development may be effective in early-stage parent engagement.

With respect to behavioral outcomes, there were no significant differences in outcomes by condition. However, for all 3 variables (ie, mouse clicks, time spent on resource page, and requests for information), the neuroscience-enhanced video had nonsignificantly higher levels of engagement. It is possible that the effects of neuroscience information on parental intent to engage are small, such that this sample size was not large enough to detect a significant difference. In addition, it is possible that the effects of neuroscience information are more related to perceptions of acceptability than to behavioral outcomes indexing intent to engage. All 3 behavioral outcomes were theorized to capture parental *intent to engage*. However, of the 3, only requesting additional resources at baseline was positively associated with prospective use of parenting resources at follow-up. Thus, our behavioral measures may actually reflect other processes, such as general interest or arousal during the survey. It is also possible that behavioral outcomes might have differed at other levels of engagement (eg, actual enrollment and quality of engagement with parent resources). Researchers have highlighted the importance of assessing the effects of engagement techniques at multiple levels of engagement [20,67]. Future work should test the SANE effect on the rates of actual enrollment in a parent skills training program.

Limitations, Strengths, and Future Directions

It bears noting that the manipulation used was weak, consisting of 37 seconds of additional video content pertaining to basic neuroscience. Although this study was a “proof-of-concept” investigation, future work may achieve greater external validity and larger effects by increasing the dose of the SANE effect (ie, infusing neuroscience information throughout the engagement process). In addition, future work could assess whether the addition of neuroscience explanations to parenting education content enhances outcomes in either engagement or child behavioral improvements. Given the dearth of previous research on this topic, it is difficult to estimate this study’s power to detect true effects. A larger sample size may be needed for a fully powered study.

Following the video manipulation, it is possible that participants found the resources presented to be uncompelling and, thus, general levels of behavioral engagement might have been too low to detect differences across conditions. In this study, we were unable to discern which type of resource parents were most likely to engage with while on the resource page (ie, books, web-based programs, websites, and local resources). Future research could examine which types of resources parents are most likely to behaviorally engage with among a menu of parent resource or training options using methods such as eye tracking and advanced mouse tracking.

Emerging evidence has yielded some support for other theory-driven methods of engagement [28,29], including strategies based on the Health Belief Model [68], which emphasizes attitudes and beliefs about health-promoting behaviors, and the theory of planned behavior and reasoned action [64], which links beliefs and attitudes to perceived social pressure and behavioral capacity to perform an action. The manipulation used in this study—based on the SANE—shared an overlap with the Health Belief Model. Future studies could directly compare engagement strategies based on different theoretical models. In addition, the survey collection methodology may have excluded particularly vulnerable groups of caregivers (eg, single parents caring for multiple young children, those unable to complete a web-based survey at home, or those without access to a computer). Finally, this was a predominantly White, high–socioeconomic status, community sample; SANE effects may differ by race or ethnicity or by socioeconomic status. In addition, SANE effects may differ based on the severity of parent problems, child problems, or parent-child interaction problems. However, with this sample, we were able to examine intent to engage in non–treatment-seeking parents. Most initial parent engagement research focuses on treatment-seeking populations, and influences are examined post hoc instead of a priori. This design allowed for the inclusion of parents across a broad range of behavioral intents to engage with parenting resources.

With respect to future directions, it will be important to test the SANE effect, in addition to the psychometric properties and measure invariance of the PRAM, in more nonparents and non–primary caregivers; caregivers who are treatment-seeking; populations of children with mental or behavioral health diagnoses (ie, clinical samples); and various racial or ethnic, cultural, linguistic, and socioeconomic groups. The effect of presenting neuroscience information related to child development may vary across cultures and across parents with different levels of engagement with mental health care. Indeed, the degree to which these findings may be generalized to other populations—for example, to non-English speakers—is unclear. This study’s lack of linguistic and other cultural diversity is a limitation. Future research should also elaborate and expand on the PRAM. Importantly, the PRAM could be used in research on additional stages of engagement beyond intent to engage (eg, actual enrollment, attrition, and implementation of parenting strategies learned). Future work should also examine the associations between PRAM factors and other constructs, such as parent stress or family empowerment [69]. In addition, the PRAM could be modified for use with different groups (eg, treatment-seeking groups, specific diagnostic groups, and parents with records of child maltreatment) or different prevention contexts (eg, web-based parent interventions and group parenting programs). Finally, this study broadly assessed engagement with parenting education resources; future work should examine the specific effects of engagement interventions on the acceptability of certain *types* or *formats* of resources provided. For example, it is unknown whether there are different factors that are associated with parental engagement in evidence-based resources versus other types of parenting resources (eg, a parenting community on social media) or in web-based training programs versus self-help books.

Conclusions

This pilot study represents a novel merging of 2 literatures: the SANE and parent engagement in education or training. Extant research on the SANE effect was extended by testing this effect on parents. Moreover, a novel method of parent engagement was tested, with preliminary evidence suggesting that the presentation of parenting education and resources may be more compelling in the short term with the inclusion of simple child brain neuroscience information. The findings have implications for public behavioral health efforts that target parents and may advance the state of parenting prevention science. Researchers should continue to strive toward a better understanding of the factors that drive parental engagement, developing and testing novel methods to enhance engagement and engaging caregivers as active stakeholders in this process. This study is one of a handful of studies to experimentally examine initial engagement; it is possible that a combination of variegated strategies, or simple behavioral "nudges" (eg, inclusion of neuroscience information, style and wording of advertisements, and other yet unidentified enhancements), will ultimately prove instrumental in increasing parent engagement in parent education and training. To the best of our knowledge, this study also represents the first psychometrically validated measure to assess initial parent engagement.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Parenting Resources Acceptability Measure.
[DOCX File , 15 KB - pediatrics_v5i3e37449_app1.docx]

Multimedia Appendix 2
Intervention videos, resource page, and prospective engagement by resource type.
[DOC File , 150 KB - pediatrics_v5i3e37449_app2.doc]

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Abbreviations

EFA: exploratory factor analysis
PEEBS: Parent Engagement in Evidence-Based Services
PLOC: Parental Locus of Control
PRAM: Parenting Resources Acceptability Measure
PSOC: Parenting Sense of Competence
RM: repeated measure
SANE: Seductive Allure of Neuroscience Explanations
SDQ: Strengths and Difficulties Questionnaire

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Original Paper

Experiences, Motivations, and Perceived Impact of Participation in 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 (CCNs) often require considerable support to ensure the well-being of their families. Social media present an opportunity to better support caregivers through computer-mediated communication for social support. Peer-to-peer (P2P) support groups are a way in which caregivers are accessing needed support; however, the experiences of caregivers who use these groups and the perceived impact that participation has on caregivers of children and youth with CCNs are not known.

Objective: This study aimed to explore the experiences of caregivers of children and youth with CCNs who use a Facebook-based P2P support group to communicate, understand their motivations to use the group, and investigate its perceived impact on knowledge of programs and services and sense of community belonging among caregivers.

Methods: A qualitative descriptive design was used to explore the experiences and perceived impact of a Facebook-based (Meta Platforms) P2P support group for caregivers of children and youth with CCNs in New Brunswick, Canada. The group was launched on the web in October 2020, during the COVID-19 pandemic, and resulted in 108 caregivers joining the group. A web-based survey was distributed, and semistructured interviews were conducted in February 2021 with a subsample of members. Thematic analysis was used to identify and report patterns related to caregivers' experiences and perceived impacts of participation.

Results: A subsample of members in the Facebook group completed the web-based survey (39/108, 36.1%) and interviews (14/108, 12.9%). A total of 5 themes emerged from the interviews: safe space, informational support and direction, web-based connection with peers, impact on knowledge of programs and services, and degree of community belonging. Participants reported joining the group to obtain geography-specific information support and connect with peers. Many participants reported an improvement in their knowledge of programs and services and felt connected to the community; however, the short observation period and diversity among the caregiver population were cited as barriers to community belonging.

Conclusions: Social media present an important opportunity to facilitate the exchange of support between patients and caregivers in an accessible and curated environment. Findings from this study suggest that involvement in web-based, geography-specific P2P support groups can influence perceived knowledge of services and resources and sense of community belonging among caregivers of children and youth with CCNs. Furthermore, this study provides insight into the experiences and motivations of caregivers of children and youth with CCNs who participate in a private social media environment.

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KEYWORDS

caregiver experiences; peer-to-peer support; social support; social media; children with complex care needs; Facebook group

Introduction

Overview

Despite representing only 15% to 18% of the childhood population, children and youth with complex care needs (CCNs; aged 0-25 years) account for a substantial portion of health care costs and resource use in Canada [1]. Although pressure on the resources needed to treat these conditions is challenging the sustainability and effectiveness of Canadian health care systems, it also affects the well-being of children and youth with CCNs and their caregivers. Caregivers of children and youth with CCNs (eg, parents, guardians, and extended family members) face numerous challenges and barriers [2]. Obstacles faced by caregivers of children and youth with CCNs include the following: managing care from multiple providers and services, lack of information and access to resources, and emotional challenges [3,4]. These challenges have been exacerbated by the COVID-19 pandemic, leading to increased caregiver stress and loneliness [5]. For example, caregivers of children and youth with CCNs have experienced reduced access to and delays in health and social care, because of the pandemic [6], and increased stress owing to their child's immunocompromised status [7]. Web-based peer-to-peer (P2P) support groups through social media are a way in which caregivers of children and youth with CCNs are accessing needed support [8]. However, the experiences of caregivers who use these groups and the perceived impact that participation has on caregivers of children and youth with CCNs are not known. This study aimed to explore the experiences of caregivers of children and youth with CCNs who use a geography-specific Facebook-based (Meta Platforms) P2P support group and investigate its perceived impact on knowledge of programs and services and sense of community belonging.

Background

Caregivers of children and youth with CCNs often require considerable support to ensure the well-being of their families. Additional pressures on these caregivers can result in significant stress and isolation, particularly when attempting to navigate the health care system [3]. Social media websites and applications offer an opportunity to better support caregivers through computer-mediated communication for social support [9]; specifically, social media–based P2P support. Web-based support groups provide an environment for the exchange of informational, emotional, and instrumental support [9-11]; however, caregivers of children and youth with CCNs report primarily using these groups as a source of informational support [12]. Despite the prevalence of social media platforms available to users, Facebook, YouTube, and Twitter remain among the most popular websites for health-related P2P support [13].

Web-based P2P support offers an accessible and inexpensive source of informational knowledge and emotional support for caregivers [14], such as parents of children and youth with CCNs [15]. Caregivers of children and youth with CCNs who participate in web-based P2P support can acquire specific advice for their circumstances [9] and often consider the experience to be more relevant to their needs than the information provided by their professional care providers [16]. In some cases, the information exchanged within these groups goes beyond the knowledge of care providers, particularly for conditions that may be rare, not well understood, or beyond the scope of physical health care (eg, how to dress an infant with a feed tube) [17]. Web-based P2P support groups have been reported to supplement information received from a care provider [18-20] and help patients prepare for medical appointments [21]. In a 2014 survey involving parents of children with neurofibromatosis type 1, parents indicated that they were very likely to use internet P2P groups to seek research studies (87%), talk to parents with similar diagnoses (67%), and obtain answers to questions (50%) [22].

Although these communities are not meant to replace professional health care [23], they provide several important benefits to caregivers and their families. P2P support groups can promote access to information and create a sense of community belonging in patients and caregivers [24,25]. Web-based support can increase feelings of control, reduce isolation, and lower depression and anxiety in caregivers of children and youth with CCNs [26]. Health-related communication is often associated with risks including the privacy and reliability of information [27,28] and members' ability to appraise relevant information [29]. However, observations of P2P support groups suggest that misinformation is often self-corrected over time by members who validate or correct the posted information [30]. Moderators have also been identified to play an important role in decreasing the spread of misinformation in groups [31].

One of the strongest motivations to engage in health-related P2P support is the desire to connect with individuals in similar situations [27]. Dumaij and Tijssen [32] reported four characteristics that play a role in an individual's decision to use a particular website to connect with peers: (1) whether it is a closed-access website (ie, private), (2) nature of topics discussed, (3) ease of use, and (4) type of users and structure of discussions. Engagement with these groups can differ depending on various factors, including their target population. For example, parents of children with CCNs report using geography-specific groups for locally based informational or navigational support and condition-specific groups (eg, autism) for support specific to their child's symptoms or diagnosis [8].

Belonging to a social group that is valued by contributing members can lead to a shared social identity [33]. This sense of social connectedness is an important consideration in P2P support groups that target caregivers of children and youth with CCNs. A poor sense of belonging has been associated with low caregiver well-being, which can affect the health outcomes of their child or children [34]. Lack of social belonging, or social isolation, can be defined as “a state in which the individual lacks a sense of belonging socially, lacks engagement with others, and has a minimal number of social contacts” [35,36]. Web-based platforms used for P2P support can promote a sense of social inclusion and belonging among informal caregivers [35], such as older adults [37,38]. The impact of these groups on caregivers of children and youth with CCNs specifically has not been previously explored; however, face-to-face parent support groups have been shown to increase the sense of community belonging among these caregivers [39].

Health literacy, broadly known as the ability to read and understand health information [40], is associated with knowledge of health-related services and has been identified as a barrier to navigating the health care system [41]. Low health literacy presents additional barriers when interacting with professional care providers, who often assume a higher level of understanding than an individual might possess [42]; this can be problematic for caregivers of children and youth with CCNs who often manage the care of their child [43]. Web-based P2P support offers an opportunity for individuals to engage with health information in a variety of ways, which can promote access to information [24] and improve knowledge of health-related resources [44,45]. Associations between web-based P2P support and health-related knowledge have been observed in breastfeeding mothers of preterm infants [20] and caregivers of persons with type II diabetes [46]; however, it has not been previously explored among caregivers of children and youth with CCNs. Specifically, the extent to which participation in web-based P2P support, through social media, affects health-related knowledge within this population is unclear.

Objectives and Research Questions

The primary objective of this study was to explore the experiences, motivations, and perceived impact of involvement in a geography-specific P2P support group on Facebook and the motivations to use these groups among caregivers of children and youth with CCNs. More specifically, this study aimed to investigate the impact of participation in a group based in New Brunswick, Canada, which targets caregivers of children and youth with CCNs in New Brunswick, on perceived knowledge of resources and programs and sense of community belonging. The following research questions formed the basis for this study:

1. What are the experiences of caregivers of children and youth with CCNs who use the Facebook group to communicate with other caregivers?

2. Why do caregivers of children and youth with CCNs use the Facebook-based P2P support group?

3. In what ways does participating in the Facebook group affect the perceived knowledge of services or resources among caregivers of children and youth with CCNs in New Brunswick?

4. In what ways does participating in the Facebook group affect the perceived sense of community belonging among caregivers of children and youth with CCNs in New Brunswick?

Methods

Design and Sample

A qualitative descriptive design was used to explore the experiences and perceived impact of a Facebook-based P2P support group for caregivers of children and youth with CCNs in New Brunswick. Qualitative description is a pragmatic qualitative approach that facilitates obtaining simple, straightforward answers to questions in applied health research [47], while offering a comprehensive summary of an event or experience in everyday language [48].

A Facebook group was launched in October 2020; the details of this group have been described in 2 other publications [12,49]. Briefly, a group was created on Facebook, specific to caregivers of children and youth with CCNs who live in New Brunswick, Canada. Prospective members were screened at the time they provided consent for the study. Content in the group (including posts and the membership list) is closed to current members; however, the title, description, and profiles of moderators are visible to the public. The group was designed in collaboration with the NaviCare/SoinsNavi’s Family and Patient Advisory Council (PFAC), which provided insight into the following variables: language, group description and title, moderators, recruitment strategy, research observation, and evaluation. The PFAC consists of 6 parents of children and youth with CCNs and 1 young adult who experienced CCNs as a child; this council advised the research team at each stage of the research process to ensure its relevance to the target population. Group content is available in English and French and is closed to members (ie, private). The group was moderated by a member of the PFAC and the NaviCare/SoinsNavi patient navigator; the navigator provided support in both English and French. A description of the use of the group by caregivers and the factors that influenced group activity (eg, posts and interactions) have been published elsewhere [12].

Caregivers of children and youth with CCNs were recruited through advertisements on other relevant Facebook groups (eg, New Brunswick–specific groups for parents), media releases to relevant community organizations (eg, NaviCare/SoinsNavi), and word of mouth. The group attracted a total of 108 caregivers over the 6 months of the study period and has been primarily used by members to find answers to inquiries related to their child’s care and for the exchange of informational support, such as navigational support [12].

Data Collection and Analysis

A web-based survey was distributed to members of the Facebook group in February 2021, which consisted of 19 questions related to their experience in the group. Items for the survey were developed for the purpose of this study and were pilot-tested among the PFAC and research team members for comprehension. The survey consisted of items in four categories: (1) sociodemographic information (including information about their child or youth with CCNs, such as age, condition or diagnoses, etc), (2) social media use (including how often they visit Facebook, membership with other health-related Facebook P2P support groups, etc), (3) use of the Facebook support group (including length of membership, visibility of content from the group on participants' time line, frequency of interactions in the group, motivation for joining the group, etc), and (4) perceived impact of group membership on knowledge of services and resources and sense of community belonging (eg, "Have you learned about any services or resources for children or youth with health care needs in New Brunswick as a result of your membership in [the Facebook group]?"). The lead author (KJK) conducted the interviews using the Zoom videoconferencing software in February 2021 and March 2021; interviews lasted between 25 and 40 minutes. A pilot interview was conducted with a patient navigator from NaviCare/SoinsNavi in February 2021. Interviews were recorded using Zoom and transcribed verbatim manually by the lead author.

Members of the P2P support group were invited to participate in the survey through a direct link that was pinned to the top of the group. The bilingual survey was developed using Qualtrics Experience Management (Qualtrics International Inc). Semistructured interviews were conducted with a subsample of members in the group in February 2021 and March 2021 using Zoom videoconferencing software. Similarly, interview participants were recruited from existing members of the Facebook group and from members who indicated in the survey that they would be interested in participating in a follow-up interview. Interview participants were required to have been a member of the group for a minimum of 3 months; this was confirmed with participants by a direct message before scheduling an interview. All interview participants received a CAD $25 (US $19.32) Amazon gift card as compensation. Participants who completed the survey were entered into a draw to receive a $50 (US $38.63) Amazon gift card.

Open-ended survey questions and interview transcripts were analyzed using thematic analysis [50], as a means of identifying, analyzing, and reporting patterns across the data set and organizing and describing the data in rich detail [51]. 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 [51] and grouped into broad themes using an iterative process to ensure that the original contexts of the quotes were preserved. Microsoft Excel was used to analyze both the quantitative and qualitative data.

Ethics Approval

This study was approved by the University of New Brunswick's Research Ethics Board (040-2019).

Results

Web-Based Survey: Demographic Information

A total of 36.1% (39/108) of the individuals who were members of the Facebook group completed the web-based survey. Most survey participants were women (29/39, 74%), and the remaining participants (10/39, 26%) chose not to answer. All the participants (39/39, 100%) were aged >25 years, with 41% (16/39) reporting their age between 25 and 44 years. Only 3% (1/39) of the participants was aged >55 years.

Most survey participants (21/39, 54%) reported caring for 1 child or youth with CCNs, 23% (9/39) of the participants reported caring for 2 children, and the remaining 23% (9/39) of the participants did not provide a response. Most participants reported caring for children aged 6 to 12 years (13/39, 33%), followed by children aged 4 to 5 years (11/39, 28%). Participants reported caring for 4 young children aged between 2 and 3 years and 4 youths aged between 13 and 18 years (Table 1).

Table 1. Age (in years) of children or youth under the care of survey participants (N=33).

Demographic	Children or youth, n (%)
0-1	1 (3)
2-3	4 (12)
4-5	11 (33)
6-12	13 (39)
13-18	4 (12)

Participants were able to select multiple responses if they were caring for >1 child or youth.

Conditions identified by caregivers were grouped according to 6 categories: mental health conditions (8/39, 21%), developmental conditions (16/39, 41%), neurological and genetic conditions (9/39, 23%), movement and motor conditions (8/39, 21%), cancer (1/39, 3%), and undiagnosed CCNs (7/39, 18%). The most common type of mental health condition included anxiety (3/39, 8%) and attention-deficit/hyperactivity disorder (2/39, 5%). Autism (9/39, 23%) was the most commonly reported developmental condition, followed by global developmental delay (4/39, 10%). Neurological and genetic conditions consisted of 9 different very rare conditions; these are not reported to protect the anonymity of participants in the study. Cerebral palsy (7/39, 18%) was the most common movement condition. The total number of conditions reported exceeded the number of survey participants (n=39), as approximately one-third of participants (12/39, 31%) reported caring for a child with multiple diagnosed conditions.

Web-Based Survey: Motivation to Participate and Perceived Impact of Participation

Most survey participants reported becoming aware of the group through a friend or acquaintance (11/39, 28%) or through NaviCare/SoinsNavi (7/39, 18%). A total of 10% (4/39) of the participants reported learning about the group through another support group on the platform. When asked about their motivations for joining the Facebook group, the survey participants reported the topic to be relevant to their needs (23/39, 59%), the need for information or support (16/39, 41%), and the desire to make connections with others (13/39, 33%), among other reasons (Table 2). *Other* reasons included the foresight to use the group as a resource for future support needs.

Table 2. Indicated motivation or motivations for joining the Facebook group (n=76).[a]

Reason for joining the group	Participants, n (%)
The topic is relevant to me	23 (30)
I was or am in need of information or support	16 (21)
I was or am looking to make connections with others	13 (17)
The content appeared to be trustworthy	10 (13)
It is an active group	10 (13)
A mutual friend invited me	3 (4)
I heard about the group offline	1 (1)

[a]The total number of motivating factors (n=76) exceeds total survey participants (n=34) as participants were able to choose multiple responses.

Approximately one-third of respondents (14/39, 36%) indicated that they had learned about new services or resources relevant to their child's or children's care from participation in the Facebook group. Another 31% (12/39) of the participants indicated that they did not learn anything new. Totally, 10% (4/39) of the participants responded that they did not know whether they had learned anything new. When asked about the impact of the group on caregivers' role in caring for their child or children using an open-ended question, 5% (2/39) of the participants stated that the group improved their sense of community belonging. None of the participants in the surveys or interviews (0/39, 0%) reported that the group negatively affected their knowledge of services or resources or sense of community belonging.

Thematic Analysis of Interviews

Description of Themes

A total of 12.9% (14/108) of the participants who were members of the Facebook group completed the interviews; all interview participants also completed the web-based survey. A total of five themes emerged from the interviews that related to caregivers' experiences in the Facebook group and the perceived impact that being a member had on their knowledge of services and resources and sense of community belonging. The themes were as follows: (1) safe space, (2) informational support and direction, (3) virtually connect with peers, (4) impact on knowledge of programs and services, and (5) degree of community belonging. These themes are described in further detail in the following section.

Theme 1: Safe Space

Participants described their experience in the Facebook group as a positive environment for the exchange of P2P support. Many participants characterized the group as a safe space that was inclusive of all caregivers, regardless of conditions or diagnoses:

> *I feel like this space is inclusive to everyone at different levels, in their diagnosis and in their journey.* [Participant 10; March 4, 2021]

Compared with other Facebook support groups, this group was considered to be safe by some members owing to its specificity to caregivers of children and youth with CCNs and the culture in New Brunswick:

> *I find sometimes with like, for instance, my [condition specific] group and things like that it's people all over the world. So, you know, I understand that sometimes things aren't translated the same? [laughs] Or the intentions are not the same, or sometimes, you know, people can comment on something and it meant to be good, but you read it, you're like, 'oh, okay, that was saucy, or that was like,' you know what I mean? But I find this Facebook group, I don't see any of that, we're all kind of, at the same, you know what I mean? Like, ...it's in New Brunswick. It's here, I could bump into you at Costco or...I could meet them for coffee somewhere. Their kids could meet ours you know what I mean?* [Participant 14; March 18, 2021]

When initially joining the group, some members reported feeling inadequate or doubtful about their place within the group, which they referred to as the imposter syndrome. However, these participants explained that this quickly dissipated after spending time in the group:

> *[My friend] messaged me [that] this group actually just started, you should join it [laughs]. So, I did and then I immediately got, I think it's called, is it imposter syndrome or something? Cause I just, like to me cancer is no big deal anymore and all these children that are, like, to me, are 'real special needs,' which I know is not, like, the right way to look at it, but it's just the way that I, the brain works. So I definitely feel, not intimidated, not the right word, but I just felt like, oh like, we don't belong in this group, right away. But I'm over that now [laughs].* [Participant 07; February 23, 2022]

Theme 2: Informational Support and Direction

Many participants described significant gaps in their support needs, particularly related to informational needs and navigational support regarding relevant programs, services, and resources. In some cases, participants reported being provided with an overwhelming amount of information upon recognition of a condition or diagnosis and left to determine the next course of action:

> *I think the thing is that once you get your child's diagnosis, for me, I felt like I was given pamphlets, I was given appointments, like you're being pulled, like your life just was just turned upside down. And you're given all this information and sometimes you just don't know what to do with it. It slips through the cracks, you're grieving, you're processing, you're trying to figure out all of a sudden, you know, you thought your life was going one way with a child and all of a sudden, it's like, whoa, now it's brand new...So you're trying to figure it out. And it took a lot of my husband and I having to figure it out calling and asking questions and making sure that we weren't missing something, and it's exhausting...We all have children with disabilities that we are trying to get the best care for and offer them the best quality of life. And I feel like that the [NB] group is set up to support [us] in that.* [Participant 14; March 18, 2021]

Participants described the mental load associated with being a caregiver of a child or youth with CCNs and explained that the Facebook group has been an important informational resource to help ease some of the pressure:

> *So going to that Facebook page and then there's people coming to it with questions and right away someone says 'well I did this' 'I did that' and I think, wow, that's, that's, you know. Those are the hours and hours that I spent looking for information where now I can go and look and see someone's experience. That narrows my search into 'I'll try this first, if it works, great. If it doesn't, I can at least, you know.' Where I didn't even know where to start [laughs].* [Participant 11; March 4, 2021]

Specifically, the group was viewed as an important source of informational support, one that could provide a starting place and direction in the overwhelming amount of information provided to caregivers when their child or children experience a new diagnosis or crisis:

> *Just getting that advice from others parents is huge and it kind of helps you direct yourself. When it's very overwhelming, that kind of gives your brain a place to like, settle on, and then "OK how do we approach this" and then it usually spirals, you can get a lot more information.* [Participant 06; February 19, 2021]
>
> *Having the Facebook group is helpful, where it's like, 'Oh, I didn't realize that.' Maybe we were given the information at first, but we forgot about it, or misplaced it, or...you didn't think that that was applicable to you at that time and you were just so heavy in the grief.* [Participant 14; March 18, 2021]

Many members described a need for informational support owing to an expressed lack of control that is associated with caring for a child or youth with CCNs. More specifically, seeking informational support was described to elicit a sense of empowerment:

> *There's a lot of lack of control when you have a kid with special needs. I'm a control freak, [my husband] will say that. So I feel some sense of control and some power in her diagnosis if I have more knowledge of it. So if I know this is what we need to do or this treatment might help or whatever, whatever, it makes you feel like you have a little power in a very powerless situation. [The group] is a nice avenue to have if I have questions.* [Participant 04; February 18, 2021]

Participants described feeling reassured by their membership in the group, knowing that it was a place that they could turn to for support if and when needed:

> *I find that even just having the Facebook group, just having it there is helpful. Just knowing that you can comment or post if you need to post. Like, just having it there.* [Participant 02; February 17, 2021]

Theme 3: Virtually Connect With Peers

Participants described a desire for a group specific to caregivers of children and youth with CCNs in New Brunswick before the implementation of the study group. A participant explained having attempted to start a support group in the past, which was not successful:

> *I have been searching for this type of support for the last 6 years, even to the point of trying to start my own group, which was a super flop. I very much appreciate confidentiality of medical situations, but I think that was the biggest barrier. The therapists and doctors that everyone saw were unable to connect people together and there is no place to put up a poster or advertise really just to look for other real people, not just professionals who help, who are going through similar circumstances. I love the fact that it is a small, provincial group. I never would have guessed there were so many people here! I really felt like we were the only ones for a long time. The only people who even knew someone who had a complex need that is. And that is real lonely.* [Participant 03; February 17, 2021]

Many participants were motivated to join the Facebook support group to engage in communication with individuals who were experiencing similar situations and understood their challenges:

> *You know, something could happen with a child that morning and they get through it with the doctor, blah, blah, blah, and then they want to talk about it...And you can't talk to anyone but your own family members, and friends, but...they haven't lived your life. I think with this group you're able to say, I need some help. And people are doing that, so that's good.* [Participant 11; March 4, 2021]

More specifically, the solidarity associated with membership in a group of peers facing similar challenges in the same province was identified as an important reason why some participants used the group:

> *Which is helpful, because you have your support of your family and friends and that's always valuable, but the support that you get from people who are going through a similar journey is just a different, you just feel heard, and you feel valued, and you feel understood, even if it's online, it's very, very helpful. I don't think anything could replace that, especially when you have children that have any type of rare syndrome, you might not meet anyone that has that syndrome. So it's been a benefit...just having the [NB Facebook] group community, a huge support.* [Participant 06; February 19, 2021]
>
> *When my daughter first got her chair, I wish we could have talked with other people too. I think there is a lot to gain from talking with people who are living the experience and not just professionals who support you. Not just about the facts of wheelchair life, but just knowing that there are other people going through the same challenges and success as you and connecting with them.* [Participant 03; February 17, 2021]

Some participants pointed to the web-based aspect of the support group as an important factor for their use. The availability and accessibility of the group were perceived as particularly important facets by caregivers, many of whom felt overwhelmed by the daily pressures associated with raising a child or youth with CCNs:

> *As a caregiver, it's completely different. You're burnt out, you're tired at the end of the day, you don't want to go to a support group. You...just want to sit if you can [laughs]. We're talking parents that are...doing heavy lifting still with their four or five teenage kids, you're talking parents that are doing diaper changes...anything that's in a routine for kids is more complex for us.* [Participant 14; March 18, 2021]

Theme 4: Impact on Knowledge of Programs and Services

Participants described engaging in web-based research of resources and information, which often occurred during the early stages of a condition or diagnosis. Participants reported feeling that they had a good understanding of the available programs and resources for their child or children. However, most participants speculated that there may be additional resources and programs beyond their knowledge, owing, in part, to their difficulties in navigating among services:

> *I feel like I know about a lot of them, but I also don't know about a lot of them. Like, even through the Facebook group and...through other doctors or people, I'm still learning about things. Or maybe something that's available in another province that's just starting in New Brunswick or should be available in New Brunswick too and like, things like that.* [Participant 03; February 17, 2021]

When asked about their perceived impact of membership in the group on their knowledge of programs and resources, many participants reported feeling that it had improved their awareness of the available support:

> *It's only been five months [in the group], but in our case we've already searched for resources. We managed to find some but I imagine that parents who have just learned that their child is sick with disabilities, it will help them.* [Participant 1; February 17, 2021; French translation]

Participants described learning about programs and services by reading posts made by other members and directly making inquiries to the group. Some participants reported learning about programs and services that may be relevant to their child's needs, but were located in other parts of the province. However, learning about programs or services that may not be applicable to their specific geographic location was described as providing an opportunity to ask if anyone knew about similar services in their region:

> *I definitely learned about more. Not all of them in my area, but just knowing that other parts of the province makes me feel like, I could still maybe ask of some. Um, yeah, I've definitely been more aware of different programs.* [Participant 03; February 17, 2021]

Some participants reported no increase in their knowledge of available programs and services through participation in the group, but instead reported perceiving the group as a place where they could go to if they had specific questions related to programs or services:

> *I haven't hit a groove yet that this has improved it, or I've felt supported, but I also wouldn't say that I'm not going to follow this page anymore cause I'm not interested. So I would say that I'm middle of the road on that.* [Participant 08; February 23, 2021]

In some cases, these individuals felt that they did not know what support they needed and lacked the language to ask for informational support about the available services and programs. In other words, participants described feeling uncertain about the types of services or programs that may exist or be beneficial to them in the care of their child or children:

> *We haven't found any resources. And to say that, I couldn't even tell you an example of what we're looking for because I don't, I'm a first-time cancer mom, so I actually don't know what resources I am seeking out.* [Participant 07; February 23, 2021]

Theme 5: Degree of Community Belonging

The extent to which caregivers of children and youth with CCNs felt that they belonged to a community within the P2P support group varied. Despite the short length of time since the inception of the Facebook group, most participants reported feeling a sense of community belonging within the group:

> *It's definitely just helped me to see that there's a lot of families in New Brunswick, a lot more than you think...are in the same-ish boat that you are in. I thrive off of community now that we're in this situation. I*

> *just, I love to just talk to other parents who are feeling the same thing, it reassures me, it makes me think that I'm not alone in this crazy ordeal. Um, so to me, I just like to be a part of this group.* [Participant 07; February 23, 2021]

Some members attributed this reported sense of community belonging to the group's membership exclusivity. More specifically, the group was private and only permitted caregivers of children and youth with CCNs who reside in New Brunswick:

> *It's made me feel more connected to our province, knowing that there are other parents out there going through, you know, similar experiences. 'Cause a lot of the networks that I'm a part of are either like, Canada wide, or you know, different countries, so it's nice to be in a group that's just New Brunswickers.* [Participant 10; March 4, 2021]

More specifically, despite differences in the ages and conditions of their children, the shared experiences among caregivers were reported to facilitate a sense of community belonging within the group:

> *Even, even if you don't post a lot, ...it just feels like you're a part of...something similar, even if it's not even the same thing. It's similar enough that people understand the medical stays, the hospital stays, they understand the day to day, how much extra you do in a day. So, I think that, just that, initially creates an initial sense of community support.* [Participant 06; February 19, 2021]

A total of 29% (4/14) of the participants reported that they did not feel a sense of community belonging within the group. These individuals attributed this lack of community belonging to the short time since the implementation of the group. Some members described the same reason for experiencing few social ties with other members within the group. However, these individuals reported that they may benefit from a sense of community belonging over time:

> *I think that the relationship is still very new and very fresh...I think that it's something that will, that has benefitted me and will continue to benefit me and my family, so yeah.* [Participant 05; February 19, 2021]

A participant, who reported feeling disconnected from the web-based group, explained that they did not identify with other members, many of whom are caring for young children:

> *I'd be more interested if something came across my Facebook page from somebody who might be 55 with a 30-year-old and what they're doing for care and support...I haven't seen a lot of that.* [Participant 08; February 23, 2021]

Discussion

Principal Findings

Consistent with previous studies, most participants reported using the group as an important source of informational support in the care of their child or children [52]. Findings indicate that participants felt reassured by their membership in the group, describing it as a resource that could help ease pressures, or *mental load* associated with being a caregiver of a child or youth with CCNs. The emphasis on informational support rather than emotional support, which was reported to be more predominant in condition-specific Facebook groups, resulted in caregivers reporting the group to be a positive space, rather than a reminder of emotional difficulties beyond their control. Other Facebook groups were frequently described as *triggering* negative emotions, whereas the geographical specificity and inclusive nature of this group was perceived by caregivers to be more conducive to the exchange of informational and navigational support.

Most participants in the web-based survey were women and aged 25 to 44 years, which was consistent with previous investigations, which found that women are more likely to engage in P2P support on social media for health-related concerns [53]. Although there was a wide variety of ages and conditions experienced by caregivers, participants felt that the inclusive nature of the group contributed to feeling as if it is a *safe space* for the exchange of P2P support. Findings related to the reported social media use by survey participants, including membership in other Facebook support groups and use of the caregiver support group, have been reported elsewhere [12].

Participants in this study described a lack of control associated with being a caregiver of a child or youth with a CCN. This lack of control was described as a particularly important motivation for seeking Facebook-based P2P support. These findings support previous investigations suggesting an association between participation in P2P support groups and knowledge of health-related resources among caregivers of children with disabilities [54]. The availability and accessibility of the Facebook group was also identified as a reason why participants used the group; many participants described feeling overwhelmed in their role as a caregiver, with very less time.

As the group was closed to caregivers who reside in New Brunswick, there was exclusivity regarding membership that led to some participants valuing a sense of shared cultural norms. Using Facebook support groups to find like-minded people who share similar health practices has been previously observed. For example, Zhang et al [55] noted that members of a Chinese depression support group began using the group to connect with others who shared Chinese health beliefs and practices, which differ from traditional medical practices. The geographical specificity of the group was identified by many participants in this study as a motivating reason for joining, as it offered a notably different experience than condition-specific support groups on the platform with international members.

Approximately all the participants in this study reported difficulties in navigating services and resources related to their child's care owing to lack of knowledge of relevant services and programs; this was described as a reason for joining the Facebook group. Some interview participants disclosed that they had directly asked for informational support in the group, which, in turn, increased their knowledge of programs or other resources. Others learned about locally available support by passively reading comments or posts by other members. Considerable number of studies has demonstrated an association between offline support groups and increased knowledge among caregivers [56]. The impact of web-based groups is less clear; however, a recent systematic review of the impact of web-based P2P support for caregivers of stroke survivors [57] supports the finding that participation is associated with increased caregiver knowledge.

Despite the short time since the group's inception, most participants reported feeling a sense of community belonging within the group. The immediate sense of community belonging reported by some members was attributed to the group's exclusivity, specifically to caregivers of children and youth with CCNs in New Brunswick, despite the diversity in reported ages and conditions. Some participants did not feel a sense of community belonging with the group cited, in part, owing to the short time since the group's creation. One of these individuals was caring for an older youth and did not identify with other members, most of whom were raising children aged <12 years. This finding corroborates previous observations that a sense of community in web-based groups is facilitated by more homogenous membership [58].

The finding that social belonging was facilitated by group membership may have been owing to the exclusivity of the group. Caregivers reported feeling a sense of solidarity with other members, knowing that they faced similar challenges. The use of web-based groups for coping resources have been attributed to a lower risk of threat to one's personal social ties compared with the mobilization of offline resources [59]. In other words, although participants in the Facebook group shared many of the same characteristics, such as geographic location, engagement with the group for social support could be obtained even without social interaction (eg, passive interaction). Moreover, the closed (ie, private) nature of the group may have resulted in greater relational intimacy between members, which led to a shared sense of community than if the group had been public [60]. However, this perceived relational intimacy may pose a risk to web-based communities of this nature, whereby reduced nonverbal cues, facilitated by the computer-mediated environment, may result in misplaced credibility or *hyperpersonal* interaction [61]. Specifically, the social information processing theory posits that individuals enter into a loop of intense interpersonal interactions that can lead to the perception that others may be more trustworthy or credible than in actual fact [62]. However, more studies are needed to better understand the effects of hyperpersonal interactions on perception of support providers [63].

Social comparison theory can be used to contextualize some of the findings of this study. Social comparison theory suggests that individuals compare their situations with those of similar others to make assessments about their own health and well-being [64]. Although the evaluation of this theory is limited in the study of web-based support groups [65], it may be applicable to understanding why caregivers may have experienced perceived benefits from participation in this study. Many caregivers reported the perceived benefits of participation, specifically on their knowledge of services and resources and sense of community. Social comparison theory suggests that individuals make lateral, upward, and downward comparisons with others within their social network. Lateral comparisons with similar others may have led to a sense of normalization and comradery between caregivers, thus affecting the perceived sense of community. Upward comparisons occur when individuals compare themselves with others who appear to have more experience or better coping skills; this can lead to inspiration to improve one's situation and learn from their experiences. In contrast, upward comparisons can result in feelings of frustration. Downward comparisons occur when individuals compare themselves with others who appear to be struggling, which can result in an altruistic desire to share one's knowledge and experiences. These social comparisons may explain why caregivers perceived benefits as a function of participation in the Facebook group.

Limitations

Limitations of this study include the small sample size of caregivers of children and youth with CCNs who participated in the Facebook group, particularly in the survey and interviews. The survey and interviews may have oversampled caregivers who are more involved in the care of their child or children. Items in the survey were not validated, and we did not evaluate the reliability of the questions owing to limited time and resources. Moreover, findings from the survey may have been affected by the response rate of 36.1% (39/108). None of the participants in this study identified as male, which would affect the generalizability of the present findings to male caregivers. Participants who participated in the survey and interviews were not independent samples; there was overlap between these 2 subsamples from the Facebook group participants. More specifically, 12 (86%) of the 14 participants who completed the survey also participated in the interview to elaborate on their experiences. It is possible that the explicit emphasis on research within the group (eg, requiring consent to join the group) may have influenced the sample of individuals who joined the group and their subsequent experiences. Individuals who joined the Facebook group were required to undergo screening to ensure that they identified as a caregiver of a child or youth with CCNs and resided in New Brunswick; however, this information was self-reported and could not be verified. Therefore, it is possible that some of the members in the group did not fit the target population of the study. However, all participants in the survey and interviews reported information on their role as caregivers of child or children or youth with CCNs. Finally, the study intervention and investigation were conducted during the COVID-19 pandemic, which has been identified to particularly affect caregivers of individuals with CCNs [5]. It is unclear to what extent the pandemic may have affected the behaviors of caregivers in this study and whether these individuals would have used the group to the same extent. Therefore, the pandemic may have affected the generalizability of these findings.

Future Studies

This study demonstrated that participation in a closed Facebook group can positively impact the sense of social belonging in a caregiving population that often experiences isolation and exclusion [58]. Moreover, some participants in this study reported learning about health-related and social services and resources that directly affected the care of their child. These findings suggest that Facebook groups, which are low-cost and relatively accessible, can be leveraged to fill the gaps in the support needs of patients and caregivers. However, more studies are needed to systematically determine both positive and negative impact of participation in these groups on these populations. A novel component of this study was the use of a patient navigator as a moderator; although a crowdsourcing effect was observed in this study between caregivers of children and youth with CCNs, the presence of a patient navigator likely may have provided additional information about relevant services or resources or influenced the nature of discussions within the group. Future studies could consider the role and impact of patient navigators and other health professionals on Facebook-based P2P support groups.

Many participants in this study were caregivers of young children with CCNs; future studies are needed to explore how caregivers at different stages of their caregiving journey experience and benefit from web-based P2P support groups. Previous study has suggested that caregivers of young children with CCNs look to caregivers with older children and youth with CCNs to see where their own children may end up [8]; however, findings from this study suggest that some caregivers view this longitudinal perspective as *triggering* and become overwhelmed. More studies are needed to understand this distinction between caregivers of children and youth with CCNs.

Although it is beyond the scope of this project, future studies may explore the impact that participation in web-based P2P support groups may have on offline relationships between caregivers of children and youth with CCNs. More specifically, future studies may consider that knowledge gained from these web-based P2P interactions can influence offline conversations, such as with care providers; this may provide further context into why caregivers use web-based support groups [66].

The findings that participation in the Facebook group was identified by some participants as positively affecting their sense of social belonging was significant, particularly given the short time between the group's inception and evaluation. Caregivers of children and youth with CCNs often report a sense of isolation and exclusion owing, in part, to significant caregiver burden and disease stigma [65,67]. Combined with high levels of stress and physical exhaustion, this population is at risk of mental health conditions such as anxiety and depression, thus posing an additional risk to the care of their vulnerable child [68,69]. This has become particularly salient during the COVID-19 pandemic, as a result of social distancing measures and fear associated with caring for an immunocompromised child [7]. Improving the sense of social belonging in caregivers of children and youth with CCNs is paramount to ensuring the well-being of both the caregiver and child or youth. This study has important implications for the integration of social media–based support groups into existing organizations and entities that provide health and social support to this population and other patient and caregiver cohorts living with CCNs.

Conclusions

Social media present an important opportunity to facilitate the exchange of support between patients and caregivers in an accessible and curated environment. Caregivers of children and youth with CCNs engage in web-based P2P support to connect with peers who possess invaluable knowledge gained through lived experiences and exchange support. This study found that caregivers used a geography-specific Facebook group to exchange informational and navigational support in what was perceived as a safe environment. Caregivers of children and youth with CCNs reported social connection with other members within the group, despite a short observation period. This study demonstrated that involvement in web-based support groups can influence perceived knowledge of services and resources and the sense of community belonging, thus helping to meet previously unmet support needs.

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Conflicts of Interest

None declared.

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Abbreviations

CCN: complex care need
P2P: peer-to-peer
PFAC: Family and Patient Advisory Council

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Original Paper

Positive Psychology Themes in Interviews of Children With Atopic Dermatitis: Qualitative Study

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Abstract

Background: Atopic dermatitis is a pruritic chronic condition associated with significant sleep disturbance, inattention, and sometimes behavioral problems. Enhancing resiliency in children with atopic dermatitis may promote coping strategies to improve quality of life. Positive psychology is one strategy that can be used to strengthen resiliency.

Objective: Our objective was to identify positive psychology concepts mentioned by children with atopic dermatitis and their parent to inform strategies to strengthen resiliency in children with atopic dermatitis.

Methods: A total of 20 patient-parent dyads were interviewed to share their experience with atopic dermatitis to help develop a novel psychologic intervention for atopic dermatitis. Patients were 8 to 17 years old and diagnosed with atopic dermatitis. Trained coders analyzed transcripts using a coding dictionary developed based on Seligman’s PERMA (positive emotion, engagement, relationships, meaning, and accomplishment) model of positive psychology. The frequency of unprompted mentions of PERMA themes and relevant quotations was captured. Transcripts were also separately coded for resiliency, which is the ultimate goal of PERMA.

Results: Positive psychology concepts were mentioned by 100% (20/20) of children and 95% (19/20) of parents. Engagement and relationships, both negative and positive aspects, were the most common unprompted PERMA themes mentioned by children (14/20, 70%) and parents (13/20, 65%). Emotion elicited the most negative comments from children (19/20, 95%) and parents (17/20, 85%). When analyzed for resiliency, 8 participants were identified with at least one resiliency code. On average, participants with a resiliency code mentioned PERMA concepts 9.1 (SD 4.7) times compared to those who mentioned none (mean 5.9, SD 4.6) (*P*=.14). When participants were stratified by disease severity, on average, more positive psychology concepts were mentioned by patients with mild atopic dermatitis (mean 13, SD 3.0) than those with moderate symptoms (mean 6.2, SD 4.9) or severe symptoms (mean 6.1, SD 4.0) (*P*=.03).

Conclusions: Among PERMA themes, engagement and relationships are the two most commonly mentioned categories for children with atopic dermatitis. Strategies targeting PERMA such as affirmations and positive reframing may improve psychosocial well-being and resiliency in pediatric atopic dermatitis. Future directions will look at incorporating “positive medicine” into atopic dermatitis treatment to not only relieve symptoms but also strengthen positive aspects of life.

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KEYWORDS

positive psychology; PERMA; positive emotion, engagement, relationships, meaning, and accomplishment; atopic dermatitis; pediatric; dermatology; children

Introduction

Background

Atopic dermatitis, also known as eczema, is a common pediatric chronic disease characterized by severe itch that is prevalent in the pediatric population. About 10% to 20% of children in the United States have atopic dermatitis, which can cause significant sleep disturbance, inattention, and sometimes behavioral problems [1,2]. Patients with atopic dermatitis are generally not severely ill and rarely require hospitalization. However, they experience significant psychologic stress and poor quality of life. Some examples include difficulty participating in sports due to sweat-induced itch, stigma with potentially disfiguring visible lesions, and psychologic repercussions of chronic sleep disturbance, such as depression and anxiety [3]. Enhancing resiliency in children with atopic dermatitis may promote coping strategies to improve itch, attention, and behavioral problems [4]. One study that included adult patients with atopic dermatitis looked at the consistent use of an internet-based positive psychology intervention and demonstrated improved well-being [5].

One strategy for strengthening resiliency in children is via positive psychology. This emerging field of study is in contrast to traditional problem-based psychology, which focuses on the deficits in one's life, such as how mental health diagnoses negatively impact one's well-being. Positive psychology looks at what makes the individual feel well and considers ways to enhance their well-being. High levels of feasibility and acceptability of positive psychology interventions make this a relevant approach for atopic dermatitis, specifically to translate positive psychology interventions to enhance well-being and health outcomes [6]. The field of positive psychology presents unique opportunities to enhance the well-being of children with chronic disease. This is particularly important as the prevalence of pediatric chronic disease has increased in the past decades [7].

Goal of This Study

Our objective was to analyze interview transcripts from child-parent dyads about atopic dermatitis using the PERMA (positive emotion, engagement, relationships, meaning, and accomplishment) model to determine which positive psychology themes were mentioned and whether there were areas of improvement for the well-being of children with atopic dermatitis using a positive psychology approach.

Methods

Recruitment

Patient-parent dyads of children aged 8 to 17 years old with atopic dermatitis were identified as a convenience sample recruited from the dermatology or allergy clinic at the Ann & Robert Lurie Children's Hospital of Chicago. Inclusion criteria included children with physician-diagnosed atopic dermatitis currently receiving treatment in clinic. Disease severity was assessed by an allergist or dermatologist. Exclusion criteria included non–English-speaking parent-child dyads, history of intellectual disability or psychosis, and uncontrolled atopic dermatitis. A total of 49 dyads were screened for recruitment, 24 pairs were eligible for the study, 23 patients were enrolled, and 3 dropped out, with 20 patient-parent dyads ultimately completing the study. Participants were interviewed to share their personal experiences with atopic dermatitis to develop a psychologic intervention. Positive psychology themes emerged during the analysis, which were further explored in this study.

Trained coders analyzed the qualitative data using a coding dictionary developed based on Seligman's PERMA model of positive psychology (Multimedia Appendix 1). The PERMA model breaks down positive psychology into 5 categories that may be targeted to improve well-being: positive emotion, engagement, relationships, meaning, and accomplishment. Two coders independently reviewed all interview transcripts, coding for mentions of PERMA themes or the lack thereof. Coders then had a discussion to reconciliate differences in codes. Any persistent discrepancies were resolved by a third party. Transcripts were also analyzed by a separate pair of coders using a constant comparative approach. The emergent themes included resiliency, which was investigated for this study.

Ethics Approval

Approval was granted by the Institutional Review Board of Ann & Robert Lurie Children's Hospital of Chicago (#IRB 2019-2560).

Results

Among the 20 child participants, the average age was 12 (SD 1.9) years. Of the participants, 9 (45%) were male, 11 (55%) were female, 7 (35%) identified as White, 7 (35%) as Black/African American, 3 (15%) as Latino or Latina, and 3 (15%) as Asian. Disease severity was assessed by a clinician global assessment or the exam-based Eczema Area and Severity Index: mild (n=3, 15%), moderate (n=9, 45%), and severe (n=8, 40%). At the time of the interview, all patients were on topical prescription therapies, and 7 (35%) participants were on oral or subcutaneous systemic therapy for atopic dermatitis. In terms of other chronic allergic diseases, 11 (55%) participants had asthma, 6 (30%) had allergic rhinitis, and 6 (30%) had food allergies.

Unprompted mentions of engagement and relationships were the most common PERMA themes raised by children (n=14, 70%) and parents (n=13, 65%) (Table 1). Interestingly, children and parents equally brought up negative and positive aspects of engagement and relationships due to eczema. Emotion elicited the most negative comments from children (n=19, 95%) and parents (n=17, 85%).

We also stratified participants by disease severity to analyze the frequency of positive psychology concepts mentioned. Positive psychology concepts were mentioned more frequently by patients with mild atopic dermatitis (concepts: mean 13, SD 3; patients: n=3, 15%) versus those with moderate atopic dermatitis (concepts: mean 6.2, SD 4.9; patients: n=9, 45%) and those with severe atopic dermatitis (concepts: mean 6.1, SD 4; patients: n=8, 40%) (*P*=.03).

Transcripts were also analyzed for resiliency codes. Eight participants had at least one resiliency code. A sample of resiliency quotes is summarized in Textbox 1. Participants with a resiliency code mentioned 9.1 (SD 4.7) positive psychology concepts on average throughout their interview, whereas participants without a resiliency code mentioned 5.9 (SD 4.6) positive psychology concepts on average (*P*=.14).

Table 1. Positive psychology examples of PERMA (positive emotion, engagement, relationships, meaning, and accomplishment) themes and counterexamples mentioned unprompted in interviews.

PERMA category	Participants who mentioned the concept, n (%)		Example
	Parent	Child	
Positive emotion	3 (15)	9 (45)	“So it’s actually comforting…to be at home.” [Child]
Negative emotion	17 (85)	19 (95)	“[The itching] is frustrating for him that he can’t stop.” [Parent]
Engagement	10 (50)	18 (90)	“I don’t want to let [the itch] keep me from the stuff so I keep doing the things.” [Child]
Lack of engagement	9 (45)	17 (85)	“If I’m trying to do something and I feel itchy, it’s hard to do that thing ‘cause it’s distracting.” [Child]
Unhindered relationships	11 (55)	15 (75)	
Adults	9 (45)	12 (60)	Interviewer: “How do you talk about [your eczema] with adults?” Participant [child]: “As if I’m talking to my friends, it’s not that big of a deal.”
Peers	5 (25)	13 (65)	“If somebody new that doesn’t know her would ask her about her eczema ‘what is that?’… her friends will say something ‘it’s eczema.’ So she’s got a good support group.” [Parent]
Other	2 (10)	11 (55)	“Most people aren’t going to say anything [about your eczema] but if they do, just ignore them. It doesn’t matter what they say.” [Child]
Hindered relationships	11 (55)	16 (80)	
Adults	5 (25)	8 (40)	Interviewer: “Do you ever avoid meeting new adults because of your itching?” Participant [child]: “If they ask too many questions, then yeah.”
Peers	5 (25)	10 (50)	“She’s gotten made fun of [because of her eczema].” [Parent]
Other	3 (15)	7 (35)	“I just try to avoid the subject [of my eczema]…I don’t think they understand.” [Child]
Meaning	4 (20)	6 (30)	“I’m not really scared of having to itch…it doesn’t matter whether it’s here or not.” [Child]
Lack of meaning	4 (20)	2 (10)	“She’ll scream and say why do I have to be born this way, I hate my skin.” [Parent]
Accomplishment	8 (40)	7 (35)	“he handles [the itch] all by himself. I actually didn’t realize it gave him a lot of trouble…[he takes] care of it himself.” [Parent]
Lack of accomplishment	4 (20)	5 (25)	“I can’t really do anything about [my frustration due to eczema].” [Child]

Textbox 1. Sample of resiliency quotes from parent and child transcripts.

Parent

- “They’re not self-conscious about [their eczema]…I believe that’s because there are other children in the school system that have eczema.”
- “She’s becoming independent, which is good, she likes to do [her eczema care regimen] herself…she does a great job”
- “I try to tell her…‘[child], I think that overall life is gonna be somewhat easier for you because you’ve had to learn how to deal with this, so I think some things are gonna come a lot easier to you’”
- “No one made fun of me [for my eczema]. So, I’m thinking maybe people just understand and other people have their own issues too…he hasn’t complained about it”

Child

- “If someone’s making fun of your skin just don’t be friends with them.”
- “[I] think about like long-term effects, just thinking about like oh, right now it would be best if I just don’t itch. Like it’s great if my skin looks clean now just focus on it right now, don’t like worry about how it’ll look like a month from now.”
- “Especially the kids who I talk to, they get it because they, everybody has a problem, nobody is perfect so when I talk about it I just say…I have eczema blah blah blah and then they don’t care that much afterwards”
- “We do all this stuff to help [my eczema], I know it’s not going to stay bad forever”
- “I know [the itch] it’s gonna to come back but it doesn’t worry me too much”
- “I’ve had eczema severely my whole life so like just if you do it in front of people nobody really cares that much because eczema is the thing that tons of people have so…I just tell them that it’s a normal thing”
- “I would tell [people who ask about my itching] that it gets better as life goes on if you just find the right thing”
- “I feel like I don’t like want to let [my eczema] keep me from the stuff so I keep doing the things”

Discussion

Principal Findings

Our small but diverse sample of children with atopic dermatitis frequently mentioned positive psychology concepts in qualitative interviews about their personal experience with atopic dermatitis. Children with severe disease were less likely to mention positive psychology concepts. Across all patients, the concepts of relationships and engagement were most frequently mentioned. Previous work in pediatric chronic disease shows similar findings that the concepts of relationships and engagement are consistently impacted.

With regard to relationships, children with chronic disease report difficulty maintaining relationships with family and friends [8,9]. They must also deal with concerns including how to share their diagnosis with others [10] and how to cope with unwanted attention [11]. Atopic dermatitis itself can become a source of conflict, especially given the stigma around having a visible skin condition. Children with chronic conditions need a supportive community to cope with the stress of their disease and management [12]. As several patients and parents mentioned, a supportive home environment and group of friends helped boost relationship building for them. Encouraging positive relationships, even by simple questions in clinic about close friends or family members, should be considered by providers treating atopic dermatitis.

With regard to engagement, children with chronic disease report worse school experiences and less participation in extracurricular activities compared to their healthy counterparts [8,13,14]. For many, their disease causes significant limitation of normal functions [15]. As an example, children with atopic dermatitis might limit physical activity, as they frequently report sweat-related itch and skin pain when sports equipment rubs against their skin. These children may benefit from additional support to help them engage with activities despite these physical limitations or pivot to activities with less physical discomfort to increase levels of engagement. Providers should consider querying about enjoyable activities.

While all PERMA categories are valuable to cultivate in patients with atopic dermatitis, our study identified positive emotion as the most needed area to cultivate. This is not surprising as previous work in atopic dermatitis demonstrated a correlation with negative emotion, poor quality of life, and disease severity [16]. Children with chronic conditions often experience significant negative emotions related to their disease, including but not limited to functional impairment, treatment burden, and acute as well as long-term stress [17]. Positive psychology alone cannot eliminate these negative emotions, but positive psychology interventions can enhance positive emotions, with favorable outcomes including enhanced resiliency and coping [18]. Positive emotion interventions include exercising gratitude and affirmations, which can be elicited by the parent or provider and also via several apps [19]. Cultivating gratitude through apps or physically writing letters of gratitude is easy to learn and can be frequently practiced to help strengthen positive emotion.

There is potential utility in adopting positive psychology interventions for children with atopic dermatitis, particularly in populations with severe disease to inspire them to build resilience and improve psychosocial health that could lead to improved health outcomes through, for example, less rumination and medication adherence.

Limitations and Conclusion

Limitations to our study include the small sample size, the exclusion of non–English-speaking patients, and interview questions that were not specific to positive psychology. Interview questions tended to focus on how atopic dermatitis has negatively impacted patients' lives, without specifically soliciting more information on how positive psychology concepts could or are improving participant well-being (Multimedia Appendix 2). We hope to encourage further research on the application of positive psychology in pediatric atopic dermatitis and other pediatric chronic diseases.

Conflicts of Interest

WSB has served as an advisory board member for Incyte and Pfizer and has received honoraria. She has also received grants from Pfizer as an investigator. The other authors have no relevant conflicts of interest to disclose.

Multimedia Appendix 1
Coding dictionary, developed based on Seligman's PERMA (positive emotion, engagement, relationships, meaning, and accomplishment) model of positive psychology.
[DOCX File , 18 KB - pediatrics_v5i3e38725_app1.docx]

Multimedia Appendix 2
Interview questions.
[DOCX File , 18 KB - pediatrics_v5i3e38725_app2.docx]

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Abbreviations

PERMA: positive emotion, engagement, relationships, meaning, and accomplishment

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Original Paper

Evaluation of Positive Choices, a National Initiative to Disseminate Evidence-Based Alcohol and Other Drug Prevention Strategies: Web-Based Survey Study

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Abstract

Background: To prevent adolescents from initiating alcohol and other drug use and reduce the associated harms, effective strategies need to be implemented. Despite their availability, effective school-based programs and evidence-informed parental guidelines are not consistently implemented. The *Positive Choices* alcohol and other drug prevention initiative and website was launched to address this research and practice gap. The intended end users were school staff, parents, and school students. An 8-month postlaunch evaluation of the website showed that end users generally had positive feedback on the website's usability, and following its use, most of them would consider the evidence base and effectiveness of drug education resources. This study extends this initial evaluation by examining the effectiveness and impact of the *Positive Choices* initiative over a 3-year period.

Objective: Guided by the five dimensions of the RE-AIM (reach, effectiveness, adoption, implementation, and maintenance) framework, the study assessed the impact of the *Positive Choices* initiative in increasing awareness and implementation of evidence-based drug prevention.

Methods: Data were collected between 2017 and 2019, using web-based evaluation and community awareness surveys. Data from the surveys were merged to examine reach, effectiveness, adoption, implementation, and maintenance using descriptive statistics. Google Analytics was used to further understand the reach of the website. The System Usability Scale was used to measure website usability. In addition, inductive analysis was used to assess the participants' feedback about *Positive Choices*.

Results: A total of 5 years after launching, the *Positive Choices* website has reached 1.7 million users. A national Australian campaign increased awareness from 8% to 14% among school staff and from 15% to 22% among parents after the campaign. Following a brief interaction with the website, most participants, who were not already following the recommended strategies, reported an intention to shift toward evidence-based practices. The System Usability Scale score for the website was *good* for both user groups. The participants intended to maintain their use of the *Positive Choices* website in the future. Both user groups reported high level of confidence in communicating about topics related to alcohol and other drugs. Participants' suggestions for improvement informed a recent website update.

Conclusions: The *Positive Choices* website has the capacity to be an effective strategy for disseminating evidence-based drug prevention information and resources widely. The findings highlight the importance of investing in ongoing maintenance and promotion to enhance awareness of health websites. With the increased use and acceptability of health education websites, teams should ensure that websites are easy to navigate, are engaging, use simple language, contain evidence-informed resources, and are supported by ongoing promotional activities.

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KEYWORDS

alcohol and other drugs; prevention; adolescence; schools; drug prevention; drug prevention website

Introduction

Background

Adolescence is marked by considerable emotional, social, and physical changes, including increasing autonomy from parents, greater influence from peers, and increased likelihood to engage in risk-taking behaviors [1]. Corresponding to this period of experimentation, harms associated with risky behaviors such as alcohol and other drug (AOD) use peak during adolescence and early adulthood [2-4]. Globally, alcohol, tobacco, and cannabis are the most commonly used drugs among adolescents [4]. This also holds true for Australia, where a 2017 national survey among secondary school students aged 12 to 17 years showed that 46% had consumed a full serve of alcohol, 14% had used cannabis, and 13% had smoked cigarettes in the past year [5]. Early initiation of AOD use is associated with a range of negative outcomes including poor school performance, truancy, school dropout, juvenile offending, and increased risk of drug dependence and mental illness during adulthood [6-9]. To interrupt this trajectory and reduce the harms associated with AOD use, effective strategies are needed to prevent the onset and escalation of their use.

Studies have identified a number of modifiable individual risk factors that are consistently associated with AOD use among adolescents [10]. They include peer AOD use, low self-efficacy to refuse alcohol or other drugs, poor school engagement and connectedness, and mental health disorders such as depression and attention-deficit/hyperactivity disorder [10-12]. Studies also highlight the importance of parents in influencing and preventing adolescents’ AOD use. Recent evidence shows an association between parental supply of alcohol and increased risk of alcohol-related harm during adolescence and early adulthood [13,14]. This has challenged the commonly held perception that allowing teenagers to drink alcohol under parental supervision protects them against alcohol-related harms. Similarly, less restrictive parental attitudes toward alcohol use are likely to lead to earlier and more frequent alcohol use and increased drunkenness among adolescents [15].

Prevention programs targeting individual and parental risk factors are effective in reducing AOD use among adolescents [16-22]. A number of prevention programs implemented during secondary school have consistently demonstrated effectiveness in reducing AOD use [18,21], and school-based delivery offers a number of advantages including tailoring of messages to students’ developmental level and universal delivery to achieve wide reach [22,23]. Internet- and computer-based AOD prevention programs offer additional benefits in terms of engaging youth and increasing implementation fidelity and have been found to be effective in reducing adolescent AOD use [17]. Despite the growing evidence base, only a small proportion of schools implement effective AOD prevention strategies. A 2003 review of 3 decades of AOD education studies concluded that worldwide, effective AOD prevention is not widely implemented [24]. More recently, our 2017 survey of Australian schoolteachers found that <25% of teachers had implemented evidence-based AOD education programs. The study identified lack of confidence, resources, time, and support from school; attitude of parents and students; and difficulty in communicating as the main barriers to implementing programs [25].

Parenting strategies that are consistently associated with delayed initiation of alcohol use include parental monitoring, limited access to alcohol, parent-child relationship quality, parental involvement, and communication [20,26]. However, studies show that parents do not always act in accordance with evidence-based parenting strategies, which may be related to lack of clear guidance or confidence [27,28]. Although parents actively seek information about illicit drugs and parenting practices to prevent AOD use, primarily from friends or the internet, they often report low-to-moderate confidence in communicating and influencing their children’s choices regarding AOD use [29]. Programs aimed at modifying parenting practices and promoting the use of effective prevention strategies have shown promise in reducing adolescent AOD use [30-32]. Honest communication between parents and adolescents, established on the basis of positive parent-adolescent relationship, has been associated with reduced alcohol use among adolescents [32-34]. This highlights the importance of engaging parents in efforts to reduce harms associated with adolescent AOD use.

It is critical that effective AOD prevention strategies are implemented consistently and widely to alleviate the considerable burden associated with AOD use. Therefore, teachers, school staff, and parents need to have easy access to evidence-based information, strategies, and programs that equip them to respond most effectively. The *Positive Choices* national AOD prevention initiative was funded by the Australian Government Department of Health to enhance access to and implementation of evidence-based AOD prevention strategies within school communities. The initiative responds to a call from school principals for support to implement evidence-based AOD prevention resources (Australian National Council on Drugs; 2013) and was developed iteratively with experts and end users. School staff, parents, and students provided input and feedback across two phases (for full details refer to the study by Stapinski et al [25]): (1) formative consultation to clarify scope and identify user needs and (2) review and feedback on a beta version of the website [35]. The final website was launched in December 2015 and provides web-based training, support, and access to a centralized database of evidence-based AOD prevention programs, recommendations, and resources [25]. The website emphasizes the importance of implementing resources that are supported by research evidence—only evidence-based resources are listed, and each resource page provides a rating to indicate the strength of the supporting evidence according to the Australian National Health and Medical Research Council's evidence hierarchy [36]. To facilitate implementation, resources are categorized based on purpose and intended audience in a searchable database, with brief factsheets to guide users about when and how to implement evidence-based prevention strategies. A survey was conducted 8 months after the launch to determine the initial impact of *Positive Choices*. Among teachers who accessed the website, most found it useful and reported that they would continue using it, would recommend it to others, felt more comfortable discussing AOD use prevention following website access, and felt that their students were more engaged with AOD education since using the website [25]. When compared with a general teacher sample, teachers who used *Positive Choices* were more likely to consider the evidence base and effectiveness of AOD education resources before using them in class [25]. Despite highlighting these benefits associated with the use of *Positive Choices*, this initial evaluation did not reveal the specific factors or features that facilitated the dissemination of evidence-based AOD prevention strategies.

Objectives

In this study, we extended this initial evaluation by conducting a more comprehensive examination of the effectiveness and impact of the *Positive Choices* initiative over a 3-year period, between 2017 and 2019. This is the first evaluation of a web-based health initiative that specifically promotes translation of evidence-based AOD prevention resources to school communities, parents, and youth. To guide this evaluation, we applied the reach, effectiveness, adoption, implementation, and maintenance (RE-AIM) framework, which was developed to facilitate comprehensive and rigorous evaluation of health promotion initiatives, spanning these 5 key dimensions. It has been widely applied to evaluate the implementation and real-world impact across a variety of settings, including educational settings [37-40]. Guided by this framework, this study assessed the impact of the *Positive Choices* initiative in increasing awareness and implementation of evidence-based AOD prevention strategies. The study aimed to evaluate the reach of the *Positive Choices* website, its effectiveness in improving access to and uptake of effective AOD prevention strategies, and its adoption in accessing evidence-based prevention strategies. Furthermore, implementation will be evaluated by users' capacity to interact with the website, and maintenance will be evaluated by users' intention to continue using the website for evidence-based strategies. The study also obtained feedback from end users to improve and optimize the *Positive Choices* website.

Methods

Data were collected between 2017 and 2019, from several sources to evaluate the dimensions aligned with the RE-AIM framework, as described in the following sections.

Reach

Overview

Reach was assessed via the measurement of access and awareness, using 2 data sources. Access was measured using site use analytics and operationalized as follows: How many unique users have accessed *Positive Choices*? Awareness was assessed via community awareness surveys and operationalized as follows: Have you heard of *Positive Choices* before?

Site Use Analytics

Google Analytics was used to obtain a detailed analysis of website traffic between January 2017 and March 2021. This included information on the number of unique website users and page views, pages viewed per session, and average time users spent on each page.

Community Awareness Survey: School Staff and Parents

A web-based survey was administered in July 2018 to assess the Australian community's awareness and use of *Positive Choices* resources. Using voluntary response sampling, school staff and parents were recruited via targeted advertisements on *Positive Choices* social media channels or mailing lists. Participants who completed the survey were offered the chance to enter a prize draw to win a laptop. Within this general sample, the proportion of the community that was aware of the website was identified by using a single question: Have you heard of *Positive Choices* before? Information was also collected to ascertain the number of participants who were using sources other than *Positive Choices* and how participants were accessing AOD information. The same survey was administered after 6 months (November 2018) and 12 months (May 2019) to determine whether awareness increased following a national social media campaign promoting *Positive Choices.*

Effectiveness

Overview

Positive Choices aims to improve access to and uptake of effective AOD prevention strategies. Accordingly, effectiveness was assessed via an evaluation survey completed by *Positive Choices* end users (school staff and parents). It was measured through examination of whether engagement with *Positive Choices* was associated with increased intention to implement evidence-based AOD education and was operationalized as follows: Has the use of *Positive Choices* changed users' intentions in implementing evidence-based teaching and parenting practices?

Evaluation Survey: School Staff and Parents

To capture the effectiveness of *Positive Choices*, two anonymous evaluation surveys were administered: the first between August 2017 and September 2017 and the second between May 2019 and June 2019. Using voluntary random sampling, participants were recruited via the *Positive Choices* mailing list and social media campaigns. Eligible participants were school staff or parents or guardians of children or adolescents, were Australian residents, and had access to the internet and a device to complete the survey. Participants were reimbursed for their time with an

Aus $40 (US $28) gift voucher (2017) or the opportunity to enter a prize draw to win a laptop (2019).

Participants were asked to spend time reading and interacting with the *Positive Choices* resources, after which they reported on their intentions to implement evidence-based prevention strategies. Data were collected via a web-based survey platform, Survey Monkey, and responses from the 2 evaluations were collated to provide an overview of the effectiveness spanning from 2017 to 2019.

For school staff, questions assessed whether they intended to (1) implement teaching resources that have been tested in schools and proven to prevent AOD use, (2) communicate with students about the risks and effects associated with AOD use, and (3) correct the misperception that AOD use is *the norm*. For parents, questions assessed whether they intended to (1) encourage open communication with their children about AOD, (2) have explicit conversation with their children about AOD use, (3) correct the misperception that AOD use is common, (4) clearly communicate about their expectations to their children, (5) change their own AOD use to model appropriate behavior, (6) avoid parental supply of alcohol, and (7) closely monitor their children’s whereabouts. School staff and parents responded to these behavioral intention items by selecting whether they (1) already do or have done this, (2) plan to do this after viewing *Positive Choices*, or (3) do not plan to do this in the future.

Adoption and Implementation

Similar to the effectiveness dimension, the adoption and implementation dimensions were assessed via the web-based evaluation surveys. Adoption was assessed by identifying barriers to and enablers of access and uptake of evidence-based prevention strategies by school staff and parents. A single question assessed which of the following characteristics of web-based AOD prevention resources or information were most valued by school staff: (1) evidence-based information, (2) resources that had been tested in schools and proven to prevent AOD use, (3) engaging website, (4) interactive website, (5) website that is easy to navigate and use, and (6) simple and easy-to-understand language. Similarly, enablers for parents and guardians were identified through the same items with the addition of the following two items that pertained specifically to parents: (1) parental strategies that have been proven to be effective and (2) website with advice from other parents.

Implementation was evaluated using the System Usability Scale (SUS) [41]. It is a standardized instrument used to measure the usability of products, software, apps, and websites. It provides participants with 10 usability-related statements on a 5-point Likert scale, ranging from “strongly disagree” to “strongly agree.” SUS scores range from 0 to 100, with score ≥85 representing *exceptional usability*, score between 50 and 70 representing *good usability*, and score <50 representing *unacceptable usability* [41,42]. As such, participants’ capacity to interact with the website to access and subsequently deliver evidence-based strategies was assessed using the SUS scores.

Maintenance

This dimension was assessed using the website evaluation surveys, as described previously. For the participating school staff and parents, the question assessed whether users intended to access *Positive Choices* in the future. It was conceptualized as follows: Did participants intend to maintain their use of the *Positive Choices* resources?

General Impression

To assess school staff and parents’ general feedback about the *Positive Choices* website, the evaluation survey included the following open-text items: (1) Do you have any suggestions for improving the website? and (2) Do you have any final comments about the website?

Data Analysis

The evaluation surveys were administered via *Survey Monkey*, and the data were exported to Stata (version 14; StataCorp), which was used to generate descriptive data, including mean scores and response frequencies. Data from the 2017 and 2019 evaluation surveys were merged to examine reach, effectiveness, adoption, implementation, and maintenance, using descriptive statistics, separately for school staff and parents. The SUS score was calculated by converting raw individual scores for each question to a number; these scores were summed to obtain the total score, 5 was subtracted from the total score of all odd-numbered questions, and 25 was subtracted from the total score of all even-numbered questions. Then, the total score of the new values was multiplied by 2.5 [43].

Data on community awareness were also collected via *Survey Monkey* and exported to Stata to generate descriptive data. The data were examined separately for school staff and parents at baseline, 6 months, and 12 months.

Inductive analysis was used to assess participants’ feedback about *Positive Choices* [44], using the qualitative data analysis software, NVivo (version 12; QSR International). Feedback from participants was examined by SN, who then developed a coding framework. Using the framework, common themes were identified independently by two coders (SN and TG).

Ethics Approval

The 2017 survey was approved by the Human Research Ethics Committee, University of New South Wales (project number HC12548), and the 2019 survey was approved by the Human Research Ethics Committee, University of Sydney (project number 2018/873).

Results

Sample Characteristics: Evaluation Survey

From 2017 to 2019, a total of 200 participants completed the evaluation surveys, of which 73 (36.5%) participants were school staff and 127 (63.5%) were parents.

School Staff

Table 1 shows the demographic characteristics of the school staff who completed the evaluation surveys. The average age of the participants was 40 (SD 10.71) years and ranged between

24 and 63 years. Most participants were women (56/73, 77%), resided in New South Wales (NSW; 29/73, 40%), and were based in major cities (36/73, 49%). Most school staff worked in coeducational, secondary schools (ie, years 7-12; 51/73, 70%), and were employed as teachers (48/73, 66%).

Table 1. Demographic characteristics of school staff and parents (evaluation survey).

Characteristics	School staff (n=73)	Parents (n=127)
Age (years), range	24-63	26-63
Gender, n (%)		
Women	56 (77)	108 (85)
Men	16 (22)	19 (14.9)
Nonbinary	1 (1)	0 (0)
State or territory, n (%)		
Australian Capital Territory	5 (7)	4 (3.1)
New South Wales	29 (40)	45 (35.4)
Queensland	10 (14)	23 (18.1)
South Australia	6 (8)	6 (4.7)
Tasmania	4 (5)	2 (1.6)
Victoria	16 (22)	28 (22)
Western Australia	3 (4)	15 (11.8)
Northern Territory	0 (0)	4 (3.1)
Location of school or residence, n (%)		
Major city	36 (49)	78 (61.4)
Regional	33 (45)	48 (37.8)
Remote	4 (5)	1 (0.8)
Year levels taught or children’s year levels[a], n (%)		
Foundation	5 (7)	10 (7.9)
Year 1	8 (11)	6 (4.7)
Year 2	8 (11)	5 (3.9)
Year 3	8 (11)	10 (7.9)
Year 4	7 (10)	13 (10.2)
Year 5	9 (12)	11 (8.7)
Year 6	8 (11)	15 (11.8)
Year 7	38 (52)	26 (20.5)
Year 8	37 (51)	29 (22.8)
Year 9	38 (52)	23 (18.1)
Year 10	40 (55)	24 (18.9)
Year 11	39 (53)	35 (27.6)
Year 12	39 (53)	33 (25.9)
N/A[b]	18 (25)	N/A
School type, n (%)		
Coeducational	63 (86)	N/A
Single sex	10 (14)	N/A
Profession, n (%)		
Teacher	48 (66)	N/A
School counselor chaplain	10 (14)	N/A
Youth worker	2 (3)	N/A
Researcher	2 (3)	N/A

Characteristics	School staff (n=73)	Parents (n=127)
Other	11 (15)	N/A
Employment status, n (%)		
Full time	N/A	52 (40.9)
Part time or casual	N/A	42 (33.1)
Home duties (including carer)	N/A	19 (14.9)
Unemployed	N/A	6 (4.7)
Unable to work	N/A	2 (1.6)
Student	N/A	5 (3.9)
Other	N/A	1 (0.8)

[a] Respondents were able to select multiple responses; thus, the column total for this item does not add to 100%.

[b] N/A: not applicable.

Parents

Table 1 also shows the demographic characteristics of the parents who completed the surveys. The average age of the parents was 46 (SD 6.63) years, and they were aged between 26 and 63 years. Most parent respondents were women (108/127, 85%), resided in NSW (45/127, 35.4%), and were based in major cities (78/127, 61.4%). Most parents were employed full time (52/127, 40.9%), with most of them having children who attended secondary school (ie, years 7-12; 122/127, 96.1%).

Sample Characteristics: Community Awareness Survey

Overview

A total of 1435 participants completed the community awareness surveys across baseline, 6-month follow-up, and 12-month follow-up. At baseline, participants were 48.55% (201/414) school staff and 51.45% (213/414) parents. At the 6-month follow-up, participants were 51.45% (249/484) school staff and 48.55% (235/484) parents. Finally, at the 12-month follow-up, participants were 50.09% (269/537) school staff and 49.91 (268/537) parents.

School Staff

All school staff who completed the community awareness surveys were high school staff (719/719, 100%), most resided in NSW (259/719, 36%), and were based in major cities (381/719, 52.9%; Table 2). Most school staff (432/719, 60.1%) worked in public schools in a number of different roles (eg, head teacher, curriculum coordinator, language teacher, mathematics or science teacher, advanced skills teacher, student support or school counselor, and teacher assistant) and worked with Aboriginal or Torres Strait Islander students.

Table 2. Demographic characteristics of school staff and parents (community awareness survey).

Characteristics	School staff (n=719), n (%)	Parents (n=716), n (%)
State or territory		
Australian Capital Territory	5 (0.7)	15 (2.1)
New South Wales	259 (36)	207 (28.9)
Queensland	147 (20.4)	136 (18.9)
South Australia	46 (6.4)	75 (10.5)
Tasmania	32 (4.5)	19 (2.7)
Victoria	134 (18.6)	168 (23.5)
Western Australia	85 (11.8)	88 (12.3)
Northern Territory	11 (1.5)	8 (1.1)
Location of school or residence		
Major city	381 (53)	379 (52.9)
Regional	185 (25.7)	192 (26.8)
Rural	93 (12.9)	93 (12.9)
Remote	34 (4.7)	29 (4.1)
Very remote	26 (3.6)	23 (3.2)
Works with Aboriginal and/or Torres Strait Islander student (school staff) or identified as Aboriginal and/or Torres Strait Islander (parents)		
Yes	568 (78.9)	21 (2.9)
No	122 (16.9)	687 (95.9)
Prefer not to answer	29 (4)	8 (1.1)
School		
Public	432 (60.1)	N/A[a]
Faith-based	145 (20.2)	N/A
Independent	95 (13.2)	N/A
Coeducational	21 (2.9)	N/A
Single sex (female)	12 (1.7)	N/A
Single sex (male)	9 (1.3)	N/A
Selective	5 (0.7)	N/A
Family structure[b]		
Single-parent household	N/A	192 (26.8)
2-parent household	N/A	500 (69.8)
1 child	N/A	69 (9.6)
2-4 children	N/A	397 (55.4)
≥5 children	N/A	39 (5.4)
Step siblings (cohabiting)	N/A	27 (3.8)
Prefer not to answer	N/A	2 (0.3)

[a] N/A: not applicable.

[b] Respondents were able to select multiple responses; thus, the column total for this item does not add to 100%.

Parents

All parents who completed the community awareness surveys (716/716, 100%) were parents of high school students. Most of them resided in NSW (207/716, 28.9%), were based in major cities (379/716, 52.9%), and did not identify as Aboriginal and/or Torres Strait Islander (687/716, 95.9%; Table 2). Most parents were part of 2-parent households (500/716, 69.8%) and had between 2 and 4 children (397/716, 55.4%).

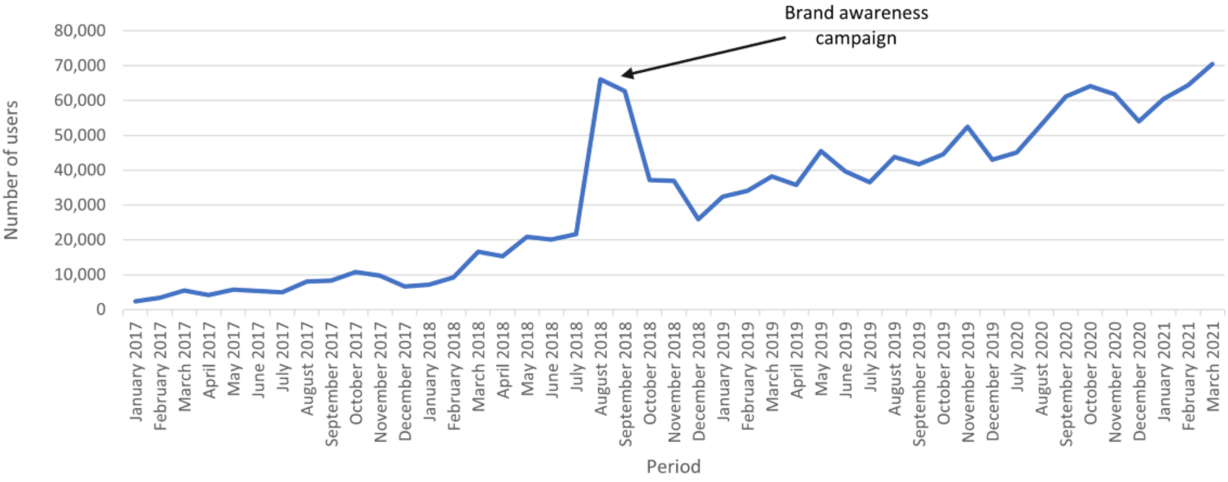
Evaluation of the Positive Choices Website (RE-AIM Framework)

Reach: How Many Users Have Accessed Positive Choices?

Overview

Between January 1, 2017, and March 31, 2021, *Positive Choices* had been visited by 1.7 million unique users, of which 1.53 million (90%) were first-time users. Figure 1 shows that the number of monthly users has consistently increased since January 2017. Similarly, the number of monthly page views have increased from 8367 in January 2017 to 123,699 in March 2021. In terms of geographical reach, most of the website's visitors are Australian residents (41%); however, the website is also frequently accessed by international users from countries such as the United States, India, the Philippines, and the United Kingdom.

Figure 1. Monthly Positive Choices website visitors, between January 2017 and March 2021.



Community Awareness

The spike in website visitors seen between July 2018 and November 2018 (Figure 1) coincided with the community awareness campaign run from June 2018 to October 2018. During this period, there was an 84% increase in the average monthly users of the *Positive Choices* website from 20,115 to 37,047. There was also an increase in users' engagement on the *Positive Choices* Facebook page, with the number of *likes* increasing by 86%, from 670 to 1243. Results from the surveys showed that awareness about *Positive Choices* increased among school staff from 8% at baseline to 14% at 6 months (immediately after the awareness campaign) and 15% at 12 months. Among parents, awareness increased from 15% at baseline to 22% at 6 months (immediately after the awareness campaign) before returning to 15% at 12 months.

According to the 12-month survey, of the school staff who were not using *Positive Choices* for AOD education resources and information (191/269,71%), 45.5% (87/191) were using Alcohol and Drug Foundation, 18.3% (35/191) were using Drug Free Australia, 14.1% (27/191) were using Australian Drug Information Network, 18.3% (35/191) were using Drug Help, 4.7% (9/191) were using Prevention Smart, and 6.3% (12/191) were using other sources (*headspace*, general practitioners, guidance officer, etc). Similarly, among the same group that was not using *Positive Choices*, approximately 69.6% (133/191) of school staff used websites (government, Google, or other websites) to access AOD information; 43.5% (83/191) obtained information through school administrators (eg, Department of Education and Catholic Education Office); and 13.6% (26/191) used other sources including AOD professionals, books, police, and so on. Similarly, among parents who were not using *Positive Choices* (201/268, 75%), 60.7% (122/201) parents reported that they accessed information through Google or other websites; 26.4% (53/201) from other parents; 30.3% (61/201) through government websites; 8.5% (17/201) through their general practitioners; 4.9% (10/201) through their children's classroom teachers; and 7.9% (16/201) of parents were using other sources such as *headspace*, other health professionals, presenters at local AOD prevention events, and so on.

Effectiveness: Has the Use of Positive Choices Changed Users' Teaching and Parenting Practices?

School Staff

Table 3 shows that approximately half of the school staff sample (35/73, 48%) were already implementing AOD education resources that were tested and found to be effective in schools; among those who were not implementing those resources, 89% (34/38) intended to after using *Positive Choices*. Most respondents were already communicating to their students about the risks and effects of AOD use (52/73, 71%), and of the remaining respondents, 90% (19/21) intended to do so after using *Positive Choices*. When it came to correcting students' misperceptions about AOD use, most respondents were already doing this (52/73, 71%) and of the remaining respondents, 81% (17/21) intended to commence this after viewing the *Positive Choices* website.

Table 3. Effectiveness in changing intentions to use evidence-based strategies (school staff).

	Respondents who are currently implementing evidence-based strategy (n=73), n (%)	Among respondents who were not implementing evidence-based strategies, those who intend to after viewing *Positive Choices*, n (%)	Respondents who will not implement evidence-based strategies in the future, n (%)
Implement teaching resources that were tested in schools and proven to prevent alcohol and drug use	35 (48)	34 (89)[a]	4 (11)[a]
Communicate with students about the risks and effects of alcohol and drug use	53 (73)	18 (90)[b]	2 (10)[b]
Correct the misperception that alcohol and other drug use is common or "the norm"	52 (71)	17 (81)[c]	4 (19)[c]

[a] Sample size, n=38.

[b] Sample size, n=20.

[c] Sample size, n=21.

Parents

Table 4 shows that most parents reported that they were already having open (100/127, 78.7%) and clear conversations (95/127, 74.8%) with their children about AOD use. Among those parents who were not already doing this, 85% (23/27) planned to have open and 78% (25/32) planned to have clear conversations with their children after viewing resources on *Positive Choices*. Most parents reported that they were already having explicit conversations about AOD with their children (88/127, 69.3%), and most of the remaining parents (36/39, 92%) planned to do so after using *Positive Choices*. Most parents in the survey were already avoiding supplying alcohol to their children (103/127, 81.1%). Of those who were not doing this, 38% (9/24) reported that they would avoid supplying alcohol after viewing resources on *Positive Choices*. Similar to the school staff, most parents reported that they were already correcting misperceptions about AOD use being *the norm* (80/127, 62.9%), and of the remaining parents, 83% (39/47) planned to implement this behavior after using *Positive Choices*. Most parents reported that they have already adapted their own AOD use to model appropriate behavior for their children (87/127, 68.5%), and of the remaining parents, 45% (18/40) planned to modify their behavior after using *Positive Choices*. After viewing resources on *Positive Choices*, most parents reported that they will monitor their children's whereabouts more closely (64/74, 86%).

Table 4. Effectiveness in changing intentions (parents).

	Respondents who are currently implementing evidence-based strategy (n=127), n (%)	Among respondents who were not implementing evidence-based strategies, those who intend to after viewing *Positive Choices*, n (%)	Respondents who will not implement evidence-based strategies in the future, n (%)
Encourage open communication with my child about alcohol and other drugs	100 (78.7)	23 (85)[a]	4 (15)[a]
Have an explicit conversation with my child about alcohol and other drugs	88 (69.3)	36 (92)[b]	3 (8)[b]
Correct the misperception that alcohol and other drug use is common or "the norm"	81 (63.8)	38 (83)[c]	8 (17)[c]
Clearly communicate my expectations about drug and alcohol use to my child	95 (74.8)	25 (78)[d]	7 (22)[d]
Change my own drug or alcohol use to model appropriate behavior	87 (68.5)	18 (45)[e]	22 (55)[e]
Avoid supplying my child with alcohol	103 (81.1)	9 (38)[f]	15 (63)[f]
Monitor my child's whereabouts more closely	54 (42.5)	63 (86)[g]	10 (14)[g]

[a] Sample size, n=27.

[b] Sample size, n=39.

[c] Sample size, n=46.

[d] Sample size, n=32.

[e] Sample size, n=40.

[f] Sample size, n=24.

[g] Sample size, n=73.

Adoption and Implementation

School Staff

Overview

School staff reported that they spent between 5 and 10 hours per semester on AOD education. Most school staff rated the following factors highly (either “very important” or “important”) when selecting web-based AOD prevention resources: evidence-based information (69/73, 95%), easy-to-navigate and easy-to-use website (69/73, 95%), engaging website (70/73, 96%), simple and easy-to-use language (68/73, 93%), and resources tested in school and found to be effective (62/73, 85%). Although school staff also valued interactive features of prevention websites (55/73, 75%), the proportion of participants who rated this factor highly was lower than those for the other factors facilitating effective AOD prevention. When discussing AOD topics, school staff displayed high levels of confidence, with 41% (30/73) feeling “very confident,” 38% (28/73) feeling “confident,” and 16% (12/73) feeling “somewhat confident”; only 4% (3/73) reported feeling “not very confident.”

Implementation

Regarding usability of the *Positive Choices* website, the mean SUS score was 75 (SD 15.1; range 35-100), indicating *good* website usability.

Parents

Overview

Most parents rated the following factors highly (either “very important” or “important”) when selecting web-based AOD prevention resources: evidence-based information (119/127, 93.7%); strategies that were tested and proven to be effective in AOD use prevention (119/127, 93.7%); simple and easy-to-use language (109/127, 85.8%); and engaging (115/127, 90.6%), interactive (72/127, 56.7%), and easy-to-navigate and easy-to-use (123/127, 96.9%) website. In addition, 57.5% (73/127) of the parents valued prevention advice from other parents.

Parents also reported high confidence in discussing AOD topics: 48.8% (62/127) were “very confident,” 31.5% (40/127) were “confident,” 17.3% (22/127) felt “somewhat confident,” and 2.4% (3/127) felt “not very confident.” These ratings suggest that confidence was not a significant barrier to evidence-based prevention in this sample. This is in contrast to the general community sample, from the community awareness survey, where lack of confidence was reported as the greatest barrier for parents to having conversations with their children about AOD use.

Implementation

The mean SUS score for the parent group was 74 (SD 12.9; range 40-100), indicating *good* website usability, similar to that found in the school staff group.

Maintenance: Are Users Likely to Continue Accessing Positive Choices?

School Staff

Most school staff reported that they would use *Positive Choices* in the future (66/73, 90%), use the website frequently (53/73, 73%), and recommend the website to friends or colleagues (68/73, 93%).

Parents

Most parents also reported that they would use *Positive Choices* in the future (116/127, 91.3%), use the website frequently (78/127, 61.4%), and recommend the website to friends or colleagues (113/127, 88.9%).

User Feedback on the Website

The main themes that emerged from the analysis of users’ feedback on the website centered around the website’s content and features and promotion and increasing the usability and diversity of the website. Most responses from participants were suggestions to improve the *Positive Choices* website’s layout to make it less cluttered and more visually appealing and engaging (especially to the student user group) and to improve website navigation. The other subthemes that were identified included feedback about making the website more accessible to multicultural communities and students with additional learning needs, suggestions for new content and features, and the need to increase promotion. In response to this feedback, redesign of the *Positive Choices* website was conducted from December 2020 to January 2021, in consultation with a specialist user experience company. The themes and subthemes from the participants’ feedback and actions taken in response to user suggestions are described in Multimedia Appendix 1.

Discussion

Principal Findings

Adolescence is a time of increased susceptibility to engaging in risk-taking behaviors such as AOD use. Prevention strategies designed to target modifiable risk factors have been demonstrated to be effective in reducing AOD use and related harms among adolescents [16,18]. Despite this evidence, effective AOD prevention strategies are not widely implemented in schools or by parents. *Positive Choices* was developed to help overcome some of the barriers faced by school communities and parents and promote widespread implementation of evidence-based prevention. This study used the RE-AIM framework to evaluate the success of *Positive Choices* in increasing awareness and implementation of evidence-based AOD prevention practices among school staff and parents across the five domains: reach, efficacy, adoption, implementation, and maintenance.

A total of 5 years following its launch, this Australian AOD prevention website has reached >1.7 million users, and the page views have continued to grow. The user reach of *Positive Choices* has expanded beyond Australia, with 59% of users currently being international. Promotion via a national social media campaign proved to be an effective method for increasing awareness within the Australian community, with awareness increasing from 8% to 14% among school staff and from 15% to 22% among parents after the campaign. The findings suggest that sustained promotion efforts may be required to maintain high levels of awareness about *Positive Choices*. Even among participants who were not using *Positive Choices*, most reported using other web-based sources to obtain AOD education information and resources, thus supporting the value of the internet as a tool for disseminating health information and promoting evidence-based prevention strategies [45,46].

Although evidence shows that effective AOD prevention strategies are not commonly implemented by schools [24] or parents [27], most school staff and parents in this study reported that they were already implementing evidence-based AOD prevention strategies. Moreover, following a brief interaction with the website, most school staff and parents reported an intention to shift toward evidence-based practices in cases where they were not already following the recommended prevention strategies for young people. The exception was the recommendation that parents modify their own alcohol use to model appropriate behavior for their children, which may indicate that changing their own behavior is a significant challenge for parents, which requires additional attention and support. The sample intended to maintain their use of the *Positive Choices* website in the future to obtain evidence-based information and resources. The enablers that facilitated adoption and implementation were ease of availability and good website usability. Both user groups reported high level of confidence in communicating about AOD-related topics. Study participants' suggestions for improvement pertained to some of these enablers (eg, improving navigation and making the website more engaging), and thus, have informed a recent website update.

The widespread use of web-based health promotion tools and websites by school staff and parents to access information and resources highlights the need for quality control measures. This will ensure that they are evidence-based, up to date, and engaging and use simple language. In addition, the websites themselves should be accessible and easy to use and navigate. Findings from robust evaluations will allow critical assessment of the benefits of such tools and websites, inform content, and inform website updates and developments to optimize their usability. Although there have been evaluations of mental health information websites [47,48], to the best of our knowledge, this is the first evaluation of a web-based health initiative that specifically promotes the translation of evidence-based AOD prevention resources for school communities, parents, and youth.

Limitations

A limitation of the study is that the findings rely on users' self-reported intentions to implement evidence-based strategies, rather than actual assessment of their subsequent behavior. Furthermore, the study design assessed participants' feedback and behavioral intentions after they interacted with the website for a relatively short period. Future studies with a pre-post study design will enable a more comprehensive evaluation, including assessment of whether the website affected subsequent behaviors and implementation of evidence-based strategies by school staff and parents. Another limitation is that the targeted campaign used to recruit participants for the evaluation study may have resulted in a sample selection bias. Most of the surveyed school staff and parents in the current sample reported that they were already implementing evidence-based prevention strategies and were confident about discussing alcohol and drug use. These results contrast with previous evidence suggesting low confidence and implementation of evidence-based AOD prevention strategies among parents and in schools [24,27], and thus, may reflect that our recruitment strategies attracted a sample who were already interested in and aware of evidence-based AOD prevention approaches.

Conclusions

The findings from the evaluation of *Positive Choices* demonstrate that the website reached 1.7 million users, and it has the capacity to be an effective strategy for disseminating evidence-based AOD prevention information and resources. Furthermore, this evaluation highlights the importance of investing in ongoing promotion to maintain or enhance awareness of health websites. As the use and acceptability of health education websites increase, developers and health care and research teams should ensure that health websites developed in the future are easy to navigate, are engaging, use simple language, contain evidence-informed resources, and are supported by ongoing promotional activities. This study provides methodology and recommendations to guide future evaluations of web-based health tools to determine their effect on behavioral and health outcomes.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Themes and subthemes from participants' feedback on the website.
[DOCX File , 30 KB - pediatrics_v5i3e34721_app1.docx]

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Abbreviations

AOD: alcohol and other drug
NSW: New South Wales
RE-AIM: reach, effectiveness, adoption, implementation, and maintenance
SUS: System Usability Scale

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Original Paper

Social Media Perceptions and Internet Verification Skills Associated With Human Papillomavirus Vaccine Decision-Making Among Parents of Children and Adolescents: Cross-sectional Survey

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Abstract

Background: Human Papillomavirus (HPV) vaccination is recommended for children aged 11-12 years in the United States. One factor that may contribute to low national HPV vaccine uptake is parental exposure to misinformation on social media.

Objective: This study aimed to examine the association between parents’ perceptions of the HPV vaccine information on social media and internet verification strategies used with the HPV vaccine decision-making stage for their child.

Methods: Parents of children and adolescents aged 9-17 years were recruited for a cross-sectional survey in North Texas (n=1192) and classified into 3 groups: children and adolescents who (1) were vaccinated, (2) unvaccinated and did not want the vaccine, and (3) unvaccinated and wanted the vaccine. Multinomial logistic regression models were estimated to identify factors associated with the HPV vaccine decision-making stage with children and adolescents who were vaccinated as the referent group.

Results: Of the 1192 respondents, 44.7% (n=533) had an HPV-vaccinated child, 38.8% (n=463) had an unvaccinated child and did not want the vaccine, and 16.4% (n=196) had an unvaccinated child and wanted the vaccine. Respondents were less likely to be “undecided/not wanting the vaccine” if they agreed that HPV information on social media is credible (adjusted odds ratio [aOR] 0.40, 95% CI 0.26-0.60; *P*=.001), disagreed that social media makes them question the HPV vaccine (aOR 0.22, 95% CI 0.15-0.33; *P*<.001), or had a higher internet verification score (aOR 0.74, 95% CI 0.62-0.88; *P*<.001).

Conclusions: Interventions that promote web-based health literacy skills are needed so parents can protect their families from misinformation and make informed health care decisions.

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KEYWORDS

HPV vaccination; human papillomavirus; social media; decision-making; vaccination; teens; adolescents; parent; USA; United States; misinformation; internet; survey; unvaccinated; child; online; health; literacy; decision; health care; decision; teen; vaccine

Introduction

Human papillomavirus (HPV) causes 34,800 anogenital and oropharyngeal cancer cases in the United States annually [1]. To prevent these cancer cases, the HPV vaccine is recommended for children aged 11-12 years. Additionally, unvaccinated persons can receive catch-up vaccination until the age of 26 years or participate in shared decision-making with a provider until the age of 45 years [2]. Despite this evidence-based recommendation, the rate of HPV vaccination is suboptimal. Healthy People 2030 aims to achieve a rate of 80% HPV vaccination coverage for adolescents [3], and although gains have been steady over the years, only 58.6% were up to date as of 2020 [4].

Parental exposure to health information on the internet and social media platforms may influence HPV vaccine awareness, decisions, and uptake. Most parents use the internet to search for information regarding their child's health, especially to help prepare for questions when seeing a doctor [5]. In a study on Google searches related to preventable infectious diseases, looking for vaccine information generally was not prevalent; however, the HPV vaccine was the exception [6]. Thus, exposure to web-based content regarding HPV vaccination may be common for some parents prior to discussing with health care providers. Furthermore, a North Carolina study found that parents who learned of the HPV vaccine on the internet were more willing to get their daughters vaccinated [7]. Similarly, adult internet users were more likely to be aware of the HPV vaccine compared to noninternet users [8].

Despite being a source of factual information regarding HPV vaccination, social media and internet sources can increase exposure to *misinformation* (ie, false information aiming to deceive the reader [9]). From 2014-2017, Twitter bots (ie, Twitter accounts that are automated to post content and create impressions) were used to spread vaccine misinformation on social media platforms [10]. HPV vaccine content on social media is often user-generated [11] and includes positive (in favor of vaccines) and negative (against vaccines) messages [12-18], which can mean that parents, children, and adolescents are exposed to a variety of content on social media—some of which is not credible.

Health literacy and internet verification skills may improve information seeking and help counteract the spread of misinformation. Health literacy refers to how a person accesses, understands, appraises, and uses health information [19]. Internet verification skills may assist in identifying the veracity of information [19]. Given the expansive amounts of misinformation and negative information about vaccines on social media [20], especially on HPV vaccination [13,17], internet verification skills assessing content and source may help individuals better distinguish between credible and noncredible sources. Developing strategies to combat misinformation and increase confidence in the HPV vaccine via social media is a goal for HPV vaccine–related research [21]. In this study, we examined the association between parents' perceptions of HPV vaccine information on social media and internet verification strategies used with the HPV vaccine decision-making stage for their child.

Methods

Sample and Data Collection

We used a purposive sample of parents of children and adolescents aged 9-17 years residing in 13 counties in North Texas. We contracted with 2 survey sampling and administration companies, 2M Research and Qualtrics, to field web-based surveys in English and Spanish. Both companies worked with third party vendors (eg, Marketing System Group and Poll Pay) to sample participants with children and adolescents aged 9-17 years residing in the 13-county catchment areas. Sample sizes for each county were based on county population densities. We used 2 different companies because they deployed different recruitment strategies to ensure a diverse sample. 2M Research mailed potential participants letters written in both English and Spanish introducing the study and directing the parent to the web-based survey URL. Qualtrics pushed the survey link via email to research panel participants. Data were collected in 2018.

The 80-item survey assessed factors hypothesized to influence HPV vaccine decision-making and vaccine hesitancy. Before beginning the survey, parents were oriented to the study and that continuing on to answer questions indicated consent. If parents reported having more than 1 child, the survey instructed them to complete the survey for the child whose age was closest to 11 years. The survey took approximately 15-20 minutes to complete. Only participants who completed the survey were included in the final analysis. Participants received a US $25 gift card.

Ethics Approval

The University of Texas Southwestern Medical Center Institutional Review Board approved this study (STU 092017-076).

Measures

The outcome variable was parental HPV vaccine decision-making for their child (see Multimedia Appendix 1 for specific items). This variable was operationalized as children and adolescents who were (1) already vaccinated, (2) unvaccinated and the parent was not aware, undecided, or did not want the HPV vaccine, and (3) unvaccinated and the parent wanted the HPV vaccine. This operationalization follows the World Health Organization's definition of vaccine hesitancy incorporating behaviors and attitudes [22]. Our analysis retained the subgroup of parents who accepted HPV vaccination for their child, which enabled comparisons among the 3 groups.

Independent variables included those related to perceptions about information on social media, trust in providers, internet verification skills, and demographics. Respondents specified their level of agreement to 2 statements regarding HPV vaccine information on social media ("is credible" and "makes me question the HPV vaccine"; see Multimedia Appendix 1). Due to the data distribution, response categories were collapsed from a 5-point Likert scale into 3 categories: strongly agree/agree, neutral, and disagree/strongly disagree. The "completely trust the doctor or nurse's judgement about my child's medical care" item was categorized as trust (strongly agree and agree) and distrust (neutral, disagree, and strongly disagree). Internet verification behaviors was measured with 9 items [23,24] on a frequency Likert scale (see Multimedia Appendix 1 [23,24] for details). Items were summed (range 0-9) with higher scores indicating more performance of verification skills (Cronbach α=.92) [23,24]. Demographic variables included the sex and age of the parent and child, parent's race/ethnicity, parent's educational attainment, the number of children, and the type of residence (rural, urban, or suburban).

Data Analysis

The distribution of participant characteristics was reported with descriptive statistics, stratified by child HPV vaccination status. All testing across child HPV vaccine status was reported with descriptive statistics, where the chi-square (categorical data) or Kruskal-Wallis (continuous data) test was used as appropriate. The Dwass-Steel-Critchlow-Fligner method was used for multiple comparisons testing. Univariate and multivariate multinomial logistic regressions were performed to identify factors associated with the 3-category HPV vaccine decision stage (children and adolescents who were vaccinated [referent], unvaccinated and did not want the HPV vaccine or was undecided, or unvaccinated and wanted the HPV vaccine). All data analysis was performed using SAS statistical software (version 9.4; SAS Institute).

Results

Sample Description

Overall, 1192 parents responded to the survey (Table 1). Among the 1192 parents, most were women (n=782, 65.6%), aged 35-44 years (n=518, 43.5%), who identified as white (n=716, 60.1%) and hold a college degree (n=747, 62.7%). Almost half (n=566, 47.5%) had a child aged 13-17 years and half (n=598, 50.2%) had 1 child. The participants resided across urban (n=471, 39.5%) and suburban (n=411, 34.5%) settings.

Most (n=1070, 89.8%) participants reported trusting their health care providers. With regard to social media, most were neutral about whether they perceived the HPV vaccination information on social media as credible (n=580, 48.7%) and were neutral about whether information on social media made them question the HPV vaccine (n=467, 39.2%). For HPV vaccination status, 533 (44.7%) parents had their child vaccinated for HPV, 463 (38.8%) had an unvaccinated child and did not want the vaccine, and 196 (16.4%) had an unvaccinated child and wanted the vaccine. The HPV vaccine decision stage was significantly associated with the parent's gender (*P*<.001), the parent's age (*P*=.02), the child's age (*P*<.001), the number of children (*P*=.007), trust in health care providers (*P*<.001), the credibility of HPV vaccine information on social media (*P*<.001), information on social media making them question HPV vaccination (*P*<.001), and internet verification behaviors (*P*<.001).

Table 1. Descriptive characteristics of parents of children and adolescents from the Dallas-Fort Worth area by human papillomavirus (HPV) vaccine decision-making status (N=1192).

Characteristic	Vaccinated[a] (n=533)	Unvaccinated did not want the vaccine[a] (n=463)	Unvaccinated and wanted the vaccine[a] (n=196)	Total (N=1192)	*P* value
Parent's gender, n (%)					<.001
Female	325 (61)	298 (64.4)	158 (80.6)	782 (65.6)	
Male	208 (39)	164 (35.4)	37 (18.9)	409 (34.3)	
Parent's age (years), n (%)					.02
18-24	15 (2.8)	14 (3)	7 (3.6)	36 (3)	
25-34	52 (9.8)	72 (15.6)	35 (17.9)	159 (13.3)	
35-44	228 (42.8)	208 (44.9)	82 (41.8)	518 (43.5)	
45-54	184 (34.5)	142 (30.7)	53 (27)	380 (31.9)	
55-64	48 (9)	22 (4.8)	17 (8.7)	87 (7.3)	
≥65	6 (1.1)	3 (0.6)	2 (1)	11 (0.9)	
Child's age (years), n (%)					<.001
<11	71 (13.3)	154 (33.3)	84 (42.9)	310 (26)	
11-12	133 (25)	127 (27.4)	57 (29.1)	317 (26.6)	
13-17	329 (61.7)	182 (39.3)	55 (28.1)	566 (47.5)	
Parent's race, n (%)					.14
White	325 (61)	264 (57)	127 (64.8)	716 (60.1)	
Non-White	208 (39)	198 (42.8)	68 (34.7)	475 (39.8)	
Parent's education, n (%)					.11
Did not attend college	84 (15.8)	101 (21.8)	35 (17.9)	220 (18.5)	
Some college	97 (18.2)	91 (19.7)	36 (18.4)	224 (18.8)	
College graduate	352 (66)	270 (58.3)	124 (63.3)	747 (62.7)	
County type, n (%)					.39
Urban	227 (42.6)	173 (37.4)	71 (36.2)	471 (39.5)	
Suburban	177 (33.2)	162 (35)	72 (36.7)	411 (34.5)	
Other	129 (24.2)	128 (27.6)	53 (27)	311 (26.1)	
Number of children, n (%)					.007
1	279 (52.4)	228 (49.2)	91 (46.4)	598 (50.2)	
2	194 (36.4)	167 (36.1)	82 (41.8)	443 (37.2)	
3	32 (6)	55 (11.9)	18 (9.2)	106 (8.9)	
4	8 (1.5)	5 (1.1)	4 (2)	17 (1.4)	
5	20 (3.8)	8 (1.7)	1 (0.5)	29 (2.4)	
Trust in providers, n (%)					<.001
Trust providers	516 (96.8)	370 (79.9)	183 (93.4)	1070 (89.8)	
Distrust providers	17 (3.2)	93 (20.1)	13 (6.6)	123 (10.3)	
HPV information on social media is credible, n (%)					<.001
Agree/strongly agree	226 (42.4)	96 (20.7)	50 (25.5)	372 (31.2)	
Neutral	217 (40.7)	259 (55.9)	104 (53.1)	580 (48.7)	
Disagree/strongly disagree	90 (16.9)	107 (23.1)	42 (21.4)	240 (20.1)	
Information on social media makes me question the HPV vaccine, n (%)					<.001
Agree/strongly agree	162 (30.4)	150 (32.4)	29 (14.8)	341 (28.6)	

Characteristic	Vaccinated[a] (n=533)	Unvaccinated did not want the vaccine[a] (n=463)	Unvaccinated and wanted the vaccine[a] (n=196)	Total (N=1192)	*P* value
Neutral	155 (29.1)	236 (51)	76 (38.8)	467 (39.2)	
Disagree/strongly disagree	216 (40.5)	75 (16.2)	91 (46.4)	383 (32.1)	
Internet verification scale[b], median (IQR)	3.9 (3.3-4.4)	3.6 (3.0-4.1)	3.8 (3.1-4.2)	3.8 (3.1-4.2)	<.001

[a] Outcome groups: vaccinated for HPV; unvaccinated and did not want or undecided about HPV vaccination; and unvaccinated and wanted HPV vaccination.

[b] Scale: range 0-9; higher value=more internet verification skills used.

Patterns of Association in the Multivariable Multinomial Model

Parents who were undecided or did not want their child to be vaccinated were compared to those with a vaccinated child. In the multivariable model (Table 2), the following characteristics were significantly associated with *increased* odds of being *undecided or not wanting the HPV vaccine* as compared to parents with a vaccinated child: having a child aged <11 years (vs aged 11-12 years; adjusted odds ratio [aOR] 2.38, 95% CI 1.56-3.63; *P*<.001); distrusting providers (vs those who trusted providers; aOR 6.37, 95% CI 3.58-11.32; *P*<.001); and disagreeing that HPV information on social media is credible (vs neutral; aOR 1.90, 95% CI 1.25-2.87; *P*=.002). Characteristics significantly associated with *decreased* odds of being *undecided/not wanting the vaccine* compared to parents with a vaccinated child included having a child aged 13-17 years (vs aged 11-12 years; aOR 0.53, 95% CI 0.37-0.76; *P*=.001); being a college graduate (vs not attending college; aOR 0.65, 95% CI 0.43-0.98; *P*=.04); agreeing that HPV information on social media is credible (vs neutral; aOR 0.40, 95% CI 0.26-0.60; *P*=<.001); disagreeing that social media made the parent question the HPV vaccine (vs neutral; aOR 0.22, 95% CI 0.15-0.33; *P*=<.001); and having a higher mean internet verification score (aOR 0.74, 95% CI 0.62-0.88; *P*=.001). Table 3 illustrates the consistent pattern of how the use of each verification skill is associated with a higher prevalence of having a vaccinated child than parents of an unvaccinated child who did not want the vaccine or were undecided.

Parents who wanted their child vaccinated were compared to those who have already vaccinated their child. In the multivariable model, the following characteristic was significantly associated with *increased odds* of *wanting the HPV vaccine* as compared to parents with a vaccinated child: having a child aged <11 years (vs aged 11-12 years; aOR 3.07, 95% CI 1.89-5.00; *P*<.001). Characteristics significantly associated with *decreased* odds of *wanting the vaccine* compared to parents with a child already vaccinated included being a male parent (vs female parent; aOR 0.42, 95% CI 0.27-0.64; *P*<.001); having a child aged 13-17 years (vs aged 11-12 years; aOR 0.34, 95% CI 0.21-0.54; *P*<.001); and agreeing that social media made parent question the HPV vaccine (vs neutral; aOR 0.41, 95% CI 0.23-0.74; *P*=.003). The mean internet verification scale was not significantly associated with parents wanting the HPV vaccine compared to the vaccinated group (*P*=.96).

Table 2. Multinomial logistic regression modeling of the human papillomavirus (HPV) vaccine decision-making stage among parents of children and adolescents in the Dallas-Fort Worth area (N=1192).

Characteristic	Unvaccinated and did not want the vaccine[a], aOR[b] (95% CI)	*P* value	Unvaccinated and wanted the vaccine[a], aOR (95% CI)	*P* value
Parent's gender				
Female	Reference		Reference	
Male	1.19 (0.87-1.62)	.28	0.42 (0.27-0.64)	<.001
Parent's age (years)				
18-24	Reference		Reference	
25-34	1.31 (0.51-3.37)	.57	1.06 (0.33-3.34)	.93
35-44	1.19 (0.49-2.90)	.70	0.76 (0.25-2.28)	.62
45-54	1.15 (0.46-2.87)	.77	0.74 (0.24-2.31)	.61
55-64	0.61 (0.22-1.74)	.36	1.12 (0.33-3.85)	.86
≥65	1.19 (0.20-7.18)	.85	1.51 (0.20-11.33)	.69
Child's age (years)				
<11	2.38 (1.56-3.63)	<.001	3.07 (1.89-5.00)	<.001
11-12	Reference		Reference	
13-17	0.53 (0.37-0.76)	<.001	0.34 (0.21-0.54)	<.001
Parent's education				
Did not attend college	Reference		Reference	
Some college	0.82 (0.51-1.32)	.42	0.78 (0.42-1.43)	.42
College graduate	0.65 (0.43-0.98)	.04	0.92 (0.55-1.55)	.76
Number of children				
1	Reference		Reference	
2	1.03 (0.75-1.42)	.86	1.17 (0.79-1.74)	.43
3	1.42 (0.82-2.46)	.21	1.11 (0.56-2.22)	.77
4	0.88 (0.22-3.47)	.85	1.49 (0.39-5.74)	.57
5	0.51 (0.18-1.39)	.19	0.18 (0.02-1.49)	.11
Trust in providers				
Trust providers	Reference		Reference	
Distrust providers	6.37 (3.58-11.32)	<.001	1.84 (0.83-4.07)	.13
County of residents				
Urban	Reference		Reference	
Suburban	1.34 (0.95-1.89)	.10	1.17 (0.76-1.80)	.47
Other	1.30 (0.90-1.89)	.17	1.21 (0.76-1.92)	.42
HPV information on social media is credible				
Agree/strongly agree	0.40 (0.26-0.60)	<.001	0.64 (0.40-1.03)	.07
Neutral	Reference		Reference	
Disagree/strongly disagree	1.90 (1.25-2.87)	.002	1.08 (0.65-1.79)	.77
Information on social media makes me question the HPV vaccine				
Agree/strongly agree	0.95 (0.64-1.41)	.80	0.41 (0.23-0.74)	.003
Neutral	Reference		Reference	
Disagree/strongly disagree	0.22 (0.15-0.33)	<.001	0.98 (0.63-1.51)	.92
Internet verification scale	0.74 (0.62-0.88)	.001	0.99 (0.80-1.24)	.96

[a] Reference group for outcomes: having a child who was vaccinated.

[b] aOR: adjusted odds ratio.

Table 3. Proportion of participants who report the use of internet verification skills every time/almost all the time by human papillomavirus (HPV) vaccination status among parents of children and adolescents in the Dallas-Fort Worth area (N=1192).

Internet verification skill	Vaccinated (n=533), n (%)	Unvaccinated and wanted the vaccine (n=196), n (%)	Unvaccinated and did not want the vaccine (n=463), n (%)	*P* value
Check if the website information is up to date	388 (72.8)	134 (68.4)	288 (62.2)	.005
Check if the website information is complete with all the need-to-know info	378 (70.9)	128 (65.3)	278 (60)	.007
Think about whether the writer is giving facts or opinion	402 (75.4)	140 (71.4)	298 (64.4)	<.001
Check other places to see if the information is true	387 (72.6)	140 (71.4)	310 (67)	.15
Think about why the author posted the information	297 (55.7)	95 (48.5)	208 (44.9)	.003
Check to see who wrote the website	326 (61.2)	104 (53.1)	236 (51)	.01
Look for recommendations from someone they know	289 (54.2)	83 (42.4)	209 (45.1)	.01
Check to see if the website or author gives contact information	268 (50.3)	92 (46.9)	151 (32.6)	<.001
Check to see if the author lists their expertise on the topic	336 (63)	113 (57.7)	246 (53.1)	.004

Discussion

Prior to entering a physician's office, parents may be exposed to information on HPV vaccination via the internet and social media. Although some information may be useful for informed decision-making on HPV vaccination, misinformation also exists [17]. This study explored how internet verification skills and perceptions of HPV vaccine information on social media relate to HPV vaccination and decision-making among parents of children and adolescents. Overall, we found that parents' trust in providers, perceptions of HPV vaccine information credibility on social media, reporting that social media information makes one question HPV, and internet verification skills were related to *not* wanting HPV vaccination for their child. The parent's gender, younger age of the child, and prompts for questioning HPV vaccination based on social media information were related to wanting the vaccine.

Parents of vaccinated children and adolescents reported performing more internet verification behaviors compared to parents in the unvaccinated and unwanted group. These behaviors included checking that the website is up to date and has a credible author and cross-checking with other sources. Our finding may explain why parents with a vaccinated child do not question information they see on social media, because they have the internet verification skills to filter through misinformation. Previous research has found that parents desire guidance on how to search and assess the reliability of information found on the internet [5]. Empowering parents with health literacy skills to filter health information on the internet, particularly related to vaccines, may be an important strategy to promote positive attitudes and intentions toward vaccination and, ultimately, HPV vaccine uptake.

Overall, many people find it difficult to distinguish credible and noncredible information sources [25]; however, this finding may be changing with exposure to more information on the vaccine development process with COVID-19 vaccines. The field needs to examine how COVID-19 vaccine–specific attitudes influence the attitudes and uptake of other vaccines. For example, parents with fewer internet verification skills may question the HPV vaccine more given the COVID-19 media coverage, which could result in additional questioning when discussing the HPV vaccine with providers [26]. The ubiquitous nature of social media results in high exposure to potential misinformation, which may increase parental hesitancy and potentially frustrate health care providers due to the challenges associated with managing patient concerns from social media sources. To encourage vaccination, providers must attend to parents' concerns in a nonconfrontational and nonjudgmental manner with parents who question vaccines [26].

Provider recommendation and discussion are imperative to HPV vaccine initiation and completion among adolescents [27,28]. Although provider-patient communication is a component of most medical education curricula, some providers express low confidence in their ability to influence parents regarding vaccination [29]. In a recent study, about a third of providers reported that over 10% of parents of adolescents in their practice expressed HPV vaccine hesitancy, whereas over 50% of pediatricians in the same study did not feel confident responding to parents' misinformation obtained from the internet/social media or the news [30]. The quality of provider recommendations has consistently predicted HPV vaccine initiation and completion, and multiple interventions to educate providers on reliable techniques (patient reminders, presumptive recommendation, and reference to HPV vaccination as cancer prevention) are available to support providers and reinforce vaccine communication skills [31,32].

Perceptions of credibility of social media HPV vaccination information is relevant for parents' HPV vaccine decisions.

Specifically, parents who did not believe that the information they saw on social media is credible were more likely to not want the vaccine. This finding may be attributed to the types of information parents are exposed to on social media. Although information on HPV vaccination on the internet is both positive and negative [17], social media algorithms and social networks may bias the types of information parents are exposed to so that it aligns with their beliefs. As such, additional research is needed to explore how an individual's beliefs, health literacy skills, and information-seeking behaviors intersect with community and group norms driven by social media platforms. Moreover, researchers should test novel interventions that adapt messaging in real time based on evolving social media content; recent advances in artificial intelligence and machine learning are potential avenues moving forward. However, previous research has found that tools, such as web-based smart assistants, do not always provide credible HPV vaccine information [33]. There is also evidence that combatting misinformation in a "myth-versus-fact" format tends to backfire and reinforce the preexisting belief in the myth [34,35].

Similarly, parents who did not want the HPV vaccine were less likely to question the vaccine based on exposure to information on social media than the vaccinated group. In contrast, parents who wanted their child vaccinated were less likely to think the information on social media makes them question the HPV vaccine than parents with a vaccinated child. Thus, persons who do not intend to vaccinate their child for HPV may already be exposed to information that confirms their beliefs on vaccination, whereas persons who intend to vaccinate their children may not have enough information to transition to the vaccine decision-making stage. Social media users on Facebook and Twitter are likely to be exposed to like-minded posts via the echo chamber effect [36]. For example, parents with a vaccinated child could have been exposed to more pro-vaccine messages, which could heighten perceptions of credibility and lead to vaccination behaviors. Additional longitudinal studies are needed to examine the temporality of the types of information exposure on the internet/social media and future vaccine behavior. Moreover, as social media is used to share information, developing novel strategies to combat misinformation on various platforms is urgently needed. Promoting evidence-based information on vaccination on the internet and social media via trusted messengers, such as providers, may be an effective approach compared to the removal and censorship of anti-vaccine content alone [37]. Given that not all persons engage in internet verification skills when consuming health information, providers and other trusted messengers, such as other parents [38], could be an accurate dissemination channel on social media and the internet. This process would require the development of social media strategies to reach intended audiences and relying on algorithms so that the content is more prominent in search results and social media feeds. However, a recent study found that anti-vaccine social media posts are associated with increases in mothers' general vaccine hesitancy and decreases in their children's HPV vaccination rates, whereas pro-vaccine content were not associated with hesitancy nor vaccination rates [39]. As a whole, the literature on social media and HPV vaccination is in its infancy, and a recent systematic review by Ortiz et al [40] recommends more rigorous and systematic research.

Finally, another key finding was that parents who did not want their child vaccinated for HPV were more likely to distrust providers than parents who vaccinated their child. Taken in context with other study findings, the parents who do not want their child vaccinated may be going to social media to corroborate their beliefs or are exposed to misinformation on the internet contributing to their beliefs. Studies are needed to experimentally test how exposure to misinformation and correct information on social media influences decisions for vaccination, and how and who is best to intervene in this evolving setting. Ultimately, a segmented approach to vaccine information dissemination is needed to reach different parental groups on the hesitancy spectrum.

These findings should be recognized in the context of study limitations. First, this study was cross-sectional, and we could not assess the temporality between exposure to information on social media, internet verification skills, and the vaccine decision-making stage. As such, respondents may have adopted attitudes that align with their current behavior to reduce cognitive dissonance. Second, these data were derived from a sample in North Texas and may not be generalizable to other US regions. Additionally, HPV vaccination status was self-reported, and misclassification bias for the outcome variable may be present. Finally, these data were collected prior to the COVID-19 pandemic, and perceptions regarding social media and credibility may have shifted. Internet verification skills and strategies, however, could similarly impact COVID-19 vaccine decision-making. These findings could be relevant to apply toward vaccine hesitancy studies about COVID-19.

Although many strategies to promote HPV vaccination have focused on the provider recommendation during a visit, extensive exposure to social media before a visit may inform parents' beliefs and attitudes toward HPV vaccination and, ultimately, their decision to vaccinate their child. Thus, interventions that promote web-based health literacy skills are needed so that parents can make informed health care decisions with their providers. Social media will remain an ongoing obstacle to evidence-based health information, and public health responses must adapt to this challenge accordingly.

Conflicts of Interest

ELT is a consultant with Merck Pharmaceuticals for human papillomavirus (HPV) vaccination work unrelated to this manuscript.

Multimedia Appendix 1
Survey items used in the analysis.

[DOCX File , 24 KB - pediatrics_v5i3e38297_app1.docx]

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Abbreviations

aOR: adjusted odds ratio
HPV: human papillomavirus

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Original Paper

User Experience of a Computer-Based Decision Aid for Prenatal Trisomy Screening: Mixed Methods Explanatory Study

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Abstract

Background: Mobile health tools can support shared decision-making. We developed a computer-based decision aid (DA) to help pregnant women and their partners make informed, value-congruent decisions regarding prenatal screening for trisomy.

Objective: This study aims to assess the usability and usefulness of computer-based DA among pregnant women, clinicians, and policy makers.

Methods: For this mixed methods sequential explanatory study, we planned to recruit a convenience sample of 45 pregnant women, 45 clinicians from 3 clinical sites, and 15 policy makers. Eligible women were aged >18 years and >16 weeks pregnant or had recently given birth. Eligible clinicians and policy makers were involved in prenatal care. We asked the participants to navigate a computer-based DA. We asked the women about the usefulness of the DA and their self-confidence in decision-making. We asked all participants about usability, quality, acceptability, satisfaction with the content of the DA, and collected sociodemographic data. We explored participants' reactions to the computer-based DA and solicited suggestions. Our interview guide was based on the Mobile App Rating Scale. We performed descriptive analyses of the quantitative data and thematic deductive and inductive analyses of the qualitative data for each participant category.

Results: A total of 45 pregnant women, 14 clinicians, and 8 policy makers participated. Most pregnant women were aged between 25 and 34 years (34/45, 75%) and White (42/45, 94%). Most clinicians were aged between 35 and 44 years (5/14, 36%) and women (11/14, 79%), and all were White (14/14, 100%); the largest proportion of policy makers was aged between 45 and 54 years (4/8, 50%), women (5/8, 62%), and White (8/8, 100%). The mean usefulness score for preparing for decision-making for women was 80/100 (SD 13), and the mean self-efficacy score was 88/100 (SD 11). The mean usability score was 84/100 (SD 14) for pregnant women, 77/100 (SD 14) for clinicians, and 79/100 (SD 23) for policy makers. The mean global score for quality was 80/100 (SD 9) for pregnant women, 72/100 (SD 12) for clinicians, and 80/100 (SD 9) for policy makers. Regarding acceptability, participants found the amount of information just right (52/66, 79%), balanced (58/66, 88%), useful (38/66, 58%), and sufficient (50/66, 76%). The mean satisfaction score with the content was 84/100 (SD 13) for pregnant women, 73/100 (SD 16) for clinicians, and 73/100 (SD 20) for policy makers. Participants thought the DA could be more engaging (eg, more customizable) and suggested strategies for implementation, such as incorporating it into clinical guidelines.

Conclusions: Pregnant women, clinicians, and policy makers found the DA usable and useful. The next steps are to incorporate user suggestions for improving engagement and implementing the computer-based DA in clinical practice.

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KEYWORDS

shared decision-making; computer-based decision aid; prenatal screening; trisomy; Down syndrome; mixed methods

Introduction

Pregnant women and their partners must decide whether to undergo prenatal screening to assess the risk of certain genetic conditions (eg, the presence of Down syndrome) in the fetus [1]. However, they may be unaware of the implications of the various options, unclear about which implications matter most, or unaware that they can choose not to do the test at all [1]. The decision regarding screening is complex as it may lead to other difficult decisions (eg, pregnancy termination) [2]. Thus, pregnant women and their partners have numerous decisional needs regarding prenatal screening that are rarely addressed by health care systems [1]. As a result, many experience decisional conflicts (discomfort with the decision made), which may later translate into decision regret [3].

Shared decision-making (SDM) is both a patient-centered philosophy of care and a process whereby clinicians engage patients as partners to make choices about care based on clinical evidence and patients' values and preferences [4]. This fosters both informed consent and patient empowerment [1,5-7]. In deciding about prenatal screening, SDM seems a promising approach to supporting women and their partners, as it is a preference-sensitive decision (ie, one for which there is no "best choice"). To support women in these decisions, physicians must solicit patients' values and preferences and communicate probabilistic evidence in an understandable manner. Women and clinicians are both usually willing to engage in SDM but require effective decision support tools. This is especially true for women with less education, who exhibit lower decision self-efficacy (self-confidence about decision-making) [8]. Therefore, there are increasing calls for improving strategies for communicating risks and benefits, and for deliberation tools such as decision aids (DAs) [9].

DAs provide a detailed, specific, and personalized focus on options and outcomes to prepare people for decision-making before or between consultations with their physicians [7]. They can be in the form of brochures, booklets, webpages, or apps that provide users with information and help clarify their values and preferences regarding options [7,10-12]. They have been shown to be effective in increasing knowledge, patient-clinician communication, and the use of options that are beneficial to most while reducing the overuse of options that are not beneficial [7]. In pregnancy care, the use of DAs has shown positive effects on informed decision-making [13] and is associated with more value-congruent choices [14].

Computer-based DAs, such as in the form of an app, have the advantage of being accessible to people on their digital devices, can be customized to fit the needs of users, and can automatically integrate the latest medical evidence. Mobile health (mHealth) apps such as computer-based DAs have been shown to have a favorable impact on SDM and patient satisfaction with patient-clinician interactions [15].

We recently developed a computer-based DA for prenatal screening in partnership with a commercial mHealth firm [16]. In preparation for a large-scale rollout, we sought to assess its usability and usefulness among pregnant women, clinicians, and policy makers.

Methods

Study Design and Settings

This mixed methods sequential explanatory study pilot-tested the new computer-based DA. For reporting, we used the Mixed Methods Article Reporting Standards (MMARS) [17] and the Standards for Universal reporting of patient Decision Aid Evaluation studies (SUNDAE) checklists (Multimedia Appendix 1) [18].

Participants and Recruitment

The participants were pregnant women, clinicians, and policy makers. Pregnant women were recruited at 3 clinical sites in Quebec City: (1) the *Maison des naissances de la Capitale-Nationale* (a birthing center), (2) the Obstetrics and Gynecology Department at the *Centre hospitalier universitaire de Québec*, and (3) the Family Medicine Unit at St-François d'Assise Hospital. Approval for recruitment was obtained from each clinical site manager. A research assistant and students recruited pregnant women in the waiting rooms of the participating sites. Clinicians involved in prenatal care were recruited from the same birthing center and 2 other clinical sites in Lévis, Quebec: the Obstetrics and Gynecology Department of the Hôtel-Dieu de Lévis Hospital and the *Maison des naissances Mimosa*. We identified policy makers from the organigrams of organizations and institutions interested in prenatal screening (eg, Quebec's Ministry of Health, its public health authority, and a rehabilitation centre, the *Institut de réadaptation en déficience physique de Québec*) and contacted them by email. Clinicians and policy makers were also recruited from professional and social networks using the snowball sampling method.

Eligibility Criteria

As we did not want to interfere with the outcome of their decisions regarding prenatal screening, we recruited women who had already made the decision to answer questions about the DA. Women in Quebec make the decisions at 16 weeks of pregnancy. Therefore, eligible women had to (1) be >16 weeks pregnant or have given birth in the previous year, (2) have made a decision about prenatal screening for trisomy, and (3) be aged at least 18 years. A cutoff of 1 year was chosen to minimize the forgetting bias effect. We excluded women who had participated in previous studies on prenatal screening conducted by our team [19-21]. We also excluded women who presented with a high-risk pregnancy (eg, pre-eclampsia, gestational diabetes, or multiple pregnancies) because of ethical considerations. High-risk pregnancies can be emotionally distressing and accompanied by physical disabilities. Eligible clinicians were involved in prenatal screening, and eligible policy makers had decisional responsibilities in the health and social services sector. All participants had to be able to speak and write in French or English and be able to give informed consent.

Computer-Based DA

On the basis of a validated paper-based DA [22], the computer-based DA was developed and tested by the project leader and 2 professionals from Greybox Solutions Inc. It is available on their platform [16]. The computer-based DA menu has 5 tabs: home, trisomy, tests, test comparison, and questionnaire. The home page outlines the options available and provides advice on how to make informed decisions. The trisomy page presents information on trisomy 21, 18, and 13, as well as the main risk factor (maternal age) and the estimated risk of trisomy by maternal age in a population of 10,000 pregnant women. The tests page presents details on screening and diagnostic tests for trisomy available in the province of Quebec. The comparison page compares the overall performance of different tests or combinations of tests (eg, sensitivity and specificity). The questionnaire page includes a values and preferences clarification exercise to help users consider what matters most about the benefits and risks of the options. It has 5 subtabs. The first presents the benefits and risks of performing or not performing a test (any test). It also has empty boxes where users can enter the benefits and risks not included in our list. Users rate the importance they attach to each benefit and risk on a scale of 0=not important to 10=very important. The second subtab summarizes the user's benefit and risk assessment for performing a test or not performing a test (any test) to help them decide whether to take the test. If they decide to take the test, the third subtab provides information on the available tests for comparison purposes based on the week of pregnancy at which the test can be done, waiting time for results, detection rate, accuracy, potential cost, and other factors (to be completed by the user), whose importance is rated by the users on a scale from 0 to 10. The fourth subtab provides a summary of the importance that users had assigned to each factor to help them select the best test. Once they have made their selection, the fifth subtab presents the *SURE* test for evaluating the person's certainty about the decision made (Sure of myself, understand information, risk-benefit ratio, and encouragement) [3]. On this page, users may enter their email address and receive a summary of their answers to be discussed later with their partners and accompanying clinicians. The computer-based DA is available in French and English.

Data Collection

Overview

Meetings with pregnant women lasted for approximately 45 minutes. First, the research assistant invited women to participate and, if they agreed, presented the study details and collected signed consent forms. Subsequently, women were each given a tablet (iPad Wi-Fi, 6th Generation, model 1893) with a link to the computer-based DA, which they could navigate at their leisure. There were no specific instructions, and research professionals were available to answer questions. Women then self-completed a questionnaire on sociodemographics (including the partner's), perceived usefulness, self-efficacy, usability, quality, acceptability, and satisfaction with the content in their own time. A total of 3 main objectives directed the choice of variables. First, based on the social learning theory [23], we used variables that would inform us about whether the DA would give women the self-confidence (self-efficacy) to make a health decision and whether it prepared them adequately to meet with a health provider to make an informed, value-congruent decision (perceived usefulness), in line with the goals of SDM. Second, using scales developed specifically for digital tools, we examined women's perceptions of whether the DA was efficient, easy, and enjoyable to use (usability and quality). Third, we sought perceptions more specifically of the DA content; that is, variables such as comprehensibility, presentation (eg, balance), and length (acceptability and satisfaction with content). Finally, participants were interviewed, and their experiences with computer-based DA were audio-recorded. The questionnaire and interview guide were reviewed in a team meeting, and, in keeping with the comments received, questions were reformulated for better comprehension. The participating women received compensation for CAD $40 (US $30.7). Data collection for clinicians and policy makers was different: recruits were contacted by email and asked to sign and return a consent form to begin the study. After receiving consent, we emailed them the link to the computer-based DA and the questionnaire. They tried the computer-based DA, filled out the questionnaire at their own pace, and emailed it back. We then scheduled a 15-minute audio-recorded interview at a time that suited them. Clinicians and policy makers did not receive any compensation for their participation. Meetings took place either at our research center or at the participants' place of choice (home or workplace).

Outcomes and Measures

We assessed perceived usefulness and decision self-efficacy among women using the Preparation for Decision-Making scale [24] and the Decision Self-Efficacy scale [25], respectively. We assessed perceptions among women, clinicians, and policy makers regarding the usability, quality, and acceptability of the computer-based DA and their satisfaction with its content using the System Usability Scale [26,27], the user version of the Mobile App Rating Scale (uMARS) [28], the acceptability questionnaire by O'Connor and Cranney [29], and a self-developed satisfaction with the content questionnaire (Table 1). The perspectives of clinicians and policy makers on these outcomes are important as SDM is a 2-way process, with clinicians sharing evidence and patients reflecting their life experiences, preferences, and values. Clinicians and policy makers are also likely to be involved in integrating DAs into clinical pathways and protocols. The satisfaction questionnaire was developed by our team and, therefore, was not validated. We asked participants to rate (*disagree very much* to *agree very much*) whether they were satisfied with the content of the computer-based DA on a 5-point scale. Specifically, we asked participants whether they were satisfied with the information regarding the prevalence and description of trisomy 21, screening tests, risks associated with each screening test, advantages and disadvantages of each screening option, and preferences and decisional comfort.

Table 1. Variables and measurement tools.

Variable	Measurement tool	Authors	Purpose	Number of items, scale	Example of question	Psychometric properties in the literature	Psychometric properties in the study sample
Perceived usefulness	Preparation for Decision-Making scale	Graham and O'Connor [24]	Evaluates how useful the computer-based DA[a] is in preparing participants to communicate about the decision with their practitioner in a consultation	10 items, 5-point Likert scale (1=strongly disagree to 5=strongly agree)	"Did this educational material help you think about which pros and cons are most important?"	Cronbach α ranging from .92 to .96	Cronbach α of .85 for pregnant women
Self-efficacy	Decision Self-Efficacy scale	O'Connor [25]	Measures self-confidence or belief in one's abilities of decision-making, including shared decision-making	11 items, 5-point Likert scale (1=not at all confident to 5=very confident)	"I feel confident that I can get the facts about the choices available to me"	Cronbach α coefficient of .92	Cronbach α of .88 for pregnant women
Usability of the computer-based DA	System Usability Scale	Brooke [30]	Used to improve prototype mobile technologies by measuring preliminary needs of users, user experience, and usability, including the efficacy and satisfaction with which users accomplish specific tasks	10 items, 5-point Likert scale (1=strongly disagree to 5=strongly agree)	"I thought there was too much inconsistency in this system."	Cronbach α coefficient of .91	Cronbach α of .88 for pregnant women and .87 for clinicians
Quality of the computer-based DA	User version of the Mobile App Rating Scale	Stoyanov et al [28]	Measures the quality of an app through its 5 criteria categories: entertaining (whether the app is fun or entertaining to use), interest (whether it is interesting to use), customization (whether it allows the customization of settings and preferences), interactivity (whether it allows user input, provides feedback, and contains prompts), target group (whether its content is appropriate for the target audience)	20 items, 5-point Likert scale (1=inadequate, 2=poor, 3=acceptable, 4=good, and 5=excellent)	"Entertainment: Is the app fun or entertaining to use? Does it have components that make it more fun than other similar apps? 1) Dull, not fun or entertaining at all; 2) Mostly boring; 3) OK, fun enough to entertain user for a brief time (<5 minutes); 4) Moderately fun and entertaining, would entertain user for some time (5-10 minutes total); 5) Highly entertaining and fun, would stimulate repeat use."	Cronbach α=.90	Cronbach α of .61 for pregnant women and .75 for clinicians

Variable	Measurement tool	Authors	Purpose	Number of items, scale	Example of question	Psychometric properties in the literature	Psychometric properties in the study sample
Acceptability of the computer-based DA	Acceptability questionnaire	O'Connor and Cranney [29]	Evaluate the comprehensibility of components, length, amount of information, sufficiency of information, balance in option presentation, and overall suitability for decision-making through structured and semistructured questions	10 items, variable (2-4 choices of answers for the structured questions)	"The amount of information was: 1) too much information; 2) too little information; 3) just right."	N/A[b]	N/A
Satisfaction with the content of the computer-based DA	Satisfaction questionnaire developed based on the literature	Self-developed	Each item related to a specific page of the computer-based DA	6 items, 5-point Likert scale (1=strongly disagree to 5=strongly agree)	"I am satisfied with the information on the various screening tests for Trisomy 21."	Not validated	Cronbach α of .77 for pregnant women and .83 for clinicians

[a] DA: decision aid.

[b] N/A: not applicable.

Interview Guide

We qualitatively explored the participants' reactions to the computer-based DA and solicited their suggestions. We developed a dynamic interview guide based on the uMARS scale and its subscales (engagement, functionality, aesthetics, information, and global evaluation) [28]. After the participants completed the questionnaire, the research assistant selected items receiving a poorer evaluation (ie, a rating of 1=inadequate, 2=poor, or 3=acceptable) and asked for explanations and suggestions for improvement. When all items received a good rating, the research assistant asked general questions, as well as suggestions for improvement. Clinicians and policy makers were also asked for ideas about implementing the DA. The interviews were conducted by a research professional assisted by a trainee or student who took notes.

Sample Size

We recruited a purposive sample of pregnant women, clinicians, and policy makers. We recruited identical sample sizes for the quantitative and qualitative phases [31]. Using data from a study involving 60 in-depth interviews, Guest and al [32] found that data saturation occurred within the first 12 interviews. Thus, we planned to recruit up to 15 pregnant women per clinical site (a total of 45 women), 15 clinicians per clinical site (a total of 45 clinicians), and 15 policy makers until data saturation was achieved. This translated into a total of 105 participants.

Data Analysis

We used descriptive statistics (means, SDs, percentages, and 95% CIs) for the sociodemographic characteristics and quantitative variables. Quantitative analyses were performed using SAS (version 9.4; SAS Institute). We proceeded to imputation using means to treat the missing data.

The interviews were audio recorded and transcribed verbatim. The transcripts were checked by a second individual. We performed deductive and inductive thematic analyses of the transcripts using qualitative data analysis software (NVivo, version 12, QSR International). We used the Braun and Clarke [33] step-by-step guide to conducting thematic analyses. Qualitative analysts independently read the transcripts to familiarize themselves with the data and attached initial codes according to the most basic elements of the raw data. Coding was performed by TTA, CP, and 2 trainees. They then met to cross-check their coding and analyzed the categories and links between them. Discrepancies were discussed until a consensus was reached.

Ethics Approval and Consent to Participate

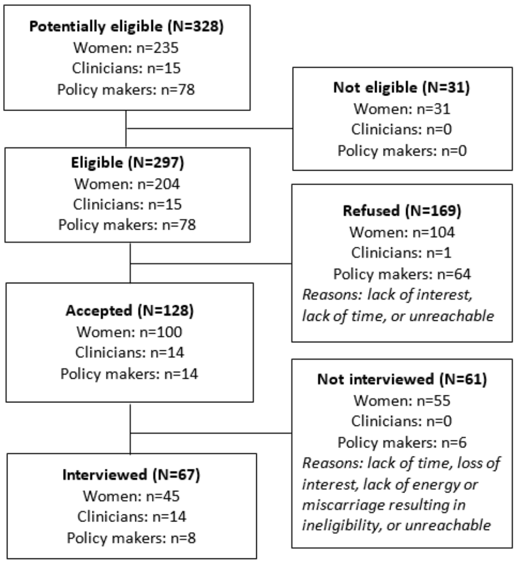
This project, entitled "TechnOlogy assisted PrenaTal screEning deCisions," was approved by the ethics committee of the Centre hospitalier universitaire de Québec-Université Laval (MP-20-2019-4451) and the Centre intégré de santé et de services sociaux de Chaudière-Appalaches (MEO-20-2019-632). The project was described to eligible participants, and they were informed that the data were anonymous and confidential. Those who wished to participate provided written informed consent.

Results

Participants' Characteristics

From February 2019 to May 2020, a total of 328 participants were approached, of whom 297 (90.5%) were eligible, 169 (51.5%) declined to participate, and 128 (39%) agreed to participate. Of these 128 participants, 67 (52.3%) were interviewed, including 45 (35.1%) pregnant women, 14 (10.9%) clinicians, and 8 (6.2%) policy makers (Figure 1). Participants who declined to participate cited a lack of interest or time. Participants who canceled their participation mentioned a lack of time, loss of interest, lack of energy, or miscarriage resulting in ineligibility. The others were either unreachable or did not respond to calls or messages.

Figure 1. Flowchart of participants: pregnant women, clinicians, and policy makers.



Most pregnant women participating in the study were aged between 25 and 34 years (34/45, 75% women, and 23/45, 51% partners), White (42/45, 94% women, and 40/45, 89% partners), and university educated (29/45, 64% women, and 25/45, 56% partners), and had a relatively high socioeconomic status (21/45, 47% had an annual family income of ≥CAD $100,000 [US $76,875]; Table 2).

Most clinicians were aged between 35 and 44 years (5/14, 36%), women (11/14, 79%), and White (14/14, 100%). Four types of clinicians participated in this study: midwives (7/14, 50%), family physicians (3/14, 21%), gynecologist-obstetricians (3/14, 21%), and neonatologists (1/14, 7%). The average number of years of experience was 13.3 (SD 11.5) years, and the average number of pregnancy follow-ups per week was 10.4 (SD 9; Table 2).

Most policy makers were aged between 45 and 54 years (4/8, 50%), women (5/8, 62%), and White (8/8, 100%). The 8 policy makers included 2 (25%) managers, 2 (25%) socioeconomic research and planning officers, 2 (25%) researchers, 1 (12%) assistant director, and 1 (12%) expert advisor. The mean number of years of experience was 17 (SD 9.5) years (Table 2).

Table 2. Participant characteristics (N=67).

Characteristics	Women (n=45)	Partners (n=45)	Clinicians (n=14)	Policy makers (n=8)
Age (years), n (%)				
18-24	3 (7)	0 (0)	0 (0)	0 (0)
25-34	34 (75)	23 (51)	3 (21)	2 (25)
35-44	7 (16)	16 (36)	5 (36)	0 (0)
45-54	1 (2)	1 (2)	1 (7)	4 (50)
55-64	0 (0)	0 (0)	4 (29)	2 (25)
Missing data	0 (0)	5 (11)	1 (7)	0 (0)
Gender, n (%)				
Woman	N/A[a]	2 (5)	11 (79)	5 (62)
Man	N/A	42 (93)	3 (21)	3 (38)
Other	N/A	0 (0)	0 (0)	0 (0)
Missing data	N/A	1 (2)	0 (0)	0 (0)
Ethnicity, n (%)				
White	42 (94)	40 (89)	14 (100)	8 (100)
African or African American	1 (2)	2 (5)	0 (0)	0 (0)
Indigenous	1 (2)	1 (2)	0 (0)	0 (0)
Asian	0 (0)	1 (2)	0 (0)	0 (0)
Other	1 (2)	0 (0)	0 (0)	0 (0)
Missing data	0 (0)	1 (2)	0 (0)	0 (0)
Language, n (%)				
French	44 (98)	41 (90)	14 (100)	8 (100)
English	0 (0)	2 (5)	0 (0)	0 (0)
Other	1 (2)	0 (0)	0 (0)	0 (0)
Missing data	0 (0)	2 (5)	0 (0)	0 (0)
Residency status, n (%)				
Canadian	39 (87)	39 (87)	14 (100)	7 (88)
Permanent or temporary resident	6 (13)	4 (9)	0 (0)	1 (12)
Missing data	0 (0)	2 (4)	0 (0)	0 (0)
Civil status, n (%)				
Single	10 (22)	10 (22)	—[b]	—
Married or in a common law relationship	34 (76)	32 (71)	—	—
Separated	1 (2)	1 (2)	—	—
Missing data	0 (0)	2 (5)	—	—
Education, n (%)				
Elementary school	0 (0)	1 (2)	—	—
High school or professional diploma	6 (14)	13 (29)	—	—
College diploma	10 (22)	5 (11)	—	—
University, bachelor's degree, or equivalent	15 (33)	15 (33)	—	—
University, master's degree, or equivalent	12 (27)	8 (18)	—	—
University or PhD	2 (4)	2 (5)	—	—
Other	0 (0)	1 (2)	—	—

Characteristics	Women (n=45)	Partners (n=45)	Clinicians (n=14)	Policy makers (n=8)
Annual family income (CAD $ [US $]), n (%)				
<29,999 (<23,061)	1 (2)	1 (2)	—	—
30,000-59,999 (23,062-46,123)	4 (9)	4 (9)	—	—
60,000-99,999 (46,124-76,873)	19 (42)	19 (42)	—	—
≥100,000 (≥76,874)	21 (47)	21 (47)	—	—
Years of experience, mean (SD; range)	N/A	N/A	13.3 (11.5; 1.5-36)	17 (9.5; 1.5-30)
Number of pregnancy follow-ups per week, mean (SD; range)	N/A	N/A	10.4 (9; 0.4-30)	N/A

[a] N/A: not applicable.

[b] Data not available.

Pregnant Women’s Decision-making Characteristics

All the women had made prenatal screening decisions. Most had made the final decision with a clinician (15/45, 33% with an obstetrician-gynecologist; 12/45, 27% with a midwife; 10/45, 22% with a family physician; and 1/45, 2% with both a midwife and family physician). However, some women made the decision alone (5/45, 11%) or with their partner (2/45, 4%). Most women had chosen to take the prenatal screening test (38/45, 84%), and some (28/45, 62%) of them had selected the integrated biochemical test with nuchal translucency before participating in this study.

Quantitative Results

Table 3 shows participants’ perceptions of usability, quality, and satisfaction with the content of the computer-based DA. Mean scores of perceived usefulness and of self-efficacy for pregnant women were 80 (SD 13) and 88 (SD 10) out of 100, respectively. Table 3 also shows mean scores of usability, quality, and satisfaction with the computer-based DA for all 3 populations together (overall score) and for each one of them. The mean scores of clinicians were lower than those of pregnant women and those of policy makers. Women who were temporary or permanent residents also rated the DA lower overall than did Canadian citizens (data not shown). The mean overall usability score was 82/100 (SD 14). The mean overall quality score was 79 (SD 10) out of 100. The lowest scores were for engagement (how engaging users found the computer-based DA), especially for entertainment (mean 53, SD 22), customization (whether the computer-based DA allows the customization of settings and preferences that they would like; mean 45, SD 23), and interactivity (mean 53, SD 25). These slightly lower quality scores suggested areas for improvement in our DA (detailed in Table 3) and were the items used in our interview guide for further qualitative exploration.

The mean score for overall satisfaction with the content was 82 (SD 14) out of 100.

Table 4 shows participants’ perceptions of the acceptability of the computer-based DA. Of the 66 participants, 26 (39%) rated the presentation as “excellent,” 52 (79%) rated the amount of information as “just right,” 31 (47%) rated the worksheet as “good,” and 58 (88%) rated it “balanced.” However, 12% (8/66) of participants found that the information presented oriented users toward choosing to take the screening test. Approximately 58% (38/66) of participants found that the computer-based DA was useful, and 76% (50/66) found that the information was sufficient.

Table 3. Participants' perceptions of usability, quality, and satisfaction with the content of the computer-based decision aid (N=66)[a].

Variables	All 3 populations, mean (SD)[b]	Pregnant women (n=45), mean (SD)	Clinicians (n=13)[b], mean (SD)	Policy makers (n=8), mean (SD)
Perceived usefulness	N/A[c]	79.9 (13.4)	N/A	N/A
Self-efficacy	N/A	88.0 (10.6)	N/A	N/A
Usability (SUS[d])	82.6 (14.4)	83.9 (14.3)	76.5 (14.0)	79.4 (22.5)
Quality (uMARS[e])				
Engagement	62.7 (14.4)	64.7 (13.5)	58.4 (14.0)	57.9 (17.0)
Entertainment	52.9 (22.5)	55.0 (23.0)	41.7 (20.4)	60.7 (18.2)
Interest	82.2 (20.3)	84.4 (18.7)	71.2 (23.7)	89.3 (18.2)
Customizable	44.7 (23.0)	44.8 (24.2)	47.5 (18.2)	39.3 (26.2)
Interactivity	52.9 (24.9)	55.6 (23.8)	51.9 (18.2)	39.3 (37.5)
Target group	78.1 (21.4)	83.3 (18.5)	71.2 (19.2)	60.7 (29.4)
Functionality	90.5 (9.9)	92.4 (7.9)	82.7 (13.3)	92.9 (9.2)
Aesthetic	82.1 (13.6)	83.5 (12.4)	74.4 (16.5)	86.9 (11.6)
Information	79.6 (13.1)	81.1 (11.6)	72.4 (17.5)	83.4 (10.1)
Global evaluation	78.7 (9.9)	80.4 (8.9)	71.9 (11.7)	80.3 (8.7)
Satisfaction	81.5 (13.7)	84.4 (12.6)	72.8 (16.3)	73.4 (19.8)

[a] Scale 1 to 100.

[b] Missing data=1.

[c] N/A: not applicable.

[d] SUS: System Usability Scale.

[e] uMARS: user version of the Mobile App Rating Scale.

Table 4. Participants' perceptions of acceptability of the computer-based decision aid (N=66).

Dimensions of acceptability and answer choice	All 3 populations, n (%)	Pregnant women (n=45), n (%)	Clinicians (n=13[a]), n (%)	Policy makers (n=8), n (%)
Presentation				
Excellent	26 (39)	20 (45)	3 (23)	3 (38)
Good	24 (36)	15 (33)	5 (39)	4 (50)
Fair	15 (23)	9 (20)	5 (38)	1 (12)
Poor	1 (2)	1 (2)	0 (0)	0 (0)
Amount of information				
Too little information	12 (18)	8 (18)	3 (23)	1 (12)
Just right	52 (79)	37 (82)	9 (69)	6 (75)
Too much information	2 (3)	0 (0)	1 (8)	1 (12)
Worksheet				
Excellent	5 (8)	3 (7)	1 (8)	1 (12)
Good	31 (47)	21 (47)	6 (46)	4 (50)
Fair	23 (35)	17 (38)	3 (23)	3 (38)
Poor	4 (6)	2 (4)	2 (15)	0 (0)
N/A[b]	3 (4)	2 (4)	1 (8)	0 (0)
Balance				
Slanted toward choice to be tested	8 (12)	5 (11)	2 (15.4)	1 (12)
Slanted toward choice to not be tested	0 (0)	0 (0)	0 (0.0)	0 (0)
Balanced	58 (88)	40 (89)	11 (84.6)	7 (88)
Usefulness				
Very useful	20 (30)	14 (31)	3 (23)	3 (38)
Useful	38 (58)	26 (58)	8 (62)	4 (50)
Somewhat useful	8 (12)	5 (11)	2 (15)	1 (12)
Useless	0 (0)	0 (0)	0 (0.0)	0 (0)
Sufficient information				
Yes	50 (76)	38 (84)	7 (54)	5 (62)
No	16 (24)	7 (16)	6 (46)	3 (38)

[a] Missing data=1.

[b] N/A: not applicable.

Qualitative Results

Here, we report themes related to (1) general reaction, (2) the engagement aspects of the computer-based DA (entertainment, customization, interactivity, and target audience) as these uMARS subscales were rated lower than other subscales, (3) the questionnaire, and (4) themes emerging from responses by clinicians and policy makers (eg, strategies for implementation), along with related suggestions. We received >300 suggestions that we synthesized and grouped by theme, and we present those most relevant to usefulness and usability, along with some illustrative quotes (translated from French).

General Reactions

Almost all participants expressed some general reaction (64/67, 96%) to the computer-based DA. More participants gave positive comments (60/67, 90%) than negative comments (39/67, 58%). More than half (35/67, 52%) provided both positive and negative comments. The 3 most common positive comments were related to the quantity and quality of information, ease of use, and usefulness in making a decision:

> *It's really well done, I was like, wow! Why didn't we have this before? It would have helped me a lot...when I made an informed choice or even when [pregnant women] come to the information evening here.* [TT-PS-SF-02]

The 3 most common negative comments were that the information was too dense, incomplete, and the questionnaire was too difficult to use. Regarding density, 2 clinicians commented as follows:

> *It was, like, a bit overwhelming. [When I] tried to put myself in the patient's shoes, I thought, she'd have to read it more than once to be able to fill it out...I found it heavy-going.* [TT-PS-MF-03]
>
> *I read it to...a friend of mine who just has a high school education but is super intelligent...and she said, "Wow that's heavy-going, that thing, I wouldn't even want to finish it, I'd say let's go walk the dog instead."* [TT-PS-SF-02]

Regarding incompleteness, one of the clinicians commented that chorion biopsies, not mentioned in the DA, were often performed rather than amniocenteses; and another commented that shorter wait times in the private system were missing.

Engagement

Entertainment

Of 67 participants who answered this question, 31 (46%) did not think that the computer-based DA should be too entertaining:

> *I don't expect to be entertained in a jokey way when I'm looking for this kind of information. It's not an entertaining app, but then I don't expect to be entertained—so it's doing a good job of providing information.* [TT-GMF-33-03]

Moreover, 2 (3%) participants thought it should be more entertaining:

> *It should be somewhat fun, so it won't take too long. [And] then the partner might say "Can I have a go?"* [TT-PS-SF-05]

Customization

Overall, of the 67 participants, 16 (24%) thought the computer-based DA was sufficiently customizable (ie, could be adapted to users' profiles), whereas 28 (42%) participants wanted it to be more customizable:

> *It's a good idea...so people could go "okay, I want to do the nuchal scan, where's my nearest health centre, is it in Beauce or in Quebec?" so then the couples can also decide to make an appointment, that would be great.* [TT-PS-SF-06]

Moreover, of the 67 participants, 21 (31%) were against any customization, and 2 (3%) were ambivalent:

> *It could be hurtful...if they [adapted it to my literacy level], because it's like I'm not smart enough to understand all the information—it's putting people in boxes, it's a bit discriminatory.* [TT-PS-SF-06]

Suggestions for what could be customized included (1) geolocation (or postal code) for indicating local clinical screening sites, (2) maternal age, (3) risk factors, (4) week of pregnancy, (5) amount of information desired, or even (6) allowing customization by desired criteria (ie, *à la carte* menu). However, some were concerned about the threat of data theft:

> *If you open the thing and the first thing they ask is your name, your age and your postal code, I go, EW, they're collecting data on me! I think if you don't want to answer, you [should be able to] stay with the generic version, but if you want to personalize it, it's your choice, and it won't block you.* [TT-DP-08]

Interactivity

Overall, of 67 participants who answered this question, 20 (30%) thought the computer-based DA was sufficiently interactive, although 6 (9%) wanted it to be more interactive:

> *It's a very linear app, there are no links to other sites, to other information...you're in one section then you click "next" and you're in the next section, then the next.* [TT-MN-27-49]

Three major suggestions for improving interactivity were (1) adding hyperlinks to other sites (eg, government sites) and relevant statistics and adding more clickable information, (2) adding a frequently asked questions section, and (3) providing a web-based chat window for live questions. The latter did not meet with unanimous approval; a few participants were against it (8/67, 12%), of whom some explained that chat agents lack credibility (3/8, 38%).

Target Audience

Overall, 6 clinicians or policy makers (6/67, 9%) felt that the computer-based DA would not be useful for people with high levels of anxiety and with little time, or for socioeconomically disadvantaged or uneducated clienteles. One of the clinicians explained that written information was not useful to many patients:

> *One in three people [have difficulty reading], even if they have a job... I'm always surprised. I give them less and less information on paper...It's already hard to explain the risks, then risks by age...and when I call them back with the results, just to say everything's fine, there's easily one-third who don't understand.* [TT-PS-SF-05]

Another commented that as people with limited literacy will not use it anyway, it is fine the way it is:

> *I think it's simple enough for those who want to read and inform themselves on the subject, which is the vast majority, but for those who can't read, it'll take videos, just with "there's this" and "there's that."* [TT-PS-OB-02]

Some thought the DA was only useful for those who were undecided and that it might be misleading:

> *This app is more for people who are undecided. I think when they use it, they expect that by the end it'll make the decision for them somewhat.* [TT-PS-SF-04]

Values and Preferences Questionnaire

Most participants thought that the statements (benefits and risks of undergoing a screening test or not) were difficult to understand (40/67, 60%) and that the 1 to 10 scale was difficult to use (13/67, 19%):

> *I found it a bit vague, it was too much...I'm okay with proportions, but I'm not that comfortable—so I had to read the question two or three times...So I'm not likely to say to someone else "Do this questionnaire,*

> *it's really helpful." Because even when I'd finished a question, I still wasn't sure if I'd answered it properly.* [TT-GMF-29-38]

Although the DA only summarizes users' answers, half of the pregnant women (23/45, 51%) expected it to direct them to a choice based on the information they had provided. At the same time, a large proportion (27/45, 60%) did not want the DA to guide them to a specific choice:

> *I think it's good that it doesn't tell you yes or no you should do it...But imagining myself as a woman who's not sure—then at the end it just tells you what you've already said...Then you're, like, so should I do it or not? I think it's good...that it doesn't guide people too much.* [TT-GMF-30-27]

Suggestions by women, clinicians, and policy makers for improving the questionnaire were to (1) use decision trees, (2) use a visual diagram to summarize the weight of each advantage and disadvantage, (3) present the questionnaire results in the form of a "compass" that analyzes user responses to help them position themselves among the options [34], (4) give users a simpler way of weighing the benefits against the risks, (5) show the general direction of the person's choices, (6) show users' prioritized advantages and disadvantages in the order of importance in the summary table, (7) highlight gray areas (score of 4, 5, and 6) to indicate that users should discuss it with their health care provider, (8) color-code the factors assigned an importance of 6 to 10, and (9) use a simpler rating system than a 10-point scale.

Additional Themes Raised by Clinicians and Policy Makers

Perceptions of Usefulness

Overall, 6 clinicians or policy makers thought that the computer-based DA would be used by >50% of their colleagues but that not everyone would be comfortable using an app (ie, added support would be needed for vulnerable women):

> *For sure, people...who have fairly limited literacy, the concepts with initials [abbreviations], and the prevalence rates, all that this person would need to be accompanied by...a health professional to understand what the impacts are, the advantages, and disadvantages.* [TT-DP-17]

However, the health professional who would accompany the woman would also need to be fully informed:

> *The shortcomings we come back to are about when the person returns to the professional. Yes the professional has the expertise, has probably been trained to welcome the pregnant woman and discuss [testing] with her correctly, present the options. But from what we have seen, there is so much to remember...to be sure they re-train now and then, when new techniques and/or consent practices have evolved.* [TT-DP-15]

When clinicians were asked whether the information was what their patients needed, most (5/14, 36%) said that it was similar to the information they offered and that they sometimes gave more, such as on markers, on available tests privately, on chorionic biopsy, and on the fact that screening detects trisomy but other anomalies cannot be detected yet.

Implementation of the Computer-Based DA in Clinical Practice

Policy makers all thought that clinicians should integrate SDM into their practice and recommended that the use of computer-based DA should be incorporated into practice guidelines and into continuing professional education for clinicians.

They also recommended providing a link or number for women to call if they had questions and suggested conducting a DA implementation pilot project followed by rollout on a large scale.

Clinicians (11/14, 79%) thought that the computer-based DA should be promoted and given to pregnant women and their partners as early in pregnancy as possible: (1) before their first consultation with the prenatal care specialist, (2) during the information session at approximately 8 to 10 weeks at the birthing center, (3) at approximately 5 to 8 weeks during the meeting with the nurse, (4) at between 7 and 10 weeks to give parents time to prepare for the decision, (5) by phone during the first call with the secretaries who would refer them to a download link, or (6) when the physician sends a prescription for nuchal translucency (if there is no consultation before testing). They also thought that the computer-based DA should not be used during consultations but during a later encounter to discuss any questions it may have raised (6/14, 43%):

> *[A nurse] could tell them to go on the site, go through the process, and then talk about it...it could be repeated with the doctor to assimilate the information, they could talk to their partner, prepare specific questions, etc...Most of our doctors see them around 10 weeks, that's when we have to prescribe what to do—like, are we doing [the test], or not? But if the process is all done in the doctor's office, it will never end. Doctors won't get on board with that, I don't think.* [TT-PS-MF-03]

Other Suggestions

Participants also suggested (1) using more neutral and unisex colors; (2) using a denominator smaller than 10,000 for the presentation of risk by age; (3) using video clips instead of text; and (4) collaborating with pregnancy tracking applications, which could include a link to the computer-based DA and send a notification to users when it is time to make a decision.

Discussion

Principal Findings

We assessed the usability and usefulness of a computer-based DA among pregnant women, clinicians, and policy makers. Participants found that it improved self-efficacy for decision-making, was helpful for preparing for decision-making, was usable, and was of good quality overall. They were also satisfied with its content, and based on the scores for the various dimensions of acceptability, the computer-based DA was also found to be acceptable. In the qualitative interviews, the participants were mostly positive but less so about how engaging the app was. They made suggestions for improving the questionnaire and proposed implementation strategies.

First, participants reserved their lowest scores for engagement. They proposed that more advanced digitization features, such as customization and interactivity, would make it more engaging. Customization is necessary for better culturally adapted DAs [35] and to avoid information overload [36]. In another screening context (colorectal cancer), a computer-based DA was customizable for age and gender, and participants were asked for further customizable features such as family history and medical history [37]. However, some types of customizability are easier to operationalize (eg, age) than others (eg, geographic location) as the latter requires continuous updating of the registry of clinical sites available for screening. This would require input from the Ministry of Health and Social Services, which holds this registry [38]. In addition, a geolocation feature, whereby users would provide personal data such as their postal or zip code, poses a privacy risk [39].

Second, the study participants had difficulty in both using the values clarification questionnaire and interpreting the results. In a previous study evaluating an earlier, paper-based version of this DA [22], participants also had difficulty using a values clarification exercise with 5 rating stars, with 1 meaning “not important” and 5 meaning “very important” [40]. This suggests that we explore values clarification methods that simply offer users options without asking them to measure their importance to them on a scale (ie, users choose the elements they wish to consider before deciding whether to do the test). Participants also highlighted the difficulties they encountered in interpreting the results after completing the values clarification exercise. Moreover, most pregnant women expected the DA to make the choice for them based on the information they provided. When faced with a difficult decision, the human tendency is to offload it onto someone (or something) else, especially when the choices have potentially negative consequences [41]; however, the use of mHealth should not remove users’ responsibility for the decision. For a DA or clinician to make the decision for them would go against the principle of empowerment conveyed through their active participation in SDM [42,43]. If the expectation of a ready-made decision was raised by the computer-based DA itself, it will be stated more clearly on the home page that the DA will provide them only with the elements to make their decision.

Finally, women who were Canadian citizens were more satisfied with the content of the computer-based DA than temporary or permanent residents. It is very likely that this explanation lies in the diverse cultures of immigrants and their language limitations. Further research is needed to understand immigrant women or couples’ expectations of and attitudes toward the DA. This difference in satisfaction demonstrates the importance of developing a culturally sensitive DA, such as translating it into other languages.

Limitations

This study had several limitations. First, we recruited women after they had already made their screening decisions. They had to imagine that they were still in the situation of making the decision to answer the questions. This may have biased our results. However, the time between their decisions and the study was relatively short. Second, in Canada, prenatal care requires the collaboration and coordination of many different health care providers, including nurses, who were not involved in the study [44]. However, approximately 98% of pregnancies are monitored by the types of clinicians involved in this study [45,46]. Third, education level and household income were higher in our sample than in the general population. However, the participants mentioned that our DA needed to be adjusted for use by less-educated women. Finally, we did not meet our sample size requirements for clinicians and policy makers. However, their experience provided important data on how to improve and implement the computer-based DA in primary care settings.

Conclusions

We assessed the usability and usefulness of a computer-based DA among pregnant women, clinicians, and policy makers. They informed us that the tool could be improved with more customization options, more interactivity, and a simpler value clarification exercise. The next step will be to incorporate participants’ suggestions and implement the computer-based DA in primary care settings across Quebec prenatal care clinics.

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Data Availability

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

Authors' Contributions

The study was led by FL, chairholder of the Tier 1 Canada Research Chair in shared decision-making and knowledge translation. All authors contributed to the conception and writing of the manuscript. TTA and CP participated in the recruitment of pregnant women and their partners, clinicians, and policy makers at the clinical sites. TTA and CP also contributed to data collection, audio transcription, and qualitative analysis. TTA drafted the preliminary manuscript. TTA trained the trainees who contributed to the various phases of the project. FL conceived the study, participated in its design and coordination, and helped draft the manuscript. All authors have read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Standards for Universal reporting of patient Decision Aid Evaluation studies (SUNDAE) checklist.
[PDF File (Adobe PDF File), 110 KB - pediatrics_v5i3e35381_app1.pdf]

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Abbreviations

DA: decision aid
mHealth: mobile health
MMARS: Mixed Methods Article Reporting Standards
SDM: shared decision-making
SUNDAE: Standards for Universal reporting of patient Decision Aid Evaluation studies
uMARS: user version of the Mobile App Rating Scale

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Original Paper

Intervention Mapping of a Gamified Therapy Prescription App for Children With Disabilities: User-Centered Design Approach

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Abstract

Background: Mobile health (mHealth) apps for children are increasing in availability and scope. Therapy (physiotherapy, speech pathology, and occupational therapy) prescription apps to improve home or school program adherence work best when developed to be highly engaging for children and when they incorporate behavior change techniques (BCTs) within their design.

Objective: The aim of this study was to describe the development of a user-centered therapy prescription app for children (aged 6-12 years) with neurodevelopmental disabilities (eg, cerebral palsy, autism spectrum disorder, and intellectual disability) incorporating intervention mapping (IM) and gamified design.

Methods: We used an iterative, user-centered app development model incorporating the first 3 steps of IM. We conducted a needs analysis with user feedback from our previous mHealth app study, a literature review, and a market audit. Change objectives were then specified in alignment with the psychological needs of autonomy, competence, and relatedness identified in self-determination theory. From these objectives, we then selected BCTs, stipulating parameters for effectiveness and how each BCT would be operationalized. A gamification design was planned and implemented focusing on maximizing engagement in children. In total, 2 rounds of consultations with parents, teachers, and therapists and 1 round of prototype app testing with children were conducted to inform app development, with a final iteration developed for further testing.

Results: The IM process resulted in the specification of app elements, self-determination theory–informed BCTs, that were embedded into the app design. The gamification design yielded the selection of a digital pet avatar with a fantasy anime visual theme and multiple layers of incentives earned by completing prescribed therapy activities. Consultation groups with professionals working with children with disabilities (4 therapists and 3 teachers) and parents of children with disabilities (n=3) provided insights into the motivation of children and the pragmatics of implementing app-delivered therapy programs that informed the app development. User testing with children with disabilities (n=4) highlighted their enthusiasm for the app and the need for support in the initial phase of learning the app. App quality testing (Mobile Application Rating Scale-user version) with the children yielded means (out of 5) of 4.5 (SD 0.8) for engagement, 3.3 (SD 1.6) for function, 3.3 (SD 1.7) for aesthetics, and 4.3 (SD 1.1) for subjective quality.

Conclusions: mHealth apps designed for children can be greatly enhanced with a systematic yet flexible development process considering the specific contextual needs of the children with user-centered design, addressing the need for behavior change using the IM process, and maximizing engagement with gamification and strong visual design.

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KEYWORDS

neurodevelopmental disability; mobile health; self-determination theory; gamification; physiotherapy; occupational therapy; speech pathology; behavior change; mobile phone

Introduction

Background

Mobile health (mHealth) apps designed for children have grown dramatically in availability and scope, coinciding with enhanced accessibility to mobile technologies worldwide (6.38 billion smartphone users in 2021) [1,2]. In 2011, the World Health Organization identified the potential of mHealth technology to transform the delivery of health care and optimize health outcomes [2]. In 2020, the COVID-19 pandemic fast-tracked acceptance of the use of digital technology for augmenting clinical services [3,4], including clinicians who support children with disabilities [5,6]. In this global environment of digital health innovation, mHealth apps are recognized for their potential to augment and enhance clinical care, particularly in terms of their scalability and availability [4].

mHealth apps have the potential to improve adherence to exercise programs in children with neurodevelopmental disabilities (eg, cerebral palsy, autism spectrum disorder, intellectual disability, and Down syndrome) [7]. Children with neurodevelopmental disabilities are often prescribed home and school therapy programs (physiotherapy, occupational therapy, or speech pathology) to increase the amount of therapy activity practice between face-to-face sessions; however, providing programs that children fully engage with at home is challenging for therapists and parents [8,9]. Parents of children with neurodevelopmental disabilities report that children's adherence to home programs is affected by the clarity of the instructions, the ability to adapt prescribed exercises to individual circumstances, guidance and reassurance with exercise performance, the provision of reminders, collaborative goal setting, monitoring, and the incentivization of adherence [8,10,11]. The potential of mHealth technology to address some of these issues with the use of tools such as exercise videos, adherence tracking, and reminder notifications has been identified [7] but not fully realized. In 1 study, for example, an existing mHealth exercise prescription platform suitable for all age groups but not tailored to children offered little additional benefits compared with traditional paper-based programs for improving exercise adherence in children with disabilities [12]. This finding may be better understood by considering studies that suggest that effective mHealth technology for children demands that app interventions be tailored to their needs and interests and designed to be highly engaging [1,13].

Engagement with digital interventions encompasses both the behaviors of the user (the amount, frequency, duration, and depth of use) and the subjective experiences of the user (ie, attention, interest, and affect) [14]. Apps that are *engaging* are theorized to optimize effectiveness because app use is maintained over time, increasing participants' exposure to the intervention [13]. Identifying features to increase engagement is an important mHealth app design strategy to enhance long-term behavior change in children [1]. Gamification—the use of gaming elements in a nongaming context [15]—can be a helpful feature for improving engagement with mHealth technology by using intrinsically motivating features such as feedback mechanisms, relatedness support, and autonomy support [16].

Planning behavior change strategies is foundational in the design process for digital health interventions in children [17,18]. Partnerships between app developers and behavioral scientists are needed to use health behavior theory to guide mHealth app development [18]. This partnership enables careful selection of behavior change techniques (BCTs) with consideration of determinants of change as well as the parameters for the effectiveness of each technique [19]. This process is complex as it demands attention to multiple interacting components that often span several spheres of one's socioecological contexts. Intervention mapping (IM) represents a systematic method of planning behavior change interventions [20] that encourages interventionists to embrace such complexity within the mHealth app development process [21].

Objective

Incorporating theory-based BCTs and gamification within the design of an mHealth app specifically for children with neurodevelopmental disabilities is indicated to optimize engagement [12]. We reported the app development process for a children's therapy prescription app designed to optimize engagement and improve program adherence.

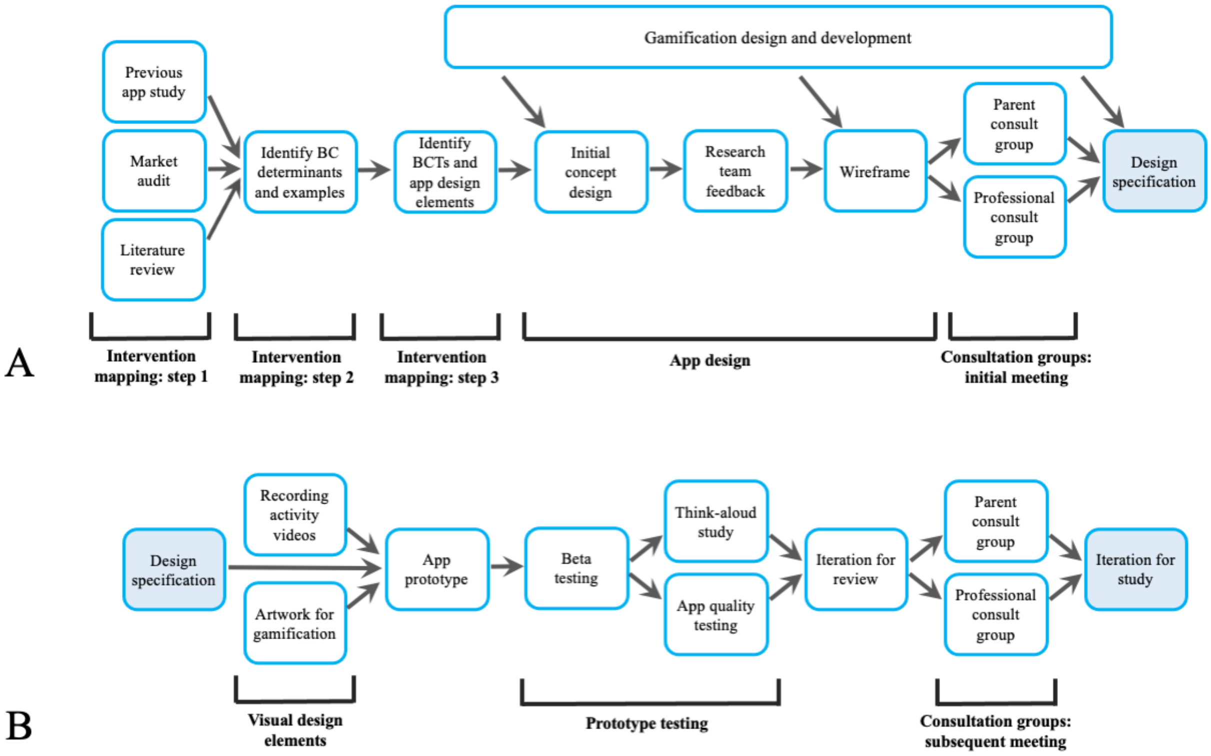
Methods and Results

App Development Overview

An mHealth app was developed from July 2018 to September 2019 based on a 2-stage model by White et al [22] with the goal of enabling children with disabilities to complete prescribed therapy programs. We are a multidisciplinary team with expertise in behavioral science, app development, and exercise and therapy for children with disabilities. The project lead (RWJ) is a physiotherapist with experience in the management of cerebral palsy across the life span and experience in mHealth research for children with disabilities. Our adapted model for the development of the app included several phases (Figure 1), including IM [19,20] to embed BCTs into the app design, development of a video library of children performing commonly prescribed therapy activities, consultation with parent and professional (teacher and therapist) groups at 2 time points, and quantitative and qualitative user testing with children with disabilities.

We used an alternative structure to this paper similar to that of previous manuscripts incorporating IM [23,24], where the methods and results are integrated to maintain a logical and chronological reporting exposition.

Figure 1. Zingo app development diagram: (A) formative research and (B) design, testing, and iteration. BC: behavior change; BCT: behavior change technique.



Ethics Approval

Ethics approval was obtained from the Human Research Ethics Committee, Curtin University, Perth, Western Australia (reference HRE2018-0696) before recruitment of the study participants.

IM Overview

IM is a systematic approach to planning health interventions that guides researchers through a decision-making process incorporating theory, empirical findings from the literature, and analysis of the population needs [20]. IM is supported by a taxonomy of behavior change methods that capture the active ingredients of an intervention, mechanisms of action that link these techniques with theories, and specification of the essential parameters for the effective use of these BCTs [19]. We used the first 3 steps of the IM process: (1) needs assessment, (2) specification of goals and change objectives, and (3) theory-informed methods and applications. These first 3 steps have previously been identified as the most useful in mHealth app development for yielding a program design incorporating both suitable BCTs and methods for implementation [21]; steps 4 to 6 of IM are of particular relevance to broader health promotion programs rather than “the technical how” [21] of app development, which we implemented using other methods, as described in the following sections and shown in Figure 1.

IM Step 1: Needs Assessment

Step 1 of IM involves conducting a needs assessment to understand the problem [20,21], which, in the context of our study, was the clinical experience of poor adherence to prescribed therapy programs [7,8].

Previous App Study

The needs assessment leveraged findings from our previous work on a commercially available app and web-based platform for exercise prescription (Physitrack). Via a randomized controlled trial involving 46 children with neurodevelopmental disabilities undertaking an 8-week home exercise program, we found that Physitrack did not improve program adherence, exercise performance, or goal attainment compared with conventional paper-based methods [12]. Feedback from parents and physiotherapists of participating children highlighted the limitations experienced using Physitrack for children with disabilities:

> *Kids liked the technical component, but it probably needs more motivational features.* [Physiotherapist 1]
>
> *It needs increased motivation/rewards/games built into the app...Needs more videos of kids demonstrating exercise. Needs to be more fun.* [Physiotherapist 2]
>
> *The app is boring and does not have any built-in reward for completing each task.* [Parent 1]

Market Audit

A unique element of our needs assessment involved a market audit to understand what exercise and therapy apps targeting children were available. We evaluated their strengths and weaknesses relative to our goal of developing an engaging gamified therapy prescription app for individualized home and school programs. The search was not intended to be exhaustive but to provide an understanding of the market. In July 2018, we identified iOS apps on the App Store targeted for physiotherapy, occupational therapy, and speech pathology for children by entering the following search terms: (“children” OR “kids”) AND (“physiotherapy” OR “physical therapy” OR “speech therapy” OR “occupational therapy”). We also considered apps that the research team had come across in clinical and general experience (eg, GoNoodle). We chose to focus on iOS apps rather than Android apps as this work was funded to develop a tool for school therapy programs for children aged 6 to 12 years. iOS tablets (iPads) are known to be ubiquitous in local primary schools (including kindergarten to grade 6) in our geographical context (Perth, Western Australia), which was later confirmed by teachers in our consultation groups.

A total of 34 apps were identified, of which 22 (65%) were speech pathology apps (targeting articulation; none targeting language development); 10 (29%) targeted physical activity, exercise, and physiotherapy; and 2 (6%) were occupational therapy apps. The identified apps with gamification strategies included physical activity (eg, Biba series and GoNoodle) and articulation (eg, Speech Blubs). The apps identified in this search did not allow therapists to prescribe individualized programs of exercises or therapy activities. In total, 2 children’s apps that did allow some basic exercise prescription (ie, CP-Fit and Sworkit Kids) had limitations relating to exercise selection or ability to customize parameters, and gamification was absent. We did not identify any apps that provided an individualized and customizable therapy prescription for children with disabilities or any apps incorporating recognized BCTs (even those with associated publications), and there were no apps for multidisciplinary therapy programs.

Literature Review

A literature review to inform the needs analysis for IM step 1 was conducted to identify key learnings from studies on mHealth apps for children. The review was conducted by 1 author, RWJ, with oversight from DFG using search terms referencing the following 4 elements: apps, mobile technology, children, and therapy (physiotherapy, occupational therapy, or speech pathology). This search, conducted in August 2018, yielded 213 papers. Of 213 papers, screening of titles removed 77 (36.2%) papers (duplicates, lecture notes, viewpoint articles, and commentaries), and the remaining 136 (63.8%) abstracts were reviewed (RWJ) and classified into the following categories: relevant original research, relevant reviews, or nonrelevant. Articles deemed to be relevant met the following criteria: the participants were aged 0 to 17 years; the primary intervention used mobile or web-based technology; and they included promotion of therapy interventions (physiotherapy, occupational therapy, or speech pathology), physical activity, exercise, or behavior change for health promotion. Despite our target audience being children aged 6 to 12 years, publications that included both children and adolescents (ie, a broader pediatric age band) were included to scope the breadth of the available literature; however, where papers were able to draw separate conclusions for adolescents and children [1,18], we were informed by the recommendations for children only. We excluded publications that targeted adult behavior (eg, perinatal care and breastfeeding), other technology (eg, virtual reality, computer software, and communication devices), physical activity and nutrition outcomes without behavior change analysis, specific medical conditions or procedures (eg, health screening, pharmacological studies, and hospital care), studies on general mobile technology use not on mHealth apps, or research not focused on technology or apps (eg, technology just used as an adjunct to the research process). A total of 37 publications were included in the final review, of which 8 (22%) were reviews and 29 (78%) were original research papers. Of the 37 reviewed publications, a summary of 9 (24%) that were deemed the most relevant (to our target group) and informative publications (to behavior change in children delivered via mHealth apps) is provided in Multimedia Appendix 1 [1,13,18,25-30], which illustrates how the literature informed our (IM step 1) needs analysis.

This review highlighted several important considerations for this project. Modeling behavior, promoting practice, and social support appear to be important BCTs that can be incorporated into mHealth for children [18]. However, there is a disconnect between the most frequently used BCTs in mHealth apps and those that are known to be the most effective in children: social support and modeling [1]. The literature highlighted low levels of engagement with mHealth apps among children [1]. Common solutions identified to improve engagement with an app included (1) tailoring the app to specific population groups, (2) having a gamified app design, (3) incorporating elements to personalize the app, and (4) a variety of content and rewards to incentivize the target behavior [1,26-28].

This literature review revealed the significance of embedding key BCTs known to be effective for children while also using engaging gamification elements to drive behavior change toward increasing activity participation in children. These key findings from the literature review were particularly useful for informing the needs analysis and were incorporated into IM step 2, in particular in determining the performance objectives.

IM Step 2: Specification of the Goal and Change Objectives

In the specification of the goal and change objectives [20,21] conducted by 2 of the authors (RWJ and DFG), 4 performance objectives were selected for the mHealth app focusing on its purpose of engaging children in regular therapy activity practice (Table 1).

Self-determination theory (SDT) was selected to guide the process of identifying behavioral determinants (based on the needs of the population and purpose of the intervention from step 1) and progressing toward selecting BCTs. SDT was selected because of its focus on motivational quality versus quantity, in which the reasons for performing a behavior lie on a continuum from purely intrinsic to extrinsic regulation [31]. We selected the psychological needs as the targets for the following behavior determinants: *autonomy* (“individuals’ propensity to self-organize their behavior and to act in accordance with their integrated self”) [32], *competence* (“the capacity to have an effect on the environment and to attain valued outcomes within it”) [32], and *relatedness* (“the desire to feel connected to others, be loved and cared”) [32]. To complete IM step 2, examples of the desired change in behavior were selected for each of the performance objectives in each of the 3 determinant fields (Table 1), and these informed IM step 3.

Table 1. Intervention mapping step 2: matrix of performance objectives and behavior determinants.

Performance objectives	Theory-informed determinants		
	Autonomy	Competence	Relatedness
Child engages in learning about performance of prescribed therapy activities[a]	• Child is curious about therapy activities[a] and how to implement them as recommended • Child seeks out information about activity[a] performance available in the app	• Child is confident of attaining required information of therapy activity[a] performance in the app • Child is capable of navigating the app with minimal external supports	• Child feels supported to learn via the app from social agents[b] • Child is encouraged to ask questions about desired performance of activities[a] from social agents[b]
Child physically participates in the therapy program	• Child self-initiates app use with therapy activities[a] (with a level of independence expected for age and ability) • Child chooses to participate in the preparation of the environment for activities[a] (eg, furniture setup, exercise equipment, or activity resources)	• Child is guided by prescribing therapists to participate in activities[a] that are graded to physical capacity • Child has appropriate expectations for performance based on knowledge of their physical capacity	• Child feels supported by key social agents regardless of the effort enacted or outcomes of participation in the therapy program • Child feels valued based on social agents seeking child's feedback on their experience of activity[a] performance
Child cognitively participates in the therapy program	• Child demonstrates interest in engaging with the app and the therapy program embedded therein • Child appreciates the importance of engaging with the therapy program using the app • Child demonstrates choice-making in how they engage (or not) in therapy program activities[a]	• Child demonstrates ability to engage directly with the app functions (or, where prevented by physical impairment, to communicate to social agent how they want them to engage with the app as a proxy) • Child communicates their expectations of extent of following therapy activities[a] and app engagement • Child communicates their personal successes and challenges with completing the therapy program	• Child feels valued as the app enables social agents to seek out their contributions (eg, preferences) to the therapy program • Child is encouraged to ask questions about therapy program activities[a] • Child has the opportunity to celebrate achievements with peers or key social agents[b]
Child reviews activity[a] performance and experiential participation	• Child self-identifies problems or difficulties faced with completing the program (with guidance on self-reflection offered by social agents[b]) • Child communicates what activities[a] or app elements they enjoyed and why	• Child has the opportunity to express success, challenges, and problems to parents, educators, or therapists • Child knows how to access summary of activity[a] completion, feedback on performance, and gamification elements	• Child feels supported in understanding challenges • Child experiences that their active participation is recognized

[a] Prescribed therapy activity examples: functional strengthening exercises such as abdominal crunches, balance exercises such as walking on a narrow beam, ball skills such as dribbling a football around cones, fine motor activities such as snipping paper with scissors, activities of daily living such as tying shoelaces, receptive language activities such as following specific instructions with colored blocks, expressive language activities such as describing a hidden object to a person guessing, and literacy skills such as constructing words with jumbled sounds or letter cards.

[b] *Social agents* refers to the child's parent or guardian, teacher, education assistant, or therapist.

IM Step 3: Theory-Informed Methods and Practical Applications

Drawing on the taxonomy of behavior change methods for IM developed by Kok et al [19], the BCT taxonomy by Michie et al [33], and the classification of motivation and BCTs by Teixeira et al [34], we (RWJ and DFG) selected pertinent motivationally informed BCTs for each determinant and the parameters for effective implementation stated (Table 2). The plan to operationalize each of these techniques was recorded and then, finally, the app design elements to achieve this were specified (Table 2).

This third step concluded a key process of our app development planning using IM to identify theory-based behavior change strategies that were informed by the literature and could be incorporated into our mHealth app. However, another key element in the app design was concurrently underway: gamification design.

Table 2. Intervention mapping step 3: behavior change techniques (BCTs), parameters, and app design elements.

Determinant and BCT	Parameters for effectiveness	Operationalization	App design element
Autonomy			
Goal setting (behavior)	Requires commitment to the goal; feedback on results; challenging but achievable goals; appropriate situational support and context	Children and therapists collaboratively set or agree on a goal in terms of percentage of tasked therapy program completed per week. The goal is reviewed and updated	• Opportunity for therapist, after consultation with parent and teacher, to input goal (eg, 80% adherence to program) • Therapist receives automated email with percentage of adherence update each week with prompt to update adherence goal as required
Information about health consequences	Requires presentation of information in ways that are appropriately tailored to individuals with sufficient time to do so (eg, text vs infographic)	Information about the health reasons for each activity and opportunity for adult explanation	• Therapist required to enter "Purpose" for each custom-made activity (textbox) or has the opportunity to edit precompleted "Purpose" from activity video library instructions, thereby promoting consideration and discussion of health benefits • Purpose appears in activity display for child and parent or teacher
Provide choice	Requires choice from a collaboratively devised set of options. It includes the decision not to participate, to delay, or to change focus, including changing the timing or pace of outcomes	Child can choose the order in which prescribed activities are tackled and change that order on any day the activities are completed	• Child can select any activity from therapist-prescribed program with guidance from parent or teacher as appropriate, thereby facilitating choice of order of activity completion (within a day) • Interface specifies frequency of each therapy activity in terms of attempts per week (rather than identifying specific days of the week), thereby facilitating the child's choice of program structure (across each week) with adult guidance where required
Competence			
Demonstration of behavior	Requires instruction and enactment with individual feedback	Providing visual examples of how to perform activities	• Videos of therapy activities: children modeling activity performance in video library • Therapist can use custom video of the child themselves modeling the activity and incorporate it into the program
Self-monitoring of behavior	The monitoring must be of the specific behavior (not a health outcome). The data must be interpreted and used. The reward must be reinforcing to the individual	Providing the opportunity for children to self-monitor and evaluate their behavioral experience and performance as well as initiate feedback discussions with therapists	• After each activity completion, the child has the opportunity to reflect and provide feedback on their experience • Brief or detailed feedback options available for each activity • Multiple feedback options available, including activity difficulty, emoticons, written emotions experienced, and blank textbox • Feedback for each activity available to the therapist and to the child and family on their interface for reflection as well as automated duration and frequency data
Instruction on how to perform behavior	Requires communication with language that suits the learner	Pre-existing activities from library include written instructions on how to perform the specific tasks, or customized activities require therapists to document those instructions	• App provides the therapist with the opportunity to customize activity purpose description and instructions

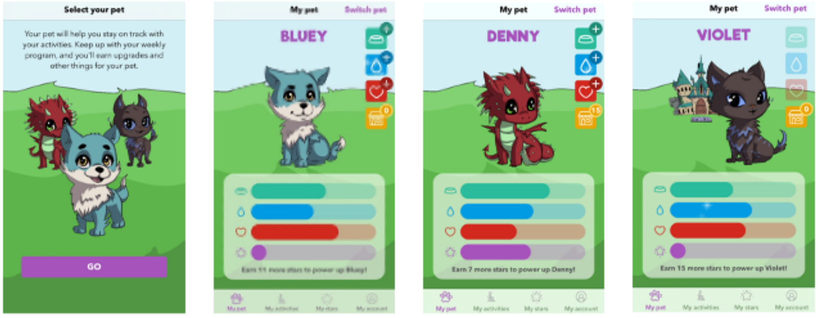
Determinant and BCT	Parameters for effectiveness	Operationalization	App design element
Feedback on behavior	Requires availability of data and monitoring of behavior; data must be interpreted and used	Children-friendly feedback on task completion and performance	• “My Stars” tab with overview of weekly therapy activity performance summary (out of total number of activities per week recommended) • Simple visual representation of weekly program completion with circular progress chart incorporating completion goal (percentage) set by the therapist and progress toward 100% completion • Prompt in gamified rewards section (“Pet shop”) to review progress in “My Stars” to earn incentives
Relatedness			
Social support (emotional)	Requires availability of positive support	Prompt parents to discuss progress with child and encourage them	• Weekly automated email to parent on progress with positive wording and prompt to parent to encourage the child with their achievements and progress
Material and social rewards (behavior)	Requires tailored rewards and that the rewards are seen as a consequence of the behavior	Providing written reinforcement (social) and valued objects (material) for positive behavioral progress	• Gamification incentives when achieving goals, involving interaction with digital pet (pet emotional state progression, pet evolution, and pet purchases)

Gamification Design

The use of mHealth apps that use gamification for promoting health-related behavior change has been investigated across different fields of health [16,35] and is particularly relevant when developing interventions for children [1,16]. Gamified systems have been linked to autonomous motivation, as defined in SDT [36], by using motivational features such as immediate success feedback, continuous progress feedback, and goal setting [16]. The gamification strategy for this app was designed with consideration of the context: supporting children in a classroom or home environment to complete nondigital therapy activities and exercises. A considered decision was made not to develop a full-featured electronic gaming app, known for engrossing children in a state of intense focus (ie, a *flow-state*) where they may have reduced awareness of the world around them [37] and that may be a distraction from therapy activities. Rather, gamification elements that are highly engaging but have a specific start and end were chosen so that the child is able to put down the device and continue with the next therapy activity. We designed several different systems of gamified goals and incentives to keep users engaged [28] (Figure 2). The child using the app can achieve gamified goals and incentives by completing the prescribed therapy activities. Using this strategy, engagement with the app is more likely to be maintained as, once the child achieves 1 gamified goal and incentive, there is a different goal and incentive to work toward.

The gamified systems revolve around looking after and rewarding a digital pet. We chose digital pets as they have previously been used in mHealth gamification design for children [28] and in popular entertainment and games (eg, Pokémon and Tamagotchi). We incorporated a fantasy anime (Japanese animation style) design theme and bright colors into our digital pet design to appeal to children. These concepts around gamification developed progressively, with the basic themes being identified and incorporated into the initial concept design (Figure 1A). Further gamification mechanics were introduced at different points in the development and incorporated into the wireframe and design specification (each described in the following sections) before being actualized in the initial app prototype and refined concurrently with other app elements to the final iteration (Figure 1B).

Figure 2. Gamification design features.



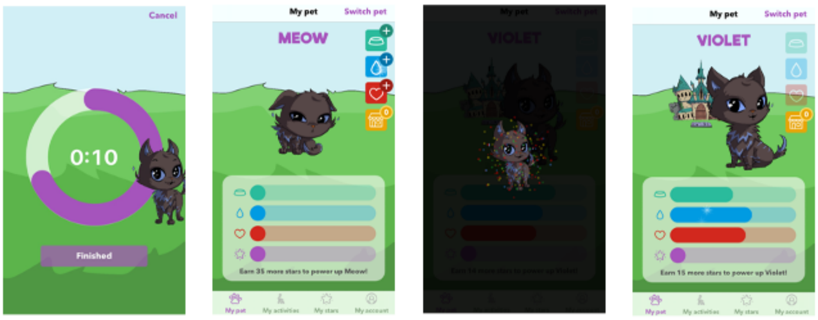
Your pet will help you stay on track with your activities. Keep up with your weekly program, and you'll earn upgrades and other things for your pet.

Earn 11 more stars to power up Bluey!

Earn 7 more stars to power up Denny!

Earn 15 more stars to power up Violet!

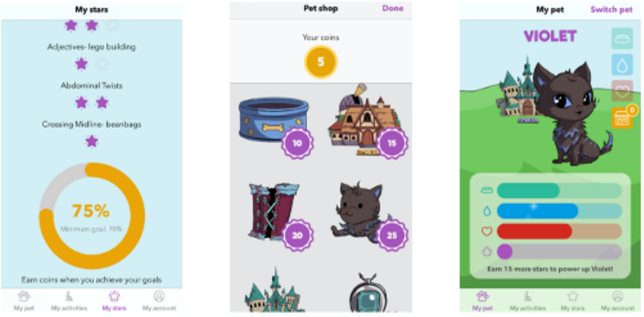
A. Opening gamification feature- choose and name pet



Earn 35 more stars to power up Meow!

Earn 15 more stars to power up Violet!

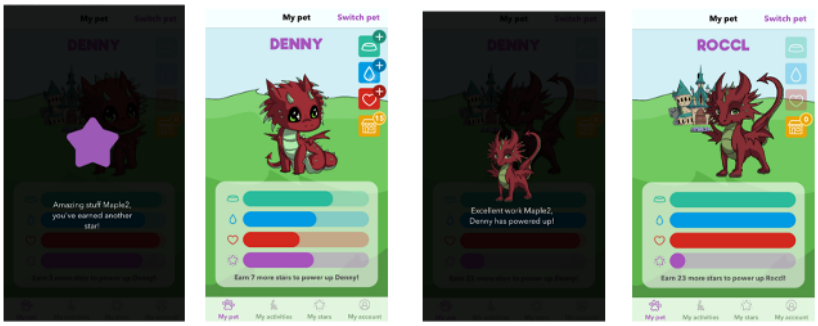
B. Activity incentive- give food, water or love to improve emotional state



Earn coins when you achieve your goals

Earn 15 more stars to power up Violet!

C. Weekly activity monitoring and incentive- earn coins to purchase pet item



Amazing stuff Maple2, you've earned another star!

Earn 7 more stars to power up Denny!

Excellent work Maple2, Denny has powered up!

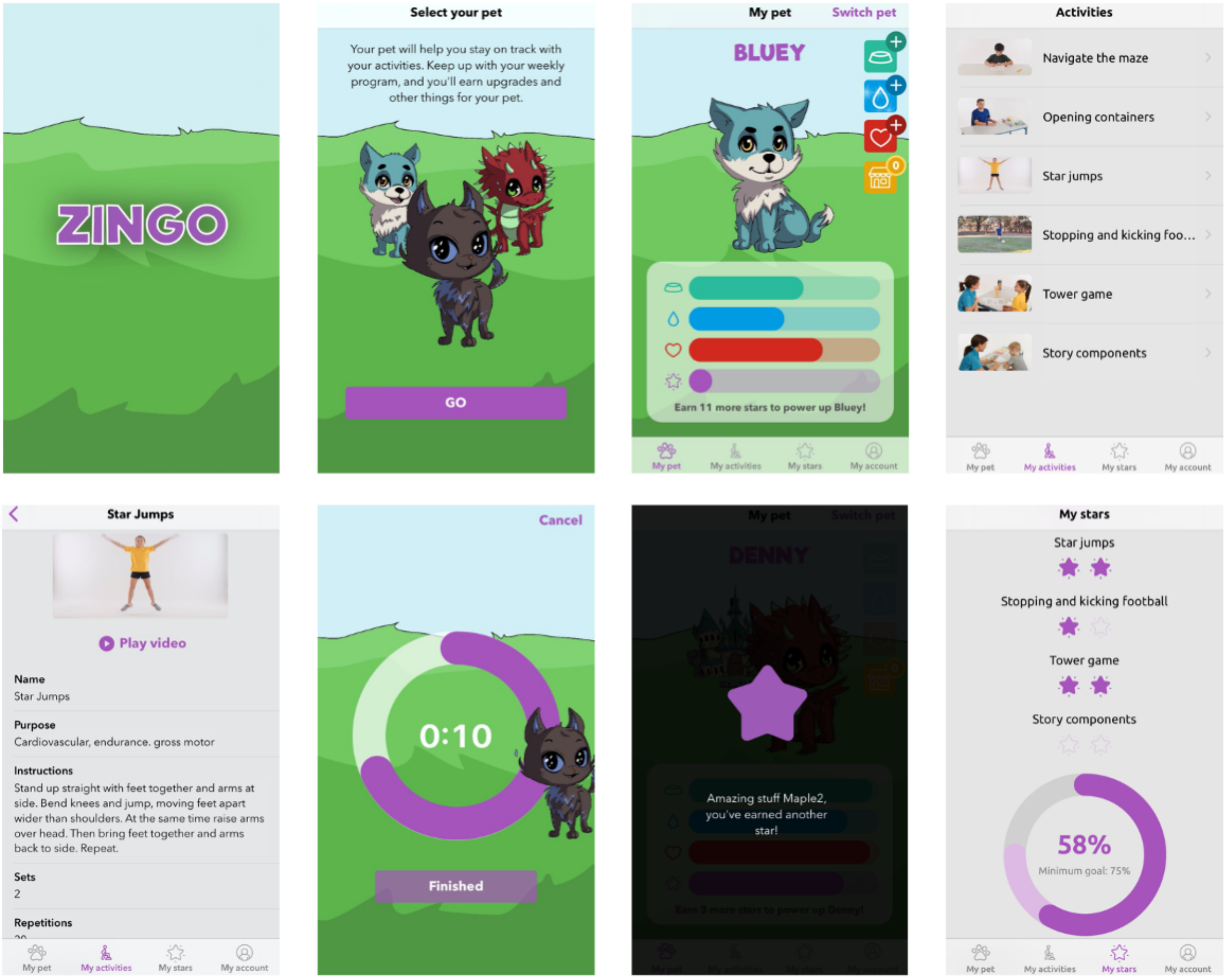
Earn 23 more stars to power up Roccl!

D. Progressive activity completion incentive- earn stars towards pet evolution

App Design

The concept design of the app incorporated sketches of different screens, a description of the functionality of each screen, and a flow chart demonstrating how the screens would be integrated. Concept designs were completed for a therapist interface and a child interface (Figure 3). The therapist interface was for creating and editing individualized therapy programs for multiple children; the child interface is where the BCTs and gamification elements were used. The interface was designed not only to maximize the screen size and functionality of an iPad but also to operate effectively on an iPhone. The research team provided feedback on this initial design to clarify and refine the concept for the next step—the development of a wireframe, which is "a representation of the skeletal structure of a mobile application [outlining the] relationship between the elements that make up a mobile application" [38]. The wireframe excludes visual design and graphic elements (to be added later in the app) but provides a semifunctional, basic prototype for early investigation. The wireframe was then brought to our consultation groups for review and feedback.

Figure 3. Zingo app user interface overview.



Your pet will help you stay on track with your activities. Keep up with your weekly program, and you'll earn upgrades and other things for your pet.

Earn 11 more stars to power up Bluey!

Name
Star Jumps

Purpose
Cardiovascular, endurance. gross motor

Instructions
Stand up straight with feet together and arms at side. Bend knees and jump, moving feet apart wider than shoulders. At the same time raise arms over head. Then bring feet together and arms back to side. Repeat.

Sets
2

Amazing stuff Maple2, you've earned another star!

Consultation Groups

Recruitment

A total of 2 consultation groups were recruited to attend 2 separate meetings each: an education and health professional group and a parent group. We did not recruit children with neurodevelopmental disabilities for our consultation groups; instead, we chose their advocates because of the complexity of the concepts to understand the app and recommend changes, particularly given the real-world context of app use enmeshed with home or school therapy activity performance. We sought the views of children in our testing process (refer *Prototype Testing*) and in the feasibility study that followed the app design.

Potential participants for both groups were identified by word of mouth through existing networks. Once potential participants were identified, they were contacted by a third party (research volunteer) to inform them of the consultation groups and gauge their interest. Interested parties were then contacted by the lead researcher to discuss their role, and those who agreed to participate signed a consent form.

Initial Meeting: Wireframe Review

All participants were familiar with using smart devices (phones and tablets) with children in either a parenting or professional context. Consultation group sizes were chosen pragmatically considering the feasibility of recruitment, seeking a diversity of views from a range of professional backgrounds and parental experiences and allowing for in-depth analysis and feedback on the wireframe. For the professional group, 3 teachers working with children with neurodevelopmental disabilities and 4 therapists working for a nongovernment community disability service provider (1/4, 25% speech pathologists; 2/4, 50% occupational therapists; and 1/4, 25% physiotherapists) were recruited. For the parent group, 3 parents of children aged 6 to 14 years with disabilities (1/3, 33% fathers and 2/3, 67% mothers) were recruited through word-of-mouth communication with therapists to identify parents who may be interested. One of the mothers was unable to attend the first group meeting because of illness but attended the second group.

The first meeting was early in the development process to review the app’s wireframe. The second meeting was later in the development process to review an early prototype of the app (Figure 1B). The consultation groups began with the lead investigator taking participants through the relevant app interface and features (on either the wireframe or app prototype), with time for the participants to explore the app and ask questions or provide spontaneous observations and feedback. Subsequently, the participants engaged in a semistructured discussion with set topics covering the purpose and framing of the app for children with disabilities, the app content and BCTs used, gamification and other engagement strategies, and the pragmatics of using the app in a school environment for the purpose of practicing exercises and activities prescribed by therapists for the child. The consultation sessions lasted 60 to 90 minutes.

The initial consultation groups reviewing the wireframe of the app provided important insights into motivation for children, support systems, and gamification recommendations. They were also able to outline pragmatic considerations for the implementation of app-delivered therapy programs in the classroom environment. Motivators of children and app features that would promote such motivators were a key theme. Tools such as an in-app timer during exercises with a 3-2-1 (or *ready-set-go*) lead-in were identified by both groups as exciting and were incorporated into subsequent app prototypes. The parents and professionals were enthusiastic about the game-inspired design. The topic of possible types of digital avatars was raised, and parents settled on digital pets as being motivating:

> *I think the pet idea would be the most exciting...so the idea of looking after a pet, 'cause [children with disabilities] tend to be more nurturing, the ones that I've met.* [Parent 1]
>
> *I'd go with pets as well. So, I've got two girls and they play a lot of games involving pets, so "Animal Jam" is one of them...my one daughter she's 12, who's got a disability, but she loves this game...I think she likes the characters and she likes the fact that you can change them, they can evolve over time.* [Parent 2]

The parents also alluded to a digital pet being superior to an animated child avatar because of potential issues with self-perception for children with disabilities—they might not fully identify with an avatar of a child who appears able-bodied (or avatars with visual indicators of disability may not appeal to children with mild disabilities). This issue of self-perception also came up when discussing a potential function for the app to collect a video of the child performing a prescribed activity as a feedback mechanism:

> *I know my daughter doesn't like looking at herself.* [Parent 2]

This feedback aligns with previous work investigating physical activity participation in people with disabilities, which identified poor self-perception as a common barrier to participation [39] but also feelings of improved self-worth when they do participate [40]. In terms of the pragmatics of using this app in the classroom, when the interviewer raised the topic of the potential for an app to be so engaging that it distracts from active therapy or educational time, the parents acknowledged this potential but conversely spoke of the need for the child to have some time to be fully engaged in the app and "fall in love with it" (parent 1) so that it might improve their motivation to practice. Similarly, the teachers identified that some students would lose interest if they could not hold the iPad and spend some time interacting with it themselves.

Adult social support for children practicing therapeutic exercises was discussed, and the parents suggested that the app could provide an update for parents on their child's progress in performing activities at school. This could best be delivered as a weekly email with a simple graphic summary. Teachers who provide active support to the child in the classroom were clear that they did not want an *alert* or *help* feature that would generate noise as the teacher and aides would always be attentive to the child's needs. The teachers and therapists were also able to specify some key features that they thought were important (eg, a feature to generate a printable PDF of the program) or unhelpful (eg, incorporating reminder alerts or notifications when flexible use of the app was described as preferable in the classroom).

Design Specification for Prototype App

Feedback, concepts, and functionality requirements derived from the parent and professional consultation groups who reviewed the wireframe were amalgamated with the app design elements identified from the IM process (steps 1-3). These were considered along with feedback on the wireframe from the research team and developer to formulate the design specifications for the app (Figure 1A) and build the first prototype of the app. Ongoing communication between the developer and research team was maintained to clarify the functional tools, interface layout, and other app function elements.

Visual Design Elements

Following the design specifications, we began work on the visual elements of the app to create an engaging app for children. In total, 2 BCTs identified from IM, "demonstration of behavior" and "instruction on how to perform behavior," along with reflections from participants in our previous study requesting videos with children (rather than adults) [12] informed the development of a library of therapy activity demonstration videos using children as models. A team of experienced therapists (a speech pathologist, occupational therapist, and physiotherapist), including RWJ, worked with a professional videographer and child volunteers to film commonly prescribed therapy activity and exercise demonstration videos (Figure 4) along with written activity goals and instructions. In addition, RWJ worked with a professional artist to develop key images for the gamification elements: background art, drawings of purchasable items (eg, custom pet bowls and fantasy pet houses), and 3 digital pets drawn in anime style. Each pet was drawn with 4 emotional states (sad, content, happy, and elated) and 3 progression states (child-like, maturing, and strong), resulting in 36 pet images for use with game-inspired app design (Figure 2).

Figure 4. Therapy activity videos: sample of still images taken from videos.

Prototype Testing

All design elements were incorporated into the app prototype (Figures 2 and 3) before user testing, for which there were 2 phases. First, 4 experienced app testers performed beta testing to look for software bugs, crashes, layout issues, and other technical errors. The second testing phase involved user evaluation of the quality, function, engagement, and usability of the app. Recruitment for prototype testing targeted children who met our inclusion criteria of being aged 6 to 12 years; having a neurodevelopmental disability; being interested in testing a new therapy app; having the fine motor skills to use an app and visual acuity to see the screen, including the various app interface elements; and being able to effectively communicate their experiences and opinions. We set the recruitment target at 4 to 6 children as this number of participants is recognized as sufficient to yield 75% of usability problems, with diminishing returns with more participants [41]. Interested and consenting participants undertook a testing protocol over a single session in a private room with a parent present using 2 methods (Textbox 1; Figure 1B).

Textbox 1. Methods for the app testing protocol.

Testing protocol methods

- Think-aloud walk-throughs are an industry-recognized method of testing mobile health apps [42]. RWJ demonstrated the think-aloud process to the children using another app as an example. The participants then opened the app prototype for the first time and were asked to describe what they were doing and their thoughts about using the app. The children were prompted to use the essential features of the app (determined before the walk-throughs) only if they did not access them spontaneously. Several therapy activities were included in the example program for the children to try, and necessary equipment was provided to simulate a real experience of using the app for therapy practice. We voice-recorded and transcribed their *think-alouds*. Transcripts were analyzed by a single reviewer (RWJ) to identify think-aloud content about the participants' app experiences, including app usability, app navigation, engagement, and emotional expressions.
- The Mobile Application Rating Scale-user version (uMARS) was selected as a broad app quality questionnaire that has submeasures for usability, engagement, aesthetics, information, and subjective quality. Following the think-aloud walk-through process, the children completed the uMARS with the support of their parents and guidance from RWJ. Guidance included reading the question and possible responses out loud and explaining any terms or concepts using language suitable for the child's age and level of understanding.

We recruited 5 participants for the user testing process, of whom 4 (80%) completed the process and 1 (20%) did not arrive for the scheduled testing date and was lost to follow-up. Implementing the testing processes with the children who volunteered proved challenging. We intended to engage a sample of children representing the target age range of 6 to 12 years, yet the 4 participants who completed the process had a mean age of 6.8 (SD 1.0 years; female: 2/4, 50%; diagnosis: 3/4, 75% cerebral palsy and 1/4, 25% Joubert syndrome); therefore, the children's cognitive development was a factor, particularly in the think-aloud walk-through. We observed that the children were limited in their capacity to interact with the app and talk about their experiences simultaneously. The limited literacy of children of this age group impeded their ability to navigate the app independently as the in-app pictorial cues are supported by simple written descriptions, and the interviewer needed to read labels and instructions for the children. The children needed prompting to tell the researcher what they were doing and thinking as they used the app, deviating from the intended think-aloud walk-through process of spontaneous verbalization of the technology experience. In addition, one of the children who arrived did not meet the criterion of having effective verbal communication despite previous parent confirmation that they did. Despite these challenges, we obtained helpful information from the 3 participants with effective verbal communication. Initially, the children showed confusion regarding how to progress with the app, and the importance of adult support became evident. Also observed was the children's enthusiasm for the app after the initial learning process and their perception of it as a gaming app:

> *I like this game, I want to download it.* [Child 1]

The children were enthusiastic about trying the therapy activities that had been selected. The 3 children with verbal communication ability completed the relevant sections of the Mobile Application Rating Scale-user version (uMARS) assessment with means (out of 5 for each) of 4.5 (SD 0.8) for engagement, 3.3 (SD 1.6) for function, 3.3 (SD 1.7) for aesthetics, and 4.3 (SD 1.1) for subjective quality. After completing the prototype testing, we prepared an app iteration for review in the final round of consultation groups.

Consultation Groups—Subsequent Meeting: Prototype App Review

In the second round of consultations, the app prototype was reviewed with a strong positive reception in both the parent and professional groups:

> *I think the kids will definitely, they [will] definitely like it.* [Professional 3]

There was a clear theme in the discussions around the process of learning how to maximize the gamification and reward features, with both groups expressing some initial confusion with some aspects of the different pet rewards. Some of these were due to glitches or reward systems not functioning as planned. An aspect of the gamification, *activity completion rewards that improve pet emotional state,* was revealed to be insufficiently responsive to change, whereas some other issues of app mechanics were identified as part of the normal learning process. Additional topics were app esthetics, which received widespread approval in terms of the general interface, activity videos, and gamification elements:

> *Very beautiful. Good colors, nice and bright. The animals themselves are exactly what I was hoping they would look like...in line with that kind of Pokémon, you know, cuteness.* [Parent 1]

Feedback was also provided on the interface—it was described as simple and effective, but they identified the need to increase the size of the icons and text in the tab buttons. The parents identified this element as important to meet the needs of children with visual impairment. Excellent advice was provided on how the app could work in terms of actual therapy practice in the school environment and methods of communication of performance at school with parents. The groups also identified the app as highly motivating for children:

> *It's so similar to other games that you would have to purchase stuff...[ie, in app purchases].* [Parent 1]
>
> *And that's the beauty of it. This game you buy things based on the effort you put in, not money, which is great. So, the child says I want...the pendant, well "you need to go and do some more exercises and get it," and that's great motivation.* [Parent 3]

This final consultation group completed the testing and feedback process. We implemented some immediate changes based on the feedback received in the beta testing, user testing, and consultation groups; for example, we improved the responsiveness of the incentives (Figure 2) that affect pet emotional state to yield rapid changes to reassure the user that their efforts were *helping* their pet, and we increased the font size. In later iterations, more substantial changes could be implemented, including an onboarding in-app tutorial to assist users in learning the functions, particularly the systems of pet rewards, and a printable PDF of the therapy program so this could be on display as an additional reminder and aid to do the therapy program. With these changes, the *Zingo* app was completed for further planned evaluation: a feasibility study of a 4-week therapy program using *Zingo* to take place with students aged 6 to 12 years with childhood disabilities in Western Australia.

Discussion

Principal Findings

We have reported on the development of an app for the prescription of home and school therapy activity programs for children with disabilities incorporating theory-based behavior change and gamification. We carefully selected BCTs based on SDT using the first 3 steps of the IM process that were then incorporated into the app design. We developed an app that is designed to be engaging and fun for children and effective for therapists based on user consultation throughout the development process and is ready for further evaluation.

Comparison With Prior Work

Our study is the first to incorporate IM and, more broadly, behavioral science principles into the design and development of a therapy or exercise prescription app for children. We used the first 3 steps of the IM process in a similar approach to Direito et al [21], who used IM steps 1 to 3 to develop an app to increase physical activity in adults, and DeSmet et al [24], who used IM steps 1 to 3 in serious game design to address cyberbullying among adolescents. An app-based parenting program to prevent childhood obesity by Karssen et al [43] used all 6 steps of IM in its design and implementation. The execution of IM steps 1 to 3 in the latter study has foreseeable congruity with our process; however, further similarities can be identified between the implementation of IM step 4 by Karssen et al [43] and the iterative, user-centered development process we used (Figure 1), including that both studies implemented consultation groups with parents and health care professionals to inform app design. Our process went a step further by incorporating specific app testing and feedback from our end users, children with disabilities, into the development process. Furthermore, Karssen et al [43], in IM step 6, implemented a thorough program evaluation via 2 randomized controlled trials, whereas we similarly implemented a specific trial to evaluate the Zingo app with a feasibility study that we will report separately. As an approach to app development, we can see how the IM process for selecting and implementing BCTs in the first 3 steps of IM can be used in conjunction with other methods and that these other processes are complementary to the IM protocol.

We planned and embedded gamification elements in the Zingo app design to maximize the engagement of Zingo app end users—children with disabilities. Some traditional methods of gamification such as leaderboards and badges were discarded to focus on elements that would be highly motivating for children. We incorporated some recognized gamification interface design elements—avatar use and fantasy theme [44]—but modified them for increased engagement in children; for example, the avatar element was modified to a digital pet that does not directly represent the user but draws on interest in animals and anime (ie, Japanese-style cartoon) characters. We used some recognized game mechanics, including clear goals, progression, and immediate feedback [44], along with recognized gamification point systems—experience points and redeemable points [45]—but added themed twists to adapt for children; for example, experience points are earned with every activity completion but are in the form of *stars*. Stars earned by children are tracked on the progress page for each activity and in a graphic representation of overall weekly progress and are also used on the primary gamification page with a star bar that fills up and, when full, the digital pet evolves to a more advanced state. Some of these elements that we used can be defined as "deep gamification," in which core processes of the app are changed for gamification and a "game design" approach is used to redesign the app to facilitate game mechanics [45]. By contrast, shallow gamification is where the activity is unchanged but enhanced with gamified elements (eg, points and badges) [45]. This approach, along with a targeted design interface for children and adaptation of game mechanics to maximize engagement, can be recommended from our study for future mHealth app design for children.

In the field of physiotherapy, there are feasible gamified apps for children focused on increasing physical activity [29,46,47], but there is a dearth of literature that describes or evaluates gamified apps for prescribing individualized exercise programs for children. In the field of occupational therapy, a high uptake in app use has been reported along with a great diversity of apps and their uses, including fine motor skills, activities of daily living, writing, visual motor skills, and play [48,49]. Some of the referenced apps use engaging and fun elements for children; however, gamification is not directly reported on, and these apps are most frequently used as a direct (ie, face-to-face) intervention tool rather than being designed as a home program tool [49]. For speech pathology, an abundance of apps for children have been recognized, many with gamification elements; however, in existing apps, there is a predominant focus on articulation and phenology (eg, Articulation Station, Articulate it!, and Articulation Scenes) [50], not language development. For example, in a review of 132 speech pathology apps, those for children with language disorders were excluded as they were found to be solely clinical assessment tools; there were no intervention apps targeting language for children to use [50]. These findings support the clinical utility of an app that is specifically for developing home and school programs where each child can be prescribed a unique program by their therapist rather than predetermined activities and that is multidisciplinary in its design, includes language development activities, and uses deep gamification features for an engaging experience for children.

Strengths and Limitations

Key strengths of this mHealth app design include a comprehensive approach to development and testing, incorporation of app design elements to support the functional use of the app in schools and homes, real-time feedback mechanisms and other features identified by therapists, and app design to address key psychological needs for building intrinsic motivation. Despite the rigor taken in this app development, we identified some limitations in the process that should be considered. Think-aloud testing processes were ineffective among some of the testing users despite our efforts to check eligibility during recruitment; their young age and neurodevelopmental disability meant that they had limited capacity to perform the think-aloud process of describing their thoughts and experiences while using the app prototype. In addition, our other user testing evaluation tool, the uMARS questionnaire, yielded some helpful information, but it required modification and support from the researcher and a lot of prompting from parents in some cases. An app quality rating scale developed specifically for children with disabilities is needed to improve testing.

Zingo is suitable for children with a broad range of neurodevelopmental disabilities, but some children with more severe disabilities will require additional assistance when using the app. When considering suitability, it is important to acknowledge that, in common clinical practice for therapy programs, a child will perform the program with parent, teacher, or caregiver supervision or assistance. Zingo app therapy programs are not intended to be performed completely independently. Another consideration is that Zingo cannot be used without the involvement of a therapist to set up the program; therefore, a therapist will use professional knowledge and parental consultation to determine suitability. To engage physically with Zingo, a child requires sufficient fine motor skills to tap a single *button* (ie, on-screen image) in the app, so the motor demand is not high. In our clinical experience, most children with disabilities can achieve this, with aides if required (eg, postural support seating), particularly when using a tablet device rather than a smaller screen as is common practice for this age group. However, children with severe upper limb contracture and deformity or significant visual impairment may not be able to activate the screen themselves. In these scenarios, the parent or caregiver could complete the fine motor component of pressing *buttons* on the app as a proxy. To cognitively engage with the app, most children with disabilities will need some support from a therapist or caregiver in the initial learning period and varying levels of support after this. To be independent with the app (with only adult supervision), the child requires a moderate level of reading capacity to select the correct options, although, wherever possible, we supplemented words with icons. Children without early literacy will require more parental support throughout the process. The app may be of limited benefit for children with profound intellectual and physical disabilities although, if the parent chooses to use Zingo for the child (eg, showing the screen to the child but pressing *buttons* for them), the child may still find the bright colors, music, digital pet images, and activity videos more engaging than conventional paper-based therapy programs.

Conclusions

We developed a gamified therapy prescription app embedded with theory-informed BCTs for the delivery and implementation of individually prescribed therapy programs for children with neurodevelopmental disabilities. We can recommend the use of the IM process to select and implement the most effective BCTs. A strong user-centred design process, as outlined here, with testing and feedback at multiple stages was important for adapting the app outcome to best suit the needs of the users and could be effectively used in future mHealth app development projects. We recommend that other methods for user testing with younger children with disabilities be explored in future studies. We prepared the *Zingo* app in this development phase for future study in *real-world* environments; a mixed methods feasibility study is planned to gain a stronger understanding of the *Zingo* app's function to deliver therapy programs in a way that is fun and engaging for children to improve adherence to those programs and thereby maximize the benefits of regular therapy activity practice for children with disabilities.

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Authors' Contributions

RWJ conceived the idea for the trial, reviewed the literature, sought ethics approval, coordinated recruitment, implemented outcome measures, conducted analyses, and drafted the paper. DFG provided supervision; guided the intervention mapping process; consulted on behavioral science elements; and supervised the literature review, ethics approval, and editing of the paper. BKW provided guidance on the model for app development and provided consultation for each step, in particular the consultation groups and testing processes; performed beta testing of the app; and edited the paper. NG assisted in the development of the trial concept, reviewing the literature, ethics approval, and editing of the paper. SAW provided supervision around the concept of the trial, literature review, and ethics application, and edited the paper.

Conflicts of Interest

BKW is a cofounder of Reach Health Promotion Innovations, which developed the Zingo app in partnership with Ability WA. There are no other conflicts to declare.

Multimedia Appendix 1

Key findings from the literature review on behavior change in children with mobile health interventions for intervention mapping step 1: needs analysis.

[PDF File (Adobe PDF File), 85 KB - pediatrics_v5i3e34588_app1.pdf]

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Abbreviations

BCT: behavior change technique
IM: intervention mapping
mHealth: mobile health
NGCS: Non-Government Centre Support
SDT: self-determination theory
uMARS: Mobile Application Rating Scale-user version

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Original Paper

Feasibility and Acceptability of Delivering Pivotal Response Treatment for Autism Spectrum Disorder via Telehealth: Pilot Pre-Post Study

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Abstract

Background: Pivotal response treatment (PRT), an evidence-based and parent-delivered intervention, is designed to improve social communication in autistic individuals.

Objective: The aim of this study was to assess the feasibility, acceptability, and clinical effects of an online model of PRT delivered via MindNest Health, a telehealth platform that aims to provide self-directed and engaging online modules, real-time coaching and feedback, and accessible stepped-care to large populations of parents seeking resources for their autistic children.

Methods: Male and female autistic children, aged 2-7 years with single-word to phrase-level speech, and their parents were eligible to participate in the study. Families were randomized to the online parent training condition or control condition. The online component of the intervention consisted of eight 20-minute online courses of content describing parent training principles in PRT. Four 1-hour videoconferences were held after course 1, course 3, course 5, and course 8. Parents were given 1-2 weeks to complete each course. Parents completed the Client Credibility Questionnaire (CCQ) at week 2 and at the study endpoint, as well as the Behavioral Intervention Rating Scale (BIRS) at the study endpoint to assess parental expectancies, and treatment acceptability and effectiveness.

Results: Nine of 14 participants completed the study curriculum in the online parent training condition, and 6 of 12 participants completed the control condition. Thus, a total of 58% (15/26) participants across both groups completed the study curriculum by study closure. Within the online parent training condition, there was a significant increase in mean CCQ total scores, from 25.38 (SD 3.25) at baseline to 27.5 (SD 3.74) at study endpoint (*P*=.04); mean CCQ confidence scores, from 6.0 (SD 1.07) at baseline to 6.75 (SD 0.89) at study endpoint (*P*=.02); and mean CCQ other improvement scores, from 5.25 (SD 0.89) at baseline to 6.25 (SD 1.28) at study endpoint (*P*=.009). Within the control condition, a modest increase in mean CCQ scores was noted (Confidence, difference=+0.25; Recommend, difference=+0.25; Total Score, difference=+0.50), but the differences were not statistically significant (Confidence *P*=.38, Recommend *P*=.36, Total Score *P*=.43). Among the 11 parents who completed the BIRS at the study endpoint, 82% (n=9) endorsed that they *slightly agree* or *agree* with over 93% of the Acceptability factor items on the BIRS.

Conclusions: The feasibility of this online treatment is endorsed by the high rate of online module completion and attendance to videoconferences within the online parent training group. Acceptability of treatment is supported by strong ratings on the CCQ and significant improvements in scores, as well as strong ratings on the BIRS. This study's small sample size limits the conclusions that can be drawn; however, the PRT MindNest Health platform holds promise to support parents of autistic children who are unable to access traditional, in-person parent-mediated interventions for their child.

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KEYWORDS

autism spectrum disorder; ASD; pivotal response treatment; PRT; telehealth; parent-implemented intervention; parent training; pediatrics; autism; children; digital health; online modules; online health; online treatment; pilot study; communication

Introduction

Background

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that is characterized by persistent social communication deficits and the presence of restricted and repetitive behaviors [1]. Currently, it is estimated that 1 in 44 people are diagnosed with ASD within the United States, and males are 4.2 times as likely to hold an ASD diagnosis than females [2]. Early diagnosis and intervention efforts aim to prevent or mitigate the severity of symptoms associated with ASD, and provide autistic children with opportunities for early socialization and communication development [3,4]. Consequently, early intervention has been linked to improved long-term outcomes in autistic children. With this understanding, the development of interventions for young children have emerged and support the importance of targeting the areas of social communication in young autistic children.

Pivotal response treatment (PRT), an evidence-based and parent-delivered naturalistic developmental behavioral intervention (NDBI), is designed to improve social communication in autistic individuals by addressing core deficits in motivation [5]. Research supports the efficacy of PRT utilizing a parent-delivered approach as apparent by increased child eye contact, directed positive affect, social communication, and engagement following the intervention [6,7].

Unfortunately, families often lack access to evidence-based behavioral interventions. It is estimated that an average time lag of 3 years exists between the time of diagnosis to the start of early intervention services for autistic children [8]. Contrary to popular belief, an early diagnosis does not translate to immediate early intervention services, as parents face uncertainty, years-long waitlists, shortages of providers, and competing time demands postdiagnosis [8]. Even when an intervention opportunity becomes available, barriers to obtain such services are extensive, such as distant location, lack of transportation, high costs, limited insurance coverage, parents' limited time availability, need for childcare, and lack of trained staff [9]. Additionally, parent engagement is limited, and attrition rates are high even among families with access to parent training programs. A recent literature review of 262 behavioral parent training studies found that over 25% of participants who met the inclusion criteria declined to enroll and an additional 26% of participants dropped out during treatment [10]. Moreover, several challenges exist that impede the implementation of parent-mediated interventions that provide feasible, approachable, and acceptable treatment alternatives to parents of autistic children.

To overcome barriers to high-quality care, telehealth—the provision of mental health or medical services via various modes of technology—has recently been implemented to facilitate access to parent-mediated interventions [1]. Telehealth allows for the dissemination of interventions in a variety of formats, ranging from self-directed courses to videoconferencing with a trained clinician.

Research comparing child outcomes of parent-mediated telehealth versus in-person applied behavior analysis interventions reported equitable success in reducing problem behaviors in autistic children, regardless of the modality by which parent coaching was delivered (ie, in person or via remote videoconferencing) [11]. Moreover, data from a pilot randomized controlled trial examining the effect of self-directed versus therapist-assisted parent-mediated telehealth interventions for autistic children found increased social skills only in children randomized to the therapist-assisted group [12]. In support of these findings, studies investigating telehealth adaptations of PRT via self-directed online modules found that following the online modules, parents successfully implemented PRT with fidelity; however, parents reported that a feedback or coaching component would have been increasingly helpful in conjunction with the self-directed media [13,14]. Self-directed parent-mediated interventions with no direct therapist involvement lack valuable opportunities to build a therapeutic alliance and rely heavily upon parent buy-in [14]. This not only illustrates the value of professional support in parent-mediated telehealth interventions but also the importance of utilizing a combined intervention approach that provides self-directed and remote parent-coaching facets in future adaptations. In addition to evaluating child outcomes in parent-mediated telehealth interventions, recent research has considered the feasibility and acceptability of such approaches to delineate if parent-mediated telehealth interventions can become a viable alternative to in-person interventions in the future. There is increasing literature investigating, and consequently supporting, the feasibility of parent-mediated telehealth interventions, wherein several studies reported high parent satisfaction and high treatment retention in addition to positive child outcomes [9,15].

Study Objectives

The aim of this study was to examine a telehealth NDBI: online PRT via the MindNest Health platform [16]. The purpose of this pilot study was to test the feasibility and acceptability of a novel intervention delivery model for autistic children. Feasibility will assess the plausibility and practicality of online PRT for families of autistic children via parent attendance throughout the intervention. Acceptability will assess if online PRT meets the needs of autistic children and their parents via parental satisfaction, confidence, and perceived treatment success. MindNest takes existing evidence-based skills and strategies used in NDBIs, and delivers them using brief and focused animated simulations in modular pieces. Moreover, MindNest provides active coaching and real-time feedback to parents in addition to self-directed online courses. Finally, MindNest is designed to be integrated into a stepped-care model of care, working to serve large populations of parents who are waiting for services or seeking to supplement existing services they are receiving.

Methods

Participants

Participants were recruited via local flyer postings and referrals from specialty clinics in New Haven, Connecticut, and the surrounding areas. Thirty-seven families expressed interest in participating, 11 of whom did not meet the inclusion criteria. A total of 26 autistic children, aged 2-7 years, and their parents were consented and enrolled in this study.

Inclusion criteria were as follows: (1) children aged 2-7 years with single-word to phrase-level speech; (2) a Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) diagnosis of ASD, based on assessment with the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) by a licensed provider [1,17]; (3) access to a mobile device and/or computer device with internet; (4) speak English fluently as a primary or secondary language, as endorsed via self-report; and (5) agree not to initiate new mental health treatments for their child for the duration of the study. Participants were excluded if they had received parent training previously, or if the child had a medical or psychiatric condition that required immediate clinical attention. Multiple parents/caregivers per child were welcome to participate in the study. In the event of multiple parents participating, a “primary” caregiver, who was available for all videoconferencing sessions and assessment measures, was determined to maintain continuity.

Ethics Considerations

The Yale University institutional review board approved this intervention study on October 10, 2018 (reference number: 2000021538). After telephone screening, written informed consent and video consent were obtained from a parent or legal guardian, and verbal assent was obtained from the children at the beginning of the visit.

Measures

Demographic Information

At baseline, parents provided demographic information, including caregiver gender and age, as well as their autistic child’s gender and age.

Medical History

At baseline and the study endpoint (week 10), parents completed a survey related to medical history and concomitant treatments (medication or psychosocial intervention) of their child, including the type of treatment, purpose, frequency or dose of treatment, start date, and stop date.

Client Credibility Questionnaire

The Client Credibility Questionnaire (CCQ) [18] is a 4-item, parent-rated measure designed to evaluate parental confidence in the efficacy and logistical nature of the treatment. Parents were asked to provide ratings about how logical the parent training seemed, how confident they are that it would be successful, and how confident they would be in recommending the parent training program to a friend. Ratings were made on an 8-point scale, ranging from 0 (not at all logical/confident) to 8 (very logical/confident), with a total score range of 0 to 32. Treatment posed the possibility of inducing different expectancies, and consequently contributing to differences in treatment response. Thus, the CCQ was used to assess parent expectancies [18]. Parents completed the CCQ at the end of week 2 and again at the study endpoint (week 10). This measure was completed at week 2 because, given the nature of the assessment measure, parents needed initial exposure to the treatment program before providing a rating.

Behavioral Intervention Rating Scale

The Behavioral Intervention Rating Scale (BIRS) is a 24-item, parent-rated measure designed to evaluate treatment acceptability and efficacy via three factors: Acceptability, Effectiveness, and Time of Effect [19]. Parents responded using a 5-point scale, ranging from 1 (strongly disagree) to 5 (agree), with a total score range of 24 to 120. BIRS Acceptability factor items (items 1-15) are used to indicate if an intervention can be deemed acceptable based on the number of *slightly agree* and/or *agree* responses from participants. Parents completed the BIRS only at the study endpoint (week 10).

Design

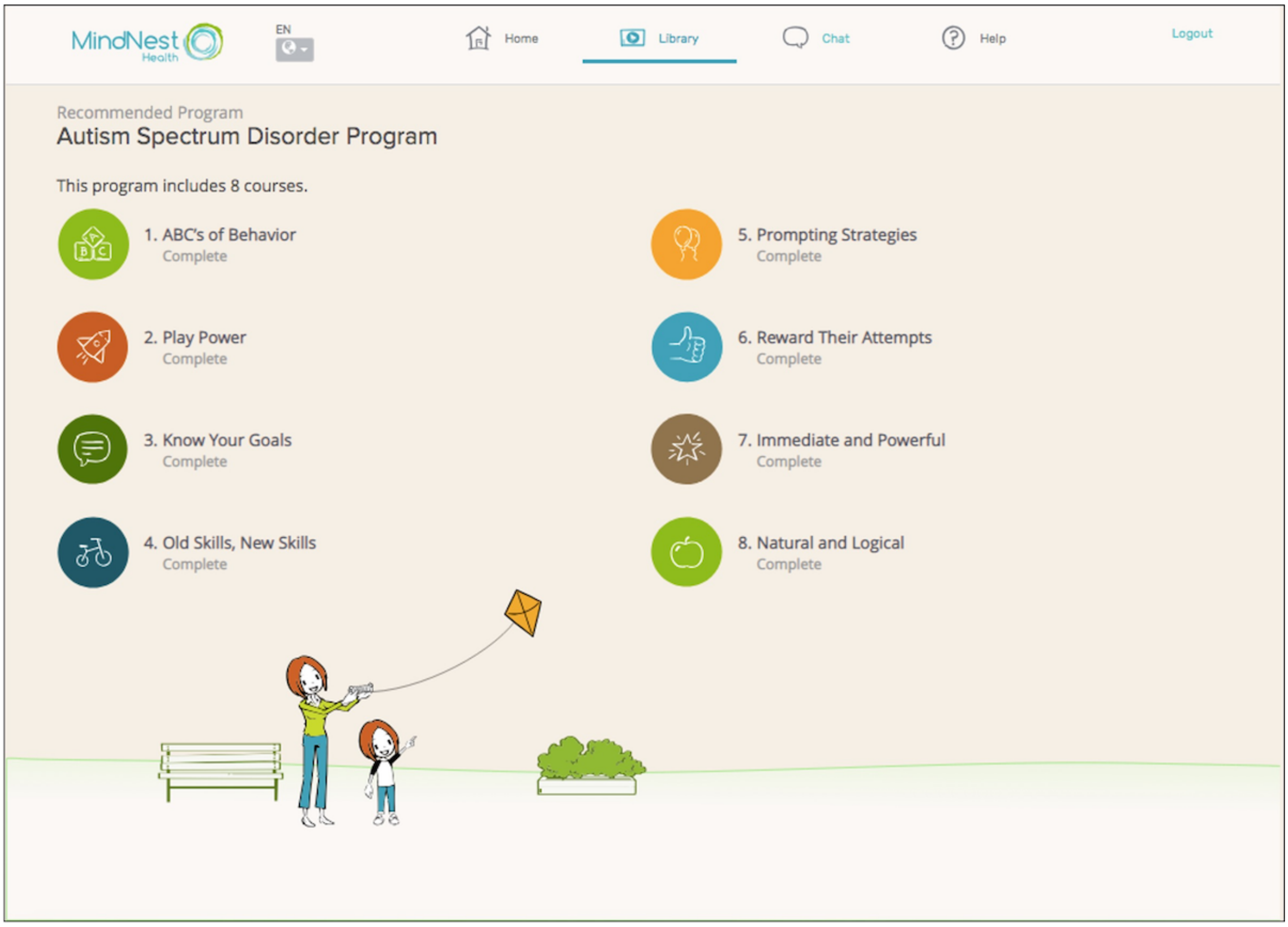
Families were randomized to the online parent training condition or to the control condition, with children matched according to sex and age. Parents randomized to the online parent training condition received access to a 10-week consultative parent-training model in PRT via the MindNest Health online platform. In the control condition, parents were provided with a written copy of the PRT manual (“PRT Pocket Guide”) to read independently [5]. All parents were instructed to practice PRT for 1 hour per day a minimum of 5 days per week, and were asked to submit a log indicating the dates and duration of their practice prior to each videoconferencing session. Specific days to practice were not prescribed; however, based on the clinical experience of the authors, 5 days per week was deemed to be a reasonable and feasible request for an at-home, independent practice of PRT. Additionally, both groups completed two follow-up videoconferencing sessions with a clinician in which parents were asked to perform PRT with their child for 10 minutes. These sessions took place in week 12 and week 14 and were recorded. Following successful completion of the control condition and all study assessments, families who were randomized into the control condition were provided access to MindNest Health and given the opportunity to receive videoconferencing with a PRT clinician.

MindNest Health

MindNest Health is an online telehealth platform that delivers evidence-based and scalable education, training, and support for parents who have a child with mental health or behavioral problems [16]. Within this study, MindNest Health was the telehealth platform used to deliver PRT to families randomized to the online parent training condition. The company was developed by a group of Yale University faculty and students.

The MindNest Health offering includes an integrated learning management system that delivers parent education and parent training in behavioral interventions (Figure 1). The lessons incorporate a blend of didactic information as well as demonstrations of PRT principles via short, animated simulations of parent-child dyads (Figure 2). Parents were able to move through animations at their own pace and are given opportunities to practice the skills and strategies as they move through the lesson (Figure 2). The platform has undergone professional user testing with parents of autistic children and children with other developmental delays, and the feasibility and acceptability of the platform were supported in a recent study [9]. The content was delivered in parent-friendly and accessible language, and the PRT principles are illustrated using animated simulations of a parent and child with voiceover from a narrator. Video examples of the PRT principles are a critical component to teaching the approach, and the technological advances in instructional design allowed for the creation of exact models illustrating complex constructs.

Figure 1. MindNest Health interface displaying the eight offered modules.



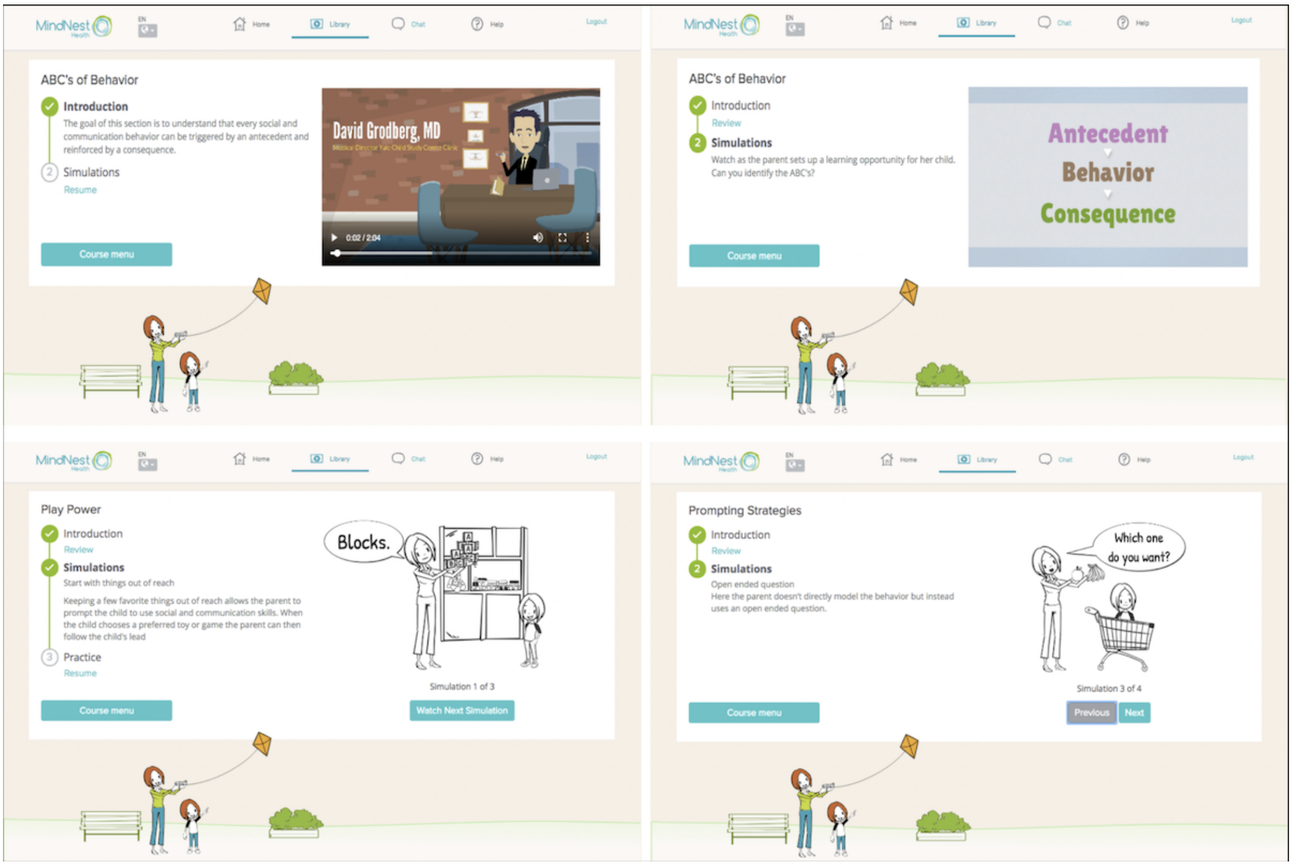
Recommended Program

Autism Spectrum Disorder Program

This program includes 8 courses.

1. ABC's of Behavior Complete
2. Play Power Complete
3. Know Your Goals Complete
4. Old Skills, New Skills Complete
5. Prompting Strategies Complete
6. Reward Their Attempts Complete
7. Immediate and Powerful Complete
8. Natural and Logical Complete

Figure 2. MindNest Health courses, including didactic information as well as demonstrations of behavioral strategies using animated simulations. For example, simulations demonstrate how a parent can prompt a child to ask or respond to questions across different settings.



ABC's of Behavior

Introduction

The goal of this section is to understand that every social and communication behavior can be triggered by an antecedent and reinforced by a consequence.

ABC's of Behavior

Simulations

Watch as the parent sets up a learning opportunity for her child. Can you identify the ABC's?

Play Power

Simulations

Start with things out of reach

Keeping a few favorite things out of reach allows the parent to prompt the child to use social and communication skills. When the child chooses a preferred toy or game the parent can then follow the child's lead

Prompting Strategies

Simulations

Open ended question

Here the parent doesn't directly model the behavior but instead uses an open ended question.

Intervention

After the initial telephone screening study visit, parents in the online parent training condition were given instructions to access the MindNest Health platform. The online component of the intervention consisted of eight 20-minute online courses of content describing parent training principles in PRT (Figure 1). Parents completed each course at their own pace and were asked to complete one course per week for the first 8 weeks of the intervention. All parents completed the following courses chronologically: “The ABCs of Behavior”; “Play Power”; “Know Your Goals”; “Old Skills, New Skills”; “Prompting Strategies”; “Reward Their Attempts”; “Immediate and Powerful”; and “Natural and Logical.” These courses respectively taught parents an overview in behavioral principles, an overview of PRT, how to create contingencies for behavior, the importance of maintenance and acquisition task, how to use behavioral prompting to support behavior, and how to reinforce behavior. Table 1 provides the sequence and description of intervention topics.

Four 1-hour videoconferences were held after course 1, course 3, course 5, and course 8. Parents were given 1-2 weeks to complete each course. These intervals were selected to spread the videoconference sessions throughout the study duration, but also specifically following core and conceptually distinct courses (eg, overview of behavioral strategies in general, overview of PRT and the importance of behavioral contingencies for beginning PRT, use of prompting, reinforcing behavior). These videoconferencing sessions took place using either FaceTime or Vidyo, a Yale-owned videoconferencing program that did not require a software download. Participants had the option to videoconference on a tablet, smartphone, or computer. Videoconferencing sessions were recorded. Videoconferences were conducted by a trained PRT clinician, and gave families an opportunity to apply, implement, and utilize the principles of PRT that the parents were learning online. The trained clinician provided feedback to parents about their individual implementation of PRT, in accordance with a practice-with-feedback model [20]. The lead clinician is a licensed psychologist with extensive experience working with autistic children and implementing PRT. The other PRT clinicians included three female, bachelor-level staff who spoke English as their primary or secondary language and had 1-5 years of experience working with autistic children. Prior to study enrollment, all study clinicians underwent intensive training in PRT and each clinician was required to meet fidelity for PRT implementation prior to participant contact. The lead clinician provided supervision and feedback to PRT clinicians throughout the duration of the study.

Table 1. Pivotal response treatment (PRT) online courses and videoconferencing session timeline.

Timeline	Course	Topic
Week 1	ABCs of Behavior	Overview in behavioral principles
Videoconferencing session 1		
Week 2	Play Power	Overview of PRT, creating learning opportunities during play interactions
Week 3	Know Your Goals	How to create contingencies for behavior and attainable target goals
Videoconferencing session 2		
Week 4	Old Skills, New Skills	Importance of using both maintenance and acquisition tasks to increase motivation
Week 5	Prompting Strategies	How to use behavioral prompting to support behavior
Videoconferencing session 3		
Week 6	Reward Their Attempts	Reinforcing attempts, even when the target goal is not achieved
Week 7	Immediate and Powerful	Reinforcing behavior via highly motivating rewards that are given immediately following behavior
Week 8	Natural and Logical	Reinforcing behavior via rewards that are natural and logically connected to the child's actions
Videoconferencing session 4		

Results

Participants

Fourteen parent-child dyads were randomized to the online parent training condition. Participants included children, 9 males (mean age 4.56 years) and 5 females (mean age 4.24 years), and their parents, 9 mothers (mean age 39.77 years) and 5 fathers (mean age 43.33 years). Twelve parent-child dyads were randomized to the control condition. Participants included children, 8 males (mean age 4.65 years) and 4 females (mean age 4.71 years), and their parents, 7 mothers (mean age 41.07 years) and 2 fathers (mean age 40.54 years). Each child is represented by one parent.

Feasibility and Acceptability

Nine of 14 participants (5 males, 4 females) completed the study curriculum in the online parent training condition, and 6 of 12 participants (5 males, 1 female) completed the control condition. A total of 15 of 26 participants (58%) completed the study curriculum by study closure. Of those who completed the study, 13 of 15 (97%) participants completed all four videoconferences and 100% of participants in the online parent training group completed all four videoconferences. Additionally, 14 of 15 (93%) participants completed at least one endpoint visit after the conclusion of treatment. One participant who completed the intervention did not attend an endpoint visit and three participants failed to return endpoint measures via mail. Of those who withdrew from the study, 6 of 11 (55%) were randomized to the control condition and 3 of 11 (27%) cited time commitment as the reason for withdrawing. Before withdrawing from the study, 8 of 11 (73%) participants completed one or more videoconferences and received treatment materials (ie, treatment manual or access to MindNest Health online courses).

Parental Perception and Acceptability of Treatment

CCQ Outcomes

Of the participants who completed the intervention and attended an endpoint visit, 12 of 15 parents (n=8, online parent training condition; n=4, control condition) completed and returned the CCQ before and after treatment. At both the baseline and endpoint, parents in the online parent training condition endorsed higher scores on the CCQ in comparison to those of parents in the control condition (baseline mean difference=+3.13, endpoint mean difference=+4.75); however, no significant differences emerged between group means (*P*=.32). The mean CCQ total score at baseline was 25.38 (SD 3.25) and was 27.5 (SD 3.74) at the endpoint for the online parent training condition. Within the control condition, the mean CCQ total score was 22.25 (SD 7.46) at baseline and was 22.75 (SD 6.18) at the endpoint.

There was a significant increase in mean CCQ total scores from 25.38 (SD 3.25) at baseline to 27.5 (SD 3.74) at the study endpoint (*P*=.04) among parents who completed the online parent training condition. Additionally, parental confidence in the intervention's ability to reduce their child's symptoms increased significantly from 6.0 (SD 1.07) at baseline to 6.75 (SD 0.89) at the study endpoint (*P*=.02). Among the same group, a significant increase was found in mean scores, indicating perceived success of the treatment's ability to improve nontargeted areas such as sadness, anxiety, and schoolwork, from 5.25 (SD 0.89) at baseline to 6.25 (SD 1.28) at the study endpoint (*P*=.009). While modest increases endured in parental confidence of treatment success (mean difference=+0.25), likelihood of recommending the treatment to others (mean difference=+0.25), and CCQ total score (mean difference=+0.50) within the control group from baseline to the endpoint, no significant differences were found (Confidence *P*=.38, Recommend *P*=.36, Total Score *P*=.43).

BIRS Outcomes

There were 11 parents (n=7 in the online parent training condition and n=4 in the control condition) that completed the BIRS at the study endpoint after completing treatment. Within the online parent training group, 6 of 7 parents certified that they *slightly agree* or *agree* with the intervention’s ability to improve their child’s difficulties on 14 of the 15 BIRS Acceptability factor items (>93%). All parents in the control condition responded they *slightly agree* or *agree* with the efficacy of the intervention on 13 of the 15 BIRS Acceptability factor items (>87%). Combined, 9 of 11 (82%) parents endorsed they *slightly agree* or *agree* with over 93% of the Acceptability factor items on the BIRS (14 of 15 items). Moreover, 8 of 15 (53%) Acceptability factor items were rated *slightly agree* or *agree* by all parents. Additionally, the highest rating (5, *agree*) was indicated by 73% (8 of 11) parents in their willingness to use the intervention in a home setting and agreement that the intervention would *not* result in negative side effects for their child (Table 2).

Table 2. Behavior Intervention Rating Scale (BIRS) Acceptability factor item data.

BIRS items[a]	Online parent training (n=7), mean (SD)	Control (n=4), mean (SD)
Item 1. This would be an acceptable intervention for my child’s problem behavior	4.57 (0.54)	4.75 (0.50)
Item 2. Most parents would find this intervention appropriate for behavior problems in addition to the one described	4.29 (0.76)	4.25 (0.96)
Item 3. The intervention should prove effective in changing my child’s problem behavior	4.29 (0.49)	4.25 (0.50)
Item 4. I would suggest the use of this intervention to other parents	4.57 (0.54)	4.25 (0.50)
Item 5. The child’s behavior problem is severe enough to warrant use of this intervention	4.0 (1.0)	4.5 (1.0)
Item 6. Most parents would find this intervention suitable for the behavior problem described	4 (0.82)	4.25 (0.50)
Item 7. I would be willing to use this in the home setting	4.71 (0.49)	4.75 (0.50)
Item 8. The intervention would *not* result in negative side effects for my child	4.57 (0.54)	5.0 (0.00)
Item 9. The intervention would be appropriate for a variety of children	3.86 (0.38)	4.5 (0.58)
Item 10. The intervention is consistent with those I have used in the home setting	4.29 (0.49)	4.0 (0.82)
Item 11. The intervention was a fair way to handle my child’s problem behavior	4.43 (0.79)	4.5 (0.58)
Item 12. The intervention is reasonable for the behavior problem described	4.43 (0.54)	4.5 (0.58)
Item 13. I like the procedures used in the intervention	4.57 (0.54)	4.25 (0.96)
Item 14. This intervention was a good way to handle my child’s behavior problem	4.57 (0.54)	4.5 (0.58)
Item 15. Overall, the intervention would be beneficial for my child	4.67 (0.52)	4.5 (0.58)

[a] Items are scored on a scale of 1-5; higher scores indicate higher agreement.

Discussion

Principal Results

This study examined the feasibility and acceptability of an individualized parent-mediated treatment for autistic children. The feasibility of this online treatment is endorsed by the high rate of online module completion and attendance to videoconferences (>70%) within the online parent training group. The dropout rate within the parent training condition was relatively low (36%) and was higher within the control condition (50%). Three families cited time commitment as the reason for withdrawal; however, all three families were experiencing outside familial stressors unrelated to treatment they had to address. The other reasons for dropout are unclear; however, in all cases, parents appeared to have difficulty responding to the phone calls and emails of the study clinicians, particularly following a delay (ie, post treatment follow-up) or when consistent communication was not established (ie, control condition).

Strong ratings on the CCQ and significant improvements in scores suggest that the treatment was highly acceptable to participating parents within the online parent training condition. Parents endorsed significantly increased feelings of confidence in the intervention’s ability to reduce their child’s symptoms and improve nontargeted areas such as sadness, anxiety, and schoolwork. Within the control condition, parents did not endorse scores of the same magnitude, and reported lower ratings on the CCQ at both baseline and the study endpoint. This indicates that parents in the online parent training condition found the intervention to be more acceptable than parents who did not participate in the online courses via MindNest Health and only received the PRT manual.

Further, strong ratings on the BIRS support the high acceptability of the intervention to participating parents. A majority of parents (>80%) agreed with all but one of the Acceptability factor items on the BIRS. General themes of parents' ratings included willingness to use the intervention in a home setting and agreement that the intervention would *not* result in negative side effects for their child. Moreover, parents in both conditions expressed satisfaction in the treatment.

The PRT MindNest Health platform holds promise to support parents of autistic children who are unable to access traditional, in-person parent-mediated interventions for their child. As this is a pilot, open feasibility study, we cannot confirm, and did not presume, that the change in clinical symptoms was due to MindNest Health rather than parents' expectations or attention from study personnel.

From an assessment point of view, the combination of a platform comprising general content with videoconferences to individualize the skills garners much value. The online videoconferences provide opportunity for a "naturalistic" observation in ways that are otherwise missed in a clinical setting. For instance, during videoconferences, the disruptions of neighbors or siblings and the logistical challenges of the house setup became more apparent. Further, a brief online intervention serves as a thorough, low-cost assessment of patients' and families' needs, strengths, and vulnerabilities, gauging whether parents and patients would be able to engage in routine therapy.

Limitations

This study's small sample size and limited parent demographic information limits the conclusions that can be drawn regarding parents' ratings of acceptability. A future iteration of this study should include additional efficacy measures and demographic information (ie, marital status, racial and ethnic identity, education) to determine if children show improvements in their social communication and behavior skills following the treatment and to understand sociodemographic factors that may influence the feasibility and acceptability of this telehealth intervention. Further, while escalated rates of attrition are evident in similar online parent training programs, the high attrition rate, particularly in the control group, may impact the generalizability of the results and should be considered when developing future iterations of this study [10,12,14,21].

Another important limitation of this study is the requirement for parents to have their own technological devices and internet access. While an aim of this study was to increase accessibility to early evidence-based interventions, this requirement precluded families who did not have access to the aforementioned technologies from enrolling. A requirement such as this may have limited study enrollment to only families of higher socioeconomic status (SES). It is acknowledged that telehealth may not be a viable solution to families of low SES due an inaccessibility of required technologies. Future studies can aim to address these issues by providing devices to families or incorporating an in-person alternative.

Conclusions

The PRT MindNest Health platform is a promising intervention that has the potential to increase access to evidence-based interventions for parents of autistic children who are unable to access in-person services via engaging online modules and videoconference coaching. Online treatments hold great potential in their ability to improve access to care. Thus, future studies are required to determine the efficacy of parent-mediated telehealth interventions and the possibility of such interventions serving as a viable and effective alternative to in-person evidence-based interventions.

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Conflicts of Interest

DG is founder and senior clinical advisor to MindNest Health. The other authors have no conflicts of interest to declare.

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Abbreviations

ADOS-2: Autism Diagnostic Observation Schedule, Second Edition
ASD: autism spectrum disorder
BIRS: Behavioral Intervention Rating Scale
CCQ: Client Expectancies Questionnaire
DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
NDBI: Naturalistic Developmental Behavioral Intervention
PRT: Pivotal Response Treatment
SES: socioeconomic status

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