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Original Paper

Effectiveness of the Volunteer Family Connect Program in Reducing Isolation of Vulnerable Families and Supporting Their Parenting: Randomized Controlled Trial With Intention-To-Treat Analysis of Primary Outcome Variables

Rebekah Grace^{1*}, BA, PhD; Kelly Baird^{1*}, BA, PhD; Emma Elcombe^{1*}, BAppSc, MBMSc, MPhil; Vana Webster^{1*}, BSc, PhD; Jacqueline Barnes^{2*}, BSc, MSc, PhD; Lynn Kemp^{1*}, BHSc, MBUS, PhD

¹Translational Research and Social Innovation, Western Sydney University, Liverpool, Australia

²Institute for the Study of Children, Families and Social Issues, Birkbeck University of London, London, United Kingdom

* all authors contributed equally

Corresponding Author:

Rebekah Grace, BA, PhD

Translational Research and Social Innovation

Western Sydney University

1 Campbell St

Level 3

Liverpool, 2170

Australia

Phone: 61 87389362

Email: r.grace2@westernsydney.edu.au

Abstract

Background: Volunteer home visiting is a widely adopted community-based approach to support families by linking isolated or vulnerable families with community volunteers who visit their homes weekly over approximately 12 months. This study seeks to robustly evaluate the effectiveness of this model of support for families with young children.

Objective: This paper reports the intention-to-treat analysis of primary and secondary outcomes for a pragmatic randomized controlled trial (RCT) of the Volunteer Family Connect intervention, a volunteer home-visiting program designed to support families with young children who experience social isolation or a lack of parenting confidence and skills.

Methods: The RCT was conducted across seven sites in Australia. Overall, 341 families were recruited: 169 intervention (services as usual+volunteer home visits) and 172 control (services as usual) families. Intervention families received the program for 3-12 months. Participants were invited to complete six data collection points over a 15-month period. Primary outcomes were community connectedness and parenting competence. Secondary outcomes included parent physical and mental health, general parent wellbeing, parent empowerment, the sustainability of family routines, and the parent-child relationship. According to the protocol, the program would be judged to be effective if at least one of the primary outcomes was significantly positive and the other was neutral (ie, intervention families did not demonstrate positive or negative outcomes compared to the control group).

Results: The intervention group demonstrated significant improvement in the primary outcome variable parenting sense of competence as compared to the control group. Overall, there was no significant difference between the intervention and control groups with regard to the primary outcome variable community connectedness, other than on the "Guidance" subscale of the Social Provisions Scale. Because there were statistically significant findings for the total score of one primary outcome variable "parenting sense of competence" and largely neutral findings for the primary outcome variable "community connectedness," the program met the previously defined criteria for program effectiveness. In relation to secondary outcomes, intervention families reported significantly higher wellbeing and were significantly more likely to feel that life was improving.

Conclusions: The Volunteer Family Connect intervention was considered an effective intervention, with a role to play on the landscape of services available to support vulnerable families with young children.

Trial Registration: Australian New Zealand Clinical Trial Registry ACTRN12616000396426; <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=370304>

KEYWORDS

volunteer home visiting; randomized controlled trial; families; support services; social relationships; community; Volunteer Family Connect

Introduction

Background

Volunteer home visiting is a widely used strategy to support those who are isolated within their communities and require additional support to engage with health and other community services that are available to them and with other local families. Typically, a community volunteer is assigned by a coordinating organization to someone who has been identified as needing social support. The volunteer will visit them on a regular basis, provide general support, and facilitate their engagement with formal services until the individual feels more connected to the community and better able to utilize services independently. Previous research has supported the importance of this less formal, relationship-based approach as complementary to other, more formal services on the service landscape. It is likely to be instrumental in breaking down barriers to service engagement, including language and cultural barriers [1]. Research supports the potential value of volunteer home visits in the distribution of health information [2], support of improved social networks to those who are isolated [3], promotion of emotional wellbeing and parenting competence [4], promotion of positive health outcomes [5], and support of those with chronic illnesses [6].

In the Australian context, volunteer home visiting programs for families with young children have come under threat in recent years, with services reporting the withdrawal of government funding because of the lack of methodologically rigorous evidence demonstrating their effectiveness. The failure to evaluate the effectiveness of this model of support utilizing a robust, gold-standard research design in an Australian context has been mistaken for a lack of program effectiveness. Rigorous trials are required to determine the effectiveness of volunteer home visiting as a form of structured social relationships to support those who are isolated.

Structured Social Relationships as Intervention

The research evidence demonstrating the importance of social relationships as protective for health and wellbeing is strong. Much of the existing research has emphasized on the role of social networks in the prevention and treatment of mental health disorders such as depression [7,8]. Holt-Lunstad and colleagues [9] refocused attention on biomedical health outcomes, looking specifically at social connection as a risk factor for mortality. They conducted a meta-analytic review and found a 50% increase in the likelihood of survival for participants with strong social relationships. Social isolation was found to place participants at a higher risk of mortality than well-known risk factors, including smoking, excessive drinking, and obesity. Although the prevention of smoking and obesity attracts considerable attention and investment across the world, social relationships are still largely conceptualized as existing within the private realm beyond the scope of service intervention and

public health campaigns. However, in recent years, at the level of policy, there has been a growing interest in the importance of social connection. For example, in January 2018, the Prime Minister of the United Kingdom announced the establishment of the Commission for Loneliness [10].

The need to address social connections in the design of service solutions is further supported by research demonstrating rising levels of perceived social isolation and disconnection in the industrialized world. This is largely credited to the increased rates of divorce, separation and single parenthood, geographic mobility, and the decline in extended families living together [11]. In Australia, for example, conservative estimates indicate that 7%-9% of Australians report feeling socially isolated or very isolated, with younger adults being at the highest risk of perceived isolation [12,13].

Addressing social connection through service intervention is not straightforward, because appropriately paid service professionals must maintain professional boundaries and are perceived to provide a service by clients rather than being part of their social network [9]. Nonetheless, increased understanding of the importance of social connection is having a direct impact on health service practice, with a growing emphasis on a relationship-based approach to nursing and allied health care [14]. Establishing support programs run by community volunteers represents an approach to supporting those who are isolated to build social connection within the local community and facilitate engagement with local services [15].

Byrne and colleagues [1] proposed that a holistic approach to family health and wellbeing requires four interconnected arms of support: universal services (eg, primary health care), targeted services (eg, specialist medical services and child protection services), informal networks (eg, friends and families), and structured social support (eg, volunteer “befriending” programs). Organized volunteer programs are clearly not as organic as natural friendships or family ties, but they potentially provide an alternative for people who do not have an informal support network within their local community and may indeed be preferable if there are family tensions. Social networks, structured or organic, play a crucial role in breaking down the barriers to engagement with professional services and in fostering a sense of personal wellbeing [2].

Structured Social Relationships to Support Parents of Young Children

Parents, especially mothers, are at a high risk of social isolation, particularly in the early years of transition to parenthood when feelings of exhaustion or unpreparedness can be overwhelming [16,17]. In research involving parents with additional challenges, such as having a child with a disability [18], newly arriving in a country [19], or experiencing cognitive or mental health difficulties [20], social isolation is a common theme. A small body of existing research has examined the role of volunteer

home visiting programs in supporting improved outcomes for vulnerable families. Collectively, the literature supports the potential value of a home visiting model in contributing to improved outcomes related to maternal emotional wellbeing and an enhanced sense of maternal parenting competence [4] as well as improved family social connectedness [21]. There is evidence to suggest that volunteer home visiting programs can also support child health outcomes such as improved immunization rates and higher rates of exclusive breastfeeding [22].

The Volunteer Family Connect Effectiveness Trial

This paper describes a pragmatic randomized controlled trial of volunteer home visiting, which was conducted across four states in the east of Australia. The project provides an exemplary model of service collaboration, bringing together three not-for-profit service organizations usually in competition with each other and all independently running volunteer home visiting programs for families with young children (Karitane, The Benevolent Society, and Save the Children Australia). The collaboration, including university research partners and a corporate partner, combined the best elements of the existing programs into one manualized “best practice” program built on research evidence, theoretical underpinning, and practice experience. This program, known as Volunteer Family Connect, was then implemented across all three organizations. Details of program implementation and the research protocol have been published previously [23].

This study addressed two primary outcomes—community connectedness and parenting sense of competence—and compared intervention families (those randomly allocated to receive Volunteer Family Connect in addition to usual care services) with control group families (those randomly allocated to continue to receive usual care services only). In the Australian context, “usual care services” includes free universal health care, government-subsidized early childhood education and care services, and either free or low-cost playgroup or parenting support programs provided by nongovernment organizations varying from one location to another. The control group was therefore still potentially able to access considerable support from within their communities if they sought it out. No restrictions were placed on the intervention group in terms of accessing any additional community support. In fact, this was actively facilitated. Consequently, this study examined the added value of volunteer home visiting within a reasonably comprehensive service context. We hypothesized that intervention families would develop a stronger sense of parenting competence and stronger community support networks than those who continued to receive usual community support services.

Methods

Study Design

A pragmatic randomized controlled trial (RCT) was undertaken to rigorously assess the effectiveness of the Volunteer Family Connect intervention in real-world conditions [24]. Supported by the Pragmatic Explanatory Continuum Indicator Summary (PRECIS) tool [24] and in keeping with the “real-world”

conditions for a pragmatic randomized trial, this study (1) recruited the full range of families referred (through usual referral pathways) to the Volunteer Family Connect intervention program delivered across the service organizations with no changes to the inclusion/exclusion criteria; (2) compared the volunteer home visiting program with other usual care support services; and (3) tested real-world implementation of the volunteer home visiting program by the service organizations with their current volunteer providers by using guidelines to support quality service provision, but acknowledging that there are variations in practice while rigorously assessing outcomes using standardized measurement tools. The use of the PRECIS tool in supporting the design of this RCT has been reported elsewhere [23].

Primary Research Question

Is Volunteer Family Connect, a volunteer home visiting intervention, effective in improving the parenting competence and community connectedness of vulnerable families with young children compared with families who receive usual community-based support services?

Hypothesis

Families receiving a volunteer home visitor will have significantly better family outcomes at program exit (ie, higher sense of parenting competence and stronger community connectedness) than those allocated to continue to receive usual care in the community.

Secondary Research Question

For the purposes of this paper, results are presented for the secondary research question: Do differences exist in the patterns of parent health, wellbeing, empowerment, parent-child relationship, and family routines over time between those who receive the Volunteer Family Connect program and those in the services as usual control group?

Participants

Eligibility Criteria

Families were assessed against the following eligibility criteria: (1) having one or more children aged 0-5 years, (2) being at-risk of geographic or social isolation, (3) seeking to develop confidence and increase parenting knowledge and skills, (4) residing in the specified service area, and (5) being unable to access resources or other support services. Research participation was supported by the use of interpreters for families with a first language other than English.

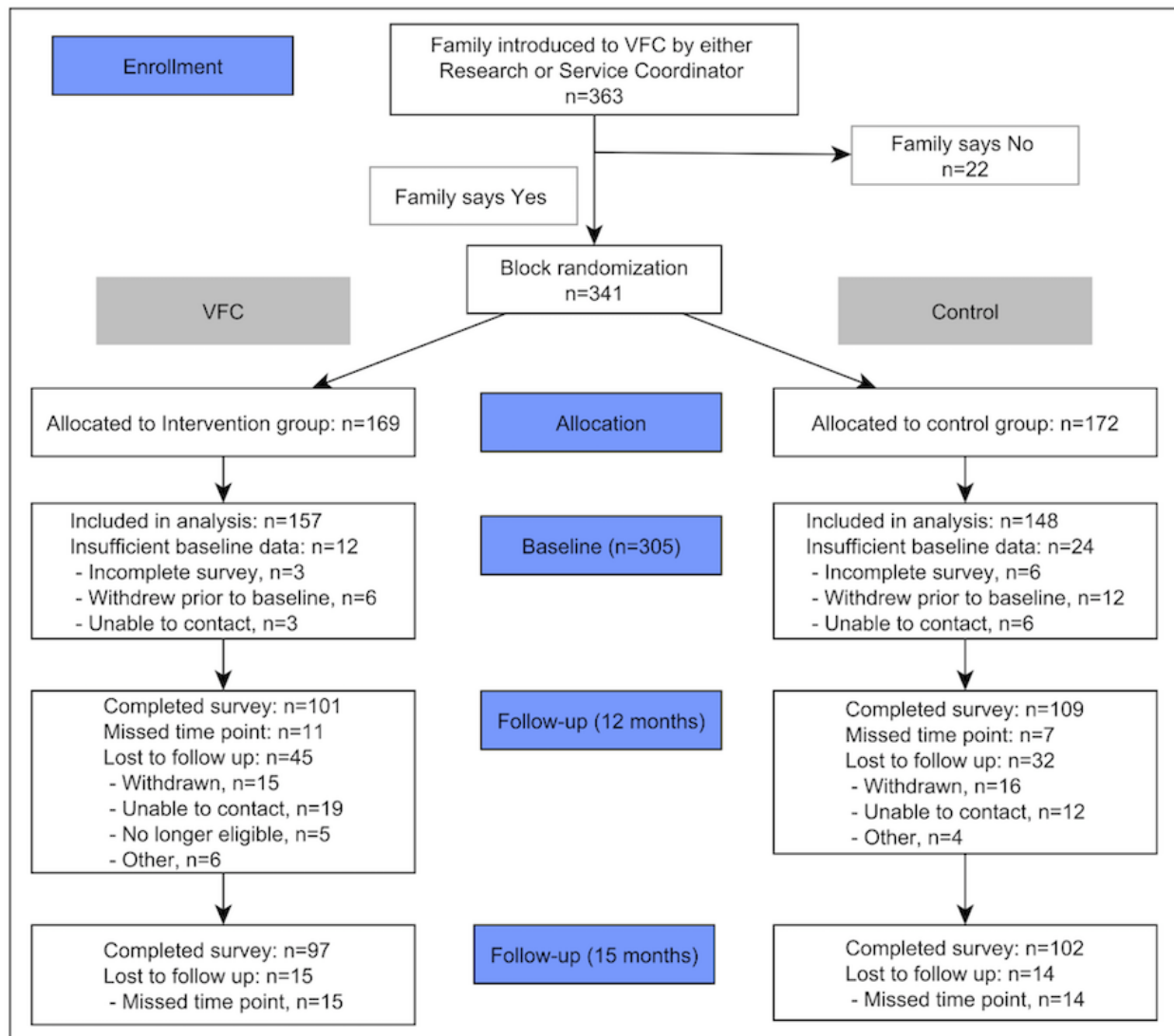
In line with usual program practice, families were unable to participate in the study if any of the following conditions applied: (1) active abuse or domestic violence within the family, (2) unmanaged mental illness within the family, (3) substance abuse issues in the family, (4) living in an environment that was unsafe for a volunteer to visit, or (5) under child protection orders or unsettled parenting arrangements. Families who experienced these challenges were referred to more specialized services.

Recruitment

Families were recruited to the study either through the usual service referral networks for the Volunteer Family Connect program (eg, child and family health nurses, general practitioners, or family support/social workers) or through self-referral to the program. Families who were eligible to receive the program were invited to speak with a researcher, and if interested, informed consent was secured. Using

computer-generated random numbers, the research manager allocated families to the intervention group (services as usual+Volunteer Family Connect) or the control group (services as usual only). The procedure used to recruit and allocate families was described in the study protocol paper [23]. Participant attrition information is provided in Figure 1. At baseline, 341 families were recruited to the study: 169 intervention families (services as usual+Volunteer Family Connect) and 172 control families (services as usual only).

Figure 1. Consolidated Standards of Reporting Trials diagram of participant retention for eligible participants. VFC: Volunteer Family Connect.



Intervention

During the trial, the Volunteer Family Connect program was implemented in seven sites across the east of Australia in New South Wales, Queensland, Victoria, and Tasmania. The sites represented city communities (n=2), suburban communities (n=3), and rural communities (n=2).

Families in the intervention group received the Volunteer Family Connect program delivered by one of the three service organizations. Program coordinators matched families with trained community volunteers who visited the family for approximately 2 hours once per week. Volunteers were

community members with some experience in working with children, either because of personal parenting experiences or their employment experiences. Volunteers participated in at least 30 hours of training before being matched with a family and underwent police checks to ensure that they could work with children and families. Depending on the needs of the family, volunteers supported families to connect with other services/facilities in their local community as well as modelled positive interactions with children and encouraged parents to identify and meet their personal and family goals.

Outcome Measures

Table 1 presents the family outcome measures and the associated standardized instrument or, if unavailable, the tool specifically designed for use in this trial. Measurement tools that are widely used within the parenting research literature were selected

wherever possible. Measures were presented to families in a single survey instrument, so that all information is parent self-report data. This survey instrument was tested in a feasibility/pilot study in advance of the trial and found to be acceptable to families [25].

Table 1. Family and parent outcome measures.

Outcomes measured	Instruments
Primary outcomes	
Parenting competence	Parenting Sense of Competence Scale [26]. All three subscales were collected, including Parenting Satisfaction, Parenting Interest, and Parenting Efficacy. The total score was also calculated.
Community connectedness	Four Community Connectedness questions were taken from the survey that is used in the Longitudinal Study of Australian Children [27]. Participants were asked to rate, on a 4-point scale, to what extent the following statements were true for them: <ul style="list-style-type: none"> “If you need information about local services, you know where to find that information.” “You feel a strong sense of identity with your neighbourhood.” “Most people in your neighbourhood can be trusted; you are well informed about local affairs.” Social Provisions Scale [28]. All six subscales were used, including Guidance, Attachment, Opportunity for Nurture, Social Integration, Reassurance of Worth, and Reliable Alliance.
Secondary outcomes	
Parent physical and mental health	Short Form-12 [29]. This is a short-form 12-item measure, which produces a physical health score and a mental health score.
Parent enablement	Modified Patient Enablement Instrument [30]. The instrument was modified because the original questions were framed within the health context. The wording was changed for the purposes of this study to apply more generically to the service system.
General parent wellbeing	The Outcome Rating Scale [31]. On this scale, participants are asked to rate how things have been going for them individually, interpersonally, socially, and overall. Two questions were added about whether life has improved over the last 3 months and whether the parent expects that life will continue to improve.
Sustainability of family routines	Questions developed based on the Ecocultural Family Interview [32]. Participants were asked to rate family functioning on seven questions relating to family routines (eg, bed time routines, mealtime routines, play time routines, and accessing transport).
Child-parent relationship	Parental questionnaire (questions from the Canadian National Survey of Parents of Young Children) [33]. Nine questions exploring the parent child relationship (ie, positive/warm parent child interactions and angry/punitive parenting) were taken from the Canadian National Survey. Participants were asked to rate on a 5-point Likert scale the extent to which the events described in the questions happen for them (eg, How often do you and your child laugh together?).

Data Collection

Families completed a survey every 3 months for 15 months, with a total of six data collection points. The first survey was completed when they were recruited to the study (baseline). The 15-month timeframe took into consideration the differing lengths of time that families remained engaged with the Volunteer Family Connect program (ie, 3-12 months) and allowed for at least one data collection point to take place after exiting from the program.

Wherever possible, baseline surveys were completed face-to-face by a research assistant with families in their home. Following this, they had the option to complete the survey with a member of the research team (ie, at the participant's home or over-the-phone) or self-complete. Surveys were available as a paper version (ie, pen and paper version completed by hand), an electronic version (Microsoft Word document emailed to the participant), or an online version (Web-based version of the survey using Qualtrics software). In addition, iPads (Apple Inc, Cupertino, California) were used for data collection with

families who completed surveys face-to-face with a research assistant using the online Qualtrics (Provo, Utah) version of the survey. All other data (ie, collected on a paper version of the survey) were entered into the Qualtrics survey by a data entry officer.

Data were stored on a password-protected Qualtrics database and backed up to a password-protected folder on a server. Only members of the research team had access to the data. Data were deidentified during data entry, with all names replaced by participant numbers. Storage of data was performed in accordance with the requirements of the Australian National Health and Medical Research Council and the Privacy Act 1988.

Statistical Analysis

Baseline characteristics were described using mean and SD for scale variables and proportions for categorical data. Statistical comparisons of baseline data were completed using Student *t* test, Mann-Whitney *U*, or Chi-squared test, as appropriate. All analyses were completed using SPSS (version 25.0.0.1; IBM Corp, Armonk, New York).

Linear regression analyses were fitted using a two-way piece-wise regression slope (baseline to 12 months and 12 months to 15 months) to accommodate for the expectation of a nonlinear trajectory. The intention-to-treat regression models were adjusted for site (the stratification variable used for randomization). All regression analyses were completed using the mixed procedure, fitted using the restricted maximum likelihood criterion with the autoregressive one covariance matrix applied to repeated statement [34].

Regression results are reported as mean differences where outcomes have been standardized to mean=0 and SD=1, enabling comparison of outcome measures on different scales. Prior to standardization, data normalization was completed for linear outcomes with nonnormal distributions.

Effect sizes (ESs) were calculated for all regression models. Overall, the program was considered to have been effective if at least one of the primary outcomes was significantly positive and the other was neutral. By “neutral,” we mean that intervention families did not demonstrate a positive or negative outcome in relation to the control group.

Ethics

Ethical approval for the study was granted by the Macquarie University Human Research Ethics Committee (reference number: 5201401144).

Results

Participants were recruited between May 2015 and April 2017. Of the 410 participants screened for the intervention, 363 were eligible and 341 consented to be randomized. Of these, 305 completed the baseline survey and were enrolled into the trial. At 12 months, 228 (75%) women completed the follow-up survey.

Baseline demographic characteristics are reported by randomization group in Table 2. At baseline, there were no statistical differences between the intervention and control groups in any of these characteristics.

All primary outcome measures showed increasing scores over the duration of the intervention, indicating improvements in parenting sense of competence and community connectedness including social provisions. Between baseline and 12 months, participants receiving the Volunteer Family Connect program improved significantly more than those in the control group in their parenting sense of competence ($F_{367,6}=11.2, P=.003$). In addition, participants receiving the Volunteer Family Connect program had a significantly improved outcome on the Guidance subscale of the Social Provisions Scale ($F_{1122,6}=4.07, P=.04$; Table 3). Findings were not significant for the other subscales of the Social Provisions Scale or for the Community Connectedness scale.

Table 2. Demographic characteristics of intervention and control families.

Demographic variable	Total (n=305)		Intervention (n=157)		Control (n=148)	
	Retained ^a (n=228)	Lost (n=77)	Retained (n=112)	Lost (n=45)	Retained (n=116)	Lost (n=32)
Categorical variable, n (%)						
Mother's education less than year 12	40 (17.5)	11 (14.3)	17 (15.2)	6 (13.3)	23 (19.8)	5 (15.6)
Culturally and linguistically diverse	50 (21.9)	25 (32.5)	27 (24.1)	14 (31.1)	23 (19.8)	11 (34.4)
High support needs ^b for participant	44 (19.3)	12 (15.6)	20 (17.9)	8 (17.8)	24 (20.7)	4 (12.5)
High support needs for other adult in house	11 (4.8)	2 (2.6)	5 (4.5)	2 (4.4)	6 (5.2)	0 (0.0)
High support needs for child in house	57 (25.0)	17 (22.1)	24 (21.4)	9 (20.0)	33 (28.4)	8 (25.0)
High support needs for person in house at baseline	62 (27.2)	18 (23.4)	28 (25.0)	10 (22.2)	34 (29.3)	8 (25.0)
High support needs for person in house at any stage in program	91 (39.9)	19 (24.7)	44 (39.3)	11 (24.4)	47 (40.5)	8 (25.0)
Aboriginal or Torres Strait islander	11 (4.8)	4 (5.2)	8 (7.1)	2 (4.4)	3 (2.6)	2 (6.3)
Scale, mean (SD)						
Mother's age	34.1 (6.8)	32.1 (5.5)	34.3 (6.7)	32.6 (5.8)	33.9 (6.9)	31.5 (5.0)
Adults living in household	0.9 (0.6)	0.9 (0.6)	0.9 (0.6)	0.8 (0.6)	0.9 (0.7)	0.9 (0.6)
Children living in household	2.2 (1.2)	2.1 (1.0)	2.0 (1.1)	2.1 (1.1)	2.3 (1.2)	2.1 (0.9)

^aRetained indicates participation to at least 12 months. Participants were also interviewed at 15 months during the postintervention period.

^b“High Support Needs” refers to a diagnosed disability, chronic health condition, or mental health condition.

Table 3. Results of univariate regression demonstrating change from baseline to 12 months, comparing intervention (Volunteer Family Connect) and control families. Descriptive statistics report the sample size, mean, and SD of each outcome measure at 12 months.

Outcomes	Descriptive statistics				Comparison statistics (baseline to 12 months)			
	Intervention		Control		Statistic ^a	Effect over 3 months ^b	Adjusted 95% CI	P value
	N	Mean (SD)	N	Mean (SD)				
Primary outcomes								
Parenting sense of competence	100	4.10 (0.67)	107	3.99 (0.75)	0.198	0.109	0.04 to 0.18	<.001 ^c
Community connectedness	101	14.85 (2.69)	109	13.90 (3.14)	-0.007	0.03	-0.04 to 0.10	.41
Social provisions scale								
Guidance	101	13.14 (2.14)	109	12.94 (2.17)	0.157	0.076	0.01 to 0.14	.03 ^c
Reassurance of worth	99	12.01 (1.99)	109	12.18 (2.01)	0.016	0.018	-0.05 to 0.09	.62
Social integration	100	12.56 (1.91)	109	12.07 (1.98)	0.148	0.06	-0.01 to 0.13	.08
Attachment	101	12.41 (2.38)	109	12.24 (2.27)	0.121	0.06	-0.01 to 0.13	.09
Opportunity for nurturance	101	13.61 (2.14)	109	13.92 (1.86)	-0.081	-0.032	-0.10 to 0.04	.38
Reliable Alliance	100	13.26 (1.98)	109	12.95 (2.13)	0.023	0.043	-0.02 to 0.11	.20
Secondary outcomes								
Short Form-12								
Physical	101	47.90 (9.53)	109	47.80 (9.93)	-0.052	-0.016	-0.08 to 0.05	.65
Mental	101	44.37 (9.88)	109	45.1 (12.24)	0.123	0.039	-0.03 to 0.11	.27
Parent enablement	97	5.27 (3.94)	109	4.50 (3.83)	0.114	0.057	-0.01 to 0.13	.11
Life in general	98	0.86 (0.73)	109	0.78 (0.72)	0.104	-0.019	-0.09 to 0.05	.60
Outcome rating scale	101	28.81 (7.22)	109	27.1 (7.55)	0.096	0.069	0.00 to 0.14	.04 ^c
Has life improved in the previous 3 months?	101	7.20 (2.26)	109	6.64 (2.21)	0.197	0.069	0.00 to 0.14	.04 ^c
Do you think life will improve in the next 3 months?	100	8.05 (1.77)	108	7.64 (1.72)	0.035	0.056	-0.01 to 0.12	.10
Family routines								
Getting out of the house	100	4.33 (2.84)	109	4.60 (3.01)	0.061	0.014	-0.05 to 0.08	.68
Access to transport	101	2.23 (2.24)	109	2.61 (2.70)	-0.122	-0.037	-0.11 to 0.03	.29
Time for tasks	101	5.61 (2.73)	109	5.64 (2.77)	0.062	0.014	-0.05 to 0.08	.68
Time with child	100	7.89 (2.33)	109	7.45 (2.42)	0.196	0.064	0.00 to 0.13	.06
Meal-time routine	101	7.87 (2.47)	109	7.38 (2.52)	0.175	0.053	-0.01 to 0.12	.12
Bed-time routine	101	7.90 (2.32)	109	7.75 (2.35)	0.174	0.049	-0.02 to 0.12	.19
Manage day-to-day tasks	101	6.96 (2.15)	108	6.94 (2.45)	0.153	0.053	-0.02 to 0.12	.13
Parent-child relationship								
Warmth	101	17.15 (2.27)	109	16.83 (2.18)	0.017	0.013	-0.06 to 0.09	.72
Angry	101	11.0 (3.07)	109	10.83 (3.09)	-0.064	-0.017	-0.09 to 0.06	.66

^aComparative statistic is the mean difference (intervention minus control) of the outcome measure after data normalization and standardization.

^bEffect over 3 months represents change between Volunteer Family Connect and control groups in standardized score during each 3-month period (estimated β).

^cSignificant results.

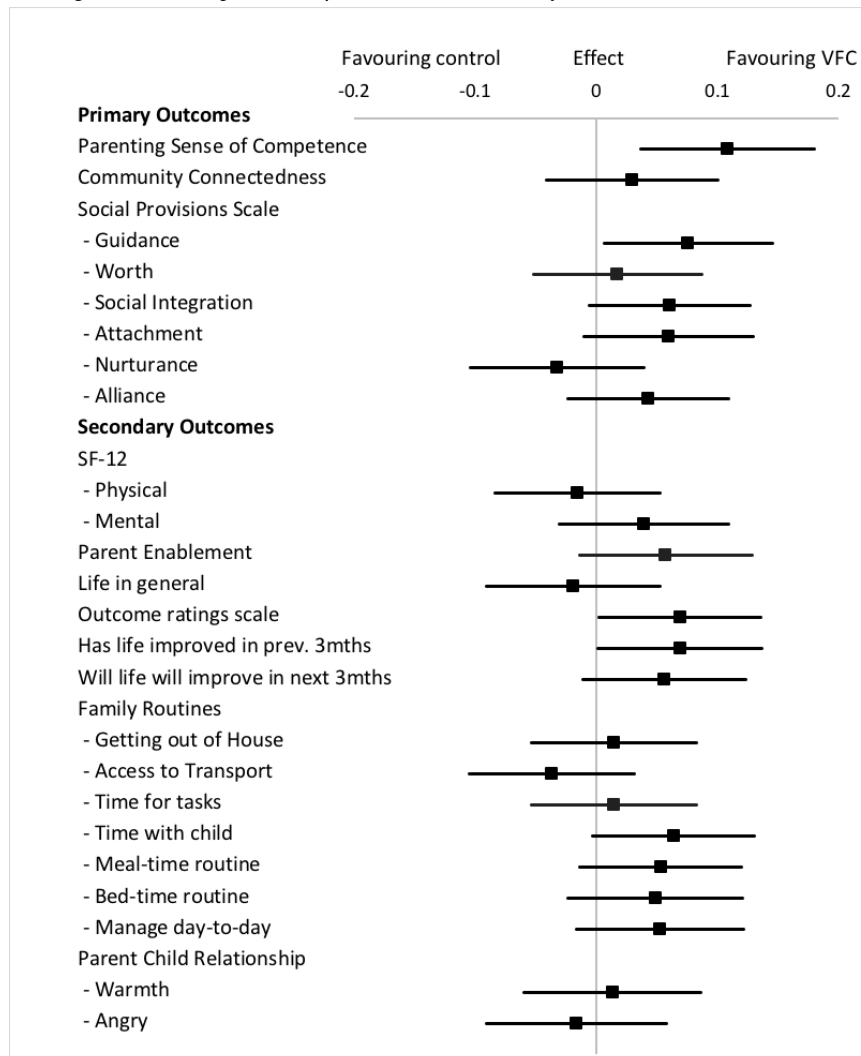
Regarding the secondary outcomes, participants in the intervention group rated their individual, interpersonal, and social lives as significantly better at 12 months after baseline than control participants ($F_{446,4}=4.10$, $P=.04$; Table 3). There

were no statistically significant changes for the intervention group families compared to the control group families in parenting style, parent enablement, physical health, or mental health over the course of the intervention. There was a trend

toward improvements (more time: $P=.06$, regular meals: $P=.12$, regular bed times: $P=.19$, life has got better: $P=.04$, and life will continue to get better: $P=.10$) in outcomes of family routines and life, including having more time to spend with their child, having more regular meal times and bed times, and feeling that

life was getting better and would continue to get better (Table 3). The forest plot in Figure 2 presents the standardized change score and 95% CI for each variable. Multimedia Appendix 1 reports the full univariate outcome models.

Figure 2. Effect of intervention on outcome measures – baseline to 12 months. Effect represents change between Volunteer Family Connect and control groups in standardized score during each 3-month period, Est β . VFC: Volunteer Family Connect; SF: Short Form.



Discussion

Principal Findings

The findings from this study met the criteria for program effectiveness defined in our previous peer reviewed protocol paper [23]. To be considered effective, the program needed to achieve positive results on at least one of the primary outcomes, with the other primary outcome achieving at least neutral results. A strong statistically significant finding was improved outcomes for the intervention group on the Parenting Sense of Competence Scale. However, the results for the Social Provisions Scale (SPS) were mixed. The SPS was a key measure of community connectedness, and only one subscale (Guidance) on this measure demonstrated a significant finding, indicating that families in the intervention group were more likely to report that there was someone in their life they could go to for advice and information. Nevertheless, the forest plot presenting effect

sizes (Figure 2) shows positive trends for the intervention group on three additional SPS subscales, including Social Integration (sense of belonging to a group), Attachment (emotional closeness with another person), and Reliable Alliance (having someone who could be counted on in times of stress).

There were some significant findings among the secondary outcomes measured. General parent wellbeing, as measured by the Outcome Rating Scale, was significantly higher for the parents who received the Volunteer Family Connect program. Volunteer Family Connect program parents were also significantly more likely to report that life had improved in the last 3 months, and there was a trend toward believing that life will continue to improve. Positive trends were present throughout the analysis, including a clear trend of improvement in parent enablement for the intervention families ($P=.11$). Of the seven variables designed to measure the sustainability of family routines, four showed improvement for the intervention

families. Those who received the Volunteer Family Connect program were more likely to feel that they were spending more time with their children, had established sustainable meal and bedtime routines, and were managing day-to-day tasks more effectively. Our findings did not demonstrate differences between the intervention and control families on measures of health or parent-child relationship. Importantly, however, there were no significant impacts for the control group over the intervention group.

Addressing the complexity of need that exists within communities in Australia requires a continuum in the range of services available: A rich service landscape that is responsive in the early identification of support needs and meaningful within the local community context [35]. The findings presented in this paper support the effectiveness of structured social relationships, in the form of a volunteer home visiting program, in improving outcomes for isolated or marginalized families with young children. The study contributes to the early intervention and prevention literature, providing evidence for the potential for communities to mobilize as an intervention force in addressing social isolation as a risk factor for vulnerable families [36]. Although the intervention families increased in their connection to community over the course of this research, so did the control group, resulting in nonsignificant findings on our measures of community connectedness for all but the Guidance subscale of the Social Provisions Scale. Our participant groups were predominantly recruited through referral from existing community services, and therefore, these findings may reflect some bias within the sample in that participants had at least some level of connection to community prior to the trial. A review of recruitment strategies to the program may be important to ensure that volunteer support is available to those families who experience significant isolation.

This study was limited by the relatively small participant numbers, and it may be that some of the trends evident within the data would have reached significance with a larger sample size. Another limitation was that it was not possible to mask the group allocation of the participants for the data collection team. Although researchers were blind at the outset, participants disclosed this information in their responses to questions about their experiences with services. This intention-to-treat analysis did not include analyses of benefit of the program for families receiving a longer or shorter duration of intervention, the characteristics of families who may be more or less likely to benefit from this volunteer home visiting intervention, or the relationship between family outcomes and the fidelity of program delivery. These important analyses will be conducted and will be published in subsequent papers, providing an opportunity to explore greater precision in the targeting and provision of the Volunteer Family Connect program.

Conclusions

The findings from this pragmatic randomized controlled trial examining the effectiveness of the Volunteer Family Connect program demonstrated significant findings in one of the primary outcome, parenting sense of competence, and mixed findings in the other primary outcome community connectedness. The results suggest that high-quality volunteer home visiting programs such as Volunteer Family Connect, with volunteers given training, guidance, and supervision, have a role to play in the landscape of services designed to support families with diverse needs—a role that is complementary to formal service provision and strengthens the parenting confidence, wellbeing, and optimism of vulnerable families.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Tests of fixed effects.

[[PDF File \(Adobe PDF File\), 242 KB - *pediatrics_v2i2e13023_app1.pdf*](#)]

Multimedia Appendix 2

CONSORT 2010 statement.

[[PDF File \(Adobe PDF File\), 194 KB - *pediatrics_v2i2e13023_app2.pdf*](#)]

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Abbreviations

ES: effect size

PRECIS: Pragmatic Explanatory Continuum Indicator Summary

RCT: randomized controlled trial

SPS: Social Provision Scale

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Review

Use of Synchronous Digital Health Technologies for the Care of Children With Special Health Care Needs and Their Families: Scoping Review

Marissa Bird¹, BA, BSN; Lin Li^{1,2*}, BFA, BSCN; Carley Ouellette^{1*}, BSCN; Kylie Hopkins^{2*}, BSCN; Michael H McGillion^{1,3*}, PhD; Nancy Carter^{1*}, PhD

¹School of Nursing, McMaster University, Hamilton, ON, Canada

²McMaster Children's Hospital, Hamilton, ON, Canada

³Population Health Research Institute, Hamilton Health Sciences, Hamilton, ON, Canada

*these authors contributed equally

Corresponding Author:

Marissa Bird, BA, BSN

School of Nursing

McMaster University

1280 Main Street West

Hamilton, ON, L8S 4K1

Canada

Phone: 1 9055259140 ext 22407

Email: birdm3@mcmaster.ca

Abstract

Background: Use of synchronous digital health technologies for care delivery to children with special health care needs (having a chronic physical, behavioral, developmental, or emotional condition in combination with high resource use) and their families at home has shown promise for improving outcomes and increasing access to care for this medically fragile and resource-intensive population. However, a comprehensive description of the various models of synchronous home digital health interventions does not exist, nor has the impact of such interventions been summarized to date.

Objective: We aim to describe the various models of synchronous home digital health that have been used in pediatric populations with special health care needs, their outcomes, and implementation barriers.

Methods: A systematic scoping review of the literature was conducted, guided by the Arksey and O'Malley Scoping Review Framework. MEDLINE, CINAHL, and EMBASE databases were searched from inception to June 2018, and the reference lists of the included systematic reviews and high-impact journals were hand-searched.

Results: A total of 38 articles were included in this review. Interventional articles are described as feasibility studies, studies that aim to provide direct care to children with special health care needs, and studies that aim to support family members to deliver care to children with special health care needs. End-user involvement in the design and implementation of studies is evaluated using a human-centered design framework, and factors affecting the implementation of digital health programs are discussed in relation to technological, human, and systems factors.

Conclusions: The use of digital health to care for children with special health care needs presents an opportunity to leverage the capacity of technology to connect patients and their families to much-needed care from expert health care providers while avoiding the expenses and potential harms of the hospital-based care system. Strategies to scale and spread pilot studies, such as involving end users in the co-design techniques, are needed to optimize digital health programs for children with special health care needs.

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KEYWORDS

pediatrics; scoping review; digital health; children with special health care needs; asthma; congenital heart disease; palliative care; co-design

Introduction

Background

Advances in neonatal and pediatric care for complex medical conditions have contributed to the increased survival of children who live with chronic health care needs [1]. Although definitions of this group vary, children with special health care needs are generally considered to be those with or at risk for chronic physical, developmental, behavioral, or emotional conditions, often requiring substantial use of health and social services [2,3]. In the United States, the prevalence of children with special health care needs is estimated to be 19.8% of the pediatric population [4]. Canadian provincial administrative data report a similar prevalence rate of 17.5% [5].

Children with special health care needs often require care from specialists, typically located in urban tertiary centers [6]. In between specialist visits, children with special health care needs frequently experience the need for urgent care, often delivered by health care providers unfamiliar with their complex histories, intersecting conditions, and intricate care regimens [7]. This scenario often leads to extemporized courses of clinical management as well as recurrent emergency department visits and hospital admissions [8]. Such unpredictability confers vulnerability for children with special health care needs in terms of exposure to medical errors and other nosocomial harms such as infection [9].

Although children with special health care needs comprise less than 20% of the pediatric population in the United States, they account for 41% of total pediatric health expenditures [10]. Substantial time and resources are also contributed by families who care for children with special health care needs, estimated at 1.5 billion hours of care in the United States in 2015 [11]. Were these care hours provided by health care aides, the cost would approximate to US \$35.7 billion or US \$6400 per child [11]. Foregone income due to caregiving responsibilities in the home, as well as out-of-pocket expenses for parent and family members, add to the cost burden. Losses in parental earnings are estimated at US \$3200 per child per year, and annual out-of-pocket expenses have been documented at over US \$1000 per year in 20%-25% of children with special health care needs families [12].

Prior Work

Recent attention has been given to synchronous digital health technologies, designed to increase access for patients and families to clinical teams in real time from their homes. Synchronous digital health technologies refer to the use of audio, video, and health information interfaces to facilitate the provision of health care remotely, in real time [13]. Both randomized and nonrandomized studies of digital health interventions in children with special health care needs to date have shown improved clinical, economic, and quality of life outcomes [14-16]. Synchronous digital health technologies have also been documented to improve parental caregiver outcomes such as quality of life, psychological health, satisfaction with care, and social support. One systematic review reported that 62 of 65 studies (95%) of synchronous digital health technologies observed significant improvements in these

outcomes for caregivers of children and adults with chronic and degenerative diseases [17].

A national survey in the United States documented 51 digital health programs providing care to pediatric populations [18], supporting the momentum for such programs. At this time, the number of existing digital health pediatrics programs in Canada is unknown. Although the evidence base in support of the effectiveness of pediatric synchronous digital health interventions is growing [16,19-21], a comprehensive description of the ways in which synchronous home digital health solutions are used to care for children with special health care needs and support for their families is not yet documented.

Purpose and Objectives

The purpose of this review is to summarize the current body of literature in order to describe how synchronous digital health technologies are used in the care of children with special health care needs and their families and to provide practical information for health care decision makers, considering digital health program implementation or expansion.

Methods

Scoping Review Phases

A scoping review was undertaken to allow for examination of the breadth of research activity on the design of digital health interventions for children with special health care needs, implementation, uptake, and evaluation of these programs as well as health care provider and family involvement in digital health solutions. Levac and colleagues' [22] revision of Arksey and O'Malley's [23] original methodology was used to conduct this work in five phases: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; and (5) collating, summarizing, and reporting the results.

Search Strategy

The search strategy was designed to capture a wide breadth of literature related to the research question, irrespective of study design. We included any type of article, book, dissertation, or report describing the use of synchronous digital health technologies to provide direct care to children with special health care needs or aimed at parents or caregivers with the intention of affecting outcomes in children. With the assistance of a librarian, a comprehensive search of the MEDLINE, CINAHL, and EMBASE databases was conducted by the first author (MB). Subject headings and keywords were used to locate articles describing the use of digital health in home settings for pediatric populations. The indexes of four key journals were also hand-searched for relevant articles. The initial literature search was run on June 30, 2018, with no date, age, or geographical limits set in order to increase the breadth of results. During the screening and data extraction phases, reference lists of highly relevant studies and reviews were scanned, and additional studies were screened for inclusion.

Inclusion and Exclusion Criteria and the Review Process

Inclusion was based on four criteria: (1) the population of interest was children (<18 years) or children's caregivers; (2) the population met the definition of children with special health care needs articulated by Newachek et al [24], ie, having a chronic physical, behavioral, developmental, or emotional condition in combination with high resource use; (3) care for the child was ongoing and occurring in the home setting; and (4) care for the child was delivered by synchronous digital health. All studies included at least one synchronous intervention element (eg, real-time phone call or video visit.). However, included studies could feature multifaceted interventions that included nonsynchronous components as well. Papers were excluded if they were not published in English, no full text was available, or if they were published prior to 2008 in order to ensure that the interventions described were relevant to stakeholders today. In accordance with scoping review methodology [22,23], no quality assessments were completed on the selected articles.

Screening and Data Extraction

A two-stage screening process using screening forms developed by the team was employed for this review. Prior to screening, a validation test of the title and abstract screening tool was first completed by two authors (MB and NC). Validation screening resulted in 90% agreement, with conflicts resolved through discussion and consensus between authors. After refinement of the screening tool, title and abstract screening was completed by one author (MB). Prior to full-text screening, all authors met to arrive at a consensus on the inclusion criteria. Test screening of three articles per author was performed, and discrepancies were resolved via email communication. Each author was then assigned articles to screen and extract data from using a standardized survey template. Authors were in frequent communication during the screening process, and weekly emails with updates, group questions, and discrepancies were circulated to ensure consistency.

Analysis

Frameworks Used

Our interest in providing decision makers with relevant information related to digital health program implementation or expansion prompted us to extract and analyze practical considerations of these applications. To this end, we analyzed digital health intervention characteristics, end-user involvement (patients, families, and health care providers) in digital health intervention design, and barriers to implementation. Data extracted from relevant articles were downloaded into Excel (Microsoft Corporation, Redmond, Washington) files and reviewed by research team members. We used two frameworks to guide analysis: Data from feasibility studies are presented using a framework by Bowen and colleagues [25], and end-user involvement in co-design and implementation was evaluated

using the Human-Centered Design framework from IDEO [26]. The two frameworks are described briefly below.

Feasibility

Our use of the term "feasibility" is broad in nature, in keeping with work by Bowen and colleagues [25], suggesting that feasibility trials encompass any study that assists investigators to prepare for a full-scale trial of intervention effectiveness. Using this definition, feasibility outcomes may be grouped into eight general areas of focus, which include acceptability (intervention recipient feedback), demand (intervention use), implementation (success of intervention deployment), practicality (interference with resource use), adaptation (necessary modifications), integration (fit of intervention to context), expansion (intervention applications to new context), and limited-efficacy testing (preliminary outcomes) [25].

Human-Centered Design

We sought out information from all papers related to the inclusion of end users in digital health intervention design and implementation using the IDEO Framework as a guide to this data extraction. Consisting of a six-stage, iterative cycle, the IDEO Framework aims to increase the relevance and appropriateness of interventions [26]. End users are included in the stages of observation (understanding the end user), ideation (brainstorming ideas), prototyping (creating rough intervention mock-ups), user feedback (soliciting input from end-users), iteration (intervention refinement), and implementation (deployment into practice) [26]. In the health care sector, the IDEO Human-Centered Design framework has been used to generate solutions such as helping patients remember to take their prescription medications and communicating messages of support to women recovering from surgical procedures [27]. Finally, consideration was given to issues of digital health implementation in relation to technological, human, and system-level factors.

Results

Numbers, Sources, and Types of Papers

Results of the screening process and overall yield of papers are presented in Figure 1. Of the 38 papers included in the review, as shown in Table 1, 50% originated in the United States—an expected result, given the size and population base. Eleven articles originated in Australia, where the use of digital health may represent a solution to timely care delivery for the country's large rural and remote population.

Table 2 depicts the variation in study design, as reported by the authors. The majority of the papers reported on evaluation of digital health initiatives through feasibility studies (n=12), program evaluations (n=8), randomized controlled (n=6), nonrandomized controlled trial (n=3), mixed methods (n=1), and cohort studies (n=1).

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram. CSHCN: children with special health care needs; DH: digital health; T&A: title and abstract.

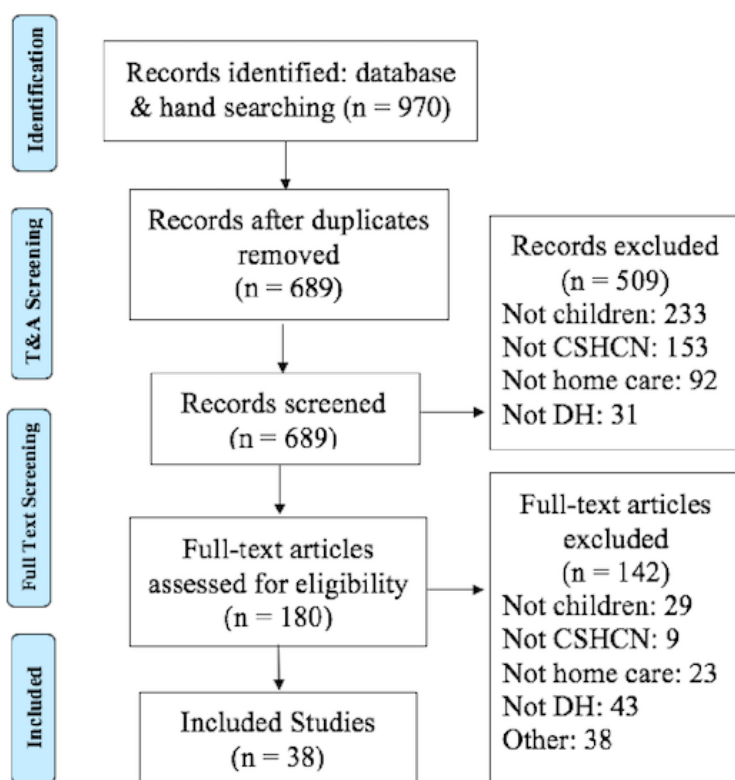


Table 1. Yield of papers by country of origin.

Country of origin	Number of papers	References
United States	19	[15-17,19,28-42]
Australia	11	[7,14,43-51]
United Kingdom	3	[52-54]
Germany	1	[55]
Israel	1	[56]
The Netherlands	1	[57]
New Zealand	1	[58]
Scotland	1	[59]

Table 2. Yield of papers by stated research method (N=38).

Research method	Number of papers	References
Feasibility studies (n=12)	12	[30,31,43,45-47,49,51,53,56-58]
Program evaluation (n=8)	8	[7,15,29,33,38,40,48,50]
Randomized controlled trial (n=6)	6	[16,19,32,35,54,55]
Nonrandomized controlled trial (n=3)	3	[28,37,44]
Discussion paper (n=2)	2	[34,59]
Review (n=2)	2	[17,42]
Cost minimization analysis (n=1)	1	[14]
Descriptive (n=1)	1	[36]
Mixed methods (n=1)	1	[52]
Cohort (n=1)	1	[41]
Qualitative (n=1)	1	[39]

Studies Reporting on Digital Health Interventions

A major focus of this review was on empirical studies that evaluated the use of digital health in caring for children and families. A large number of the empirical studies included were feasibility trials, leading us to report these separately from full-scale studies. Here, we first describe feasibility trials and then studies that used digital health interventions to provide direct care to children with special health care needs (such as employing video consultations for physical assessments), followed by interventions aimed at supporting families to care for children at home. Where possible, we have included information on published statistical results; however, many studies were performed with small samples, and therefore, the results were not analyzed for statistical significance.

Feasibility Studies

Table 3 provides details of the feasibility studies using digital health interventions. Based on Bowen and colleagues' [25] definition of feasibility studies, we identified 12 articles that reported feasibility-related outcomes. Of note, five of these studies were conducted with hematology/oncology/palliative care populations, whereas the remaining interventions targeted diverse disease groups. One intervention used telephone calls and a blog for communication [58], another used "Skype" and "WhatsApp" for video chats and text messaging [56], and all other studies utilized video formats with either embedded audio or separate telephone audio. There was a wide range of uses for digital health, including assessing acute clinical issues, providing routine care and follow-up, facilitating case conferences, providing psychosocial support, delivering therapy, and monitoring progress and adherence.

Among the included studies, six of the eight dimensions of feasibility were measured, and these outcomes are reported in Table 3. Ten studies looked at *acceptability*, with seven studies

measuring family-reported acceptability [31,45-47,53,56,57], and five studies measuring health care provider acceptability [45-47,51,53]. Overall, most families and health care providers reported high satisfaction with digital health interventions and found the equipment to be easy to use. The *demand* for digital health was reported in seven studies by describing the number and length of calls made over the study period [31,43,45,46,49,53,57]. Two of these articles also measured changes in demand over time, with both studies observing an increase in the utilization of digital health over the study period [49,57]. A total of seven studies reported *implementation* and *integration* issues in the form of technical difficulties [30,45-47,51,53,56]. These technical problems were both human related (eg, confusion with using equipment) and technology related (eg, firewall settings, poor internet coverage in remote areas, and bandwidth limitations). In terms of *practicality*, three studies conducted cost analyses [45,49], and two studies found that patient and staff availability, workloads, and scheduling influenced how the intervention was implemented [45,56].

Four studies conducted *limited-efficacy testing* of their interventions [31,53,56,58]. Gur and colleagues [56] piloted the use of text messaging and video chats with individuals with cystic fibrosis, but found no statistically significant differences in measured outcomes between the control and intervention groups. The remaining three studies did not have control groups but reported benefits of improved child functional outcomes [58], reduced parental anxiety (median State and Trait Anxiety Inventory score reduction: 6 points; $P < .05$) [53], and prevention of health care visits/admissions [31]. Among all the feasibility studies identified, none adapted a previously established program or reported on outcomes related to the expansion of an already successful intervention. Additionally, four studies led to future publications describing larger-scale interventions [30,31,43,53].

Table 3. Feasibility studies.

Study identifiers: first author (year), country (sample size) [reference]	Study purpose: objectives, uses	Intervention characteristics: technology used, diagnosis of sample, health care providers	Feasibility outcomes: acceptability, adaptation, demand, integration, implementation, expansion, practicality, limited-efficacy testing
Ludikhuizen (2016), Netherlands (n=21) [57]	<ul style="list-style-type: none"> Determine feasibility of adding video to phone consultations in order to reduce the need for patients to travel long distances Assessment and follow-up of acute bleeding 	<ul style="list-style-type: none"> Home computer with webcam or tablet/phone to hemophilia treatment center Hemophilia Registered nurse, physician - specialist 	<ul style="list-style-type: none"> Acceptability: high satisfaction with video quality. Patients/parents reported adding video led to better consultations; health care providers reported video helped them assess severity of bleeding. Demand: 29 phone or video consultations took place over 13 months with 10 of 21 enrolled patients. Use of video consultations increased over the trial period.
Katalinic (2013), Australia (n=14) [51]	<ul style="list-style-type: none"> Improve access to services, self-management of health conditions and health education; reduce social isolation for rural and remote patients. Clinical review, case conferences, education and bereavement follow-up 	<ul style="list-style-type: none"> Home tablet (iPad) to clinical service 4 clinical services, including pediatric palliative care APN^d, physician (specialist), occupational therapist, SW^b 	<ul style="list-style-type: none"> Acceptability: high usability ratings; portable and customizable Implementation: low-cost and little set-up required. Complex licensing and application purchasing; difficulties with customizing implementation. Technical problems: firewall outages, poor internet coverage, integration issues, bandwidth limitations
Bradford (2010), Australia (n=2) [43]	<ul style="list-style-type: none"> Describe two case studies illustrating the value of home telemedicine Clinical management, anticipatory guidance, and psychosocial support 	<ul style="list-style-type: none"> Computer and webcam (video only) and phone (audio) to telehealth center Palliative care Registered nurse, physician (specialist), "hospital clown doctors" 	<ul style="list-style-type: none"> Demand: case 1 had 37 calls lasting 10-20 minutes over 7 months (23 with Clown doctors and 15 with specialist team). Case 2 had one 45-minute call.
Bensink (2009), Australia (n=11) [46]	<ul style="list-style-type: none"> Determine acceptability of videotelephony for families receiving pediatric palliative care. Add video to existing telephone support provided by specialist nurses in the hospital to regional and remote families. 	<ul style="list-style-type: none"> Home computer with webcam (video) and telephone (audio), linked to a computer, webcam, audio-conferencing system in the hospital. Palliative care Specialist registered nurse, physician (specialist), SW 	<ul style="list-style-type: none"> Acceptability: 92% participant consent rate; high nurse satisfaction with video and audio quality. Demand: 25 calls with 7 of the 11 consenting families. Implementation: Technical problems were human related (n=3) and technology related (n=1). Practicality: cost analysis reported.
Bensink (2008), Australia (n=8) [45]	<ul style="list-style-type: none"> Test the feasibility of providing videotelephone-based discharge support to families with a child newly diagnosed with cancer. Provide practical, emotional, and symptom support to families. 	<ul style="list-style-type: none"> Home computer with webcam (video) and home or mobile phone (audio) Oncology APN, SW 	<ul style="list-style-type: none"> Acceptability: high family satisfaction with service; high nurse satisfaction with audio and video quality. Demand: 20 calls were made with 7 families over a 3-month period, totaling 400 minutes. Implementation: problems with video were human related (n=1) and technical (n=2). Practicality: calls required organization around ward workflows.
Gur (2017), Israel (n=18) [56]	<ul style="list-style-type: none"> Assess the feasibility of using WhatsApp and Skype to improve treatment adherence by enhancing communications between patients/families and health care providers. Evaluation and encouragement of treatment adherence, addressing barriers to adherence. 	<ul style="list-style-type: none"> Text messaging (WhatsApp) and video (Skype) CF^c Registered nurse, physician, physiotherapist, dietician, psychologist, SW 	<ul style="list-style-type: none"> Acceptability: patients were very satisfied with the intervention. Practicality: scheduling difficulties. Integration: technical issues with wireless internet in some remote areas. Limited-efficacy testing: No difference in CF-related self-rated health, CF-specific knowledge, treatment adherence, or patient-rated relations with their teams between groups.

Study identifiers: first author (year), country (sample size) [reference]	Study purpose: objectives, uses	Intervention characteristics: technology used, diagnosis of sample, health care providers	Feasibility outcomes: acceptability, adaptation, demand, integration, implementation, expansion, practicality, limited-efficacy testing
Casavant (2014), US (n=14) [31]	<ul style="list-style-type: none"> Investigate whether telemedicine is feasible, affects confidence of families in clinical management, and supports clinical decision-making. Routine health care visits, follow-up of clinical problems, and urgent assessment when home visit not possible. 	<ul style="list-style-type: none"> Family's existing computer with webcam to study team Children with chronic respiratory insufficiency on home ventilation Physician (specialist), respiratory therapist, APN, SW, program administrator 	<ul style="list-style-type: none"> Acceptability: families reported intervention ease of use, high audio and video quality, and no added costs. Families perceived health care providers were better able to assess their child and received better overall clinical management compared to phone Demand: 27 video conferences with 14 families over 9 months; 15 calls were for routine care, 10 for follow-up of specific issues, and 2 for acute illness. Limited-efficacy testing: prevented 23 clinic visits; 3 emergency department visits, and 1 hospital admission.
Jury (2014), Australia (n=not reported) [49]	<ul style="list-style-type: none"> Increase convenience for families, reduce physician travel, provide additional services, conserve physical space, and provide more equitable health care access. Follow-up, outreach for remote communities. 	<ul style="list-style-type: none"> Web-based video-consultations 37 departments at The Royal Children's Hospital in Melbourne have provided video-consultations Mixed health care provider groups 	<ul style="list-style-type: none"> Demand: increase in consultations (from 14/month to 49/month); 92% of departments had provided at least one video consultation. Practicality: 65 billed appointments per month are needed to fund a coordinator. 36% of booked appointments were not billed to Medicare.
Constantinescu (2012), Australia (n=17) [47]	<ul style="list-style-type: none"> Provide access to therapy and reduced costs for children and families living in rural and remote areas. Weekly planning and audio-verbal therapy sessions. 	<ul style="list-style-type: none"> Computer-based videoconferencing (Skype) Children with hearing loss Auditory-verbal therapist 	<ul style="list-style-type: none"> Acceptability: High parental and therapist satisfaction; parents and therapists reported moderate audio and video quality; parents reported more technical difficulties and less comfort with technology than therapists.
Miyahara (2009), New Zealand (n=7) [58]	<ul style="list-style-type: none"> Develop and implement a family-focused intervention program to improve the coordination of children with developmental coordination disorder. Progress monitoring of developmental coordination disorder. 	<ul style="list-style-type: none"> Workbook, DVDs, weekly telephone consultations, and a blog Children with developmental coordination disorder Physiotherapist 	<ul style="list-style-type: none"> Acceptability: parents voiced appreciation for the weekly telephone consultations and reported that telephone consultations encouraged program adherence. Limited-efficacy testing: all families reported improvements in their children's functional motor skills.
Cady (2008), US (n=5) [30]	<ul style="list-style-type: none"> Evaluate feasibility of videoconferencing between study office and family homes. Assessment, management of acute and chronic conditions, dissemination of health information, coordination of services. 	<ul style="list-style-type: none"> Webcam (supplied) with family's own computer to study nurse Children with medical complexities APN 	<ul style="list-style-type: none"> Acceptability: unscheduled video visits were rated by nurses as providing more information than a telephone call. Implementation: initial connections failed due to firewall settings—case-by-case resolution needed. Integration: video quality in rural settings was insufficient for clinical assessment.
McCrossan (2008), UK (n=5) [53]	<ul style="list-style-type: none"> Investigate the feasibility of videoconferencing using broadband transmission. Assessment and provision of home support and advice after hospital discharge. 	<ul style="list-style-type: none"> Twice weekly videoconferences with pulse oximeter for 10 weeks Complex congenital heart disease Clinician (not specified) 	<ul style="list-style-type: none"> Acceptability: "good" to "very good" ratings by health care providers and parents. Demand: 78 video conferences over a 6-month period with 5 patients. Implementation: technical problems related to connectivity and video quality occurred in 10 videoconferences (13%). Limited-efficacy testing: reduction in parental anxiety following video consultations.

^aAPN: advanced practice nurse.

^bSW: social worker.

^cCF: cystic fibrosis.

Interventions to Provide Direct Care via Digital Health

Ten articles representing seven studies described the use of digital health with children with special health care needs for the purposes of providing direct patient care or replacing in-person assessments (Table 4). Of these, six articles (four studies) examined digital health interventions for children with medical complexities [7,15,16,19,29,33], two articles (one study) focused on palliative care [14,44], one article focused on asthma [38], and one article focused on children with congenital heart disease [33]. Telephone was an interventional component in all studies; the next most commonly employed technologies were video [16,19,54] and email [33]. The makeup of digital health teams varied between studies: Some interventions were delivered by a single group of practitioners such as registered nurses [7,38] or advanced practice nurses [15,16,19,29], while others involved a multidisciplinary team [14,33,44]. One study did not specify the profession of the consultant involved in the intervention [54].

Studies that examined children with special health care needs–related outcomes had mixed results, while studies that examined family-related outcomes reported mainly positive results. Positive outcomes for children with special health care needs were constituted by parent-reported decreases in hospitalizations and quicker recovery from illness [29], reductions in unplanned hospitalizations (year 1 mean number

of unplanned hospitalizations per child: 1.7; year 2 mean number of unplanned hospitalizations per child: 0.8; $P<.007$) [15], reduced health care resource use (37% lower in the video conferencing group compared to the control groups; $P<.05$) [54], and improved asthma severity scores [38]. In contrast, two studies found no change in emergency department visits (18.4% enrolled patients presented to the emergency department per month in 2003 and 15.0% per month in 2006; $P=.41$) or hospital admissions (8.0% of enrolled patients hospitalized per month in 2003 and 7.3% hospitalized per month in 2006; $P=.67$) [7], and no significant differences in health-related quality of life as measured by the PedsQL based on analysis of variance scores ($F=0.90$; $P=.41$) [16] for children with special health care needs. Family members reported overall high satisfaction scores with digital health interventions, for example, average scores reported were 8.3/10 [7], and 9.3/10 [33]. Parents participating in the intervention arm of a digital health study rated their satisfaction with their child's personal doctor ($P=.001$) and level of care coordination ($P=.03$) as significantly better than control groups based on the Consumer Assessment of Healthcare Providers and Systems Clinician and Group survey [19], and in an additional study, parents perceived availability of digital health to be "very important" in assisting them in managing their child's condition at home [29]. However, using descriptive analysis, Bradford and colleagues [44] found no change in caregiver quality of life in parents of children receiving palliative care via digital health.

Table 4. Interventions to provide direct patient care via digital health.

Study identifiers: first author (year), country (sample size) [reference]	Study purpose: objectives	Intervention components: technology used, patient population, intervention, health care providers	Reported or perceived outcomes
Graham (2017), US (n=320) [33]	Describe the utilization and satisfaction of a program with 24/7 family-driven access to health care teams with the aim of providing comprehensive, individually tailored care to children with CRI ^a	<ul style="list-style-type: none"> • Telephone and email • Children with CRI • Home and clinic visits, care coordination, and ongoing access to physicians • Physician (specialist), respiratory therapist, APN^b, SW^c, program administrator 	<ul style="list-style-type: none"> • SO^d: Telephone calls accounted for 40%-50% of patient encounters over a 3-year study period, but telemedicine only accounted for 0.3%-1.1% of all visits. Average numbers of encounters per patient per year increased over the study period (increase mainly attributable to telephone and email communication); decrease in in-person visits over study period. • FO^e: Family satisfaction rating of intervention was 9.3/10.
Cady (2014), US (n=27) [29] and Cady (2009), US (n=43) [15]	Describe the attributes and effects of an APN-administered care coordination program for children with medical complexities and their families	<ul style="list-style-type: none"> • Telephone • Children with moderate/high intensity health care needs • Case management and care coordination • Primary care provider, APN, RN^f coordinator, physician (specialist), support staff 	<ul style="list-style-type: none"> • PO^g: ≥80% of parents perceived their child to be hospitalized less frequently and recover from illness faster compared to before the program [29]. • SO: Over 3 years, the number of care coordination episodes tripled, with significant increase between years 1 and 2 ($P<.001$) [29]; 48% of episodes were initiated for acute and chronic condition management [29]; statistically significant reduction in unplanned hospitalizations between years 1 and 2 ($P<.007$), with stable rates of planned hospitalizations ($P=.14$) [15] • FO: 80% of parents were more comfortable being discharged home from the hospital [29].
Looman (2015), US, (n=148) [19] and Looman (2018), US (n=163) [16]	Examine the effects of adding a high-intensity, APN-delivered digital health care coordination intervention within an existing medical home model	<ul style="list-style-type: none"> • Telephone or video • Children with medical complexities and their families • High-intensity care coordination APNs 	<ul style="list-style-type: none"> • FO: Telephone group had significantly higher satisfaction scores on the global health care rating category ($P<.05$) and the health care provider communication measure ($P<.01$) compared to the control group [19]; parents rated care coordination and children's personal doctors as significantly better in both the video and telephone intervention groups, compared to the control group ($P<.05$) [19]. Intervention did not significantly improve child health-related quality of life or disease burden on family (all $P>.05$) [16].
Sutton (2008), Australia (n=220) [7]	Determine if continuous mobile phone access to ED ^h RNs can increase families' capacities to manage care of child at home and decrease ED visits and ED length of stay	<ul style="list-style-type: none"> • Telephone • Children with medical complexities • Enrollment in a program with access to advice and rapid emergency department care • ED RNs with extensive triage and resuscitation experience 	<ul style="list-style-type: none"> • FO: Family satisfaction with the program was 8.3/10. • SO: Phone calls increased from an average of 0.24 calls/participant in 2003 to 0.3 calls/participant in 2006, 60% of which were after hours; no significant difference in the number of ED presentations as a percentage of enrolled patients ($P=.41$), number of hospital admissions as a percentage of enrolled patients ($P=.67$), or hospital admission rates after ED presentation ($P=.70$). Approximate cost of the program/child was AU \$750 (£292; USD \$511)/year.
Bradford (2014), Australia (n=not reported) [14] and Bradford (2012), Australia (n=14) [44]	Measure the effects of a home digital health program for pediatric palliative care consultations on caregiver quality of life. Compare in-person with video palliative care consultations	<ul style="list-style-type: none"> • Telephone and video • Children in palliative care • Specialist pediatric palliative care home video consultations to advise on symptom management, care planning, and emotional support. • RN consultant, physician (specialist), project officer 	<ul style="list-style-type: none"> • FO: Descriptive analysis showed no differences in caregiver quality-of-life scores between intervention and control groups [44]. • SO: digital health intervention saves AU \$244 (USD \$166)/year to AU \$7598 (USD \$5182)/year compared to outpatient or home visit appointments requiring road-only travel. Digital health intervention saves AU \$23,758 (USD \$16,205)/year to AU \$45,925 (USD \$31,330)/year compared to outpatient or home visit appointments requiring air travel [14].

Study identifiers: first author (year), country (sample size) [reference]	Study purpose: objectives	Intervention components: technology used, patient population, intervention, health care providers	Reported or perceived outcomes
Nelson (2009), US, (n=not reported) [38]	Describe a severity-based nurse-administered asthma management protocol administered to children/families at home via telephone	<ul style="list-style-type: none"> • Telephone • Children with asthma • Access to a nurse-staffed call center after hours, weekends, and holidays for care advice and treatment recommendation • RNs 	<ul style="list-style-type: none"> • PO: Urgent calls had improved severity scores at follow-up; 28% of patients recommended home treatment were referred to ED at follow-up. • FO: 95% parents reported implementing recommended home treatments.
McCrossan (2012), UK (n=83) [54]	Evaluate a digital health intervention for clinical utility and intervention quality, and determine impacts on health care resource use	<ul style="list-style-type: none"> • Telephone or video • Children with congenital heart disease • Video or telephone consultations 1-2 times per week were conducted to assess patients with congenital heart disease and address parents' questions. • Clinician (not specified) 	<ul style="list-style-type: none"> • PO: Probability of being admitted to hospital was significantly less in the video group compared with the telephone and control groups ($P=.004$). • FO: Parents reported video consultations were superior to telephone consultations with regard to facilitating communication and overall benefit ($P=.001$). • SO: Video consultation group used 37% fewer health care resources than either telephone or usual care groups ($P<.001$). • HPOⁱ: Health care providers significantly more likely to report they could address parents' concerns in video versus telephone groups ($P=.01$).

^aCRI: chronic respiratory insufficiency

^bAPN: advanced practice nurse.

^cSW: social worker.

^dSO: system outcomes.

^eFO: family outcomes.

^fRN: registered nurse.

^gPO: patient outcomes.

^hED: emergency department.

ⁱHPO: health care provider outcomes.

Interventions to Teach and Support Parents and Families

Seven papers described digital health interventions intended to train or provide support to parents of children with special health care needs (Table 5). Four of these papers involved parents of children with autism spectrum disorder [28,37,40,41], two papers were focused on asthma [32,35], and one was focused on a mental health issue [55]. In four studies, behavior consultants or therapists used video to train parents of children with autism spectrum disorders to use autism specific interventions including applied behavioral analysis [28,37,40,41]. Reported outcomes of these interventions include reduction in problem behavior [37,40] and gains in communication skills for children [28]. For example, Lindgren and colleagues [37] found a mean reduction in problem behavior of over 90% for children with autism treated by specialists in their homes (mean reduction: 95.76%), by telehealth in a clinic setting (mean reduction: 91.00%), and via telehealth in their homes (mean reduction: 97.27%). Between-group differences based on analysis of variance scores were significant ($P=.07$).

Two papers used telephone consultation to support and train parents of children with asthma [32,35], with mixed outcomes reported. Neither study reported any benefit in patient outcomes: Gustafson and colleagues [35] found no difference in medication adherence ($P=.76$) or number of symptom-free days for children ($P>.99$), while Garbutt and colleagues [32] found no improvements in either children's quality of life as measured by the Pediatric Asthma Quality of Life Questionnaire (between group difference: -0.17 ; 95% CI -0.47 to 0.12) or number of urgent events per year (between group difference: 1.15 ; 95% CI 0.82 - 1.61). However, at the family level, they reported that parental quality of life (measured using the Pediatric Asthma Caregiver's Quality of Life Questionnaire) improved with an asthma coaching program (between-group difference 0.38 ; CI 0.14 - 0.63).

Kierfeld and colleagues [55] used a telephone intervention with minimal therapist contact to train parents of children with externalizing problem behaviors. Results included improvements in the treatment group in problem behaviors, as measured by analysis of variance ($F_{1,44}=21.14$, $P<.001$, $d_{diff}=1.22$), parenting strategies ($F_{1,43}=9.43$, $P=.002$, $d_{diff}=0.92$), and parenting-related strains ($F_{1,43}=12.28$, $P<.001$, $d_{diff}=1.03$) [55].

Table 5. Interventions to train or support parents to deliver care (n=7).

Study identifiers: first author (year), country (sample size) [reference]	Study purpose: objectives	Intervention components: technology used, patient population, intervention, health care providers	Reported or perceived outcomes
Lindgren (2016), US (n=107) [37]	Determine whether challenging behavior in children with autism can be treated successfully at lower cost by using telehealth to train parents to implement applied behavior analysis	<ul style="list-style-type: none"> • Video (Skype) through the telehealth center • Parents of children with autism spectrum disorder • Weekly 60 minutes sessions where parents were coached to perform functional analysis and functional communication training • Behavior analysts or advanced graduate students 	<ul style="list-style-type: none"> • PO^a: reduction in problem behavior achieved but no different than traditional method ($P=.74$). • SO^b: reduction of costs related to treatment compared to in-home therapy (for staff salaries and travel, facilities, and family costs including telehealth equipment, mileage, and time) ($P<.01$).
Suess (2014), US, (n=parents of 3 children) [40]	Evaluate the fidelity with which parents of children with autism spectrum disorders implemented treatment procedures and the types of fidelity errors they made during coached and independent trials	<ul style="list-style-type: none"> • Video and Skype connection with telehealth center • Parents of children with autism spectrum disorder • Two sessions of didactic training, parent manual, weekly remote consultation, while parents implemented Functional Communication Training procedures • Behavioral consultant (psychology doctoral student experienced in behavior assessments and treatments) 	<ul style="list-style-type: none"> • PO: all children showed substantial reductions in problem behavior during the final treatment trials and especially during the coached trials. • FO^c: no consistent differences present in measurements of intervention implementation fidelity by parents across coached and independent trials.
Vismara (2013), US (n=8 families) [41]	Teach parents to implement autism-specific interventions	<ul style="list-style-type: none"> • Video and self-guided website • Parents of children with autism spectrum disorder • Weekly 1.5-hour parent coaching sessions for 12 weeks with 3-month follow-up • Therapist with extensive training 	<ul style="list-style-type: none"> • PO: overall improvement in rates of functional verbal utterances and non-verbal joint attention initiations, increased production and comprehension of words and gestures. • FO: steady gains in parental intervention skills, engagement style, and fidelity of intervention implementation.
Baharav (2010), US (n=2) [28]	Assess the use of technology and telepractice as a tool for coaching parents of children with autism spectrum disorders.	<ul style="list-style-type: none"> • Home laptop with Web camera and health care provider laptop • Parents of children with autism spectrum disorder • Weekly 50-minute home-based and 50-minute clinic sessions over 6 weeks • Speech and language therapists 	<ul style="list-style-type: none"> • PO: Gains in some communication and interaction skills. • FO: Parents report comfort with technology, willingness to continue to practicing strategies to deliver care to their child at home, and agree home services as valuable as those delivered by healthcare providers and would recommend to other patients
Gustafson (2012), US (n=301 parent-child dyads) [35]	Support and train parents and improve asthma control and medication adherence.	<ul style="list-style-type: none"> • Telephone • Parents of children with asthma • Electronic health intervention with interactive tools and tailored content and monthly support from nurse case manager 	<ul style="list-style-type: none"> • PO: No significant difference in symptom-free days ($P>.99$), or medication adherence ($P=.76$) between groups.
Garbutt (2010), US (n=362) [32]	Coach parents and children with asthma to improve disease-related quality of life and reduce incidence of asthma episodes requiring urgent care.	<ul style="list-style-type: none"> • Telephone from call center • Parents of children with asthma • 12-month coaching program to provide education and support • Call center RNs^d with pediatric and asthma telephone care experience 	<ul style="list-style-type: none"> • PO: No change in children's quality of life (95% CI -0.47 to 0.12) or number of urgent events per year (1.15; 95% CI 0.82 to 1.61). • FO: Significant improvement in parental quality of life with coaching program compared to control group (difference: 0.38; 95% CI 0.14-0.63). • SO: no change in number of urgent events per year (difference: 1.15; 95% CI 0.82-1.61)

Study identifiers: first author (year), country (sample size) [reference]	Study purpose: objectives	Intervention components: technology used, patient population, intervention, health care providers	Reported or perceived outcomes
Kierfeld (2013), Germany (n=48 families) [55]	Support and train parents of children with externalizing problem behavior to administer interventions with minimal therapist contact	<ul style="list-style-type: none"> • Telephone • Parents of children with externalizing problem behavior • Self-help book and weekly phone calls (average 20 min) to enhance motivation by reviewing key concepts covered in the self-help book • Child psychologist trained and supervised by senior child psychologist 	<ul style="list-style-type: none"> • PO: Improvements in parent-reported externalizing behaviors ($F_{1,44}=21.14$, $P<.001$, $d_{diff}=1.22$), and internalizing child problem behavior ($F_{1,44}=13.52$, $P<.001$, $d_{diff}=1.01$) • FO: Improvements in problem parenting strategies ($F_{1,43}=9.43$, $P=.002$, $d_{diff}=0.92$, and parenting-related strains ($F_{1,43}=12.28$, $P<.001$, $d_{diff}=1.03$).

^aPO: patient outcomes.

^bSO: system outcomes.

^cFO: family outcomes.

^dRN: registered nurse.

Family and Health Care Provider Involvement in Design of Digital Health Interventions

Across the body of included literature, there were few studies that explicitly included families and health care providers (intervention end-users) in the design and implementation of digital health interventions. However, a few key examples showcased end-user involvement, most commonly, in the early stages of intervention design such as the *observation* or *ideation* phases, as well as by garnering *user feedback*.

In one study by Miyahara and colleagues [58], the researchers actively involved families in the development, testing, and refinement of the intervention (*feedback* and *iteration*). An iterative process of two-way communication between the researchers and participants was used to evaluate and refine the intervention (a set of digital versatile discs, a workbook, and a website) throughout the study [58]. Authors reported that the impacts of end-user involvement increased participation in interventional components as well as the development of educational materials that were acceptable and useful to parents. Cady and colleagues [30] conducted a survey prior to initiating a videoconferencing intervention to find out what types of technologies were available to families (*observation*). Results of the survey supported that most families already had adequate home technology to support videoconferencing; however, apparent survey response bias led the researchers to caution of a potential “digital divide” in access to technology between Caucasian and minority populations [30]. Finally, Sutton’s group [7] engaged in a formal parent survey and the collection of anecdotal feedback from parents, health care providers, and subspecialty staff about the current care model, which spurred the development of the intervention (*observation*). Researchers then developed a study advisory group, consisting of key stakeholders such as parents and a variety of health care providers (*ideation*). Although the exact responsibilities of the advisory group are unclear, the inclusion of an end-user advisory group can lend valuable insights into intervention content and structure, making interventions more user-friendly and feasible to implement [60].

Factors Affecting Implementation of Digital Health Technologies

In addition to implementation challenges reported in the feasibility studies section, we also examined included studies for factors that may impact implementation. These factors, which we categorized as *technological*, *human*, or *system*, stem from family and health care provider perceptions as well as lessons learned by the researchers.

Technological Factors

Many studies reported encountering technical issues, which affected the implementation and acceptance of digital health interventions if the quality of videoconferencing or health care provider workflow patterns are disrupted [30,51]. For example, a barrier to videoconferencing was the limited availability of devices and broadband internet [57]. To overcome barriers to access, some interventions supplied equipment or internet services to families in varying capacities such as webcams, software packages, and computers on loan from the study with prepaid wireless connections [16,19,43,46,51,53,57]. These practical considerations are vital to acknowledge and plan for prior to digital health intervention deployment.

Human Factors

In general, patients, families, and providers were satisfied with digital health interventions and were open to learning how to use new technologies if they thought it would save them time [51]. However, digital health was not always appropriate, depending on the clinical use case. For example, Constaninescu [47] reported that therapists had difficulty engaging with younger children with hearing loss during videoconferencing appointments. Additional human factor barriers noted by Edirippulige and colleagues [48] were that social workers preferred in-person appointments to facilitate a personal connection with patients, and Seuss’ team [40] hypothesized that some parents may require face-to-face demonstrations of clinical skills for optimal treatment fidelity. With regard to human-technology interfaces, Casavant and colleagues [31] reported that the availability of real-time visual images was an important factor in decision making for health care providers

treating children on home ventilator support, and a lack of visuals was cited as a concern for health care providers in two phone-only interventions [36,52]. Additionally, some studies cited barriers of scheduling, time constraints, and workload for both patients/families and health care providers [16,45,48,56,58]. Family commitment (ie, history of good attendance in clinic) and health care provider engagement were crucial for successful implementation of the digital health interventions, with health care provider engagement being facilitated by strong leadership and rapid resolution of problems [50,51].

System Factors

Several studies reported system factor barriers to digital health related to funding, such as difficulties in obtaining consent to bill and restrictions on who could be reimbursed for delivering digital health interventions [32,49]. Additionally, connectivity issues [30,45,51,53,56] and device interoperability between systems [30,51] were additional barriers. System factors that facilitated implementation include detailed planning, high-level support, standardization and education, and adequate administrative support [50,51].

Discussion

Principal Findings

In this scoping review, we sought to synthesize the current available evidence on the use of digital health to care for children with special health care needs and their families. Our results draw attention to gaps evident in the knowledge base in this area, including the few full-scale randomized trials testing such interventions, and the dearth of literature discussing the involvement of end-users in intervention design and implementation. Despite national studies such as the SPROUT survey in the United States reporting 22 dedicated pediatric digital health programs, and an additional 29 programs providing digital health to mixed adult and pediatric populations [18], published research on such programs remains scarce.

Practical Considerations for Implementing Digital Health Technologies

This scoping review of the literature has demonstrated that digital health technologies have the potential to provide high-quality, effective interventions for children with special health care needs and their families in the convenience of their homes. Recent advances and widespread use of technology (eg, smartphones and tablets) have created an international landscape ready for implementation of digital health interventions. However, despite the pervasiveness of user-friendly technology, barriers to implementation continue to exist. Health care providers and health care administrators should consider the following implications when thinking about how to successfully implement digital health interventions.

Many of the included studies report the use of a digital health center or related infrastructure support, which may come with benefits such as having digital health-trained health care providers, dedicated technical support, and digital health-focused resources. Jury et al [50] reported the use of a website that contains staff and patient resources with how-to guides and troubleshooting material. However, other studies

have demonstrated the effectiveness of interventions delivered by independent health care providers. For example, studies by Vismara and colleagues [41] and Baharav and Reiser [28] have shown therapeutic outcomes associated with interventions delivered by health care providers from their office computers. Although many studies reported technical issues such as connectivity or interoperability conflicts, it was often unclear whether dedicated ongoing technical support was available. When considering implementing digital health solutions, it is important to be aware of the type of infrastructure available, how technical support will be provided, and what effect program implementation will have on health care provider workflows. Explicit reporting of these vital factors in published journal articles or reports may assist in moving the field of digital health forward and achieving optimal digital health intervention integration into health systems.

In addition, some health care providers and administrators may be able to capitalize on available funding for the implementation of digital health interventions [50], which can assist in rapidly implementing or scaling a digital health program. To increase the uptake of digital health, decision makers should consider that funding must be available not only to set up infrastructure, but also to inform health care providers and families of digital health intervention availability on an ongoing basis, and to assist in day-to-day operational management of the program. For example, Jury et al [50] reported using a program manager and telehealth “champions” to facilitate implementation, promoting digital health to families, and referring general practitioners. The demand created by these promotional strategies may well neutralize the added costs of personnel involved in the digital health program in for-profit situations.

Finally, care equity deserves special consideration when implementing digital health interventions. For example, in rural and remote areas, poor internet connectivity may prove to be a significant challenge for digital health programs to overcome [51,56]. One method that was used when bandwidth was insufficient for high-quality video was to utilize the Internet for video, while using the phone line for audio [43,45,46]. Using this strategy, fluctuations in picture quality were mitigated by clear and reliable audio components, and the call was not entirely interrupted. An additional care equity point to consider when implementing digital health programs is families’ access to devices that are required for using digital health. Although some studies in this review excluded participants who did not have access to the required devices or sufficient internet speeds, others provided hardware or financial support to install high-speed internet. By excluding those who do not have access to devices or adequate internet, health care systems may be further marginalizing underresourced populations and exacerbate the “digital divide.” Crucial to the successful implementation of digital health interventions is finding solutions to mitigate barriers to access. Modern technology options such as tablets are cost-efficient and easy to use, albeit reliant on Web-based software. Conversely, videoconferencing units that utilize phone lines are more expensive and require more technical support but may be more suitable for remote regions. Regardless of the types of devices and connection used, having requisite supports in place to rapidly overcome technical and user-related barriers

in the provision of digital health is essential for intervention uptake.

Teaching Parents

A promising area of results of this review is the use of digital health to teach and support parents to deliver care to children with special health care needs. Across a multitude of clinical specialties, chronic disease self-management is heralded as promoting improved patient engagement and collaborative care [61]. For children with chronic conditions, self-management necessitates the involvement of parents or other caregivers to deliver requisite proactive planning, disease surveillance, and health maintenance. Lozano and Houtrow [62] highlight the need for children and youth with chronic conditions to participate in shared care management where possible while also allowing appropriate amounts of autonomy. The positive impacts of parental training noted in this review, particularly in studies examining the parental delivery of autism therapies, could have important implications for improving clinical outcomes and conserving health care resources.

Co-Design of Digital Health Interventions

Literature in the field of intervention co-design reports that the concerns of health care practitioners and patients are often fundamentally different and that aligning program goals is a prerequisite for the successful implementation of patient-centered digital health services [63]. No studies included in this review made explicit use of co-design principles in intervention development using an established framework or theory, although a small number did incorporate end-user feedback at various stages. Few of the feasibility studies identified moved on to larger trials, supporting that uptake and integration of digital health interventions into usual clinical workflows remains problematic. Mounting evidence suggests that patient-orientated research—the inclusion of end-users in co-design and coproduction of interventions—assists in the generation of ideas and products that are feasible, appropriate, and of value to end-users [64,65]. Interventions designed to meet the requirements of end-users are associated with improved intervention acceptance, reduced user errors, and an enhanced reputation [65]. Evidence from other populations validates these points. For example, a co-design study of a flexible hip protector garment for older adults in care facilities resulted in high levels of interest from residents and support from site managers [66]. In another study, a codeveloped tool designed to improve the communication about heart failure trajectory and palliative care resulted in nurses reporting increased knowledge, improved confidence, and enhanced skills in end-of-life conversations [67]. Future work in digital health for children with special health care needs should incorporate co-design principles into the development of digital health interventions in order to increase user acceptance and intervention integration.

Limitations of this Review

Although we attempted to be comprehensive in our search, missed studies may have limited the scope of this review. To be as comprehensive as possible, we followed a rigorous process using a predefined scoping methodology framework and

assistance from an experienced librarian to develop our search strategy. We hand-searched reference lists of included articles and relevant journal databases to enhance the breadth of our search. However, we suspect that some organizations using digital health to care for children with special health care needs may be doing so without publishing their results. We did not contact experts in the field to inquire about known ongoing projects in this capacity; therefore, there is the possibility of some projects were missed.

Our team used an ongoing communication strategy, validation screening, and predefined study inclusion criteria and data extraction forms, contributing to the rigor of our data collection and extraction processes. However, due to time and resource constraints, we did not double screen the included studies. Thus, the potential for inappropriately including or excluding studies exists.

Additionally, we classified studies by methodology to the best of our ability, taking cues from authors' own descriptions or stated study type. However, some studies had methodologies that were ambiguous or not well detailed, leading to difficulty in classifying them. We suggest that authors publishing future work on digital health intervention implementation use clear language and reference a well-developed model for intervention stage such as the NIH Stage Model for Behavioral Intervention Development [68].

Finally, as per scoping review methodology, no quality appraisal was conducted on the included studies. The intent of our review was a broad overview of the literature; thus, omitting a quality appraisal was appropriate, as we did not wish to exclude smaller or less rigorously conducted studies. However, because of this, we would caution readers who are intending to use the evidence from this review to conduct their own quality appraisal of individual studies. Although we have preidentified articles for a variety of children with special health care needs, the utilization of high-quality evidence in practice is of equal importance.

Conclusions

The use of digital health to care for children with special health care needs presents an opportunity to leverage the capacity of technology to connect patients and their families to much-needed care from expert health care providers while avoiding the expenses and potential harms of the hospital-based care system. This review has summarized the use of digital health in providing care at home to children with special health care needs and their families while also highlighting challenges within the field. To move work in this important area forward, we strongly recommend the use of co-design and coproduction principles to involve end-users in meaningful ways in the design and implementation of digital health interventions. Additionally, much of the work in this area starts and ends with pilot and feasibility studies. Researchers should consider and integrate lessons learned from feasibility studies into large-scale interventions to operationalize programs with proven feasibility to better serve children with special health care needs and their families.

Conflicts of Interest

None declared.

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Abbreviations

- APN:** advanced practice nurse
- CF:** cystic fibrosis
- CRI:** . chronic respiratory insufficiency
- ED:** emergency department
- FO:** family outcomes
- HPO:** health care provider outcomes
- PO:** patient outcomes
- RN:** registered nurse
- SO:** system outcomes
- SW:** social worker

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Original Paper

Incorporating Technology Into the iCook 4-H Program, a Cooking Intervention for Adults and Children: Randomized Controlled Trial

Sarah Colby¹, RD, PhD; Lauren Moret, PhD; Melissa D Olfert², RDN, LDN, MS, DrPH; Kendra Kattelmann³, RDN, LN, FAND, PhD; Lisa Franzen-Castle⁴, RD, PhD; Kristin Riggsbee¹, PhD; Magen Payne¹; Ainsley Ellington¹; Cary Springer⁵, MS; Chelsea Allison¹, BS; Sa'Nealra Wiggins¹, BS; Rochelle Butler⁵, PhD; Douglas Mathews⁶, RD, PhD; Adrienne A White⁷, RDN, FAND, PhD

¹Department of Nutrition, University of Tennessee, Knoxville, TN, United States

²Davis College of Agriculture, Natural Resources, and Design, West Virginia University, Morgantown, WV, United States

³Health and Nutritional Sciences Department, South Dakota State University, Brookings, SD, United States

⁴College of Education and Human Sciences, University of Nebraska-Lincoln, Lincoln, NE, United States

⁵Research Computing Support, University of Tennessee, Knoxville, TN, United States

⁶University of New England, Portland, ME, United States

⁷School of Food and Agriculture, University of Maine, Orono, ME, United States

Corresponding Author:

Sarah Colby, RD, PhD
Department of Nutrition
University of Tennessee
1215 W Cumberland Ave
Jesse Harris Building Room 229
Knoxville, TN, 37996
United States
Phone: 1 865 974 6248
Email: scolby1@utk.edu

Abstract

Background: Families who cook, eat, and play together have been found to have more positive health outcomes. Interventions are needed that effectively increase these health-related behaviors. Technology is often incorporated in health-related interventions but is not always independently assessed.

Objective: The objective of this study was to describe challenges and facilitators to incorporating technology into the iCook 4-H intervention program.

Methods: Dyads (n=228) composed of children (mean 9.4, SD 0.7 years old) and an adult primary meal preparer (mean 39.0, SD 8 years) were randomly assigned to a control (n=77) or treatment group (n=151). All treatment group dyads participated in 6 in-person sessions designed to increase families cooking, eating, and playing together. We incorporated Web-based between-session technological components related to the curriculum content throughout the intervention. Assessments were completed by both groups at baseline and at 4, 12, and 24 months; they included measured anthropometrics for children, and online surveys about camera and website skill and use for dyads. Session leaders and participants completed open-ended process evaluations after each session about technological components. We computed chi-square analysis for sex differences in technological variables. We tested relationships between video posting frequency and outcomes of interest (cooking frequency, self-efficacy, and skills; dietary intake; and body mass index) with Spearman correlations. Process evaluations and open-ended survey responses were thematically analyzed for beneficial and inhibiting factors, including technological components in the curriculum.

Results: Only 78.6% (81/103) of children and 68.3% (71/104) of adults reported always being comfortable accessing the internet postintervention. Boys reported being more comfortable than girls with technological tasks ($P<.05$). Children who posted more videos had a higher level of cooking skills at 4 months postintervention ($r=.189$, $P=.05$). Barriers to website usage reported most frequently by children were lack of accessibility, remembering, interactivity, motivation, time, and lack of parental encouragement.

Conclusions: Incorporating technological supports, such as cameras and websites, into children's programs may help produce improved outcomes. Identifying barriers to and patterns of technology usage need to be considered when developing future child health promotion interventions.

Trial Registration: ISRCTN Registry ISRCTN54135351; <https://www.isrctn.com/ISRCTN54135351>

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KEYWORDS

technology; videos; intervention; cooking; child health

Introduction

Background

Unhealthy dietary patterns in childhood are associated with less than optimal growth patterns, cognitive deficiencies, emotional unwellness, and the development of many chronic diseases [1-7]. This is of concern because few children in the United States meet all dietary intake recommendations [1]. Healthier dietary behavior established in childhood has been associated with decreased lifelong risk of many chronic diseases, including obesity, diabetes, cardiovascular disease, and some cancers [8-11]. With current dietary patterns potentially increasing the risk for chronic disease later in life, it is important to develop effective intervention strategies to improve dietary behaviors among children.

While there is varying success with interventions designed to improve diet patterns of children, some technology-based interventions have been found to be more effective than nontechnology-based interventions [12-14]. Researchers have found that interventions designed with both face-to-face and technological strategies are more effective than similar interventions with only face-to-face components [15]. Technological strategies and supports can include a wide range of approaches.

Social media technology is a tool that can be used in health promotion interventions for children because children are often one of the earliest adopters of technology [16-18]. Although there is limited research on health-related interventions using social media, it is an increasingly used strategy and more research is needed to determine its effectiveness and influence on programmatic outcomes [19,20]. Many successful social media sites (eg, Facebook, Snapchat, Twitter, Instagram, and YouTube) have user-generated content (UGC) as the primary source of content [21]. The use of online UGC in interventions designed for children, including user-created videos posted to a website, may have the potential to increase program engagement leading to success. However, it is a largely underresearched intervention strategy.

Objective

The purpose of this study was to describe the incorporation of technology, including uses of and barriers to the use of technology, during an intervention by program participants; specifically, this study examined the use of technology in a child-adult dyad intervention program focused on cooking, eating, and playing together, called iCook 4-H.

Methods

Setting and Participants

The iCook 4-H intervention program was a pre-post, follow-up intervention study conducted over 2 years for dyads (9- to 10-year-old children and their primary adult meal preparer) across 5 states in the United States (Maine, Nebraska, South Dakota, Tennessee, and West Virginia). Of those adults who reported their relationship to the children (160/228, 70.2%), 151 (94.4%) of the primary adult meal preparers were parents, 6 (3.8%) were grandparents, and 3 (1.9%) were another adult.

The purpose of iCook 4-H, a series of 6 cooking lessons, was to help families learn to cook, play, and eat together to assist in the prevention of childhood obesity. After a year of curriculum development and pilot testing, we recruited 228 child-adult dyads in August 2013 using flyers, newspaper and radio advertisements, posters, emails, and postings on social media. Participants recruited for this study (1) were free from life-threatening illness or conditions, (2) were free from food allergies or activity-related medical restrictions that would prevent participation in a face-to-face nutrition and fitness program, (3) were willing to eat meat and dairy foods, and (4) had regular access to a computer with an internet connection. Participant recruitment efforts targeted low-income, rural, and diverse populations by distributing recruitment materials in communities in the 5 intervention sites.

Although this study was not prospectively registered as a randomized controlled trial, the institutional review boards at all participating universities approved the study procedures. All participants assented and consented to participate. The trial is reported in accordance with the Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth (CONSORT-EHEALTH) checklist ([Multimedia Appendix 1](#) [22]).

Study Design

We randomly assigned those who met the inclusion criteria to the control group (n=77) or intervention group (n=151), using a pattern of 1 control for every 2 treatment dyads. All participants completed baseline (0-month), postintervention (4-month), and follow-up (12- and 24-month) assessments. Assessments at these time points included measuring children's height, weight, waist circumference, and blood pressure as well as completing surveys. Survey questions assessed demographics, dietary intake, food security, cooking frequency, and cooking self-efficacy; program evaluation questions focused on cooking skills, family meals, physical activity, and goal setting [23-31]. We added questions after 12 months of the project to assess engagement with technological self-efficacy (ie, accessing the internet, and creating and uploading digital photos and videos to a study website). At 24 months, we added open-ended

questions about website usage, barriers to technology use, and preferences for technology. Stipends of US \$80 were provided to dyads, evenly distributed among the 4 assessment periods for those who completed each one. Control group participants had no other interactions with the researchers beyond the assessments during the 24-month study. The purpose of the control group was to provide a group to compare with the intervention group during analysis; we conducted this analysis to determine the effectiveness of the larger iCook randomized controlled trial in preventing excessive weight gain among children through increased family cooking, mealtime, and physical activity.

Treatment dyads participated in six 2-hour sessions held every other week, over a period of 12 weeks. Session leaders were Extension personnel or graduate students in nutrition- and health-related fields. The Extension personnel were community nutrition educators or paraprofessionals from the participating land-grant institutions. At the end of each session, leaders and dyads completed online process surveys, which included open-ended feedback questions on technology. Leaders also participated in monthly phone calls with researchers for process evaluation. Each 2-hour session included dyad-centered focus areas on culinary skills, food preparation, physical activity, family mealtime and communication, and goal setting.

We developed a password-protected website for participants to use to reinforce session content and increase connections between participants across the 5 states through status updates and comments. Participants were asked to post videos, recipes, status updates about personal goals, and reactions to other participants' postings between sessions. Videos were to be 3 to 5 minutes in length and reflect topics learned in the sessions. Video cameras were provided to the treatment group, and technological training on cameras and the study website was provided at session 1.

Beginning 1 month after the 12-week program concluded and continuing for 18 months, participants received an additional 21 months of website activities, monthly newsletters, and quarterly in-person booster sessions. For the website activities, we asked dyads to continue to create and post cooking, family mealtime, and physical activity videos. Weekly physical activities and monthly food challenges were also posted on the website [32]. An example physical activity challenge was "the plank challenge," which was a balancing *pose* to strengthen arms and spine while toning abdominal muscles. The challenge was to hold the plank pose longer each day over the week of the challenge [33,34]. An example of a monthly food challenge was "the purple food challenge," where participants were asked to cook with a new purple food. Status updates posted by

children about their physical and food challenges were entered into monthly drawings to receive monetary awards ranging in value from US \$10 to \$50, depending on the type and length of the challenge. In addition to having access to the website, children also received an age-appropriate newsletter through the mail. The newsletters contained the same content that we posted on the website. Quarterly booster sessions encouraged participants to continue the study goals of cooking, eating, and playing together. Activities at the booster sessions included bowling, field days, and picnics for sharing new recipes.

Development of Themes

To determine the issues related to website usage, 1 researcher (SC) reviewed the participants' and leaders' open-ended process survey responses to develop a codebook for thematic analysis [35,36]. Then 2 researchers (SW, CA) independently coded the open-ended survey responses using the provided codebook. Finally, a third researcher (SC) compared the codes and resolved any discrepancies that existed between the coders. We then collapsed the codes into larger groups of findings that became the themes [35,36]. We used these themes to develop an understanding of facilitators and barriers related to the iCook website.

Statistical Analysis

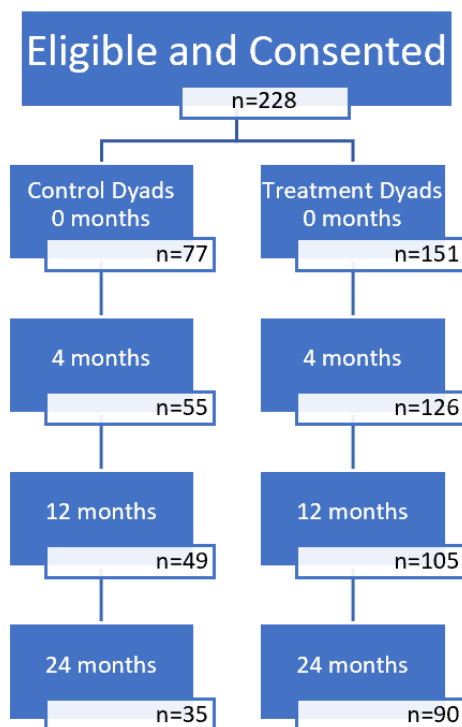
We calculated frequency statistics for demographics, technological variables, and website usage and preferences for children and adults in the treatment group. We grouped participants by video posting frequency (none: 0 videos; low: 1-3 videos; moderate: 4-7 videos; and high: ≥ 8 videos). Chi-square analysis determined whether differences existed by sex for technological variables, website usage and preferences, and video posting frequency. Spearman correlations investigated relationships between video posting frequency and outcomes of interest (cooking skills, dietary intake [fruit, vegetable, whole grain, dairy, and saturated fat], and body mass index [BMI]) at 4 months.

Results

Participant Characteristics

Dyads ($n=228$) consisted of a child (mean age 9.4, SD 0.7 years) and an adult primary meal preparer (mean age 39.0, SD 8 years). [Figure 1](#) shows the flow of the control and treatment groups through the study.

Most child participants were white (135/201, 67.2%), with over half being female (114/208, 54.8%). A total of 33.0% (66/201) of participating households were food insecure ([Table 1](#)), and 26.0% (54/208) of adults reported participating in at least one food assistance program.

Figure 1. iCook intervention study participation flow diagram.**Table 1.** Adult participant demographic information at baseline for control and treatment groups in the iCook 4-H intervention program (n=209).

Characteristics	Value, n (%)
Sex (n=209)	
Female	188 (90.0)
Male	21 (10.0)
Ethnicity/race (n=201)	
White	155 (77.1)
Black	16 (8.0)
Hispanic	13 (7.0)
Other	17 (9.0)
Marital status (n=208)	
Married	145 (69.7)
Not married	63 (30.3)
Educational level attained (n=225)	
Less than high school	12 (5.3)
High school	27 (12.0)
Associate degree	28 (12.4)
Some college or university	59 (26.2)
Bachelor's degree	66 (29.3)
Graduate school	33 (15.0)
Household food security (n=201)	
Food insecure	66 (33.0)
Food secure	135 (67.2)

Survey Results

At 12 months, 100.0% (103/103) of the children reported having access to the internet, with 83.4% (86/103) accessing the internet through a personal computer, 15.0% (15/103) using mobile devices, 1.0% (1/103) accessing the internet through work or school, and 1.0% (1/103) using a gaming console; 78.6% (81/103) of children and 68.3% (71/104) of adults in the treatment group reported that they were always comfortable accessing the internet (Table 2). The only differences identified in the chi-square analyses were with sex of the child and the following activities: accessing the internet ($\chi^2_4=10.2$, $P=.04$), downloading videos onto a computer ($\chi^2_4=10.9$, $P=.03$), and putting videos online ($\chi^2_4=12.5$, $P=.01$). More boys than girls reported being very comfortable with accessing the internet (45/93, 48.4% vs 58/112, 52.0%, respectively), downloading videos (35.8%, 33/93 vs 16/112, 14.0%, respectively), and putting videos online (32/93, 34.6% vs 14/112, 12.2%).

Although all treatment group children were asked to access the website and submit postings of their videos, only 69.0% (71/103) went on the iCook website. Of those who did post videos, 59% (42/71) posted 1 to 3 videos, 24% (17/71) posted 4 to 7 videos, and 17% (12/71) posted 8 or more videos. One person posted 26 videos and 1 person posted 29 videos. The most commonly reported reason why children visited the website was the videos, followed by functionality, recipes, information, challenges, cooking ideas, and activities. The top barriers to using the

website that children reported were accessibility issues, forgetfulness, lack of interactivity, motivation, time, and lack of parental encouragement. The top barriers for children using the website reported by adults paralleled the children's reports: forgetfulness, accessibility, lack of interactive games, and time, along with parental restriction on the child's computer time. Of the 53 treatment group adult participants who completed the 24-month postintervention surveys and reported receiving the newsletters, 37 (70%) preferred the newsletter over the website. Reasons for preferring the newsletter included that receiving the physical newsletter provided a reminder to look at the content and that it was easy to take with the family out of the house.

Session leaders identified 4 main technological issues, barriers, and limitations in the process evaluations: (1) changing participant preference for recording device from cameras to cell phones; (2) access to adequate upload speeds, which were disproportionately slower for lower-income families; (3) lack of technological knowledge and skills for children, adults, and session leaders; and (4) difficulties creating motivation and habit to use the program website.

At 4 months, children who posted more videos also reported a higher level of cooking skills ($r=.189$, $P=.05$). Frequency of posting had no relationship with any other outcomes of interest (children's dietary behaviors, cooking self-efficacy, family togetherness, or BMI).

Table 2. Treatment participants' self-efficacy for technological skills related to the iCook 4-H intervention program.

Survey item ("I can...")	Response regarding level of comfort				
	Never, n (%)	Rarely, n (%)	Sometimes, n (%)	Most of the time, n (%)	Always, n (%)
Access the internet					
Children (n=103)	1 (1.0)	2 (1.9)	12 (11.7)	7 (6.8)	81 (78.6)
Adults (n=104)	3 (2.9)	2 (1.9)	9 (8.7)	19 (18.3)	71 (68.3)
Take digital pictures					
Children (n=102)	4 (3.9)	3 (2.9)	5 (4.9)	12 (11.8)	78 (76.5)
Adults (n=104)	3 (2.9)	1 (1.0)	8 (7.7)	20 (19.2)	72 (69.2)
Download digital pictures onto a computer					
Children (n=102)	29 (28.4)	17 (16.7)	21 (20.6)	9 (8.8)	26 (25.5)
Adults (n=104)	6 (5.8)	10 (9.6)	19 (18.3)	21 (20.2)	48 (46.2)
Record digital videos					
Children (n=101)	7 (6.9)	5 (5.0)	14 (13.9)	10 (9.9%)	65 (64.4)
Adults (n=103)	3 (2.9)	10 (9.7)	12 (11.7)	30 (29.1)	48 (46.6)
Download videos onto a computer					
Children (n=103)	32 (31.1)	16 (15.5)	18 (17.5)	11 (10.7)	26 (25.2)
Adults (n=101)	12 (11.9)	19 (18.8)	16 (15.8)	25 (24.8)	29 (28.7)
Upload videos to a website					
Children (n=101)	39 (38.6)	13 (12.9)	18 (17.8)	7 (6.9)	24 (23.8)
Adults (n=102)	20 (19.6)	252 (24.5)	21 (20.6)	16 (15.7)	20 (19.6)

Discussion

Principal Findings

Although increased posting of videos was not related to changes in children's dietary behaviors, cooking self-efficacy, family togetherness, or BMI, it was associated with increased cooking skills. It is possible that posting of videos was only an indication of how engaged the children were overall in the program and not causally associated with improving cooking skills. It is also possible that as children cooked more while making videos (and experienced repeated exposure to the cooking concepts while reviewing videos), they increased their cooking skills. Future experimental research is needed to assess the impact of making cooking videos on children's cooking skills to determine causality.

The main purpose of this study was to describe the uses of and barriers to technology in the iCook 4-H intervention program. We did not specifically test the impact of students creating UGC in this study, since there was not a group that received the face-to-face intervention without the incorporation of technology. Most online UGC videos related to learning have been developed and tested for college and university populations [37,38]. Although investigations of the effectiveness of children creating videos to increase the effectiveness of class-based learning experiences are largely lacking, children creating their own UGC videos might be expected to create more excitement and engagement in program activities in part because children have an affinity for technology and online activities [39]. When children create UGC videos based on information from an in-person class, they are required to reflect on the content, synthesize information, and reinforce learning through repetition. The exercise of reflection provides children with a clear connection between the new material and previous knowledge [40]. Synthesizing requires a deeper understanding of the learned information to successfully translate and communicate material [41]. Repetition and reintroducing content is important in the learning process [42]; not only did children in our study repeat and practice skills as they made videos, but they were also repeatedly exposed to the information when they shared the videos they created and watched them with friends and family. When children created videos they also became ambassadors of the message, thereby increasing the likelihood that they would adopt the behavior because of social desirability to be in congruence with what they were saying to others; if they "walked the walk" then they were more likely to "talk the talk" [43,44]. When they were physically creating the videos they were using kinesthetic and active experiential learning techniques, which have also been found to improve learning outcomes [45]. If future research is developed to investigate the impact of this video creation strategy, many aspects related to technology need to be considered.

Limited technological self-efficacy of participants in this study needs to be considered. Even after technological training and participation in a 6-session program that included technology as a continuous component, many participants were not comfortable with basic technological skills (such as accessing the internet). Many researchers developing interventions may

be immersed in a world in which technology has saturated most aspects of daily life. These researchers may not be aware of the technological disparities that may exist in less-affluent communities. Data indicate that most individuals in the United States, despite economic status, have access to the internet, but this may not accurately reflect technological disparities in self-efficacy and skills [46,47]. Although all participants in this study did have access to the internet, this may not accurately reflect the proportion of individuals who have access in these communities. Access to the internet was an advertised requirement for participation in this project. Thus, the actual access to skills and self-efficacy with technology in these communities may be overrepresented in this sample. This concept of technological disparities may be similar to health disparities and health literacy disparities, and deserves further investigation.

Additionally, specific to this study, participants were asked to create videos showing themselves at home cooking, eating, and being active with their families. Participants were advised to keep videos to a short length of time (3-5 minutes). Because cooking takes place over a longer period than was recommended for the video length, participants needed to be able to edit cooking videos. The ability to edit a video is an advanced technological skill. With 15.0% (15/103) of the participants accessing the internet through mobile devices, this may have added an additional barrier to participation that needs to be considered. As mobile devices become easier to use and more on par with other computing technologies, this may become less of a barrier.

The ability to test experimentally the effectiveness of this technological approach in the future would likely be limited by technological skills. After technological training and participation in this program, many participants were still not comfortable with skills needed to effectively participate in the technological aspects of the program (creating and uploading videos to a website). Interestingly, children were a little more comfortable than adults in making videos and adults were a little more comfortable than children in downloading the videos to a computer and uploading them to a website. This may reflect roles the participants self-selected to complete during their participation in the project. It is also worth noting that both children and adults were more comfortable in taking and uploading digital photographs to a website than working with videos. These differing levels of technological skills should be considered when developing future research programs.

Although limited technological skills were not identified by participants as a reason for preferring the newsletter over the website, it is interesting that participants preferred printed materials over Web-based material. However, caution is needed when interpreting the preferences reported for the newsletters over website material found in this study. It is possible that what we observed was not because of differences in preferred communication strategies but instead was specific to materials developed for this study. Researchers have found that, although online technologies are beginning to be used in interventions, many websites are lacking components necessary to be effectively used [48]. Another possible explanation for the preference for print materials is that, if participants were

saturated with information from a variety of other electronic formats in other aspects of their life, receiving a printed newsletter in the mail might have been a novelty. It is also possible that participants might have had negative experiences with technology when trying to create and upload videos, and those frustrations affected their overall feelings toward use of the website. We did not anticipate these strong preferences for printed material. Other researchers have found that 90% of parents surveyed wanted Web-based interventions to help manage childhood obesity [49]. More research is needed to understand the communication preferences observed in this study. Research related to technology also needs to be continuously and frequently reinvestigated because type, access, familiarity, comfort, and skills related to technology change rapidly. The participants in this study may have very different experiences, skills, and preferences for technology even a few years later.

Many lessons learned about issues related to the incorporation of technology and UGC in this child health promotion intervention may be valuable to other researchers as they design future interventions. When this project was originally planned, mobile phones were less ubiquitous and cameras were provided to participants so that they could make their videos. By the end of the project, more participants had and preferred using their own smartphone-style mobile phones over other camera recording equipment. Future programs incorporating UGC videos may not need to incorporate the cost of providing cameras to participants (even when working with low-income communities) [47,50].

Although many participants had internet access at home and download speeds were not a reported barrier, we found that upload speeds varied. Limited upload speeds were a barrier to uploading videos for many families. Without adequate upload speeds, the time required to upload videos was impractical for many participants. We anticipate that with technological advances, access to sufficient upload speeds will become more widespread; however, the timeline for that progression is unknown and this barrier to uploading UGC (specifically videos) needs to be considered when developing interventions that incorporate these technological strategies. This is an especially important consideration when working with low-income communities that may not be able to afford more expensive internet services that have faster upload speeds [47].

Some of the community sites where sessions were taught also had limited or no access to the internet. This barrier made the incorporated technological instruction challenging and prevented the participants from being able to have lesson leaders assist with video uploading before or after the in-person sessions. Mobile hotspots were used to overcome this issue for technological training in some locations but were not adequate to overcome the barrier of upload time requirements. Although with expanding internet access, it is likely that this will be less of a problem in future interventions, internet access is an area that needs to be considered when developing technology-based community interventions.

When the project began, there were no widely used existing social media platforms that allowed children and parents to

interact in password-protected or closed online environments; thus, a password-protected website was created for use in this study. The password-protected site was needed to increase safety for the children and to alleviate concerns that parents and session leaders voiced about children interacting in online environments. However, encouraging participants to visit a newly created website and use it on an ongoing and frequent basis was challenging. Also, since videos needed to be uploaded as private YouTube files and the link then transferred to the iCook 4-H site, there may have been too many steps for participants to deal with to complete the process. A website community that would be self-generating did not arise, probably due to the relatively small number of participants available for website interaction. If a mobile app were available, it may help to increase child and adult participation in creating and uploading videos.

By the end of the study, options for creating closed communities were available on many popular social media platforms. Some researchers have had success initiating observations of successful, naturally occurring social media communities established for specific health conditions [51,52]. However, other researchers have reported limited success in their efforts to start and maintain communication about health topics on similar sites [53]. Despite conflicting research, it may be beneficial to avoid creating new websites for future interventions due to the financial and time costs needed to develop and maintain the site. Instead, future interventions using UGC online may benefit from incorporating their program into existing, familiar, and high-traffic sites; many of these commonly used sites now have the option to have closed or private, child-specific, or moderated groups.

Limitations

Although this study contributed novel perspectives in an emerging area of research, there were limitations in the study design. We did not test the effectiveness of incorporating UGC into the study design. Most participants did not participate or participated minimally in creating UGC. Because of the small sample size, this was not a representative sample of a larger national audience and the results cannot be generalized.

Conclusions

Overall, we have provided valuable perspectives on use and barrier issues that may be encountered when incorporating technology and UGC videos into programs designed to promote health for children. The effect of specifically incorporating UGC in child health promotion interventions needs to be tested with a randomized controlled trial design to isolate and test the impact of the children creating content on behavior outcomes. In this future research, the preferred communication strategies of the target population and barriers to participation in the technological components of the program need to be assessed and addressed prior to intervention implementation. This would allow for the development and implementation of an intervention that would have adequate and consistent levels of participation in the development of UGC material. This future research is needed to establish the impact of children creating videos on health-related behavior.

Conflicts of Interest

None declared.

This randomized study was only retrospectively registered. The editor granted an exception of ICMJE rules for prospective registration of randomized trials because the risk of bias appears low and the study was considered formative. However, readers are advised to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as retrospective registration does not prevent authors from changing their outcome measures retrospectively.

Multimedia Appendix 1

CONSORT-EHEALTH checklist (V 1.6.1).

[\[PDF File \(Adobe PDF File\), 95KB - pediatrics_v2i2e11235_app1.pdf\]](#)

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Abbreviations

BMI: body mass index

CONSORT-EHEALTH: Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth

UGC: user-generated content

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Original Paper

A Pragmatic Internet Intervention to Promote Positive Parenting and School Readiness in Early Childhood: Initial Evidence of Program Use and Satisfaction

Lucy McGoron¹, PhD; Hilary Horn Ratner¹, PhD; Kathryn AG Knoff¹, BSc; Erica Hvizdos¹, MSW; Steven J Ondersma¹, PhD

Wayne State University, The Merrill Palmer Skillman Institute for Child and Family Development, Detroit, MI, United States

Corresponding Author:

Lucy McGoron, PhD
Wayne State University
The Merrill Palmer Skillman Institute for Child and Family Development
71 E Ferry St
Detroit, MI, 48202
United States
Phone: 1 3136642553
Email: Lucy.K.McGoron@wayne.edu

Abstract

Background: Internet-based parenting programs have the potential to connect families to research-informed materials to promote positive child development. However, such programs can only succeed to the extent that the intended population engages with them.

Objective: This study aimed to evaluate engagement in the 5-a-Day Parenting program, a technology-based program designed with low-income families in mind, to promote daily use of 5 specific parenting activities conducive to children's school readiness. Following earlier pilot data, the program was enhanced with an initial motivational e-intervention and tailored text messages designed to promote engagement.

Methods: Parents were recruited from local childcare centers and through a participant registry. We examined rates of receipt of program text messages and use of video-based content on the program website, 3 factors that may affect website use, and satisfaction with key program elements.

Results: A total of 360 parents of young children learned about the study and had the opportunity to use the 5-a-Day Parenting website. Of these, 94 parents participated in the study, and 33% (31/94) accessed the video-based content on the website at least once. No association was found between website use and program recruitment approach, program-affiliation message, sociocontextual risk, and baseline use of the five parenting activities. Satisfaction with text messages and video-based content was high.

Conclusions: For some parents, technology-based programs appear useful; however, engagement could still be enhanced. Additional research should seek innovative strategies for promoting engagement in Web-based parenting programs.

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KEYWORDS

child rearing; child development

Introduction

Background

Young children's successful entry into school is closely associated with their social, emotional, cognitive, and academic readiness [1], each of which is strongly influenced by parenting and the home environment. For instance, parental warmth

promotes positive emotional development [2,3] and reduces children's behavioral problems [4]. Cognitively stimulating home environments, conducive to language and book sharing, enhance children's language development and early reading skills [5]. Sensitive parent-child play builds social competence [6]. Even the overall structure of children's days is important; children from families that have regular routines, share meals together, and follow a bedtime routine have stronger emotion

regulation and social skills [5,7,8]. Unfortunately, children in families experiencing heightened sociocontextual risk (eg, financial struggles) are more likely to have deficits in school readiness skills [5], in part, because high levels of sociocontextual risk creates stress for parents, which in turn can interfere with positive parenting practices [9].

Face-to-face parenting programs teach parenting strategies that promote children's school readiness skills (eg, Landry et al [10]) and reduce challenging behaviors (eg, Kaminski et al [11] and Webster-Stratton et al [12]) that can interfere with school readiness. However, McGoron and Ondersma [13] identify a number of barriers to the use and completion of such programs. Lack of access to services, practical barriers (eg, lack of transportation), stigma around seeking parenting advice, lack of information about where to find services, family stressors, and a simple lack of interest in services all serve to inhibit engagement and continued use in potentially helpful parenting programs. Internet-based delivery of parenting programs may ameliorate many of the above-noted barriers [13,14]. As is often noted, internet access is becoming ubiquitous, even among parents facing sociocontextual risk [15].

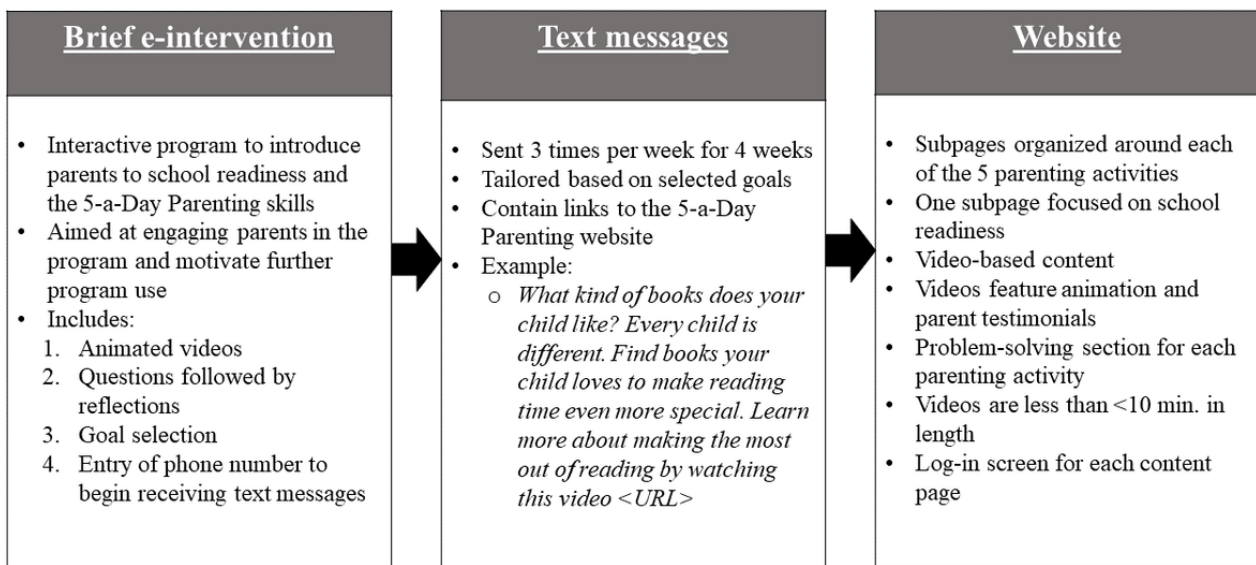
With this knowledge, we created the 5-a-Day Parenting program, a fully technology-based program, to promote school readiness in early childhood through positive parenting. Development of this program was influenced by the domain-specific approach to socialization proposed and outlined by Grusec and Davidov [16]. This approach integrates multiple theories of child socialization (eg, attachment theory, social learning theory), recognizing that there are distinct domains of parenting behavior (eg, protection, reciprocity, control and guided learning) that are related to specific child outcomes. The 5-a-Day Parenting program taps into multiple socialization domains given that the outcome of focus is school readiness, which is multifaceted and includes children's development of social, emotional, cognitive, and behavioral skills. Ultimately, the goal of the program is to distill a large body of child development research (eg, [1-8]) into 5 specific parenting behaviors. The 5 behaviors include (1) reading at least one book a day to children; (2) playing with children at least 10 min a day; (3) sharing at least one meal a day; (4) showing affection each day; and (5) following a bedtime routine. Multiple domains of optimal parenting are targeted within these specific activities. For instance, parents can learn about optimal guided learning (eg, labeling and scaffolding) while playing with their children, reading to their children, and sharing a meal.

The program is intended to be highly practical rather than intensive to keep in mind the demands faced by busy parents who may be experiencing multiple sociocontextual stressors. As such, the program was created with low-income families in mind because these families face barriers to attending the face-to-face parenting program [17,18]. The 5-a-Day Parenting program website teaches parents about the benefits of the 5 activities, how to make the most out of time spent doing these activities, and how to overcome related challenges. At the beginning, parents engage with the program by selecting which

of the 5 activities to focus on. Figure 1 outlines steps in the 3-part program.

The rate at which parents will use internet-based parenting programs in general, and the 5-a-Day Parenting program specifically, is still unclear. Current investigations of internet-based parenting programs often describe the final sample of participating parents but do not indicate what percentage of parents declined (eg, [19,20]), but there are several exceptions. In a sample of military parents, Doty et al [21] found about half (193/370) of the participating families used a Web-based parenting resource; however, more than 70% (271/370) attended a face-to-face parenting program session. For parents of children with attention-deficit/hyperactivity disorder (ADHD), Ryan et al [22] reported that nearly 60% (91/158) of parents used an educational website. Investigations with these special populations, however, provide little insight into the use of a parenting website for a *general* population of parents.

Specific to the 5-a-Day Parenting program, our initial pilot investigation [23] demonstrated that while most parents reported intentions to use the website, actual traffic to the website was low, and some parents reported needing reminders. Learning from this process, we made program enhancements to promote program engagement, including adding a brief e-intervention at initial engagement to motivate program use and text messages to reinforce content and provide reminders. Although these new program features may promote engagement, other factors may also affect parents' use of the 5-a-Day Parenting website. Unfortunately, there is little research to suggest which factors may affect parents' use of an online program. We selected 4 possible factors to explore. First, where or how parents learn about an online parenting program may affect use of the 5-a-Day Parenting website. For example, parents may be more open to using a program if they learn about it face-to-face from a trusted source (eg, a service they already use, such as childcare or a pediatric practice). Second, stated program affiliation may also affect the use of the 5-a-Day Parenting website. Consistent with this idea, the qualitative work of Bernhardt and Felter [24] found that parents rated Web-based resources created by experts or academics as more trustworthy. Moreover, Eysenbach and Kohler [25] also reported that consumers look for online health information that appears scientific. Thus, programs with an academic or scientific affiliation may engender more program use. Third, we also considered whether the level of sociocontextual risk affected use of the program. Baker et al [26] reported that low-risk and high-risk families were equally open to using an internet-based parenting program. However, sociocontextual risk, such as economic strain, creates stress and daily hassles for parents (see Masarik and Conger [27], for a review), which could inhibit the use of an online program. Thus, it is important to consider the possible impact of sociocontextual risk on *actual* program use. Finally, given that parents who already regularly engage in the five parenting activities may be less inclined to use the video-based content on the website, we explored if baseline reports of using the parenting activities were related to website use.

Figure 1. Overview of the 5-a-Day Parenting program.

Objectives

This study had 3 goals. First, we sought to evaluate the use of the 5-a-Day Parenting program; specifically looking at how many parents would continue receiving text messages after going through a brief e-intervention, intended to prompt program use, and how many parents would use the video-based content on the 5-a-Day Parenting website. Second, we sought to evaluate potential factors that may affect use of the video-based content on the program website, including engagement approach (ie, how parents learned about the program), program-affiliation message (ie, stated academic/scientific affiliation or no stated affiliation), and sociocontextual risk. We also report parents' use of the five parenting strategies at baseline and their relation to use of the video-based content on the program website. Third, we evaluated parents' satisfaction with the text messages and video-based content on the 5-a-Day Parenting program website.

Methods

Participants

Participants were parents of children aged 2 to 5 years in Detroit, Michigan. Participants were recruited from 1 of 2 sources (ie, 2 different recruitment groups). First, parents were recruited through childcare centers that are part of a community-based, university-anchored consortium (referred to hereafter as *the Consortium*; see [28], for details). A total of 6 Consortium childcare centers agreed to allow recruitment for this study. The second recruitment source was a registry consisting of Detroit-area parents of preschool-age children who had provided consent to be contacted about research opportunities.

Intervention

The 5-a-Day Parenting program is a newly developed program that encourages parents to do 5 daily parenting activities (see [23]). The program also gives parents information about optimizing time together by being responsive and cognitively stimulating during activities (eg, pointing to pictures in books, labeling shapes during play). The program was created by a

developmental psychologist (the first author) after reviewing the literature on parenting practices and positive development in young children and identifying specific parenting activities correlated with outcomes important for children's school readiness. After piloting the program, 2 program enhancements were added. First, we added an initial, brief e-intervention (<10 min) to introduce the five parenting activities, build investment in change, and promote use in the program. This brief e-intervention is interactive, with voice-over narration as well as motivational strategies and goal setting, and includes a video providing information about school readiness and the 5-targeted parenting strategies. Second, we also added a request for the parent's mobile phone number to enable receipt of tailored text messages. These text messages are sent 3 times per week for 4 weeks, and function as cues to use the video-based content on the 5-a-Day Parenting website. Text messages are tailored based on each participant's specific goals (eg, reading to their child more often). A link to video-based content in the 5-a-Day Parenting website is included in each text message.

Recruitment

The Wayne State University Internal Review Board approved all procedures before data collection. Childcare center recruitment involved distribution, at pickup and drop-off times, of folders with information about the 5-a-Day Parenting program and the URL for study participation. The project team tracked rates of folder distribution. Participant registry recruitment involved text messaging parents from the registry with an invitation that included a URL leading to further information about the study. The project team tracked the number of text messages distributed and phone numbers that were no longer in service.

Manipulation of Program Affiliation

For parents recruited through Consortium childcare centers, 3 centers were randomly selected to receive a program-affiliation message, and 3 centers were randomly selected to receive a nonaffiliated message. Similarly, participants recruited via the

registry were randomly assigned to receive a program-affiliation message or nonaffiliated message.

Program-Affiliation Message

In the program-affiliated condition, participants learned that the 5-a-Day Parenting program was developed by Consortium leaders who were experts in child development research. Specifically, the video in the brief e-intervention explicitly stated that the 5-a-Day Parenting program creators were early childhood Consortium leaders (through the University) with expertise in child development and school readiness. In addition, the flier in the folder/text message they received had a link to a subpage on the Consortium website with information about the affiliation; this page is where they began participating.

Nonaffiliated Condition

In the nonaffiliated condition, there was no indication that the program was developed by Consortium leaders or by child development experts at a university. The video in the brief e-intervention made no mention of program affiliation. Moreover, the flier in the folder/text message they received had a link to a subpage on the 5-a-Day Parenting website (which had no mention of the university/Consortium) and not a link to Consortium website.

Procedures

For all parents, those who chose to participate in the study first went to a URL (provided in their recruitment folder or text message). Participants went through an online study consent, and those providing consent then completed an online survey that took approximately 15 min. Following completion of the survey, parents were led directly to the brief e-intervention, which described the 5-a-Day Parenting program (through a brief video), and allowed them to select goals for change related to the five parenting activities (eg, reading to their child more often [see Figure 1]). Participants recruited from childcare centers received a US \$25 Target gift card after completing these baseline participation steps; participants from the participant registry received a US \$25 credit on a debit card provided to them as part of registry participation. Immediately following completion of the brief e-intervention, parents received a welcome text (see Figure 1) with a reminder that they could text *STOP* to end text messaging.

Participants were free to use the video-based content on the 5-a-Day Parenting website as much, or as little, as they chose. Parents received no compensation for their use of the website. Parents were required to enter their 3-digit ID number each time they went to a content page (ie, anything beyond the landing page). A total of 4 weeks after baseline participation, parents received a text inviting them to complete an online follow-up survey. The survey asked them to evaluate the text messages they received and the program website. Parents were compensated with a US \$25 gift card or US \$25 credit on their debit card for their time completing the follow-up survey.

Measures

Demographics

At baseline, parents answered questions about their child's gender and age. Parents also reported on their age, race, education, relationship status, and perceived financial strain.

An Accumulation of Sociocontextual Risk

We created a cumulative risk index to measure sociocontextual risk. Rutter [29] first proposed cumulative risk indices to understand how areas of risk converge to affect children's adjustment. Importantly, although the areas of risk and number of risk factors included vary across studies, cumulative risk indices in general are related to a number of outcomes from child adjustment [30], parenting [31], and dropout of parenting programs [32]. The creation of a cumulative risk index is straightforward: identify salient risk factors, dichotomize the risk factors (0=no risk; 1=risk), and sum. In all, 4 dichotomized areas of sociocontextual risk, obtained through the baseline questionnaire, were used to create a cumulative risk index. Areas of demographic risk measured were (1) struggling financially (*risk*=responding that they do not *always* have enough money to pay for basic needs), (2) being a single parent (*risk*=not selecting being married or having a romantic partner), (3) low educational attainment (*risk*=reporting no education beyond high school), and (4) and being a young parent (*risk*=being 26 years of age or younger, which was 1 *SD* below the mean for this sample). We selected these areas of risk as they likely create challenges and adversity in parents' life and may limit program use. Moreover, such areas of risk are generally included in cumulative risk indices (eg, see [33]). The dichotomized risk variables were summed to create a cumulative risk score with a possible range of 0 to 4.

Use of Five Parenting Activities Before Participation

At baseline, parents were asked to *think back to how you spent time with (child's name) over the past week. Rate how often you did the following 5 things*. Parents then went through a list of the five parenting activities and rated how many days they did each the previous week (ranging from 0 to 7 days). In addition to looking at the ratings individually, a total parenting activities score was created by summing responses to the 5 items (possible range of 0 [ie, parents did none of the parenting activities the previous week] to 35 [parents did all 5 of the activities every day in the previous week]).

Text Message Use

We recorded the frequency with which parents elected to stop receiving text messages. In addition, in the follow-up survey we asked parents, *How often did you read the text messages you received from the 5-a-Day Parenting Program?* with response options ranging from *Rarely* to *Always*.

Website Video-Based Content Use

Project staff tracked log-ins to content pages on the website and connected the log-in ID to the parents' baseline survey responses, recruitment group, program-affiliation message group, and follow-up survey responses. A binary website use variable (0=no website use; 1=website use) was computed as

well as a variable reflecting the number of times each parent logged into the website (frequencies ranged from 0 to 56 times).

Evaluation Ratings

The first author wrote the evaluation rating questions for this investigation following the Technology Acceptance Model [34]. A total of 9 items (6 positively worded and 3 negatively worded) focused on text messages. These items elicited parents' feedback on the helpfulness of the texts in making parenting changes and serving as a reminder to use the website, if parents continued reading the messages, and how much they liked/disliked the messages. A total of 16 items elicited parents' feedback on the website (11 positively worded and 5 negatively worded). These items asked parents to rate the look and quality of content on the website in general and videos specifically and the amount of information, using response options of *Not at all true*, *Somewhat true*, or *Very true*. In addition, regarding text messages, parents were asked (with yes and no responses) if they would *sign up for text messages if involved in a project like this again?*

Statistical Analysis

Before conducting analyses to examine study goals, we examined demographics of the participants. We also examined rates of sociocontextual risk and use of the five parenting activities at baseline; these rates were examined for the whole group and split by participation group. We examined the proportion of participants introduced to the research opportunity who chose to participate in the study at baseline. Next, in line with the first investigation goal, for those that participated, we computed the frequency with which they stopped text messages,

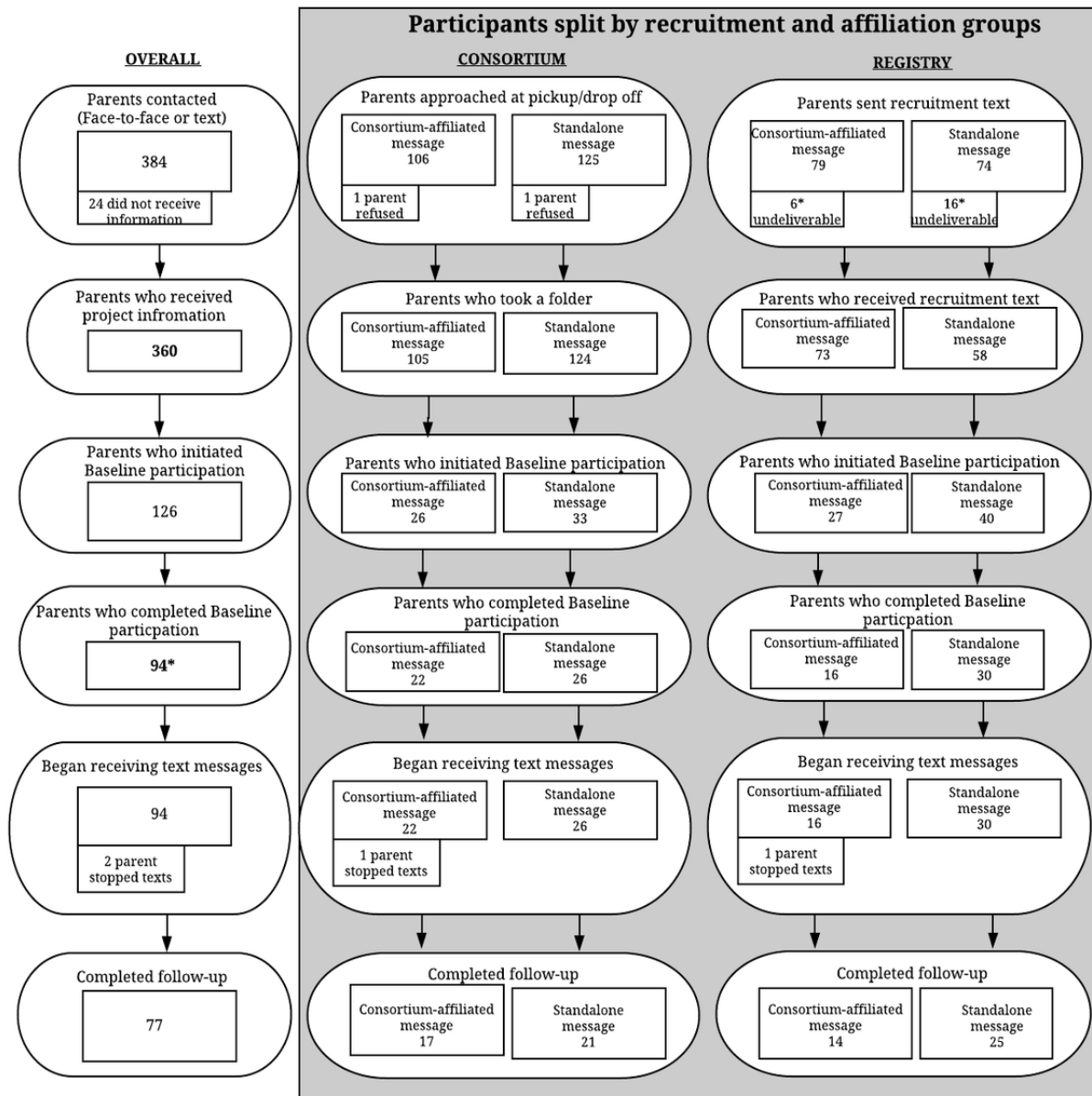
their self-reported frequency of reading texts, the frequency of using the website at least once, and the mean and standard deviation of website visits among parents who did use the website. In line with the second investigation goal, paired-samples chi-squared analyses determined if recruitment group or program-affiliation message affected website use. In addition, a bivariate correlation was computed to determine if levels of sociocontextual cumulative risk were associated with website use. A bivariate correlation was also computed to determine if baseline use of the parenting activities was associated with website use. Finally, in line with the third investigation goal, we computed frequencies of responses to parent evaluation ratings of the text messages and website (among those who used the website).

Results

Participants

Overall, participant flow is presented in Figure 2. In total, we attempted to inform 384 parents about the opportunity; however, 24 did not receive the information (2 parents refused to take a folder at the childcare center, and 22 phone numbers through the participant registry were nonworking). Thus, 360 parents learned about the 5-a-Day Parenting program by receiving a folder at their Consortium-affiliated childcare center (n=229) or through receiving a text message from the registry (n=131). Of these parents (ie, those who learned about the program), 35.0% (126/360) initiated baseline participation, but only 26.1% (94/360) fully completed the baseline assessment. A total of 81% (76/94) of study participants completed the follow-up assessment.

Figure 2. Recruitment and participation summary. *We considered what percent of these parents continued receiving text messages and used the video-based content on the website.



Demographics

Demographic data are presented for those who fully completed baseline (ie, *study participants*); results primarily focus on this group of 94 parents. Participants were primarily African American mothers; their preschool-aged children were nearly

equally divided between boys and girls. Parents were, on average, 33.56 years old (SD 6.85; for the Consortium group, mean 35.77, SD 6.30; for the Registry group, mean 31.30, SD 6.71). See [Table 1](#) for detailed information about the study participants.

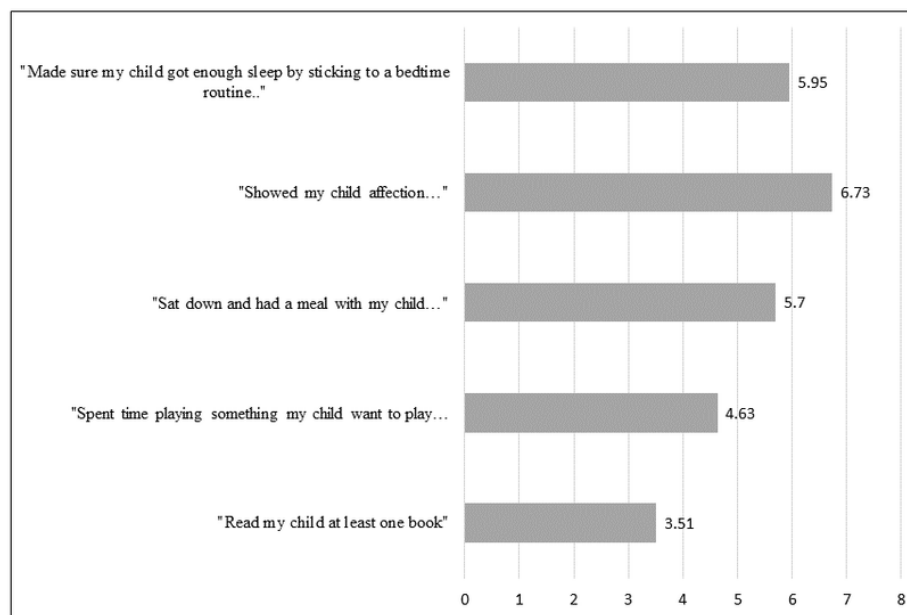
Table 1. Demographic characteristics of study participants.

Demographic reported	Overall (N=94), n (%)	Consortium (n=48), n (%)	Registry (n=46), n (%)
Parent's relationship to the child			
Mother	86 (92)	43 (90)	43 (94)
Father	3 (3)	3 (6)	0 (0)
Grandparent	4 (4)	1 (2)	3 (7)
Choose not to answer	1 (1)	1 (2)	0 (0)
Parent education			
<High school graduate	5 (5)	0 (0.0)	5 (10)
High school graduate/General Educational Development	28 (30)	8 (17)	20 (45)
Some college/associate's degree	27 (29)	10 (20)	17 (37)
Bachelor's degree	12 (13)	12 (25)	0 (0.0)
Advanced degree (master's degree, doctorate)	19 (20)	16 (33)	3 (7)
No response	3 (3)	2 (4)	1 (2)
Child gender			
Boy	49 (52)	27 (56)	22 (48)
Girl	44 (47)	20 (42)	24 (52)
Child's age (years)			
2	24 (26)	18 (38)	6 (13)
3	25 (26)	12 (25)	13 (28)
4	28 (29)	13 (27)	15 (33)
5	14 (15)	5 (10)	9 (20)
Race and ethnicity			
African American	68 (72)	27 (56)	41 (89)
Caucasian	20 (21)	18 (37)	2 (4)
Hispanic or Latino	0 (0)	0 (0)	0 (0)
Native American	1 (1)	1 (2)	0 (0)
Asian	6 (6)	5 (10)	1 (2)
Middle Eastern	5 (5)	1 (2)	4 (9)
Other	2 (2)	2 (4)	0 (0)
Choose not to answer	1 (1)	1 (2)	0 (0)
Relationship status			
Married	36 (38)	22 (46)	14 (30)
Living with romantic partner	8 (8)	4 (8)	4 (9)
Never married	40 (43)	13 (31)	27 (59)
Divorced	7 (7)	6 (13)	1 (2)
Widow	0 (0)	0 (0)	0 (0)
Choose not to answer	1 (1)	1 (2)	0 (0)
Enough money to pay for basic needs			
Rarely or never	6 (6)	2 (4)	4 (9)
Sometimes	9 (10)	2 (4)	7 (15)
About half the time	14 (15)	3 (6)	11 (24)
Always	65 (69)	41 (85)	24 (52)

Participants' Cumulative Sociocontextual Risk and Use of Five Parenting Activities

The mean cumulative sociocontextual risk score was 1.33 (SD 1.15). Sociocontextual risk was significantly higher in the Registry group (mean 1.89, SD 1.04) than the Consortium recruitment group (mean 0.79, SD 0.99; $t_{92}=-5.26$; $P=.001$). Mean ratings for use of each of the five parenting activities in the week before baseline participation are reported in Figure 3.

Figure 3. Parent reports of frequency of completing the five parenting activities in the week before participation.



Text Messages

Tracking showed that all study participants received text messages, and only 2 elected to stop receiving messages. At the 4-week follow-up ($n=76$), 46% (35/76) of parents reported *always* reading the text messages, 21% (16/76) reported reading the text messages *most of the time*, 16% (12/76) reported reading the texts *about half the time*, 9% (7/76) reported reading the texts *sometimes*, 3% (2/76) reported reading them *rarely*, and 5% (4/76) provided no response.

Website Use

Of the 94 study participants, 33% (31/94) used the website at least once. For study participants who used the website, the average number of visits was 7.1 (SD 10.6). Two parents were identified as outliers, however, as one participant used the website 56 times and one used the website 30 times, in reexamining the data with these outliers removed, mean visits decreased to 4.7 (SD 3.3). Of the parents who used the website, 84% (26/31) used it more than once.

Recruitment Group, Program-Affiliation Message, Cumulative Sociocontextual Risk, Parenting Activities Frequency, and Website Use

Of the study participants recruited from a Consortium childcare center (ie, face-to-face recruitment), 42% (20/48) used the website at least once, whereas only 24% (11/46) of participants recruited via text message from the registry used the website;

Reading was the least often reported parenting activity, with 53% of parents reading to their child 3 times or less per week. In contrast, 90% of parents reported expressing affection to their child every day in the previous week. The mean score for the total parenting activities score was 26.23 (SD 6.78); this score was statistically equivalent in the Consortium recruitment group (mean 27.35, SD 6.22) and the Registry recruitment group (mean 25.07, SD 7.20; $t_{92}=7.65$; $P=.10$).

this difference was not statistically significant ($\chi^2_1 [N=94]=3.4$, $P=.07$). For the entire sample of baseline participants, program-affiliation message did not affect website use ($\chi^2_1 [N=94]=4.7$, $P=.49$). When looking at the recruitment group separately, program-affiliation message still did not affect website use (Consortium recruitment group, $\chi^2_1 [N=48]=0.5$; $P=.49$; registry recruitment group, $\chi^2_1 [N=46]=0.4$; $P=.55$). There was also no evidence that sociocontextual risk affected parents' use of the website ($r=-0.12$; $P=.24$). Given that an accumulation of sociocontextual risk was higher in the registry group, the impact of an accumulation of sociocontextual risk on website use was considered separately by recruitment group. An accumulation of sociocontextual risk was not related to website use in either the registry group ($r=0.11$; $P=.48$) or the Consortium recruitment group ($r=-0.07$; $P=.64$). Finally, there was also no association between reported parenting activities at baseline and website use ($r=0.03$; $P=.90$).

Parents Ratings of the Text Messages and Website

Table 2 presents ratings from parents on program text messages. When asked if they would sign up for text messages if involved in a project similar to this again, 86% (65/76) reported yes, 8% (6/76) responded no, and 7% (5/76) did not respond. Parents' feedback on the 5-a-Day Parenting website is presented in Table 3; all 31 parents who participated in the baseline session and used the website completed the 4-week follow-up survey and provided feedback.

Table 2. Text message feedback from parents who received text messages and completed follow-up (N=76).

Survey items	Not at all true, n (%)	Somewhat true, n (%)	Very true, n (%)	No response, n (%)
Positively worded items				
The text messages were helpful to me.	1 (1)	36 (47)	33 (43)	6 (7)
The text messages encouraged me to spend time with my child.	10 (13)	32 (42)	39 (51)	6 (7)
The text messages helped me remember the website.	4 (5)	24 (31)	42 (55)	6 (7)
The text messages led me to use the website.	4 (5)	33 (43)	34 (45)	5 (6)
The text messages helped me make parenting changes.	14 (18)	37 (49)	19 (25)	6 (8)
I liked the text messages.	3 (4)	34 (45)	35 (46)	4 (5)
Negatively worded items				
There were too many text messages.	42 (55)	22 (29)	8 (11)	4 (5)
I stopped reading the text messages after a while.	55 (72)	15 (20)	2 (3)	4 (5)
The text messages did not change my behavior.	38 (50)	23 (30)	9 (12)	6 (8)

Table 3. Satisfaction among participants that used the video-based content on the website (n=31).

Survey items	Not at all True, n (%)	Somewhat true, n (%)	Very true, n (%)	No response, n (%)
Positively worded items				
I like the way the website looks.	1 (3)	13 (42)	17 (55)	0 (0)
It was easy to understand the information on the website.	0 (0)	3 (10)	28 (90)	0 (0)
It was easy to read through the information on the website.	1 (3)	5 (16)	25 (81)	0 (0)
I like the videos on the website.	0 (0)	16 (52)	15 (48)	0 (0)
It was easy to understand the information in the videos.	0 (0)	4 (13)	26 (87)	1 (3)
I like that there are videos.	1 (3)	5 (17)	24 (80)	1 (3)
There is lots of good information on the website.	0 (0)	7 (23)	23 (77)	1 (3)
I found the information on the website to be useful.	0 (0)	9 (29)	22 (71)	0 (0)
I had an easy time finding things on the website.	2 (7)	12 (39)	17 (55)	0 (0)
The website is well organized.	1 (3)	12 (39)	18 (58)	0 (0)
I like the animated characters in the videos.	5 (17)	15 (52)	9 (31)	2 (7)
Negatively worded items				
There is too much information on the website.	25 (81)	4 (13)	2 (7)	0 (0)
There was too much information in the videos.	25 (86)	2 (7)	2 (7)	2 (7)
The information on the website is confusing.	29 (94)	2 (7)	0 (0)	0 (0)
I do not like the website.	28 (90)	3 (10)	0 (0)	0 (0)
I did not find the website helpful.	28 (90)	3 (10)	0 (0)	0 (0)

Discussion

Principal Findings and Comparison With Prior Work

This study sought to evaluate use of a light-touch, online parenting program and program satisfaction. This study included 2 enhancements designed to promote use of the program: (1) a brief e-intervention that introduces the program and promotes engagement, and (2) tailored text messages; it further sought to evaluate the extent to which dissemination method, program-affiliation messages, sociocontextual risk, and

preintervention use of the parenting strategies might be associated with program uptake.

Among study participants (n=94), approximately a third (ie, 33%) went on to use the 5-a-Day Parenting program website. This rate of website use is lower than reported in other investigations; for example, Doty et al [21], reported that 50% (193/370) of military families used an online parenting program, and Ryan et al [22] reported that 60% (91/158) of parents of children with ADHD used an online parenting resource. However, findings must be interpreted within the context of the

sample. Notably, parents in this study were not seeking parenting assistance at the beginning of the project. In addition, no screening for challenges in parenting or child development took place before inviting parents to participate. Although parents who participated in the study were not required to use the 5-a-Day Parenting program website's video-based content and received no compensation for website use, many chose to use the website and learn positive parenting strategies. Of those who did so, the majority used it more than once, and most rated it as helpful. Moreover, most participants reported reading the messages, and only 2 elected to stop the messages. Only 1 participant responded that the text messages were not helpful, and only 3 reported not liking the messages. These results suggest that a substantial minority of parents, despite not seeking parenting assistance, will use an internet-based parenting program after being invited to do so, which is an encouraging finding.

However, the majority of the 360 parents who learned about the study (74%) chose not to participate. Virtually none of the nonparticipating parents made use of the website (despite having a log-in ID to access the website outside of study participation), suggesting initial engagement (and completion of the brief e-intervention and receipt of text messages) is essential for promoting use of the website content. We do not know enough about this wider group of parents to draw conclusions. There is a need for more research to understand the processes that promote initial engagement in parenting-focused studies and use of parenting resources. Innovative strategies are needed to prompt initial engagement. For instance, providing parents' space to complete the initial e-intervention of the 5-a-Day Parenting program through services they already use may boost program use. This may look like parents doing the e-intervention at an orientation for childcare or while waiting at a pediatric office. Moreover, direct input from parents may lead to further modifying the program to make it more attractive and appealing to parents. Hansen et al [14] found that gathering suggestions and input from parents (eg, via qualitative methods, such as focus groups), particularly from underserved populations, leads to technology-based parenting programs with higher engagement/retention rates.

We failed to uncover any factors that affect accessing the video-based content on the 5-a-Day Parenting program website. On the basis of the qualitative work of Bernhardt and Felter [24] and Eysenbach and Kohler [25], we expected that program affiliation would affect program use. Specifically, we expected that parents who saw an explicit message about the program creators being experts with an academic/scientific background would be more likely to use the 5-a-Day Parenting program website. However, we found no support to indicate that program affiliation made an impact. Interestingly, Eysenbach and Kohler [25] did note that although people *say* having a scientific source of information is important, they also found that people rarely look for information on websites to investigate the background and training of those who created internet-based resources. This may suggest that program-affiliation may not be crucial in understanding actual use of information on the internet.

Of parents recruited through a Consortium childcare center (ie, face-to-face recruitment), 42% (20/48) used the 5-a-Day

Parenting program website; only 24% (11/46) recruited through the registry (ie, via text message) used the website. Although this difference did not reach statistical significance, results may have differed in a larger sample. Further investigation is needed regarding whether differences in recruitment approach (folder vs text) or context (childcare center vs registry) can influence engagement.

There was variability in how often parents reported performing the five parenting activities at baseline. Interestingly, reading was the least often reported activity with approximately half of parents reporting reading to their child less than 3 days in the week before project participation. This is surprising given the importance of book sharing and presence of initiatives to promote it in the preschool years [35]. Expressing affection was the most prevalent activity reported by parents with most parents reporting expressing affection 6 to 7 days in the previous week. Frequency of performing the parenting activities in the previous week was not predictive of using the 5-a-Day Parenting website. This may be because the program was designed to encourage all parents to use the website, even if they already performed the activities frequently. Specifically, for parents who reported regularly performing the activities already, the e-intervention recommended parents use the website to learn how to *make the most* out of the time spent performing the activities (eg, 1 video taught parents how to be responsive and cognitively stimulating in play).

We also did not find associations between cumulative sociocontextual risk and use of the 5-a-Day Parenting program website. Although a nonsignificant finding may be due to multiple factors (eg, low power because of small sample size), the results may also be encouraging. Families facing sociocontextual risk often face practical barriers, such as lack of transportation or childcare, which make participating in face-to-face parenting programs a challenge (see [15]). Web-based parenting programs may be a way for parents facing sociocontextual risk to access the same research-informed parenting information without the challenges of attending face-to-face parenting training. Results of the current investigation echo the findings of Baker et al [15] who reported that high- and low-risk parents are equally open to Web-based parenting resources. In the previous study [23], we also found high openness to internet-based parenting information in a low-income sample. Taken together, it does not appear areas of sociocontextual risk are barriers to online parenting program use. It may be that sociocontextual risk did not deter program use because the program is online and Smartphone ownership is high in this population [23], making the program accessible.

Limitations

There are a number of limitations in this study. First, a clear limitation is the small sample size of the project. Project budget and timeline limited the sample size. The small sample, coupled with the fact that recruitment took place in only 1 US city, limits generalizability of findings. Second, it is unclear why such a sizeable minority of parents (ie, approximately 25% (32/126) of those who started baseline participation did not complete it) initiated, but did not complete, baseline assessment (see Figure 1). Some parents reported technical difficulties in completing

the brief e-intervention, but these issues were immediately rectified. However, it is possible that some potential participants experienced technical difficulties but chose to discontinue participation rather than contacting project staff. Third, although parents were not compensated for using the 5-a-Day Parenting website, parents were compensated for baseline participation, which included going through the brief e-intervention and completing the follow-up assessment. Results may have differed without compensation. Finally, it is important to note this investigation does not document impact (ie, efficacy or effectiveness) of the 5-a-Day Parenting program; future investigations are needed to document if program use leads to positive changes in parenting and child outcomes.

Conclusions

In a general sample of parents who chose to participate in a research project, despite not seeking parenting assistance,

approximately one-third of parents made use of internet-based parenting content. Furthermore, those who did use the website rated the program as helpful. These are important findings suggesting that many nontreatment seeking parents may receive benefits through online programs. However, we failed to uncover factors that differentiate those who make use of a Web-based parenting resource and those who do not. Participating parents accepted text messages at a very high rate and viewed them favorably. However, most participants chose not to initially engage in the research project at all, and approximately 70% of those who did engage in the research project did not make use of the website. More research is needed to identify factors predictive of engagement in online parenting interventions, as well as techniques for promoting greater engagement.

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Conflicts of Interest

None declared.

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Abbreviations

ADHD: attention-deficit/hyperactivity disorder

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Tutorial

Voices in Evidence-Based Newborn Care: A How-to-Guide on Developing a Parent-Facing Podcast

Joanna Parga-Belinkie¹, MD; Raina M Merchant², MD

¹Children's Hospital of Philadelphia, Philadelphia, PA, United States

²University of Pennsylvania, Philadelphia, PA, United States

Corresponding Author:

Joanna Parga-Belinkie, MD

Children's Hospital of Philadelphia

3401 Civic Center Blvd

Division of Neonatology, 2NW35

Philadelphia, PA, 19104

United States

Phone: 1 5164268898

Email: jo.parga@gmail.com

Abstract

Podcasting is becoming a more popular form of media. Its use in medical education is being researched—but what about its use in public education? In this tutorial, the authors offer a how-to-guide on starting a public or patient-facing podcast. The authors hope to inspire more physicians to utilize this type of media to share evidence-based information. More research is needed looking into how podcasting can be used to help with patient education.

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KEYWORDS

neonatology; social media; medical education; patient education

Introduction

As a neonatologist and new parent, the birth of my daughter brought with it a search for the *right way* to raise my healthy newborn. Although well versed in infant pathology, I did not know the differences in pacifier brands, how to work a breast pump, or if there was an ergonomically superior baby carrier. Parenting took my pediatric training, mixed it with a chronic as opposed to episodic sleep deprivation, upset my understanding of practical knowledge in my field, and generally upended me. I know I am not alone in feeling this way. Being disoriented and distressed is common after delivery. Baby blues strike 80% of new parents [1]. If symptoms of sadness persist for 2 weeks, concerns for postpartum depression arise [2]. Postpartum depression affects an estimated 15% of new parents [2]. To ease my unrest, I searched for solid and easily available evidence-based parenting resources. Despite being educated about scientific studies and research, I found myself confused by infant care claims on the internet and social media.

I started to wonder how parents without a medical background were navigating the highly commercialized and often unevidenced world of modern parenting. After researching different forms of media, it became evident that podcasting was

gaining a growing listenership [3]. For the first time in history, more than half of the Americans (51%) have reported listening to podcasts, that is, 144 million people up from approximately 1.4 million a decade ago in 2009 [3]. However, within the podcasting landscape there were no prominent female physician voices leading medical education for pregnancy. I saw this as an opportunity to create something in this space. I looked to starting a podcast as a way to humanize my experiences in parenting and provide factual information and commentary on infant development, practices, and products when applicable. To accomplish this, I enlisted the help of another neonatologist to cohost the episodes, and began utilizing resources within my academic institution to help with podcast growth. This study is about how to start a medical podcast, and it outlines the successes and pitfalls my team has experienced as physician podcasters.

Reviewing the Parenting Podcast Landscape

Before starting a podcast, we looked at what was already available for parents regarding pregnancy and the first 3 to 4 months of an infant's life [4,5]. Although podcasts existed on parenting experiences and breastfeeding, there were none we could find by physicians dedicated to the postpartum period. For a lot of the podcasts, the hosts were not experts in infant

care and relied on recounting their personal experiences or bringing on experts for topic interviews. Physicians did host podcasts, but the majority were aimed at educating other clinicians as opposed to the public [6]. There was room for a podcast that allowed for medical providers to recount their clinical experiences to those in nonmedical professions. This would allow for the creation of a trusted voice for medical information that could be listened to outside of the doctor's office.

Preparing to Launch and Financial Considerations

Purveying medical information can be dry—a hosting format between 2 women who are both doctors and mothers was

devised to keep topics conversational, avoid monotony, and give different perspectives from providers within the field. Use of a pseudonym, in this case Baby Doctor Mamas, was also chosen. This would allow for various neonatologists, obstetricians, or gynecologists to act as hosts on the podcast. The hope was that this would ensure longevity and marketability of the podcast.

Launching the podcast required some startup capital that we paid out of pocket (Table 1).

Table 1. Startup costs for launch of the podcast Baby Doctor Mamas.

Item	Annual costs	Supplies/other services considered
Equipment	Approximately US \$2000-US \$3000; one-time fee	Basic supplies: recorder, 2 professional microphones
Website design and logo creation	Free, services offered by another neonatologist	Use of 99designs company
Jingle for Introduction	US \$46.55; Jamendo website, full rights to content	Use of freelance composers
Domain name	US \$12.17; GoDaddy website	None
Website hosting	US \$132.00; Wordpress website with Bluehost server space	Use of wordpress.com but ultimately used wordpress.org given better user rights
Podcast hosting	US \$89.00; Blubrry hosting service	Use of Libsyn or soundcloud services
Audio editing	US \$20-30 per hour	Self-editing with Audacity, freelance sound designer
Total startup costs	US \$198.72+ ongoing editing costs	Not applicable

Startup equipment included a Tascam recorder and Rode microphones. The recording space was a spare guest bedroom in one of the host's house, with pillow padding around the microphones to buffer sounds. For help with logo creation and website development [7], another neonatologist, Dr Juanita Lewis, volunteered her services. Website development required purchase of a domain name and server space. A platform for hosting the podcast was also required, and Blubrry [8] was chosen for cost and statistical capabilities.

We wanted the podcast to sound professional as audio quality is an important metric for listener engagement. Instead of purchasing equipment for audio editing, we hired an audio editor who charged an hourly fee for edits. When launching, we decided on a regular schedule of once weekly release of the podcast to allow for predictability and growth—that way our listeners knew when to expect episode releases to follow them. We also had 4 episodes prerecorded before our launch, releasing 2 at once and allowing the other 2 to be released in the coming weeks. This allowed for varied content at the outset of the podcast, for effective time management, and for us to be prepared for future episodes.

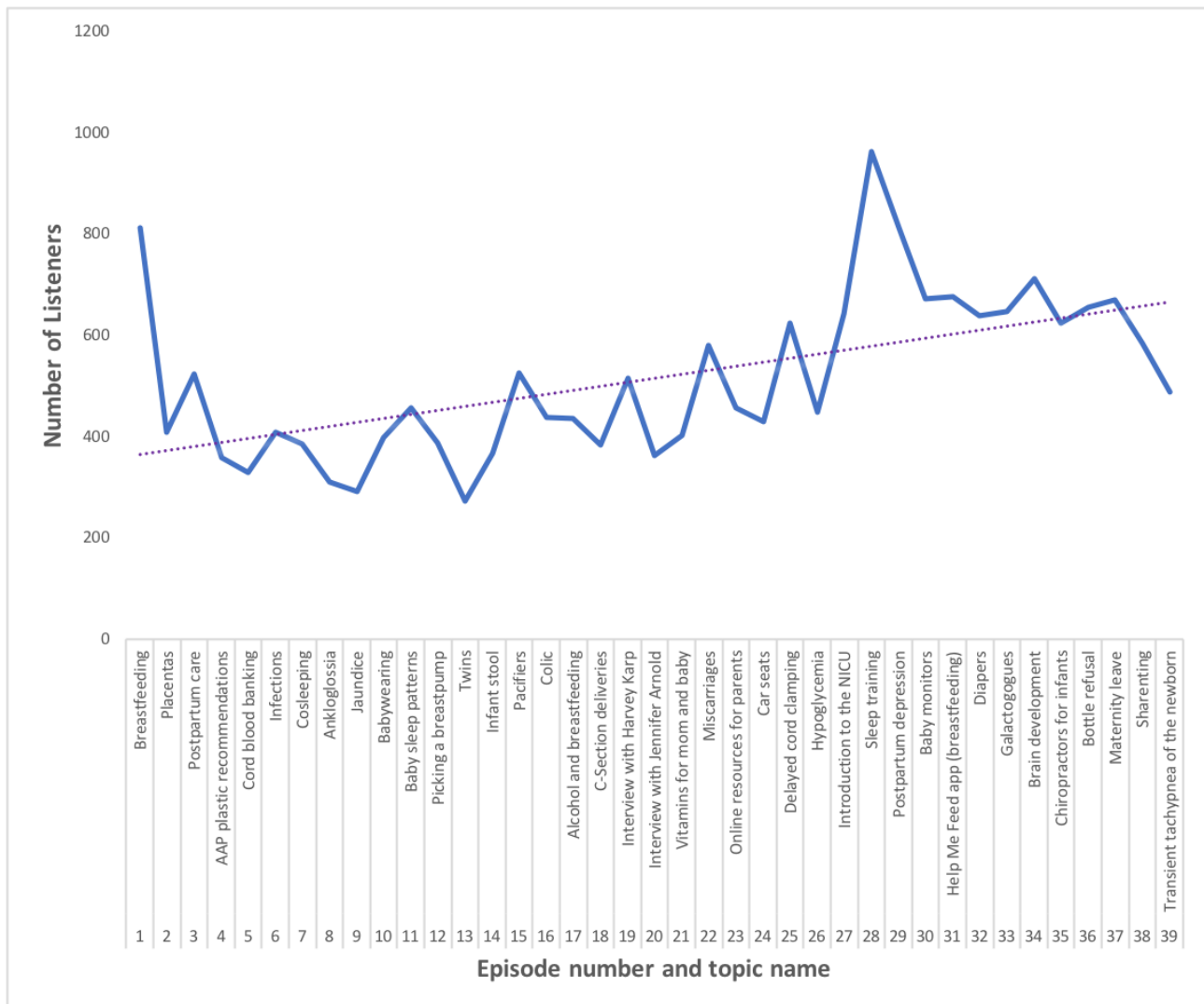
Use of Multiple Podcast Platforms and Social Media Engines for Promotion

To enhance use, we utilized several platforms and launched simultaneously on all of them to allow for listeners to find the episodes easily. Baby Doctor Mama podcasts are found on Apple iTunes, Spotify, Stitcher, iheartradio, and Soundcloud. Promotion of the podcast was done almost exclusively on Web-based social media platforms such as Instagram, Twitter, and Facebook, all under the name Baby Doctor Mamas. Posting on these platforms occurred before launch, and the accounts were all public facing to allow for feedback and discovery. The only other promotional move made was to launch the podcast during a national conference for pediatrics. Flyers were printed and distributed at this conference to gain listenership.

Thoughts on Expansion and Audience Reach

Initial episodes of the podcast engaged 200 to 400 listeners, and this has steadily grown to anywhere from 450 to more than 800 listeners per episode, with a maximum of 958 listeners on a sleep training episode (see Figure 1).

Figure 1. The number of listeners per episode of the Baby Doctor Mamas podcast from October 29, 2018, to September 1, 2019. The graph shows an increase in listeners over time and reviews the topics discussed in each episode. The blue solid line represents the number of listeners for each topic over time. The purple dotted line represents the mean number of listeners over time for all episodes. AAP: American Academy of Pediatrics; NICU: Neonatal Intensive Care Unit.



In less than 1 year, we have 719 followers on Instagram, 494 on Facebook, and 97 on Twitter. Tactics that have worked to increase social media following and downloads of the podcast/listens per episode include the following: having an expert or celebrity on infant topics (ie, Dr Harvey Karp or Dr Jennifer Arnold), interviewing an Instagram influencer with tens of thousands of followers and having them post on social media regarding the episode (ie, Dr Danielle Jones aka Mama Doctor Jones @mamadoctorjones with 55.5K followers on Instagram), and linking in an expert with a high twitter following and ability to promote through a department within the hospital (ie, Dr Ariel Williamson on sleep training who posted about the episode through the Health Policy Lab at the Children’s Hospital of Philadelphia).

Conclusions

As medical podcasters and mothers, our goals are to disseminate evidence-based medicine and provide entertaining and accessible content to listeners. Although there has been steady growth of the Baby Doctor Mama podcast through social media promotion, there is still room to grow. Eventually, working in conjunction with an academic university for podcast promotion and listenership may be a key strategy for the growth and expansion of listenership to more patients/parents. Marketing the podcast differently with a focus on creating a media packet is also an option. More research is needed into how patients/parents are utilizing podcasts for medical information.

Conflicts of Interest

None declared.

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Original Paper

Acceptability of Robotic-Assisted Exercise Coaching Among Diverse Youth: Pilot Study

Amelia K Barwise^{1,2}, MB BCh BAO, MS; Christi A Patten³, PhD; Martha J Bock³, BS; Christine A Hughes³, BS; Tabetha A Brockman⁴, MA; Miguel A Valdez Soto⁵, BA; Chung-Il Wi⁶, MD; Young J Juhn⁶, MD, MPH; Daniel R Witt⁷, BS; Stephen Sinicrope³; Samantha R Kreps^{8,9}; Henry D Saling¹⁰; James A Levine^{11,12}, MD, PhD; Joyce E Balls-Berry¹³, MPE, PhD

¹Clinical and Translational Science PhD Program, Mayo Clinic Graduate School of Biomedical Sciences, Mayo Clinic, Rochester, MN, United States

²Pulmonary and Critical Care Medicine, Mayo Clinic, Rochester, MN, United States

³Department of Psychiatry and Psychology, Behavioral Health Research Program, Minnesota BioBusiness Center, Mayo Clinic, Rochester, MN, United States

⁴Center for Clinical and Translational Science, Community Engagement Program, Department of Psychiatry and Psychology, Minnesota BioBusiness Center, Mayo Clinic, Rochester, MN, United States

⁵Center for Clinical and Translational Science, Community Engagement Program, Mayo Clinic, Rochester, MN, United States

⁶Asthma Epidemiology Research Unit and Community Pediatric and Adolescent Medicine, Mayo Clinic, Rochester, MN, United States

⁷Mayo Clinic Alix School of Medicine, Mayo Clinic, Rochester, MN, United States

⁸Health Sciences, University of Minnesota, Rochester, MN, United States

⁹Center for Clinical and Translational Science, Community Engagement Program, Minnesota BioBusiness Center, Mayo Clinic, Rochester, MN, United States

¹⁰Department of Laboratory Medicine and Pathology, Mayo Clinic, Rochester, MN, United States

¹¹Fondation Ipsen, Paris, France

¹²Division of Endocrinology, Department of Medicine, Case Western Reserve University, Cleveland, OH, United States

¹³Division of Epidemiology, Department of Health Sciences Research, Mayo Clinic College of Medicine and Science, Mayo Clinic, Rochester, MN, United States

Corresponding Author:

Amelia K Barwise, MB BCh BAO, MS
Clinical and Translational Science PhD Program
Mayo Clinic Graduate School of Biomedical Sciences
Mayo Clinic
200 First Street SW
Rochester, MN, 55902
United States
Phone: 1 5072559007
Email: barwise.amelia@Mayo.edu

Abstract

Background: Almost 80% of adolescents do not achieve 60 minutes or more of physical activity each day as recommended by current US national guidelines. There is a need to develop and promote interventions that increase physical activity among adolescents. With increased interest in digital technologies among adolescents, robotic-assisted platforms are a novel and engaging strategy to deliver physical activity interventions.

Objective: This study sought to assess the potential acceptability of robotic-assisted exercise coaching among diverse youth and to explore demographic factors associated with acceptance.

Methods: This pilot study used a cross-sectional survey design. We recruited adolescents aged 12-17 years at three community-based sites in Rochester, MN. Written informed consent was obtained from participants' parents or guardians and participants gave consent. Participants watched a brief demonstration of the robotic system-human interface (ie, robotic human trainer). The exercise coaching was delivered in real time via an iPad tablet placed atop a mobile robotic wheel base and controlled remotely by the coach using an iOS device or computer. Following the demonstration, participants completed a 28-item survey that assessed sociodemographic information, smoking and depression history, weight, and exercise habits; the survey also included

the eight-item Technology Acceptance Scale (TAS), a validated instrument used to assess perceived usefulness and ease of use of new technologies.

Results: A total of 190 adolescents participated in this study. Of the participants, 54.5% were (103/189) male, 42.6% (81/190) were racial minorities, 5.8% (11/190) were Hispanic, and 28.4% (54/190) lived in a lower-income community. Their mean age was 15.0 years (SD 2.0). A total of 24.7% (47/190) of participants met national recommendations for physical activity. Their mean body mass index (BMI) was 21.8 kg/m² (SD 4.0). Of note, 18.4% (35/190) experienced depression now or in the past. The mean TAS total score was 32.8 (SD 7.8) out of a possible score of 40, indicating high potential receptivity to the technology. No significant associations were detected between TAS score and gender, age, racial minority status, participant neighborhood, BMI, meeting national recommendations for physical activity levels, or depression history ($P > .05$ for all). Of interest, 67.8% (129/190) of participants agreed that they and their friends were likely to use the robot to help them exercise.

Conclusions: This preliminary study found that among a racially and socioeconomically diverse group of adolescents, robotic-assisted exercise coaching is likely acceptable. The finding that all demographic groups represented had similarly high receptivity to the robotic human exercise trainer is encouraging for ultimate considerations of intervention scalability and reach among diverse adolescent populations. Next steps will be to evaluate consumer preferences for robotic-assisted exercise coaching (eg, location, duration, supervised or structured, choice of exercise, and/or lifestyle activity focus), develop the treatment protocol, and evaluate feasibility and consumer uptake of the intervention among diverse youth.

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KEYWORDS

robotics; adolescents; exercise; coaching; physical activity; technology

Introduction

Engaging in regular physical activity is effective for reducing the risk of obesity and mitigating its negative impacts on health [1]. Routine physical activity is crucial for healthy growth and development and for establishing lifelong routines that promote health and well-being. Engaging in regular physical activity benefits cardiorespiratory fitness, promotes growth of strong bones, reduces anxiety and depressive symptoms, improves mental health, and help teens maintain a healthy weight [2,3].

The 2008 US Physical Activity Guidelines for Americans [4] recommends children and adolescents aged 6-17 years engage in at least one hour or more of physical activity daily, a goal that 79% of adolescents do not achieve [5]. Furthermore, as youth grow into adults, the proportion of those not meeting these guidelines increases [6-8]. Therefore, there is a need to develop methods and strategies to promote physical activity among adolescents [7].

Some work has been done to examine the role of technology to improve lifestyle habits among adolescents. A systematic review by Chen et al examined the efficacy of technology-based interventions for healthy weight management in adolescents, including interactive video gaming, tailored Web-based health information, and the use of Wii Fit (Nintendo) [9]. Overall, this review found increased physical activity and weight loss in the intervention groups. Lau et al's systematic review of information and communication technology-based interventions for promoting physical activity behavior change in children and adolescents included studies examining the effect of the Internet, email, and short message service (SMS) text messaging as assistive modes to deliver interventions. This review found evidence to support the use of information and communication-based interventions for increasing physical activity among youth [10]. Limitations of included studies in these reviews were lack of long-term follow-up and limited

measurement of intervention exposure (ie, engagement with interventions) [9,10]. A more recent systematic review found that SMS text messaging may increase physical activity, but specifics about effective intervention elements were inconclusive [11]. Among Hispanic and black youth, active video gaming was shown to be a potentially useful mechanism to increase physical activity [12]. Among adults, digital health coaching delivered through the Web or mobile phones (eg, texting or apps) is also effective for enhancing physical activity [13].

Robotic-assisted technologies are emerging, but their full potential to enhance lifestyle behavior has yet to be realized and some have expressed concerns about their limitations in specific scenarios [14,15]. Many of these technologies emulate, but do not include, the support and empathy of a live coach and this may be disquieting [16]. For example, a recent study utilizing a fully automated robot for motivational interviewing to increase physical activity found that while participants appreciated the novelty and nonjudgmental nature of the technology, their experience was limited by the lack of individualized responses from, or social interactions with, the robot [17].

Based on the literature, combining the components of digital technology with human interactions may be a useful approach. Delivering exercise interventions through a mobile robotic device is better than videoconferencing because it allows the coach to remotely move with and around the individual, providing instruction and correction of exercise form, reinforcement, and support. Robotic-assisted interventions, where the coach interacts in real time, could therefore bridge the gap between human and embodied support [18,19].

The objectives of this pilot study were to assess the potential acceptability of robotic exercise coaching among a sample of racially and socioeconomically diverse youth and explore demographic factors and other variables associated with acceptance.

Methods

Study Approval and Design

The study was approved by the Mayo Clinic Institutional Review Board. The study used a cross-sectional survey design.

Recruitment and Participants

We displayed posters and ads in select community locations in Rochester, MN, and on websites and conducted face-to-face outreach between March 5 and June 11, 2018. We recruited a convenience sample of adolescents from three community settings that serve racially and socioeconomically diverse youth and offer programs after school and on weekends. Study team members consulted with the staff at each community-based organization to determine appropriate times for recruitment and data collection. Recruitment took place four times at the Rochester Public Library and three times at the YMCA, each lasting about three hours; a local church also hosted one recruitment event.

Study staff screened adolescents in person to determine their potential to participate based on the study eligibility criteria: (1) aged 12-17 years old and (2) possessing a completed written

informed consent and assent document, signed by the parent or guardian and participant. Exclusion criteria were being older than 17 years old and younger than 12 years old. We did not track the number of adolescents who received consent forms but did not complete them.

Materials

The robotic system-human interface technology was used as a robotic-assisted exercise coach. The interface was delivered in real time via an iPad tablet placed on a mobile robotic wheel base and controlled remotely by an iOS device or computer. Developed by Double Robotics, Inc, for telecommuting and school attendance, the device measures 5 feet 1 inch in length. The “robot” iPad interface (see [Figure 1](#)) and the mobile phone device used to control it both required installation of the Double app (Double Robotics) [20,21].

Wi-Fi access on both devices was necessary to ensure functionality, which was available in each of the three community settings where the robot was demonstrated. A study staff member was designated as the exercise coach; she logged into the Double app through her mobile phone device and remotely interfaced with the iPad robot for demonstration purposes.

Figure 1. Robotic human-trainer technology.



Procedures

Prior to recruitment events, possible participants were identified at each setting by community and study staff, who gave a brief overview of the study to assess interest in participating. Those interested were asked to return the assent and consent forms, signed by the participant and his or her parent or guardian, on the day of recruitment. For some participants, these procedures all occurred on the same day. Once consent was obtained by study staff, participants observed the demonstration in a group setting in a private room with 7-10 other adolescents. The demonstration consisted of a 3-5-minute session during which a study team member played the role of the exercise coach.

The coach followed a script, included in [Textbox 1](#) below, adapted from a prior study that assessed the acceptability of a robotic human trainer among diverse adults [22]. The script and anticipated intervention is based on social cognitive theory, including a focus on social support, reinforcement, and enhancing self-efficacy by providing feedback from the coach, along with emphasizing benefits of, and reducing barriers to, exercise [23]. The trainer began with a brief introduction of herself, a discussion about the benefits of exercise, and an explanation about the potential role of a robotic trainer, followed by a demonstration of the robotic trainer in motion and performing maneuvers. The script did not focus on a specific type of exercise or physical activity.

Textbox 1. Exercise coach script.

Hi my name is ____ (coach). It's nice to see you (all of you)!

As a robotic trainer, my role is to help people to exercise more, but I also focus my time on them and how they are doing. My role is to support and encourage people even while they are exercising. I try to bring positive energy to the exercise sessions and help them see all of the important progress they are making, even when it is tough going at times.

Let's talk about some of the benefits of exercise for *you*. What is important to you?

That's good! Anything else you have noticed? (if not already mentioned): Some people also say that exercise gives you:

- More energy
- Better sleep
- A sense of accomplishment or achievement
- A way to have fun
- A way to spend time with my friends
- A way to stay healthy
- A way to stop cravings for sugar

Great, keep these benefits in mind *every time* you exercise or when you are starting to think about beginning to exercise.

That's all for today.

Thanks for stopping by, and I look forward to seeing you again.

Following the demonstration, participants were given the survey, which took about 5-10 minutes to complete. Study staff then briefly reviewed the survey for possible unanswered items and placed it in a collection box. Participants received a US \$25 gift card as remuneration for their time.

Measures

The four-page survey included 28 items and did not collect any identifying personal information. Survey items assessed selected sociodemographic characteristics: zip code, age, biological sex, current grade level, and self-reported height and weight. We assessed cigarette smoking and depression history because of the inverse association shown with these variables and physical activity [24-26]. Our depression and lifetime smoking status questions were developed for this study but were similar to other validated single-item measures [27,28]. Participants were asked about their smoking history (ie, "Have you ever tried cigarette smoking, even one or two puffs?") and depression history (ie, "Have you ever experienced depression now or in the past?"); each item had a *yes* or *no* response option. Exercise habits were assessed with the following question: "During the past seven days, on how many days were you physically active for at least 60 minutes per day? (Add up all the time you spent in any kind of physical activity that increased your heart rate and made you breathe hard some of the time)," to which they indicated 0-7 days [29].

Body mass index (BMI) was calculated for each participant using self-reported height and weight. Estimated household income was generated from the 2016 US American Community Survey by zip code (ie, postal code) [30,31]. Based on the sample distribution, household income was categorized into three categories: low, medium, or high.

The survey also included the eight-item, validated Technology Acceptance Scale (TAS). The TAS comes from the Davis Technology Acceptance Model [32-34]. Items assess (1)

perceived usefulness and (2) perceived ease of use of new technologies. Each item was rated on a 5-point Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Two items on the scale were reverse scored. Total possible scores ranged from 8 to 40, with higher scores indicating greater potential acceptance of the robotic trainer technology. For the current sample, Cronbach alpha was .70, suggesting relatively high internal consistency reliability.

Four additional questions assessed general reactions to robots, likelihood for using this technology for health promotion purposes, and reasons for engaging in physical activity. Participants were asked the following: "Do you think you and your friends are likely to use the robot to help you exercise?" and "Do you think there is a need for a robotic human trainer to help kids exercise?"; response options to each item were *yes* or *no*. In addition, adolescents were asked the following: "Where would you be most likely to use the robotic trainer?"; response options were *at school*, *local gym*, and *after-school program*, as well as *other*, in which participants could write in their response. Furthermore, adolescents were provided a list of four reasons why they might engage in physical activity and were asked to rank order each reason from most to least important (1-4): *to get or stay healthy*, *sports training*, *to have fun with friends*, and *to lose weight*.

Statistical Analyses

SPSS Statistics for Windows (IBM Corp) was used to analyze the data; the data were summarized using univariate and bivariate statistics. Acceptance ratings—TAS individual items and total score—were summarized for the overall sample using descriptive statistics. The association of TAS total score with sociodemographic characteristics was examined using *t* tests for dichotomous variables of age group (12-14 versus 15-17 years), sex (male or female), racial minority status (yes or no), meeting physical activity national recommendations (yes or

no), and depression history (yes or no). One-way analysis of variance (ANOVA) was used to examine the association of total TAS score with BMI, categorized as underweight, normal, or overweight, and estimated household income status, categorized as low, medium, or high. *P* values of .05 or less were used to denote statistical significance.

Results

Participant Sociodemographic Characteristics

Table 1 shows the sociodemographic characteristics of the 190 youth who participated in the study. Among them, 45.5%

(86/189) were female (one person did not answer the question on sex), 56.8% (108/190) were white, and 36.8% (70/190) were African American or black. A total of 5.8% (11/190) of the sample reported Hispanic ethnicity. Approximately half of respondents (94/190, 49.5%) were between the ages of 12 and 14 years. Low-income household status was estimated for 28.4% (54/190) of the sample. Only about one-quarter (47/190, 24.7%) of participants met national recommendations for physical activity. The mean BMI was 21.8 kg/m² (SD 4.0), 19.5% (37/190) of respondents were classified as overweight, and 18.4% (35/190) had experienced depression now or in the past. Very few reported they had ever tried cigarette smoking.

Table 1. Sociodemographic characteristics of adolescent survey participants (N=190).

Characteristic	Value
Biological sex (N=189)^b, n (%)	
Male	103 (54.5)
Female	86 (45.5)
Race, n (%)	
White	108 (56.8)
Black or African American	70 (36.8)
Asian	6 (3.2)
American Indian or Alaska Native	3 (1.6)
Native Hawaiian or other Pacific Islander	2 (1.1)
Ethnicity (Hispanic or Latino), n (%)	11 (5.8)
Household income category^c, n (%)	
Low (<US \$58,056)	54 (28.4)
Medium (US \$58,056-US \$70,145)	65 (34.2)
High (>US \$70,145)	71 (37.4)
Age group, n (%)	
12-14 years	94 (49.5)
15-17 years	96 (50.5)
Grade levels, n (%)	
Middle school	73 (38.4)
High school	117 (61.6)
Ever tried a cigarette (yes), n (%)	5 (2.6)
Experienced depression now or in the past (yes), n (%)	35 (18.4)
Meets national recommendations for physical activity (yes), n (%)	47 (24.7)
Body mass index (kg/m²)	
Mean (SD)	21.8 (4.0)
Range	14.4-37.6
Percent overweight, n (%)	37 (19.5)

^aPercentages are based on nonmissing data.

^bOne person did not answer the question on sex.

^cMedian household income in the United States and Rochester, MN, in 2016 was US \$59,039 and US \$65,195, respectively.

Technology Acceptance Scale

Table 2 shows the mean and total TAS scores. The mean total score was a 32.8 (SD 4.2, range 12-40) out of a possible score of 40, indicating high technology acceptance. No statistically significant associations were found between TAS total score and participant sex, age group, racial minority status, participant-estimated neighborhood household income, meeting physical activity recommendations, BMI, or depression history ($P > .05$ for all).

We found that 67.8% (129/190) of participants agreed that they and their friends would be likely to use the robot to help them

exercise; 77.8% (148/190) agreed that there is a need for a robotic human trainer to help kids exercise. When participants were asked where they think they would most likely use the robotic trainer, 71.1% (135/190) indicated a local gym such as the YMCA, 40.0% (76/190) reported in a school setting, and 46.8% (89/190) indicated at an after-school program; 71.1% (135/190) suggested *other* locations, all of whom wrote "at home." When given a list of four reasons about why they engage in physical activity, 42.1% (80/190) of respondents reported that *to get or stay healthy* was the most important reason and 46.8% (89/190) indicated that *to lose weight* was the least important reason.

Table 2. Technology Acceptance Scale items and total scores^a (N=190).

Item	Score, mean (SD) ^b
1. The robot trainer was clear and easy to understand.	4.29 (0.83)
2. I would find it easy to ask the robot trainer something.	4.32 (0.85)
3. It would take a lot of effort to interact with the robot trainer.	3.52 (1.22)
4. I would feel confident interacting with the robot trainer.	4.22 (0.91)
5. I would find it easy to interact with the robot trainer.	4.17 (0.94)
6. The robot trainer could help to encourage me to exercise.	4.12 (0.94)
7. I would find it frustrating to interact with the robot trainer.	3.97 (1.18)
8. The robot trainer could be helpful for me when exercising.	4.19 (0.89)
Total score, mean (SD)	32.8 (7.8)
Total score, range	12-40

^aAll Items were rated on a 5-point Likert scale that ranged from 1 (*strongly disagree*) to 5 (*strongly agree*). Items 3 and 7 were reverse scored so that a higher score indicated less effort (item 3) or less frustration (item 7). The total score has a possible range between 8 and 40, with higher scores indicating greater acceptability of the robot technology.

^bAll eight items have an observed range of 1-5.

Discussion

This preliminary study found that among a group of racially and socioeconomically diverse adolescents, potential receptivity to a human robotic-assisted trainer for delivering physical activity coaching was high, as evidenced by a mean score of 32.8 (SD 7.8) on the TAS. A previous study by our group found that the same robotic human-trainer technology was considered novel and acceptable as a potential tool for supervised exercise coaching among an adult population [22]. However, little is known about the feasibility and consumer uptake of such an approach among adolescents, a group that may benefit greatly from interventions aimed at increasing physical activity levels. Like other studies, only about a quarter of adolescents in our sample met national recommendations for physical activity [4]. We are encouraged by the finding that all sociodemographic groups represented in our sample endorsed similarly high potential receptivity to the robotic technology for ultimate considerations of intervention scalability and reach among minority adolescent populations, where the prevalence of obesity is highest.

This study has several strengths, including the conceptual framework, the use of a valid and reliable measure of technology acceptance, successful recruitment in multiple community

settings serving minority adolescent populations, and a racially and socioeconomically diverse sample with equal representation from both boys and girls.

Limitations of this study include the use of a convenience sample. Some sample characteristics, such as low prevalence of cigarette smoking, may limit generalizability of the findings to other settings and populations. We did not specifically ask about the use of alternatives to cigarette smoking, including e-cigarettes, hookahs, or vaping, whose use may have been more prevalent [35]. To reduce participant burden, we used self-reported data about height and weight, but these data may be unreliable. Although reasonable for a pilot study, the sample size was insufficient for conducting multivariate analyses on the association of participant characteristics and TAS score; thus, findings are exploratory. Furthermore, we assessed acceptability using a brief, mock introductory coaching session and did not measure acceptability while delivering a specific exercise intervention. It is possible that the robotic trainer will not translate into an acceptable, effective, or useful mode of engaging adolescents in physical activity.

Many studies examined the effects of school-based interventions to promote exercise, but community-engaged interventions have yet to demonstrate effectiveness [36]. As schools place less emphasis on physical activity during the school day, delivering

appropriate alternative exercise opportunities is important [37]. Given the increased connectivity with digital technologies among adolescents, such platforms are important to consider for delivering effective interventions that have already been shown to improve chronic disease parameters and adherence to physical activity regimens [38,39]. Evidence suggests that adolescents perform online searches about nutrition and fitness and download apps centered on these subjects more than any other group, indicating an interest in this topic among youth [40].

In contrast to digital health coaching through Web and mobile phone apps, robotic-assisted exercise coaching provides both dialogue support and primary task support in real time [41,42]. Moreover, the current prototype is different than Skype or videoconferencing intervention delivery formats because the robot device can move with and around the participant, providing instruction and correction of exercise form, reinforcement, and support, and the participant can remain hands-free [43].

This pilot study was the first step in determining likely acceptability of robotic-assisted exercise coaching among an adolescent population [9,10,44,45]. The high acceptability of the robotic-assisted trainer in our sample of adolescents suggests several next steps. Future research is needed to evaluate

adolescent consumer preferences for robotic-assisted exercise coaching (eg, location, duration, supervised or structured, choice of exercise, and/or lifestyle activity focus), develop a social-cognitive-based intervention protocol, and evaluate feasibility and consumer uptake of the intervention among diverse youth.

With the prevalence of obesity among minority adolescents, combined with a lack of access to exercise facilities or appropriate guided exercise, robotic trainers may be one potentially valuable tool for helping to increase physical activity in these vulnerable populations [46-48]. Because the technology requires reliable Internet or wireless access, the robotic human trainer poses a unique challenge; however, when functioning properly, it has high scalability and a large potential to reach many people. In the future, it is worth exploring this approach to reach underserved populations in the context of conditions associated with poverty and health disparities, including diabetes and other chronic illnesses that may improve with behavioral modifications [47].

With the benefits of exercise well-documented for both mental and physical health, the growing obesity epidemic in youth, and youth preferences for technology, a human robotic trainer could prove a welcome and feasible strategy for promoting and delivering healthy exercise habits to adolescents.

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Conflicts of Interest

None declared.

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Abbreviations

- ANOVA:** one-way analysis of variance
BMI: body mass index
SMS: short message service
TAS: Technology Acceptance Scale
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Review

Electronic Health Interventions for Preventing and Treating Negative Psychological Sequelae Resulting From Pediatric Medical Conditions: Systematic Review

Ashley Brook McGar¹, BA; Christine Kindler¹, MA; Meghan Marsac^{1,2}, PhD

¹Kentucky Children's Hospital, University of Kentucky, Lexington, KY, United States

²College of Medicine, University of Kentucky, Lexington, KY, United States

Corresponding Author:

Meghan Marsac, PhD
Kentucky Children's Hospital
University of Kentucky
Lexington, KY
United States
Phone: 1 (859) 323 3850
Email: meghan.marsac@uky.edu

Abstract

Background: Pediatric medical conditions have the potential to result in challenging psychological symptoms (eg, anxiety, depression, and posttraumatic stress symptoms [PTSS]) and impaired health-related quality of life in youth. Thus, effective and accessible interventions are needed to prevent and treat psychological sequelae associated with pediatric medical conditions. Electronic health (eHealth) interventions may help to meet this need, with the capacity to reach more children and families than in-person interventions. Many of these interventions are in their infancy, and we do not yet know what key components contribute to successful eHealth interventions.

Objective: The primary objective of this study was to conduct a systematic review to summarize current evidence on the efficacy of eHealth interventions designed to prevent or treat psychological sequelae in youth with medical conditions.

Methods: MEDLINE (PubMed) and PsycINFO databases were searched for studies published between January 1, 1998, and March 1, 2019, using predefined search terms. A total of 2 authors independently reviewed titles and abstracts of search results to determine which studies were eligible for full-text review. Reference lists of studies meeting eligibility criteria were reviewed. If the title of a reference suggested that it might be relevant for this review, the full manuscript was reviewed for inclusion. Inclusion criteria required that eligible studies (1) had conducted empirical research on the efficacy of a Web-based intervention for youth with a medical condition, (2) had included a randomized trial as part of the study method, (3) had assessed the outcomes of psychological sequelae (ie, PTSS, anxiety, depression, internalizing symptoms, or quality of life) in youth (aged 0-18 years), their caregivers, or both, (4) had included assessments at 2 or more time points, and (5) were available in English language.

Results: A total of 1512 studies were reviewed for inclusion based on their title and abstracts; 39 articles qualified for full-text review. Moreover, 22 studies met inclusion criteria for the systematic review. Of the 22 included studies, 13 reported results indicating that eHealth interventions significantly improved at least one component of psychological sequelae in participants. Common characteristics among interventions that showed an effect included content on problem solving, education, communication, and behavior management. Studies most commonly reported on child and caregiver depression, followed by child PTSS and caregiver anxiety.

Conclusions: Previous research is mixed but suggests that eHealth interventions may be helpful in alleviating or preventing problematic psychological sequelae in youth with medical conditions and their caregivers. Additional research is needed to advance understanding of the most powerful intervention components and to determine when and how to best disseminate eHealth interventions, with the goal of extending the current reach of psychological interventions.

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KEYWORDS

telemedicine; children; caregivers; injury; chronic disease; wounds and injuries; depression; anxiety

Introduction

Background

An estimated 6 million children are admitted to hospitals annually in the United States, often under life-threatening circumstances [1]. In addition to the physical impact of pediatric injuries and illnesses, consequences of pediatric medical conditions can often include negative psychological sequelae such as posttraumatic stress symptoms (PTSS), anxiety, depression, and impaired health-related quality of life (HRQoL) for both patients and their caregivers [2-5]. Web-based or electronic health (eHealth) interventions have the potential to mitigate these effects and to extend the reach of in-person interventions [6,7].

Psychological outcomes for acute and chronic conditions are similar [8]. For both acute (eg, burns and traumatic brain injury [TBI]) and chronic medical conditions (eg, atopic dermatitis, chronic pain, cancer, and diabetes), youth and caregivers are at risk for developing significant psychological symptoms and impairment in HRQoL, which have been associated with negative health outcomes. Approximately 30% of children with an injury or illness develop significant PTSS [8]. PTSS post injury is linked to depression, poor health outcomes, and impaired HRQoL [9]. PTSS have been associated with impaired HRQoL and subsequent health problems in youth [10]. In addition, increased anxiety before surgery has been associated with poorer health outcomes and worse postoperative recovery [11]. Similarly, children with chronic conditions, such as cancer, may experience distressing emotional reactions and lower quality of life (QoL), sometimes for years after the completion of treatment [12-14]. Thus, developing effective interventions to address these symptoms and challenges is essential for promoting full recovery (ie, physical and emotional) in youth with medical conditions.

A number of interventions currently exist to promote emotional recovery and adaptation in youth experiencing medical conditions, including education-based interventions, behavioral therapy, cognitive behavioral therapy (CBT), problem-solving therapy (PST), family therapy, multisystemic therapy, and systemic treatment [15-17]. However, limited access to psychologists, high costs of therapy, and difficulty accessing resources because of location (eg, rural areas) are all factors that can play a role in preventing many children from obtaining these treatments [17,18]. eHealth interventions may provide an avenue to distribute evidence-based strategies and treatments to children and families that may not otherwise have access to emotional health resources. Efforts are underway to translate current evidence-based in-person interventions to eHealth platforms.

Multiple reviews have been conducted to examine the use of eHealth interventions to improve health outcomes in children, suggesting promising results for this technology [19-22]. In examining emotional health outcomes, a recent review by Canter et al [23] summarized current evidence for technology-delivered interventions in improving family-centered outcomes (eg, communication, problem solving, and caregiver-child relationship) for children with chronic medical conditions.

Objectives

Results suggested that although eHealth interventions are generally effective at reducing family conflict, the findings for other family-centered outcomes varied [23]. This review expands upon the findings of the study by Canter et al [23], examining specific individual emotional health outcomes of children and caregivers. Other reviews have examined the impact of eHealth interventions on physical and dietary changes, behavior change, and various health conditions such as asthma but have generally focused on a single medical condition and often only assessed QoL outcomes [19-22]. To our knowledge, no other reviews to date have examined the use of eHealth interventions on psychological outcomes across both acute and chronic pediatric medical conditions.

eHealth interventions can be cost-effective and easily accessible, but their initial development and maintenance can be costly. Without evaluation, it is unknown whether evidence-based, effective interventions are able to maintain their effect when they are translated or adapted for eHealth platforms. Many eHealth interventions are in the early stages of development and have shown promising early results on their efficacy. We conducted this systematic review with the goals of (1) summarizing the state of the field for eHealth interventions that are designed to prevent or treat negative psychological sequelae (ie, anxiety, depression, PTSS, and HRQoL) resulting from pediatric medical conditions and (2) providing recommendations toward future development of eHealth interventions.

Methods

Literature Search Strategy

The following databases were searched for all studies conducted between January 1, 1998, and March 1, 2019: MEDLINE (PubMed) and PsycINFO. The search terms used are as follows: “medical trauma,” “medical event,” “medical condition,” “medical procedures,” “illness,” “injury,” “web-based,” “mobile,” “e-Health,” “internet,” “telehealth,” “mHealth,” “text,” “application,” “posttraumatic stress symptoms,” “PTSD,” “PTSS,” “posttraumatic stress disorder,” “quality of life,” “anxiety,” “depression”, “psychological sequelae,” “intervention,” and “prevention.” Reference lists were reviewed for all studies meeting eligibility criteria. If the title in a reference list suggested that it could be relevant for this review, the full manuscript was reviewed.

Inclusion and Exclusion Criteria

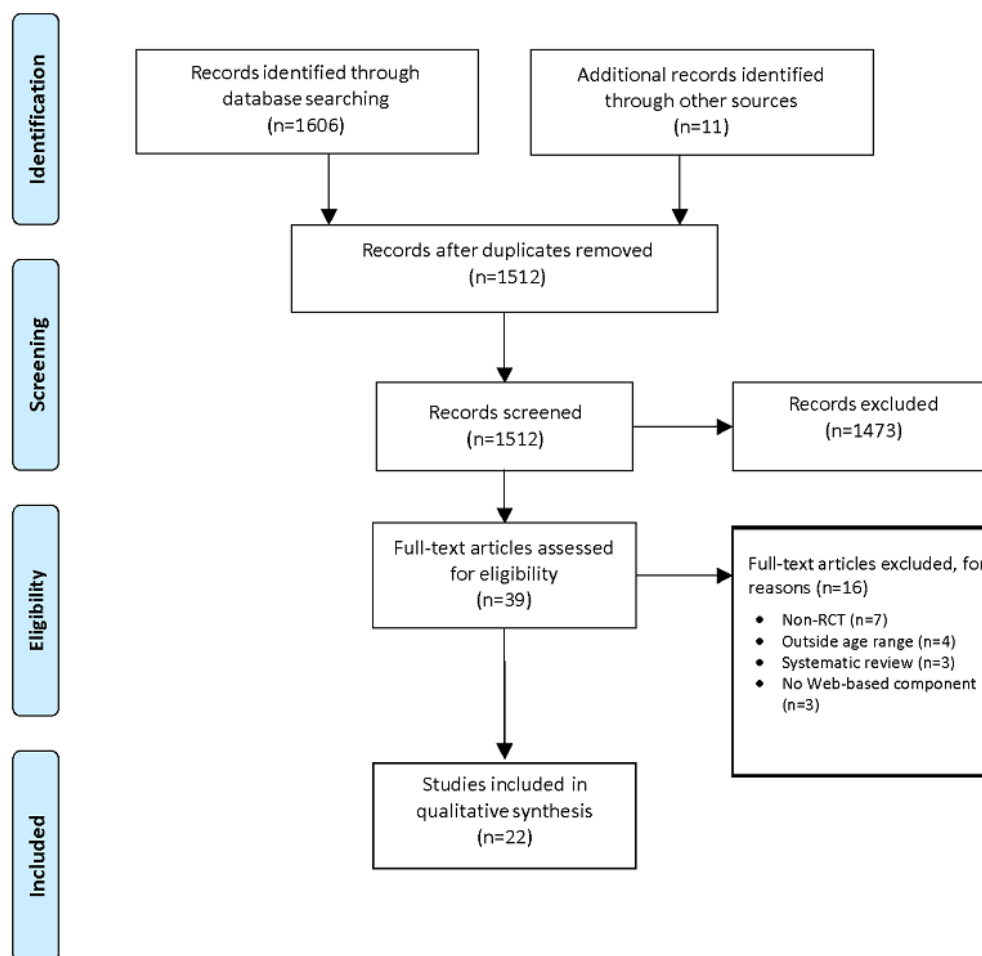
Eligible studies (1) employed empirical methods examining the efficacy of an eHealth intervention to prevent or treat negative psychological sequelae in youth (aged 0-18 years), their caregivers, or both youth and caregivers as either a primary or secondary outcome, (2) included youth or caregivers of youth with acute or chronic medical conditions, and (3) were available in English language. Studies were excluded if they failed to meet the inclusion criteria listed above. For the purposes of this review, psychological sequelae are defined as PTSS, anxiety, depression, and QoL. Studies that did not include these outcomes as a primary or secondary study outcome for either the child or caregiver were excluded.

Data Extraction

The initial search of PubMed and PsycINFO yielded 1606 results. A total of 2 authors independently reviewed titles and abstracts of relevant studies focusing on the efficacy of eHealth psychological interventions for preventing or treating psychological sequelae (ie, PTSS, anxiety, depression, and HRQoL) in youth with medical conditions. After removing 105 duplicate studies and excluding 1473 studies based on their title and abstract, the full text of the remaining 39 articles were

reviewed for eligibility. A total of 11 additional studies were selected for review from reference sections of the articles in the original search. In total, 22 studies met full inclusion criteria and were included in the review. See Figure 1 for a Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram depicting the study design of article selection. Each article that met inclusion criteria was reviewed and coded for theoretical framework, intervention delivery method, intervention outcomes, and intervention barriers.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram. RCT: randomized controlled trial.



Checklist for Measuring Study Quality

The Downs and Black checklist was used to assess study quality [24]. The checklist comprises 5 sections (27 items total) measuring reporting, external validity, internal validity, selection bias, and power. Studies were scored and placed into 1 of the 4 categories: poor (>14 points), fair (15-19 points), good (20-25 points), and excellent (26-27 points).

Results

Study Quality

The majority of studies scored within the *fair* (50%, 11/22) and *good* (41%, 9/22) categories [25-45]. Only 2 studies [46,47] were rated as *poor* (9%, 2/22). No studies were rated as *excellent*. For the 2 studies rated as *poor*, a score of 0 was given

for many items in the internal validity subscale (eg, either did not address or failed to blind participants and researchers, did not address participants lost to follow-up, and did not adjust for confounding in the analyses). Approximately 64% (14/22) of the included studies described characteristics of the participants that were lost to follow-up; 68% (15/22) of the studies accounted for this loss in analyzing study outcomes.

Study Characteristics

Of the 22 studies included in this review, 8 assessed for depression [27,33-36,40,41,43], 5 for anxiety [27,33,40,41,44], 4 for PTSS [27,31,39,45], and 10 for HRQoL [25,26,29,30,32,37,38,44,46,47]. A total of 5 studies [27,33,40,44,45] examined more than 1 outcome. All included studies were randomized controlled trials (RCTs) per inclusion criteria. Some of the studies (n=12) [25-27,30,31,34,37-39,44-47] examined

interventions that were solely delivered via Web, whereas 10 studies [29,32,33,35,36,38,40-43] used a combination of eHealth program components and sessions with a therapist or coach. See [Multimedia Appendix 1](#) for additional study details.

Study Participants

Sample sizes for the studies ranged from 37 to 164. Child participants were aged 2 to 18 years. A total of 7 interventions were designed for children alone [25,26,31,32,34,37,46], 3 for caregivers alone [36,39,45], and 11 for children and caregivers to use together [27,29,30,33,35,38,40-42,44,47]. Moreover, 10 studies focused on chronic conditions such as asthma [30,37,47], chronic headache [33], juvenile idiopathic arthritis (JIA) [25,38], inflammatory bowel disease [26], complex congenital heart disease [32], chronic respiratory condition [34], and type-1 diabetes [46]. In addition, 6 studies focused on pediatric patients suffering from psychological sequelae following a TBI [35,36,40-43]. A total of 3 studies focused on the aftermath of injuries (not focused on TBI) [27,39,45], and 1 study included children with potentially traumatic medical events (eg, injury, new diagnosis, and exacerbation of chronic condition) [31]. Furthermore, 2 studies had additional relevant criteria: one study required that participants perceived their injury as potentially traumatic [31], and another study enrolled participants who medical staff perceived as socially isolated or disadvantaged [34].

Model and Theoretical Framework of Interventions

A total of 8 eHealth interventions [25,27,29,31,33,38,39,45] used CBT as the basis for informing intervention content. Moreover, 7 [34,35,40-43,46] eHealth interventions used PST as the basis for informing intervention content. In addition, 5 studies [26,30,32,37,47] used education focused on disease management without an additional framework. A total of 2 interventions [27,44] primarily used psychoeducation to inform intervention content. Only 1 study included parent-child interaction therapy (PCIT) [36].

Problem Solving

A total of 7 studies [34,35,40-43,46] used PST as the primary framework for interventions. PST focuses on identifying problems, creating new strategies to address problems, and learning ways to implement those strategies [40]. Of the 7 studies, 5 were conducted in children with TBI [35,40-43]. The other 2 included children with type-1 diabetes and chronic respiratory conditions [34,46]. Of the 7 studies, 5 reported achieving at least one targeted outcome and included the following: (1) initial in-person visit with a therapist to introduce the intervention, (2) self-guided Web sessions accompanied by videoconferences with a therapist upon session completion, and (3) a videoconference with a therapist at the end of the intervention to practice learned skills and discuss needs for supplemental sessions [35,40-43]. For example, Petranovich et al developed a Web-based Counselor-Assisted Problem-Solving intervention aimed at identifying problem areas and learning new strategies to address TBI-related challenges [35].

Cognitive Behavioral

A total of 7 studies [25,29,31,33,39] used either CBT alone or psychoeducation based in a CBT framework [38,45] to inform

intervention content. The primary concept of CBT is to use thoughts and behaviors to modify challenging emotions [48]. Likewise, primary goals of CBT eHealth interventions were to promote adaptive cognitive appraisals [31], normalize reactions to trauma [27], and apply new behavioral strategies [38,45]. In addition, 3 interventions [31,39,45] were designed for children with acute medical events or injuries, 2 [25,38] targeted children with JIA, 1 [33] was designed for chronic headache, and 1 [29] for head or abdominal pain. A total of 6 interventions [27,29,33,38,39,45] provided information through websites and 1 [31] through an interactive game-based format. Of the 7 studies, 3 [27,31,33] reported achieving at least one intended outcome. For example, Cox et al [27] targeted trauma reactions in children with unintentional injury through a Web-based psychoeducation intervention. The intervention website for children contained information on relaxation, coping tips, problem solving, and other cognitive behavioral strategies. Caregivers were provided with an informational booklet containing tips on how to help their child recover after experiencing trauma [27]. Only 2 [29,38] of the 7 CBT interventions involved weekly telephone or email meetings with a trained coach to review intervention materials and answer questions. Although these interventions were based primarily on a CBT framework, interventions were multifaceted and included problem-solving elements and educational elements.

Parent-Child Interaction Therapy

A single intervention, developed by Raj et al, was based in a PCIT framework [36]. PCIT aims to improve the relationship between caregivers and children by teaching caregivers how to best respond to their child's behavior, listen effectively, and encourage their child's efforts to improve [49]. Raj et al [36] designed an intervention that combined traditional PCIT with additional stress and anger management to support caregivers of children with TBI. The intervention comprised 10 eHealth sessions delivered in 2 parts each: self-guided (part 1) and videoconference with a therapist (part 2). Caregivers received education on topics such as positive thinking, stress and behavior management, and disciplining their child after TBI [36]. This intervention also combined elements of other frameworks (ie, cognitive behavioral, education, and behavior management) with PCIT to provide caregivers with new skills for dealing with challenges following pediatric TBI. This intervention did not achieve significant outcomes.

Psychoeducation

Psychoeducation was a key component for 2 interventions [27,44]. These interventions focused on educating, normalizing, and relieving anxiety or trauma reactions. Both of these interventions achieved at least one targeted outcome. For example, the intervention by Fortier et al [44] provided education, skills training, and interactive games via a website to prepare children and their caregivers for what to expect before, during, and after surgery, focusing specifically on managing anxiety and pain.

Education Only

Several studies [26,30,32,37,47] used health education-only theoretical frameworks for their interventions. Out of these 5

interventions, 3 [30,37,47] used the following self-management components: disease education, self-monitoring, creating an action plan, and regular medical review. Of these 5 interventions, 3 [30,37,47] achieved at least one targeted outcome. For example, Klausen et al [32] used health education to increase perceived competence in patients with complex congenital heart disease and provide behavioral change techniques. This included information on the benefits of physical exercise, how to set goals and create an action plan, identifying barriers and problem solving, environmental structuring, social comparison, time management, and providing future rewards [32].

Electronic Health Intervention Delivery Methods

All interventions were delivered in a Web-based format. For many studies (n=10) [26,31,32,35,36,40-43,45], therapists introduced the intervention to participants during an initial in-person meeting. The majority of interventions with a therapist or coach component [29,35,36,40,41,43,45,47] included ongoing contact (eg, phone, email, or videoconferencing) to review intervention content and discuss supplemental materials. Some eHealth interventions [27,33,34,37,44,46] were used with full independence by study participants or with extra contact being limited to emails encouraging intervention use [45]. In 1 intervention [39], therapists provided written feedback on weekly homework assignments. Moreover, 1 study [25] used a combination of internet and individual instruction but gave no specific details on how individual instruction was provided. Most interventions were initiated after the child was discharged or had completed initial medical treatment. Only 1 intervention [27]—an eHealth intervention intended to provide information to parents after an unintentional pediatric injury to prevent or address early PTSS—was initiated while the child was undergoing medical treatment and then continued post discharge from hospital care.

Description of Outcomes

Research varied in whether outcomes were assessed for children only (n=7 studies) [25,26,31,32,34,37,46], caregivers only (n=3 studies) [36,39,45], or both children and caregivers (n=12 studies) [27,29,30,33,35,38,40-44,47]. Of the included interventions, 13 [27,30,31,33,34,37,39-44,47] identified significant intervention effects on at least one targeted psychological outcome.

Child Outcomes

Of the 7 studies that assessed child outcomes, 5 [27,33,34,41,42] focused on depression. Although Law et al [33] saw a brief improvement in child depression in children with chronic headaches at 3-month follow-up in both groups, no significant differences were seen between groups post intervention. Only when moderating factors were included, did some of these interventions show an effect [41,42]: after controlling for family socioeconomic status (SES) as a moderator in analyses, Wade et al [40] and Wade et al [29] found a decrease in depressive symptoms in the intervention group compared with the control group.

Interventions targeting child anxiety [27,33,41,42,44] were more successful, with 4 [27,41,42,44] of the 5 studies showing

improvement in anxiety post intervention. For example, Cox et al [27] designed an intervention for youth suffering from anxiety following an unintentional injury and offered coping strategies (eg, relaxation, coping statements, and problem solving) and a booklet containing information about the caregiver's role in the child's recovery process. Results indicated that children in the intervention group reported significantly less anxiety at a 5-month follow-up assessment compared with the control group [27].

Of the 3 studies that evaluated the impact of eHealth interventions on child PTSS, 2 [31,45] found a statistically significant improvement of symptoms post intervention. These programs primarily focused on normalizing PTSS and offered practical strategies (eg, identifying feelings, relaxation, coping statements, and working through avoidance of trauma reminders) through both text- and game-based activities. The intervention that failed to detect a statistically significant reduction in PTSS had a small sample size, which may have limited their power to detect an effect [27].

A large majority (n=7) of interventions aimed at improving HRQoL in children with chronic illness (eg, chronic respiratory conditions, chronic pain, JIA, inflammatory bowel disease, heart disease, and type-1 diabetes) focused on education about the disease and promoted self-management strategies [26,30,32,37,47]. Only 2 interventions targeting child HRQoL found significant differences post intervention, both focused on persistent asthma [30,37]. Although one intervention [37] used internet-based self-management and another [30] used internet-based multimedia asthma education, both studies utilized an interactive asthma monitoring system.

Caregiver Outcomes

A total of 4 studies [35,36,40,43] assessed caregiver depression, 2 [40,44] assessed caregiver anxiety, 3 [27,39,45] assessed caregiver trauma symptoms, and 1 [44] assessed caregiver QoL. Although all of the interventions that targeted caregiver depression were designed for children who had experienced a TBI, only 2 [40,43] out of 4 found significant effects.

Both interventions [40,44] aimed at reducing caregiver anxiety had significant effects. Wade et al found a significant decrease in anxiety in caregivers of children with a TBI after completing Web modules and videoconference sessions with a therapist, compared with caregivers who were only provided with internet resources regarding TBIs [40]. Fortier et al [44] provided a Web-based, tailored behavioral preparation program to children who were about to receive surgery and their caregivers and found that caregivers in the intervention group reported significantly less anxiety than those in the control group.

None of the 3 studies [27,39,45] that specifically examined the role of eHealth interventions in preventing or addressing parent posttrauma reactions after a pediatric medical event identified an intervention effect. These interventions were focused on children recovering from unintentional injuries and sought to address posttrauma reactions by providing parents with information about common psychological consequences following a pediatric injury.

Barriers Impacting the Efficacy and Usage of Electronic Health Interventions

Of the 22 studies included in the review, 5 [35,36,40,42,43] assessed potential intervention barriers. Of these studies, only 2 [36,40] identified significant moderating effects for potential intervention barriers (eg, SES and level of education). Specifically, Wade and Wolfe [40] suggested that caregivers with a higher income reported greater improvements from intervention use than those with a lower income. Raj et al [36] examined caregiver income and found a significant decrease in global psychological distress from baseline to follow-up for lower-income families. Furthermore, they found that only half of the lower-income families owned a computer and had internet access [36].

Discussion

Principal Findings

This review identified 22 studies of eHealth interventions designed to prevent or alleviate negative psychological sequelae (ie, anxiety, depression, PTSS, and HRQoL) in youth with a medical condition and their caregivers. This is this first review to examine multiple psychological sequelae components across acute and chronic medical conditions. By better understanding existing interventions across populations, we can improve our ability to design evidence-based, tailored interventions to improve targeted outcomes.

Overall results from this review indicate that research on eHealth interventions is in early stages and that results are mixed but promising. Results from this systematic review highlight some evidence to suggest that using eHealth interventions may help improve child and caregiver psychological outcomes (including anxiety and PTSS) and functional outcomes (ie, HRQoL) [27,30,31,33,37,40-44,47] but that more research is necessary to examine essential intervention targets, variable needs of different medical populations, and barriers to intervention implementation. In addition, there is room for improvement on designing research studies to thoroughly evaluate the selected outcomes and to explicitly report study methods, as only 41% of studies included were coded within the *good* range of study quality. As many of the studies included in this review were early stage research of new interventions, limitations to study quality are reasonable, as it makes sense to first examine intervention potential before investing in larger, complex research. However, to improve the scientific rigor of the methodology of this research as it continues to grow, future researchers may want to consider carefully examining and reporting on intervention compliance, participant dropout, and the effect of cofounders on outcomes. In addition, future studies may want to aim for larger sample sizes to improve power, the inclusion of larger proportions of the targeted population in the study, and the implementation of double blinding.

As there were very few studies that examined the effectiveness of eHealth studies on child and caregiver emotional health and QoL and as there was substantial variability in intervention components and modality, populations in which interventions are delivered, intervention modality, and outcomes assessed,

the following summaries of key findings should be interpreted as preliminary. Results from this systematic review suggest that the intervention theory that guided intervention content might have influenced the outcomes: of the studies included in this systematic review, those that primarily utilized CBT (80%) had the highest proportion of achieving at least one intended outcome [31,33,39]. This was followed by problem solving (71%) [34,40-43], education alone (60%) [30,37,47], psychoeducation (50%) [27-44], and PCIT (0%) [36]. These findings are consistent with current research supporting CBT [50-52].

In examining more nuanced study results, findings suggest that the type of intervention needed may be dependent upon the situation and goal of the intervention (ie, prevention vs treatment of symptoms). For example, information provision or educational interventions appear to be useful for decreasing anxiety and improving QoL, such as preoperative education, or when interventions are delivered within the hours after experiencing trauma (eg, injury) to prepare families for the emotional and physical challenges that lie ahead [27,44]. However, education-based interventions may not be helpful in achieving targeted outcomes for chronic illnesses (eg, JIA, inflammatory bowel disease, and congenital heart disease) [26,32,38] or if the education is provided days after a trauma [39,45]. Thus, intervention modality may need to be selected based on the challenges presented and targeted outcomes.

Results also suggest that intervention modality was fairly comparable regardless of whether the intervention was fully Web-based or not (64% [14/22] indicated significant positive outcomes), compared with Web-based plus in-person contact (44%). This is promising in that fully Web-based interventions may be less costly and have wider reach.

Potential Intervention Barriers

There are multiple factors to consider that have the potential to interfere with Web-based intervention engagement and effectiveness. Our results indicate that demographic factors such as SES, level of caregiver education, and social advantage may impact intervention efficacy [36,40]. How SES affects technology-based intervention uptake remains mixed. Although low SES is a potential barrier to intervention efficacy, some studies reported that families of lower SES might equally benefit from eHealth interventions compared with families of higher SES, when provided with computers and internet access [35,36,40,42,43]. More research is needed to better understand how intervention can be tailored to be the most efficacious across family SES.

Another potential barrier to consider is knowledge of technology. Although not included in this review because primary results are presented in another publication [40], a study by Carey et al [53] assessed past experience with technology in participants completing the intervention and found that participants who used technology less frequently showed less improvement in anxiety and depression symptoms, compared with those who used technology more often. The wide range of technology experience in target pediatric populations and their parents can be explained by the *digital divide*, defined as the gap in the frequency of information technology use and what

it is used for, which is thought to be moderated by demographic factors (eg, income, education level, gender, and race) [53]. Jackson et al [54] surveyed 515 children and found that children of parents with a full-time job used cell phones more frequently than children of parents with other employment situations. In addition, children of parents with higher education reported more use of computers and internet [54]. Female participants used cell phones more often than males, whereas males most intensively used video games [54]. Furthermore, African American males were the least frequent users of computers and internet, whereas African American females were the heaviest users of internet out of all groups [54]. For these reasons, care should be taken when designing interventions to provide the target sample with a feasible intervention platform (eg, adding more or less directions, using pictures, and content delivery method). Future studies should take into account demographical differences when formulating intervention content and deciding which delivery method to use (ie, mobile phone app, internet, or video game).

Barriers to intervention compliance should also be considered. Although not included in the final review, Worthen-Chaudhari et al [55] reported on barriers to study compliance and found that participants who dropped out of the study had discontinued medical care, faced problems with internet access, busy schedules, and experienced co-occurring illness during the study. Although these factors were not assessed after completion of the intervention, it is important to consider these as potential barriers to intervention usage that could affect study results.

Future research should directly examine potential intervention barriers such as SES, education level, location, knowledge of technology, and severity of medical condition in youth with various medical conditions. In addition, although existing

literature does not indicate how the timing of the intervention affects its efficacy, this may be an important factor to explore in future research. Studies should also aim to clearly identify their treatment outcomes and create interventions designed specifically to improve those outcomes. Finally, additional studies should examine the impact of improvements in parent outcomes on child outcomes.

Limitations

There are several notable limitations to this study that should be considered in interpreting and generalizing study results. Many studies reviewed had small sample sizes, with limited power as a result. In addition, research studies included were inconsistent in the measures used and the outcomes assessed, and many studies were not RCTs. Moreover, this study was unable to review research that was not published in English. Finally, the majority of the studies published identified an effect for at least one outcome; it is unknown whether these studies represent the majority of studies conducted in this area or whether there are a number of unpublished nonsignificant findings to take into account.

Conclusions

eHealth interventions have the capacity to broaden our reach to improve emotional health in families with children undergoing medical treatment. Although results are mixed, the results of this study suggest that eHealth interventions may be useful for improving psychological sequelae in pediatric populations with medical conditions such as TBI and other potentially traumatic injuries. More research is needed to identify the most important intervention components and how to ensure that these components are maintained in the translation to eHealth modalities.

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Authors' Contributions

All authors (AM, CK, and MLM) contributed to study design, data extraction, data interpretation, and manuscript preparation.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary of study characteristics and findings (only outcomes included in this review are reported in this table; studies might have assessed additional outcomes; and effect sizes are reported when available).

[PDF File (Adobe PDF File), 289 KB - [pediatrics_v2i2e12427_app1.pdf](https://pediatrics.jmir.org/2019/2/e12427_app1.pdf)]

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Abbreviations

CBT: cognitive behavioral therapy
HRQoL: health-related quality of life
JIA: juvenile idiopathic arthritis
PCIT: parent-child interaction therapy
PST: problem-solving therapy
PTSS: posttraumatic stress symptoms
QoL: quality of life
RCT: randomized controlled trial
SES: socioeconomic status
TBI: traumatic brain injury

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Original Paper

The Use of Information Communication Technologies Among Children With Autism Spectrum Disorders: Descriptive Qualitative Study

Theoneste Ntalindwa¹, MSc; Tanjir Rashid Soron², MPH, MSc, MD; Mathias Nduwingoma¹, PhD; Evariste Karangwa¹, MEd, PhD; Rebecca White³, MSc

¹School of Education, University of Rwanda, Rukara, Rwanda

²Telepsychiatry Research and Innovation Network Ltd, Dhaka, Bangladesh

³School of Nursing and Midwifery, University of Illinois at Chicago, Kigali, Rwanda

Corresponding Author:

Tanjir Rashid Soron, MPH, MSc, MD
Telepsychiatry Research and Innovation Network Ltd
7/34/C, Eastern Plaza, Sonargaon Road
Dhaka, 1205
Bangladesh
Phone: 880 01718827138
Email: tanjirSORON@gmail.com

Abstract

Background: The prevalence of Autism Spectrum Disorder (ASD) appears to be increasing globally due to the complex interaction of multiple biopsychosocial and environmental factors. Mobile phones, tablets, and other electronic gadgets have transformed our means of communication, and have also changed both healthcare and how we learn. These technological enhancements may have a positive impact on the lives of children, but there is currently a global scarcity of information on how information technology influences the education of children with ASD.

Objective: This study was conducted in Rwandan schools and communities, and aimed to understand the perceptions of students with ASD, their parents, and their teachers, on the use of Information and Communication Technology (ICT) in the education of those with ASD.

Methods: This qualitative descriptive study was conducted from December 2017 to July 2018. Researchers conducted four focus group discussions (FGDs) with 54 participants from different backgrounds: teachers, parents, and students with ASD. Each of the FGDs took approximately two and a half hours. A predefined set of open-ended questions were selected to discover people's perceptions regarding assistive technologies used in ASD, their effectiveness, the scope of using them in their context, and upcoming challenges during implementation. The interviews were recorded, transcribed, and analyzed.

Results: The findings of the study revealed seven key themes: (1) the use of ICT for the education of children with ASD; (2) existing augmentative facilities for learning; (3) current patterns of use of ICT in education; (4) preferred areas of learning for ASD students; (5) integration of ICT into educational programs; (6) areas of interest outside the classroom; and (7) future opportunities and challenges in Rwanda. We found most of the study participants assumed that appropriate technology and related innovations might solve the challenges faced by learners with ASD in classrooms. Moreover, they thought that children with ASD more so enjoyed watching television, playing digital games, and drawing objects using gadgets than interacting with people or playing with other children.

Conclusions: The use of various low-cost technical devices can aid with teaching and the education of children with autism in Rwanda. However, this area requires further research to discover the impact ICT can have on the education of children with ASD, so this study may become a starting point for further research in the area.

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KEYWORDS

autism spectrum disorders; information communication technologies; inclusive education

Introduction

Like any other child, those children with Autism have an equal right to education and all other basic rights [1]. However, students with Autism Spectrum Disorder (ASD) face several challenges during their education in both developed and low- and middle-income countries (LMICs) [2,3]. Despite the Ministry of Education's policy on the education of children with disabilities and other special needs in, which has been active since January 2019 [4,5], schools continue to demand comprehensive guidelines on effective teaching and education, standard infrastructural facilities, resources, professional educators, and support services. Besides that, the lack of logistical support seems to be the major source of children with ASD's generalized poor performance in numeracy, literacy and comprehension skills [6]. To overcome the challenges in schools, Rwanda is promoting the use of ICT at all levels through multiple initiatives that include the One Laptop Per Child Project at basic education levels, and loan schemes for students in higher learning institutions [7,8]. These interventions have increased the ratio of number of computers per user [9] and reduced the gap of access to Information and Communication Technology (ICT) in urban and rural populations [10]. Adoption of simulation-based multimedia technologies [11] have improved basic computer skills (eg word processing and spreadsheet applications) in ordinary Rwandan schools, but not necessarily in the country's inclusive and special schools [12].

Information communication technologies and modern education techniques can assist with the education of a person with disabilities by mitigating their challenges in different domains [13-17]. The use of assistive technology to enable those with ASD in their communities has been emphasized by The United Nations (UN) [18,19], and it has been assumed that the use of assistive technologies will improve the performance of children with ASD at school [20]. Assistive technologies benefit people with ASD by improving their ability to interact socially [21] and their self-engagement [22]. Moreover, ensuring inclusive and equitable education and promoting lifelong learning for all is also part of the UN's national comprehensive education strategy, which contributes to achieving Sustainable Development Goal-4 [23]. However, Rwanda's education

programs are still limited in many ways by limited research evidence on autism [24], specifically on the use of adapted technologies geared towards improving learning competency. Thus, this study was conducted with the deliberate aim of addressing this gap.

Methods

This qualitative descriptive study was conducted from December 2017 to July 2018, with the objective of understanding how ICT can support the education of children with ASD. The educational institutions chosen for focus group discussions were selected based on data from the National Commission of Persons with Disabilities and the Ministry of Education in Rwanda [25]. Researchers used structured interviews following the guidelines of qualitative research [26]. Participants were interviewed to find out their views and opinions on the effectiveness and use of ICT in an inclusive classroom setting. Children with ASD, their teachers and their parents participated in focus group discussions (FGDs). The FGDs were conducted in three randomly selected districts from two different provinces, and the study sites included: Groupe Scolaire Jabana (Gasabo District), Heroes Day Care Center (Kicukiro District), Autisme Rwanda within Kigali City, and the College des Amies de la Paix du Christ Roix (APAX) Janja (Gakenke District) located in the northern province of Rwanda. Teachers who participated in this study taught a variety of subjects, including mathematics, ICT, creative performance, geography, English, tailoring, chemistry, history, biology, and Kinyarwanda. Each school was represented by an equal number of teachers, parents, and children with ASD, with five teachers (N=5), three parents (N=3) and four children with ASD (N=4). Six children with standard intellectual capacity were selected from two inclusive schools which are implementing the competence-based curriculum, and they were the Groupe Scolaire Jabana (N=3) and the College des Amies de la Paix du Christ Roix (APAX) Janja (N=3).

Within the parents' group there were four fathers and eight mothers. Children with standard intellectual capacity from each school participated solely in observational sessions. Table 1 below describes 54 participants who were systematically divided into four FGDs based on the location of the four schools selected.

Table 1. Number of participants in focus group discussion (N=54).

Participants	Groupe Scolaire Jabana	Heroes Day Care Center	Autism center (Autisme Rwanda)	College des Amies de la Paix du Christ Roix Janja	Total
Teachers	5	5	5	5	20
Parents	3	3	3	3	12
Students with ASD ^a	4	4	4	4	16
Children with average intelligence	3	0	0	3	6
Total	15	12	12	15	54

^aASD: Autism Spectrum Disorder

The mobile apps chosen to support the education of children with ASD, such as *Mental Math Expert* [27] and *Milk Hunt*

[28], were randomly selected from the internet and installed on laptops and smartphones that were used by both children with

ASD and those with standard intellectual capacity to observe and compare their ability to use these digital devices. Each of the FGDs took approximately two and a half hours, and three observational sessions were performed to observe the ability of children with ASD to use ICT tools.

The answers from the interviews and results from the observational sessions were analyzed and transcribed using Word (Microsoft, Redmond, Washington). To clean the data, a coding scheme was developed with codes serving as groups of teachers, parents, and children with ASD in light of their knowledge, experiences, and perspectives. We refer to teachers, parents, and children using the following notation: T1 refers to teacher 1, P1 refers to parent 1, C1 refers to child 1, and so on.

The data were collected by recognized researchers from the University of Rwanda who have been trained on qualitative data collection, and the research project passed through the collegial ethical process. To maintain ethical standards, the researchers took formal informed consent from parents and teachers using approved consent form ([Multimedia Appendix 1](#)) and also used few prefixed questions to facilitate the Focus Group Discussion ([Multimedia Appendix 2](#)).

Results

Overview

The findings of the study revealed seven key themes: (1) the use of ICT for the education of children with ASD; (2) existing augmentative facilities for learning; (3) current patterns of use of ICT in education; (4) preferred areas of learning for ASD students; (5) integration of ICT into educational programs; (6) areas of interest outside the classroom; and (7) future opportunities and challenges in Rwanda.

The Use of ICT for the Education of Children with Autism Spectrum Disorder

Despite the financial barriers and lack of robust funding, schools and parents were provided digital tools for children with ASD. Rwandan financial leadership in education encouraged promoting facilities and increasing the capacity of ICT at the school level:

I encourage the government of Rwanda to provide technical support to develop their learning abilities as well as including them into general education system. [A teacher from Groupe Scolaire Jabana]

However, technological innovations such as educational software applications and videos need to be culturally relevant to both support students with ASD and improve their attention when they are studying. A teacher from APAX-Janja said

Special Software Applications and videos are essential in the class to help students paying attention as most of my students with ASD enjoy watching the video. When they are left alone watching, they are more focused and finally imitate what they have seen through media.

The advanced technology integrated well into teaching children with ASD, and the provision of an abundance of new tools to

educators to use in their instruction helped them be more efficient. This was especially evident when the emphasis was on symbolic notation and how children might learn from them, as supported by most of the teachers during the interview.

Existing Augmentative Facilities for Learning

The teachers from the four schools reported that only a few of them had a computer or tablet with special software applications for a person with ASD, such as games like *Matchit* and *Number Run* that are designed to work on basic mathematics skills. All schools and centers have the same educational barriers related to a lack of qualified staff that can support students with ASD, which are compounded by facility limitations including classrooms, dormitories, and teaching materials which are not adapted to them. Thus, an increase of facilities to support the education of children with ASD is recommended by school educators.

Current Patterns of Use of Information and Communication Technology in Education

It has been thought that cognitive software applications can have a positive effect on the education of a person with Autism, with one of the interviewed teachers saying:

I find the students with ASD and related disabilities are more interested in the use of mobile telephones and tablets which we are using to improve their communication at the school. They can search the application from tablet by themselves and start using it. [a teacher from the Autism Center in Rwanda]

Despite these positive intentions, teachers reported difficulties in the use of new technologies with children with ASD. Teachers at Heroes Day Care Center said:

What we do here is that we try all means to get some tools to support our children, but all of them are in English or French language which is a new language and difficult for them to learn as they have difficulty in communicating in our local language.

More teachers and parents suggested an increase of use of ICT tools with specific software applications installed, as well as training in teaching of and caring for children with ASD in an inclusive environment.

Preferred Areas of Learning for Autism Spectrum Disorder Students

In response to the question of interests of students with ASD, teachers said that the students were interested in subjects which involved vision and hearing. They said that many students with ASD liked the subjects that involved drawing and creative performance (eg, singing and dancing), while a few of them had unknown interests. This was supported by a teacher at Groupe Scolaire Jabana who said:

in my class, those children most like geometry, but when I teach algebra, they do not follow, I sometimes find them drawing the faces of their colleagues and teachers. They are also able to see some objects which other children considered as having normal intellectual capacity are not interested in.

From the researchers' observations, students who participated in the observational session demonstrated different individual capabilities, such as drawing the objects that they saw, reproducing specific images, and memorizing songs and voices that they heard.

Integration of Information and Communications Technology into Educational Programs

Parents stated that their children liked to use digital devices and recommended the provision of access to particular ICT tools. One father of a child with ASD said:

My son is very good at playing games on my smartphone, and he is the one who usually open a TV for me and forces me to watch a channel of cartoons. If the government provide ICT tools for children like mine at school, it will be better.

Teachers and parents thought that the integration of ICT and the provision of cost-effective assistive technology devices would be helpful. A teacher from APAX Janja said:

If we can provide the low-cost tablet or smartphone with special applications for each of the children customized with their interest, and provide the teaching with that, I am confident that they will be more successful in their specific domains.

This statement was supported by teachers who used ICT tools to support teaching their children in class, with all of them saying that ICT could improve both teaching and learning activities for children with ASD in inclusive settings.

Areas of Interest Outside the Classroom

Parents from urban areas said that their children liked watching television and playing digital games, while those from rural areas said that their children liked drawing objects they saw around and imitating the sounds and voices of animals and people. The parents also said that their children demonstrated a deficit in socialization with others in their families, but they were seen engaging in different activities. Another father of children with ASD said:

I have never seen my son talking about his interests or get engaged in activities I gave him. It took me a long time in observing him and I surprisingly saw him get engaged in different activities while I thought he is not able to do anything.

This testimony was also supported by a Teacher at APAX Janja who said:

I remember when I was doing my academic research, I met one man who was diagnosed as having Autism in Kigali who can imitate most of the voices of animals like, dog, cow, bird, lion, and others. If digital tools like Television is available to young children, they can imitate what they are watching.

The parents also said that their children could perform some house activities independently. From observations in the workshop room, children with ASD demonstrated a good level of skill in tailoring sweaters and performing other creative activities.

Future Opportunities and Challenges in Rwanda

The disruptive behavior of students in the inclusive classroom may be a barrier to the effective implementation of the proposed competence-based curriculum. This was supported by teachers who said:

The behaviors of children are very challenging, and it is not easy to teach them with others regardless of the policy of the government emphasizing their inclusion in schools. It will only happen if we have two or three teachers in one classroom to support them.

In this study, most teachers in the schools and centers suggested that the presence of two teachers in an inclusive classroom could help with overcoming the challenging behaviors of children with ASD.

Parents also reported a lack of awareness of ASD as a factor which supported the stigmatization of their autistic children among different families, and it also seemed to encourage them to drop out of the schools.

My family failed to accept the behavior of my daughter, and the cost of caring for her. They always ask me where I got her and I am afraid of her future when I will not be alive. But I believe in that with the help of ICT like Television broadcasts and Radio talks, they can change their beliefs within the time.
[A mother of an ASD daughter]

Using digital technologies to increase awareness of the disorder is thought to be a solution for reducing stigma among families.

In addition, the participants also said that a combination of a lack of materials, qualified teachers, awareness, and teachers' motivation was a significant challenge to including children with ASD into the Rwandan education system.

Discussion

Primary Findings

This study revealed the use of ICT was acceptable among both teachers and parents of children with Autism. The triangulation of themes developed in the findings shows that the participants in the study thought that ICT had the potential to improve the education of children with ASD in class regardless of the problem of an insufficient number of tools that have been developed [29]. The use of assistive technologies has previously proven to have the potential to improve the education of children with ASD in Rwanda and beyond, as supported by multiple studies [30-32]. Despite the importance of ICT in supporting the education sector, the lack of facilities are a significant challenge in enhancing the learning of students with autism in mainstream schools [33-35]. This results from the multidimensional constraints of culturally valid and acceptable educational curricula, inadequate training for teachers, and a lack of strategies for teachers to improve their methodologies when they are teaching in inclusive classroom settings [36-37].

These findings are supported by previous studies [38-40] and by the recommendations of the educators who participated in this study. Children with ASD perform better when an emphasis

is made on the augmentation of digital technologies, cognitive software applications, and the senses of children with ASD (ie, hearing and vision) [41-43]. This is supported by our observational findings, which indicated an improvement in the ability of the child participants to use cognitive software applications installed on the computers and smartphones provided to them.

To support previous research [44], the parents who participated in the FGDs stated that their children with ASD were motivated to engage in different activities at home, and the role of parents and teachers should be to guide and supervise rather than to compel them to work on a task. The interviewed teachers suggested improving the competency-based curriculum by focusing on mental disorders such as ASD, as supported by varying studies [45,46]. The parents and teachers also reported that some children were not attending school due to stigmatization [47]. However, the findings of this study suggest that increasing awareness of ASD by using varying means, including ICT, could help to overcome the stigma against people with ASD that has been associated with social and cultural issues [48]. This is supported by Ehsan et al [49], who found a lack of contextualized studies on ASD in less developed countries while the number of people with ASD continues to increase.

As a developing country, Rwanda has a lack of digital infrastructure that is a challenge and can lead to reduced support for people with ASD [49]. This supports studies which prove that digital technologies, when used effectively, can deliver foundational educational content to any learner so they can respond to the needs of people with ASD from different geographical contexts [40,50]. In addition to other research [51,52], this study recommends further exploration into LMICs such as Sub-Saharan Africa.

Limitations

This study used only focus group discussions and observational sessions, which could have made the results prone to selection biases, resulted in inequal engagement of the participants, and could have been influenced by the person who conducted the FGDs. However, the participants were selected randomly based

on data from a recognized National Commission of Persons with Disabilities in Rwanda, which minimizes the bias, and careful monitoring was done to ensure everyone participated and shared their opinions during the FGDs. Our results may be conservative and underestimate the full education and health benefits of children with ASD, as in the selected schools only two are currently implementing the competence-based curriculum while others are using a special curriculum to improve the lives of children with ASD. In addition, among the five selected schools only one was from a rural district of Rwanda, which may have resulted in a deficit of required study information in the rural area. Third, we based our study only on children with ASD enrolled in the school system and in caring centres, but there are others who do not attend schools or specialized centres because their education is expensive. Finally, parents who participated in the study were only those who had children enrolled in the school system or centres, but some research has found that some parents do not allow their children to attend school due to the stigma associated with ASD.

We did not include teaching models and methodologies, as this study only focused on the use of ICT for teaching children with ASD. Our results cannot replace the evidence of other existing methods and tools which are used to support the education of children with ASD, as this should be guided by different studies from multiple domains accompanied by robust independent assessment.

Conclusions

Based on these findings, the integration of ICT into the Rwandan educational system is essential to support and build the competency of children with ASD. Increasing societal awareness of ASD and enhancing the motivation of Rwandan teachers would help to reduce the stigma of ASD for families and within communities. This study will help future researchers in this domain in looking at the use of ICT for people with ASD, with program implementation, and completing a similar evaluation in a larger population sample. Recommendations also include new education-based ICT research in resource-limited settings with the general population as compared to ICT-based education within the ASD student population.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Consent form.

[[PDF File \(Adobe PDF File\)246 KB - pediatrics_v2i2e12176_app1.pdf](#)]

Multimedia Appendix 2

Predefined question.

[PDF File (Adobe PDF File)102 KB - [pediatrics_v2i2e12176_app2.pdf](#)]

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Abbreviations

APAX: College des Amies de la Paix du Christ Roix

ASD: Autism Spectrum Disorder

FGD: focus group discussion

ICT: Information and Communication Technology

LMIC: low- and middle-income countries

UN: United Nations

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Original Paper

Gender Perspectives on Social Norms Surrounding Teen Pregnancy: A Thematic Analysis of Social Media Data

Kathryn M Barker¹, MPH, ScD; S V Subramanian², PhD; Robert Selman³, PhD; S Bryn Austin², ScD

¹Center on Gender Equity and Health, University of California San Diego, La Jolla, CA, United States

²Harvard TH Chan School of Public Health, Boston, MA, United States

³Harvard Graduate School of Education, Cambridge, MA, United States

Corresponding Author:

Kathryn M Barker, MPH, ScD

Center on Gender Equity and Health

University of California San Diego

9500 Gilman Drive #0507

La Jolla, CA, 92093-0507

United States

Phone: 1 8582460066

Email: katebarker@ucsd.edu

Abstract

Background: Social concern with teen pregnancy emerged in the 1970s, and today's popular and professional health literature continues to draw on social norms that view teen pregnancy as a problem—for the teen mother, her baby, and society. It is unclear, however, how adolescents directly affected by teen pregnancy draw upon social norms against teen pregnancy in their own lives, whether the norms operate differently for girls and boys, and how these social norms affect pregnant or parenting adolescents.

Objective: This research aims to examine whether and how US adolescents use, interpret, and experience social norms against teen pregnancy.

Methods: Online ethnographic methods were used for the analysis of peer-to-peer exchanges from an online social network site designed for adolescents. Data were collected between March 2010 and February 2015 (n=1662). Thematic analysis was conducted using NVivo software.

Results: American adolescents in this online platform draw on dominant social norms against teen pregnancy to provide rationales for why pregnancy in adolescence is wrong or should be avoided. Rationales range from potential socioeconomic harms to life-course rationales that view adolescence as a special, carefree period in life. Despite joint contributions from males and females to a pregnancy, it is primarily females who report pregnancy-related concerns, including experiences of bullying, social isolation, and fear.

Conclusions: Peer exchange in this online forum indicates that American adolescents reproduce prevailing US social norms of viewing teen pregnancy as a social problem. These norms intersect with the norms of age, gender, and female sexuality. Female adolescents who transgress these norms experience bullying, shame, and stigma. Health professionals must ensure that strategies designed to prevent unintended adolescent pregnancy do not simultaneously create hardship and stigma in the lives of young women who are pregnant and parent their children.

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KEYWORDS

teenage childbearing; teen pregnancy; adolescent sexual behavior; social media; social norms; gender

Introduction

Teen birthrates in the United States have been steadily declining since the mid-1990s [1]. In 2017, a total of 194,377 babies were born to American women aged 15-19 years, for a live birth rate of 18.8 per 1000 women (or approximately 2% of women) in

this age range [2]. In the United States and other industrialized societies today, teen childbearing is viewed as a concern because adverse health and social outcomes have been observed among teen mothers and their children, including infant mortality, childhood illness, welfare dependence, academic failure, juvenile crime, and teen childbearing in subsequent generations [3,4].

A contentious debate exists in the academic literature regarding whether these negative associations reflect preexisting differences between teens who gave birth compared to those who did not [5,6]. For example, studies adjusting for background characteristics associated with teen pregnancy (eg, family background, race/ethnicity, socioeconomic position, and educational attainment) show that teen mothers are as likely as older mothers to bear and raise healthy, successful children [7-12] and that life trajectories of teen mothers are slightly altered by having children in their teens [7,13,14].

Despite this evidence, which calls into question the validity of causal assumptions between teen parenthood and poor social and economic outcomes and the fact that current teen birthrates are the lowest rates ever recorded in the United States [2], national concern with teen pregnancy remains [15]. A steady stream of professional and popular literature continues to circulate the narrative that early childbearing leads to considerable and devastating costs to the public and teen mothers and their children (for example, materials from New York City's controversial 2013 campaign against teen pregnancy; Figure 1 [16]). Indeed, the dominant narrative in the United States deems teen pregnancy a social and public health problem [17-21], unequivocally bad for young women, their children, and society [22]. This dominant narrative is represented and mutually reinforced in multiple arenas including academic literature, media and popular discourse, and social policy [22,23].

The social ramifications of adolescent fertility vary by time and context, with US social concern with the concept of "teen pregnancy" dating roughly to the 1970s [3,20,24]. This concern is informed by a shifting set of social norms in American society [25]. Social norms are group-level expectations for appropriate behavior that result in negative sanctions such as feelings of embarrassment, anxiety, guilt, and shame for individuals who violate them [26-29]. Social norms regulating pregnancy are informed by societal views on the acceptability of teen sex, contraception, pregnancy, and abortion [25] as well as age and gender norms. Childbearing is typically not discouraged when it occurs in adulthood and after transitioning to marriage and financial independence [30]. Although norms against sex and

pregnancy during adolescence apply to both males and females, normative standards are generally enforced more strongly for girls than boys [31]. Despite the importance of gender in understanding teen pregnancy norms, much of the research on teen pregnancy investigates the roles of race and class and is relatively silent with respect to gender [32].

American adolescents increasingly access online communities for social support and advice about personal matters [33-37]. These digital platforms allow adolescents opportunities to explore their identity and find support and information about developmentally sensitive issues, such as sexual health [38]. In a study of online health-seeking behaviors, it was found that 44% of individuals aged 15-24 year who have looked for health information online sought out information about sexual health, second only to information about diseases such as cancer [39]. This is, perhaps, unsurprising given that youth often feel uncomfortable directly asking parents, teachers, and physicians about topics such as pregnancy, sexuality, menstruation, and sexually transmitted infections [40,41]. This makes digital platforms such as online social networks a highly relevant data source for examining adolescents' views of teen pregnancy. Use of these types of online data is in line with existing qualitative methodologies that adapt traditional ethnographic techniques to the study of social media [42,43].

The online ethnographic research method used here draws on adolescents' anonymous, voluntary, and intentional interactions with other online users in the exchange of information and advice about teen pregnancy in a popular social media site to answer the following research questions: Are the views of contemporary adolescents shaped by norms against adolescent pregnancy? If yes, how do US adolescents utilize, reproduce, or reinterpret these dominant narratives in their discussions of teenage pregnancy? In addition, how do these norms shape the lives of contemporary teens who experience pregnancy? Given the declining rates of teen pregnancy in the United States and the variation in pregnancy norms by time and context, this research allows for the examination of whether and how the people affected by these social norms—US adolescents—use, interpret, and experience social norms against teen pregnancy.

Figure 1. NYC 2013 Teen Pregnancy Prevention campaign materials.



Methods

MTV's "Over the Line?" Platform

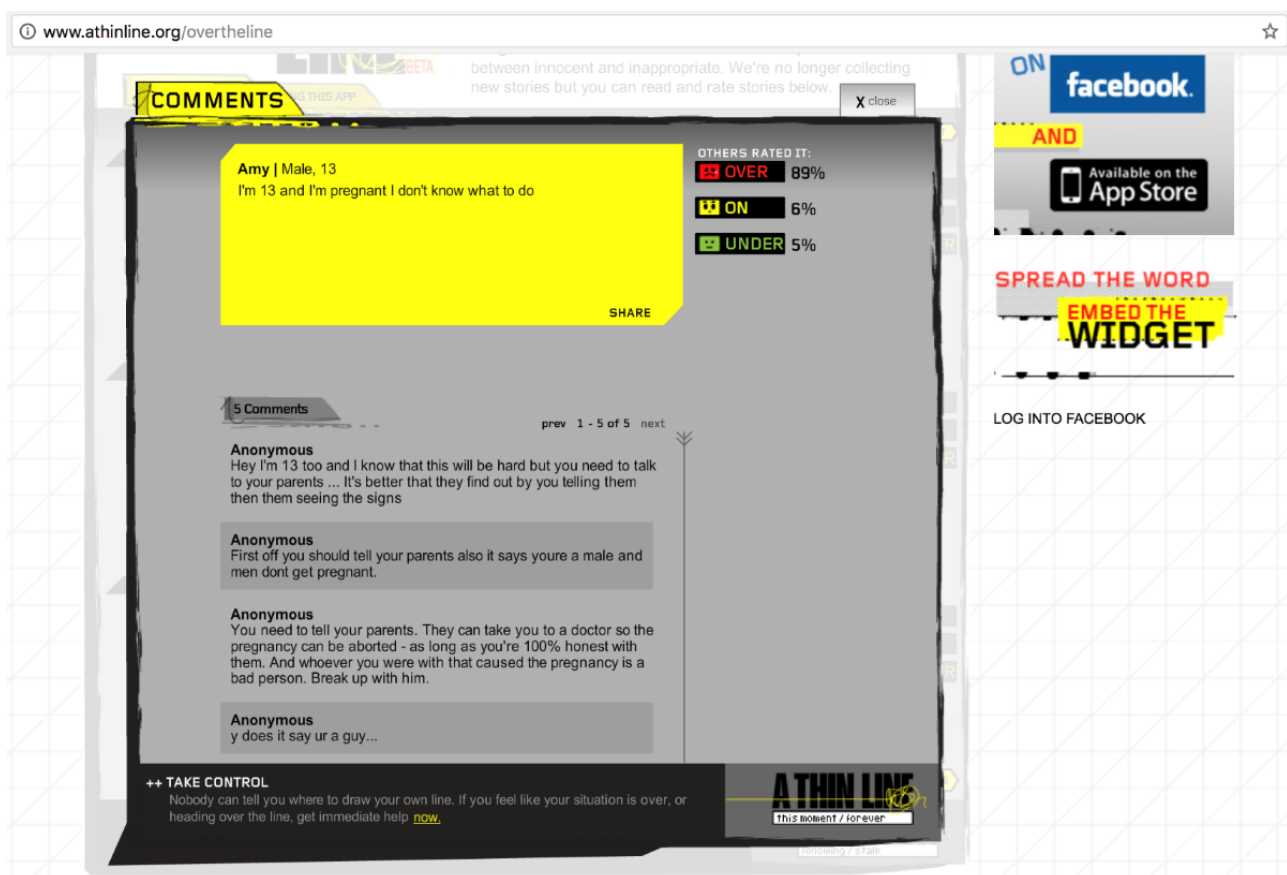
In 2009, MTV launched "Over the Line?" an online social networking site for youth aged 14-24 years to give and receive feedback and support on life experiences [44]. This popular site has over 18,000 followers [45]. Although MTV designed the platform with the intention of providing space for adolescents to share experiences of digital abuse, adolescents ultimately used the platform for multiple topics including sexual and reproductive health concerns.

As shown in Figure 2, users could interact on this platform in multiple ways. First, users seeking advice could post a comment describing their concern along with the option to provide their name, age, or gender. Second, for each user comment, other users could vote on whether the comment was "over," "on," or "under" the line. These ratings were used to indicate the acceptability of the behavior described in the comment, with "over-the-line" ratings indicating an unacceptable action or behavior. Third, online users could also provide written responses to each comment. Thus, there are three different types of data available for analysis on this platform: the original comment, quantitative votes on the acceptability of the issue

presented in the comment, and qualitative responses to the comments.

These data represent a novel approach to gaining insights into the concerns expressed by adolescents surrounding pregnancy and pregnancy-related issues. Traditional qualitative methods (eg, in-depth interviews) necessarily involve a relationship between the researcher and the participant [46], which mobilizes and may reproduce the structural positions that exist outside research contexts and thereby risk perpetuating existing power relationships [47]. This is of concern because teens have a general reluctance to discuss health and sexuality concerns with parents and health providers due to embarrassment and concerns about privacy [48,49]. The anonymous peer-to-peer exchange available to teens in MTV's Over the Line platform eschews these existing concerns and methodological issues. In addition, the MTV platform was open and available to any adolescent with access to the internet. Using this population of teenagers in online platforms allows for expansion beyond traditional contextual or localized studies of teen pregnancy. The data corpus for this analysis comprises three different types of data posted to MTV's Over the Line platform between March 2010 and February 2015: (1) pregnancy-related *comments* made by individuals between the ages of 13 and 19 years (n=208) and the subsequent (2) quantitative (n=15,445) and (3) qualitative *responses* (n=1454) associated with each comment.

Figure 2. Exemplar "Over the Line?" comment and associated quantitative and qualitative responses.



Analysis

Qualitative analysis progressed in several steps. The first step used thematic analysis to identify and isolate comments related specifically to adolescent pregnancy from the entire corpus of the MTV OTL platform. Once this subsample of all pregnancy-related comments was identified, emic codes were developed using thematic analysis [50,51]. The first author read through all comments to become familiar with the data and identify preliminary themes. Subsequently, a 10% random sample of the full sample of 208 comments was selected to develop inductive or emic codes. Following initial code identification, analytical themes were identified and conceptualizations of each theme were refined.

Throughout this process, a codebook was developed and refined, as informed by both the first author's own interpretations of the data after closely reading through the data as well as a multistep, interrater reliability (IRR) process. After the initial codebook development, the first author and a coder trained in thematic analysis coded a new random sample of 20 comments. The two researchers then held a consensus interrater discussion to clarify areas of disagreement and identify codes requiring refinement. The codebook was then revised, and a second IRR test was performed using another random sample of 30 stories. A coding-comparison query was conducted in NVivo 10 software (Doncaster, Australia). Kappa statistics were calculated for each code and high levels of agreement (ie, $\kappa > 0.75$ [52,53]) were achieved after two rounds of reliability testing.

One critical emic code, "Value Statements or Judgments Surrounding Teen Pregnancy," was identified in this process. After consultation with other authors, the first author sought to develop related etic codes from extant conceptual frameworks in qualitative studies on normative contexts of early childbearing. Three such studies were identified [22,31,54], and 10 resulting etic codes on social norms were used in analysis. Subsequently, a second codebook on social norms was developed specifically for the analysis of comments and associated responses that were initially coded as "Value Statements or Judgement Surrounding Teen Pregnancy." In the final phase of analysis, the first author checked the integrity of the themes in relation to their component coded extracts as well as to the dataset as a whole.

Results

Female Perspectives

Of the 208 total comments about teen pregnancy, the vast majority ($n=195$, 94%) were posted by females, and the subsequent analysis is restricted to comments made by females. These comments centered on two major themes: gauging the social acceptability of wanting to have a child in their teenage years and sharing experiences with bullying, social isolation, and fear due to actual or rumored pregnancy. Given the large body of data and the research focus on norms, the results are structured as follows: first, comments related to the social acceptability of wanting a baby as a teenager are examined; second, the responses to these comments are analyzed; finally, female users' experiences with bullying, social isolation, and fear due to pregnancy are presented.

Comments: Gauging the Social Acceptability of Teen Pregnancy and Motherhood

A number of adolescents (all but one female) used the Over the Line platform to gauge the social acceptability of wanting to have a child in their teenage years. These advice-seeking comments indicated the commenters' recognition of age norms regulating the timing of pregnancy. For example, "I want to had a baby but I'm 13. Is that wrong?" Other uses were more explicit in their awareness of age norms and pregnancy timing:

Im sixteen and want a baby more then anything, i know im young and with only being a junior in high school i understand it would affect things & still i want one, what should i do?

A minority of commenters provided a rationale for why they wanted to have a child, which were related to important life transitions such as marriage:

I'm 16 almost 17. I'm engaged getting married next summer. I really wanna have my fiances baby now.

As opposed to other comments that centered on experiences of pregnancy and bullying, these advice-seeking comments elicited the vast majority of responses from other online users. Given that the advice one provides is reflective of the beliefs one holds [55], the analysis of responses to these comments provides insights into the normative contexts in operation in this online platform.

Quantitative Votes on the Acceptability of Adolescent Childbearing

A total of 4292 Over the Line platform users provided quantitative responses on whether comments related to wanting a child as a teenager were over the line: 88% of platform users voted for over the line (ie, unacceptable); 7%, for on the line; and 5%, for under the line (ie, not a problem). When disaggregated by original commenters' age, votes indicated stricter age norms for younger adolescents; 90% of voters felt it was unacceptable for adolescents aged 13-15 years to consider having a baby, as compared to 81% for those aged 16-19 years. In general, a clear majority of Over the Line platform users felt teen pregnancy at *any* age was unacceptable. Users responded with many reasons for why it was unacceptable.

Qualitative Responses About Adolescent Childbearing

As with the quantitative data, qualitative responses overwhelmingly reflected the dominant view in the United States that teen pregnancy is problematic. This view was reflected through several subnorms (shown in italics). Some of the user comments reflected a general *pathologization* of teen pregnancy without any specific mention of *why* it was problematic. The lack of a need for explanation is indicative of how strong this norm against teen pregnancy is for some individuals. For example, a user responding to a teen wanting a baby simply said, "dont be stupid about this crap okay make a smart choice." Most user responses did, however, include rationales to explain why having a baby as an adolescent was a bad idea. Age norms informed many rationales. In some cases, young age was the sole rationale for why becoming pregnant was a bad idea. For example, one user noted, "You shouldn't

even be having sex at 13?!!” *Missed adolescence* reflects a view that adolescence should be a fun and carefree time, unburdened by responsibilities associated with parenthood. Users commented as follows:

*Enjoy your childhood, spend time with your bf, go on road trips! You cant do any of that easily with a baby
Enjoy teenhood with partys not diapers.*

Many users focused on the level of responsibility to dissuade fellow peers from having a baby. The theme, *Too much responsibility*, explicitly indicated concerns with the amount of time and effort required to care for a baby. As one respondent stated, “yhuu may thiink yhuu wnt t2 but no yhuu not ghunna really wnt it wen yhu have t2 ghatt upp in dha mornin t2 b changing diapers and hearin ya bby yelling [you may think you want to have a baby, but you’re not going to really want it when you have to get up in the morning to change diapers and hear your baby yelling].” Many commenters drew on age norms when describing the level of responsibility involved in having a baby:

A baby is a HUGE responsibility and what 13 year old likes any responsibility of any kind?

Other commenters drew upon the *Children having children* narrative:

You have NO idea how to raise a child when ur still one unself...wud u be ready for staying up throughtout the nite, constant crying n buying everything.

This theme implicitly informed another theme: *Limited future opportunities*. Here, user responses ranged from beliefs indicating a baby would delay or limit the attainment of life goals (for example, “Having a kid will delay your education and your childhood”) to those totally derailing chances at a good life (for example, “The chances of you being poor, unstable and unhappy for the rest of our life are very high having a baby that young and unmarried.”) Other users were not as concerned about the future of the adolescent, but the future of the baby. Overarching warnings within the theme *Not good for baby* theme included, “the baby wouldn’t be happy.” More specific warnings ranged from predictions that the child would receive limited education or would eventually also become a teen mom:

If you have a baby now there is a huge chance that that child wont finish its education and will also be a prego teen.

This theme had overlapped with *Instability* to some extent, wherein user responses focused on the unstable nature of adolescents’ relationships and finances. Concerns of relationship instability related to a sentiment that intense feelings for romantic partners during adolescence are fleeting:

Its called puppie love - 6 months from now ull be in “love” with some1 else.

Other users warned that adolescent males just wanted sex, and a boyfriend would likely leave if the commenter became pregnant:

Do not trust boys you know all they want is sex.

Ya man gone end upp leaving yhuu [you] cuz he gone thiink yhuu [you’re] t2 [too] much.

User responses also focused on adolescents’ limited independence and the continued reliance on parents:

If you want a baby at 14 you are obviously not thinking, you cant finacially support the baby your parents would have to.

Interestingly, in this sample, the concern with the impact on others focused on familial burden and not societal burden. Only one response in the entire dataset drew on the *Welfare queen* trope to explain why teen pregnancy was a problem. In addition, a very small minority of user responses centered on *Moral rationales* to explain why sexuality was problematic at this age:

Most of these children these days need to read their bible.. Your not suppose to have sex until your married.

Finally, other user responses centered on *Pathologized (female) adolescent sexuality*, illustrating that for some users, the problem is not with teen pregnancy or the challenges of raising a baby as an adolescent, but with sexuality:

*******OKAY EVERYONE IS SAYING YOUR TOO YOUNG TO HAVE A BABY; HOW ABOUT YOUR TOO YOUNG TO HAVE A BOYFRIEND AND YOUR TOO YOUNG TO BE HAVING SEX.**

Another user response illustrated that this concern centers on the sexuality of girls, drawing on age, gender, and sexual norms, for example, the following response, which is a gendered statement that aims to chasten female sexual desires:

*Keep your **** legs close you are to young.*

None of the pregnancy comments in this dataset implicated male partners as being sexually irresponsible. This reflects dominant US societal norms that deem adolescent female—not male—sexuality as problematic [20].

Female Experiences of Bullying, Social Exclusion, and Fear

About half of the commenters sought advice about negative experiences related to bullying, social isolation, and fear due to an actual or rumored pregnancy, and all but two of these comments were shared by female users. Female adolescents shared stories about being bullied because they had been pregnant or by being told they were or looked like they were pregnant. In these stories, teen pregnancy was mentioned in context of girls being “sluts” or “whores,” which are derogatory terms used to disparage women for having many sexual partners [56]. As one respondent noted:

I would never want a kid at this age...people will call you a slut.

This very scenario indeed played out in the lives of some adolescent girls:

*People im school call me a **** because i had a baby when i was 17 i dont know if i should jus ignore it and think that im better then that or do something.*

People started these nasty rumors about me being prego and aborting the baby, and ingraved "slut" on my locker.

As an indication of the extent of the damaging nature of this bullying, one poster shared that she chose to leave school to escape rumors that she was pregnant:

This girl at my school told everyone hat i was having sex with my boyfriend. but i wasn't. I couldn't deal with it so i broke up with him and tried 2 keep 2 myself. She started telling people i was pregnant. I left school and moved 2 a different 1.

Many of the female commenters also experienced social isolation and fear after a pregnancy. These types of comments indicate that the responsibility for the pregnancy rested with the girl, as opposed to a shared responsibility by both sexual partners. One young woman wrote:

Im 17 yrs old and met this guy about 4 months ago and we had sex once. i got pregnant and now he wants nothing to do with me or the baby!!

Another user was worried about the repercussions of telling her family:

I found out i was pregnant & i'm scared to tell my parents.

In the worst-case scenarios, norms of teen pregnancy as a social problem and "slut shaming" led to both bullying and social isolation in the lives of young women, as illustrated by the following comment:

*My bf took naked pics of me and video taped us having sex and all of my friends left me and I dumped him but now he's saying that I'm a ***** and I'm pregnant with this kid and he's saying it isn't him. Please help me!!!! The whole school knows!!!!*

Discussion

Principal Findings

This study draws on a novel methodology to reveal a number of key insights into how American adolescents in a popular online forum reproduce, reinterpret, and are affected by dominant American social norms surrounding teen pregnancy. First, users seeking to gauge the social acceptability of wanting a baby in their teen years received responses that were largely reflective of norms pathologizing teen pregnancy. A majority of the online respondents viewed any type of teen pregnancy to be problematic, with 88% of users indicating that comments related to having a child as a teenager were unacceptable. The vast majority of qualitative responses reflected subnorms against teen pregnancy. Second, these data highlight important ways in which pregnancy norms are also informed by age, gender, and sexual norms. On disaggregating the data according to age, there was a stronger disapproval for pregnancy in younger teens (ie, those aged 15 years or younger) as compared to older teens. This is in line with previous research indicating that teenage mothers below the age of 15 years tend to arouse more concern than their older counterparts [57]. Users also drew upon gender and sexual norms to provide rationales against teen pregnancy.

The data highlight the gendered concerns of young women as they negotiate their sexuality in the context of social norms that pathologize teen pregnancy. Finally, these data indicate that norms against teen pregnancy create a social environment that may lead to stigma, shame, and difficulty in the lives of young women who experience a pregnancy. Whether the absence of such stories in this platform among males is a reflection of their limited experience with such stigma or a lack of desire to share such stories in online settings is unclear.

Future Research

Sociological work by Vinson [58] points to the fact that men are largely absent in the dominant narrative of teen pregnancy, and the social anxiety about teen pregnancy largely focuses on women's bodies, desires, and morality. Previous quantitative research on social norms assessing adolescents' perceptions of teenage pregnancy shows clear gender differences: Girls were significantly more likely to report embarrassment at the prospect of a teenage pregnancy than boys [59]. In addition, prior qualitative research on teen pregnancy indicated that social concern among school-aged respondents centered on the female but not the male partner [31]. The public health literature is surprisingly, and perhaps, concerningly silent in its explicit mention of gender and the roles that young men play in contributing to pregnancy. Additional research must be conducted to determine how these norms may play out in the lives of US teenage males.

Second, there is limited clarity in social norms surrounding teen parenthood versus teen pregnancy. Formative research for this study demonstrated that a distinction is only sometimes made between teen pregnancy and teen parenthood in the literature [60], and it is not always a careful one. This is unfortunate, as the constructs of teen pregnancy and teen parenthood are arguably quite distinct and have gendered elements. There is ample room for additional research to disentangle these two constructs and examine how gender norms are utilized in discourse on teen parenthood versus teen pregnancy.

Finally, the dominant social narratives on adolescent childbearing in the United States are based on both race and class [22], and disparities in US teen birth rates are reported by ethnicity and socioeconomic status [59,61,62]. Data limitations here did not, however, permit an exploration of normative differences by demographic characteristics beyond age. Additional data are needed to enable a careful comparative analysis of how social norms against teen pregnancy operate across racial and class lines.

Conclusions

This analysis provides novel and valuable contributions to the literature by filling a gap in our understanding of teen pregnancy norms. Using a gender lens, the analysis provides a nuanced view of how US adolescents in online platforms use norms surrounding teen pregnancy, and demonstrates how these norms negatively affect the lives of young women who are rumored to be or are pregnant. Our study indicates that teen pregnancy norms disproportionately affect young women and operate to create stigma and social isolation in the lives of adolescent girls. The fact that this population faces stigma is a concern from not

only a reproductive justice standpoint, but also a public health standpoint; perceptions of judgmental attitudes lead some pregnant female adolescents to delay accessing health services to avoid judgement [23].

The norms against teen pregnancy remain in place, in part, due to a belief that rejecting the stigmatizing norms against teen pregnancy would be seen as synonymous with encouraging (young women's) irresponsible and risky sexual behavior [58]. This is a false binary. Demanding more respect for young pregnant and parenting women and rejecting these stigmatizing norms can and should leave room for efforts to prevent unintended pregnancy by improving access to low- and no-cost contraception and comprehensive sexual and reproductive health programs. This is in line with numerous efforts rooted in the principles of reproductive justice [63,64]. By rejecting norms that center on gendered and classed ideologies of motherhood and those that pathologize young women's, but not young men's, sexuality, we foster the required social discourse on the

structural drivers of unintended pregnancy and the contributing role of young men in pregnancy.

In a social policy book on US teenage childbearing written over two decades ago, sociologist Kristin Luker asked, "How can society's concern about teenagers and their babies be mobilized to good effect? How can such anxiety be made less confused and inchoate—be made to reflect real problems? Most centrally, how can society ensure that this anxiety—which relates to sexuality, race, poverty, gender, and a changing world economy—not simply exacerbate the existing problems of young women and their babies?" [57]. These questions remain salient but unanswered. American young women and their children would be well served by having researchers, health professionals, and social policy analysts finally answer these difficult but necessary inquiries. It is crucial for public health professionals to ensure that campaigns designed to prevent unintended adolescent pregnancy do not simultaneously create unnecessary hardship for pregnant and parenting young women.

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Conflicts of Interest

None declared.

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Abbreviations

IRR: interrater reliability

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Original Paper

Exploring an Existing Weight Management App for Use With Adolescents and Young Adults With Spina Bifida: Usability Study

Colleen Stiles-Shields^{1,2}, PhD; Brittney Garcia², BA; Kimberly Villota², BA; Elicia Wartman², BA; Adrien M Winning², BS; Grayson N Holmbeck², PhD

¹Population Behavioral Health, Department of Psychiatry and Behavioral Sciences, Rush University Medical Center, Chicago, IL, United States

²Department of Psychology, Loyola University Chicago, Chicago, IL, United States

Corresponding Author:

Colleen Stiles-Shields, PhD

Population Behavioral Health

Department of Psychiatry and Behavioral Sciences

Rush University Medical Center

1645 W Jackson Blvd

Chicago, IL, 60612

United States

Phone: 1 3125631579

Email: elizabeth_stiles-shields@rush.edu

Abstract

Background: Adolescents and young adults with spina bifida (AYA-SBs) have unique user needs, given their variable and complex symptom profile. Owing to multiple barriers to prevention and intervention treatments for secondary conditions (eg, obesity), AYA-SBs may benefit from the use of behavioral intervention technologies (BITs). However, as BITs are often designed and tested with typically developing individuals, it is unclear if existing BITs may be usable for AYA-SBs.

Objective: This study aimed to evaluate the usability of a high-quality, publicly available, weight management–focused mobile BIT (smartphone app) for AYA-SBs.

Methods: Overall, 28 AYA-SBs attending a Young Men’s Christian Association–based summer camp completed 4 structured usability tasks using a weight management app designed for the general public called My Diet Coach (Bending Spoons). Learnability was measured by (1) time to complete task, (2) number of user errors, and (3) correct entry of data when requested by the app. Satisfaction and general usability were measured via self-reported questionnaires and qualitative feedback following interactions with the app.

Results: The majority of the sample were able to complete the tasks, with increased completion rates and improved times on second attempts of the tasks ($P < .05$). Errors were common, and discrepancies emerged between quantitative and qualitative feedback such that self-reported measures indicated dissatisfaction but qualitative feedback was generally positive. Suggested improvements to the app included (1) tutorials, (2) simplifying the design, (3) more activity options for those who ambulate by wheelchair, and (4) notifications to prompt use.

Conclusions: AYA-SBs were able to learn how to complete specific tasks independently on a weight management app, but design changes consistent with previously proposed user needs were recommended. Rather than designing entirely new BITs, it may be possible to adapt existing technologies to personalize BITs for specific populations such as AYA-SBs.

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KEYWORDS

spina bifida occulta; mHealth; mobile apps; usability testing; adolescent; young adult; weight reduction programs; body weight maintenance

Introduction

Background

Spina bifida (SB) is the most common congenital birth defect affecting the central nervous system and requires the management of both a complex medical treatment regimen and a variety of cognitive and psychosocial comorbidities [1,2]. Complicating the management of this condition, adolescents and young adults (AYAs) with SB (hereafter referred to as AYA-SBs) are disproportionately impacted by obesity [3]. Beyond the typical risk factors associated with obesity as a secondary condition, obesity poses a greater risk for other outcomes, such as muscle loss, pressure sores, depression, complications of surgery, and decreased social and physical activities [3-5]. In addition, people with SB and obesity are doubly at risk for social rejection, given the combination of 2 visible vulnerabilities: physical disability and obese status [6,7]. Therefore, preventing and reducing obesity in individuals with SB is a critical goal.

Multiple emotional (eg, low motivation and depressive symptoms) and practical barriers (eg, ambulation status and transportation) to addressing obesity and healthy lifestyles have been identified for AYA-SBs [3,5,8-10]. Behavioral intervention technologies (BITs), the use of technology to deliver behavioral health interventions [11], have demonstrated promising effects on health outcomes for pediatric samples [12]. AYA-SBs report using a variety of technology and media [13]. Furthermore, a self-management behavioral intervention technology (BIT) for people with disabilities (ie, SB, cerebral palsy, and spinal cord injuries), Interactive Mobile Health and Rehabilitation (iMHere), has demonstrated feasibility and benefits to high users of the system [14]. Technology usage, in combination with the barriers faced to addressing obesity, implicates the use of BITs as a delivery mechanism for obesity and healthy lifestyle monitoring and interventions for AYA-SBs.

Given their unique user needs, calls for personalizing BITs for people with disabilities have been made [15]. For example, AYA-SBs are unique in that they have symptoms that overlap with chronic medical conditions and physical and intellectual disabilities. For this reason, a user needs model for BITs that support self-management in SB has been created [16]. The model includes (1) behavioral skills- and evidence-based change strategies that avoid abstract concepts and help to categorize behavior, (2) elements that are multisensory (eg, text and audio) and use multiple methods (eg, visualizations and passive data collection), (3) being capable of being used across multiple platforms, (4) linear and user-driven workflows, and (5) expert and/or peer support. However, before using this model to create new BITs designed for AYA-SBs, currently available BITs should be evaluated. This is for multiple reasons. First, although the previously mentioned iMHere platform already exists, it is (1) currently only available for Android devices and (2) designed to promote self-management across a variety of issues pertinent to those with disabilities. AYA-SBs without an Android and/or those who might wish to exclusively focus on an issue such as weight management face barriers to utilizing this BIT. Therefore, AYA-SBs who face such barriers are likely to search

the publicly available marketplace for another BIT to suit their needs. Second, given the high number of BITs already available for health and body image management, it is possible that elements of existing BITs may be appropriate for AYA-SBs. Therefore, evaluating how currently available BITs function for AYA-SBs is necessary to potentially avoid *reinventing the wheel* in terms of some BIT tools.

To accomplish the task of evaluating how well currently available BITs may serve this population, usability testing was utilized. Usability testing is the systematic observation of planned tasks by potential end users to improve the design of a product or technology [17]. Learnability, or how well a user can complete tasks during the first interaction(s) on an app [18], was the usability attribute of interest. Indeed, if AYA-SBs independently download a publicly available app, their ability to learn to use the app is essential for correct use. On average and based on evaluations of healthy adults, users report spending about 5 min or less learning how to use a new app [19,20], and AYAs have been found to quickly dismiss technological tools that misalign with their expectations [21,22]. Furthermore, AYA-SBs tend to have difficulties with assembled processing (ie, learning to construct and digest information) [23]. This difficulty means that even the most ideal app (eg, grounded within evidence-based behavioral change theories and high usability) might have different learnability for a user with SB. Therefore, in assessing the usability of BITs for AYA-SBs, how quickly and well the users learn to use the BIT is important.

Purpose

The purpose of this study was to evaluate the usability attribute of learnability for a high-quality [18], publicly available, weight management-focused mobile BIT (smartphone app) for AYA-SBs. We hypothesized that, in evaluating an app rated as having high quality for typically developing populations [18], the majority of users would be able to complete tasks and do so in 5 min or less by their second attempt of a task [19,20]. However, given the variable symptom and functioning profile of AYA-SBs [16], it was anticipated that high variability across the sample would be observed for all evaluated usability metrics.

Methods

Participants

Participants were recruited from the Young Men's Christian Association (YMCA)-sponsored Camp Independence during the 2018 summer sessions. Camp Independence is located in Illinois (USA) and is a sleep-away camp designed for AYA-SBs. Programming includes (1) a 1-week stay with similarly aged campers, (2) typical camp-based activities (eg, swimming) with accommodations for camper needs, and (3) camp-based interventions to promote medical and social independence [24-26]. Participants were eligible for study inclusion if they (1) had SB, (2) were aged between 13 and 30 years, (3) attended Camp Independence during the summer of 2018, (4) had previously used a mobile app independently, and (5) could read and write in English.

My Diet Coach

The app that was selected for usability testing was the My Diet Coach app. My Diet Coach was selected as it is (1) highly rated for quality using the Mobile App Rating Scale [18,27], (2) publicly available on both iTunes [28] and the Google Play Store [29], and (3) cost free (a version is also available for purchase). The app includes features such as a meal and activity journal, tips, and user-selected challenges.

Procedure

This study was approved by the Loyola University Chicago institutional review board. Participants aged 18 years and older provided informed consent. Participants younger than 18 years provided informed assent, and their parents provided consent.

Usability Testing

To assess the usability attribute of learnability, the participants were asked to complete specific tasks (eg, log a food item) with an app on a mobile device. These tasks were related to food intake and activity monitoring, which were selected because (1) they are common tasks for weight loss and management and (2) they could be evaluated relatively quickly, so as to not keep participants from their camp activities. Learnability was measured by (1) time to complete task, (2) number of user errors (tracked on a standardized paper measure by the moderator), and (3) correct entry of data when requested by the app. Improvements across these measurements were hypothesized to occur across attempts (eg, logging a food item attempt 1 versus attempt 2). Satisfaction and general usability were measured via self-reported questionnaires (please see Measures section).

Participants were brought to a private area of the main camp building to complete testing. Testing was conducted by research and graduate assistants with experience in interviewing AYA-SBs. A think-aloud protocol was used [30]; however, the majority of participants did not say what they were thinking during the usability tasks. To avoid distracting the participants, those who did not speak during tasks were given time to share any relevant thoughts after each interaction. Before the testing of My Diet Coach, participants engaged in a card-sorting task to identify barriers to the use of apps for health management. The card sorting results are reported elsewhere [13]. Next, participants were verbally queried about their typical platform for accessing apps (ie, iOS or Android) and then provided a description of My Diet Coach from the Google Play Store (ie, “My Diet Coach helps you find your inner motivation, stay on track, make healthy lifestyle changes, resist food cravings, and avoid exercise laziness and other weight loss difficulties.”). Participants were then provided an Android phone (Moto G5s Plus, 5.5-inch screen). If they were unable to utilize this device because of vision or motor dexterity problems, they were offered the option to complete the testing on an iPad (6th generation), which was encased in a handle-stand cover to improve the participant’s ability to hold the device. The verbal instructions for the first task were as follows:

Now, please imagine that you want to eat healthier. You see this description of My Diet Coach on the Google Play store and decide to download it. Let’s

pretend that you just ate one piece of pepperoni pizza for lunch. Please open the app, which is already on the home page, and select “the lightning bolt” to log the pizza you just ate. Feel free to say out loud what you are thinking while you do this. Tell me when you are finished.

This interaction was timed and audiotaped, and any observed user errors or alternative paths to complete the task were noted by the research or graduate assistant. If a participant stopped working on the task, they were prompted with “What’s going through your mind right now?”, followed by “Please do your best to complete the task and let me know when you are finished.” To avoid participant frustration, the task was ended if a user stopped working for 90 consecutive seconds. Once the task was completed, participants were asked to share their thinking with regard to alternative paths taken to complete the task. Participants completed 3 more tasks following this same methodology: (1) exercise (ie, entering a 30-min activity of their choice), (2) second food (ie, entering in eating an apple for a snack), and (3) second exercise (ie, entering a different 15-min activity of their choice). Finally, participants were asked open-ended questions about (1) their impressions of the app (eg, “What are your overall impressions of the logging features of My Diet Coach?” and “Is there anything that you feel is missing?”) and (2) the designs of technology more generally for AYA-SBs (eg, “How could technology work better for you in terms of managing your health?”).

Data Collection Approaches

The following traditional data collection methodologies that have been used in the testing of other apps [19,31,32] were selected to evaluate My Diet Coach for AYA-SBs: (1) audio recordings of the testing, (2) standardized interview questions, (3) providing the option for the research/graduate assistants to prompt participants following specific behaviors, (4) validated questionnaires (see Measures section), (5) timing of the tasks with a stopwatch, and (6) research/graduate assistant recording of errors or path deviations (on a standardized paper form).

Measures

All measures were administered following completion of the interactions with My Diet Coach. Participants were given the opportunity to answer questionnaires via paper and pencil or via an electronic version administered through Opinio [33], licensed and administered by Loyola University Chicago.

Demographics

Participants were asked to report the following information: age, sex, race/ethnicity, and SB characteristics, including type, shunt status, and lesion level. Full Scale Intelligence Quotient (FSIQ) was measured and collected for those who also participated in another camp-based study [24-26].

System Usability Scale

The System Usability Scale (SUS) is a 10-item self-reported instrument measuring a user’s rating of a product’s usability [34]. Items are rated on a 5-point Likert scale (ie, 1=strongly disagree to 5=strongly agree). Total scores are derived by converting the responses (ie, subtracting 1 from odd-numbered

items and 5 from even-numbered items), summing the converted numbers, and multiplying the total by 2 and a half. Although this scoring method yields total scores ranging from 0 to 100, this number is not meant to be interpreted as a percentage. A SUS total score of 68 is considered the cut point for an *average* score or grade of C; higher scores are considered above average and lower scores are considered below average [35]. The SUS has been utilized in previous research with youth and adults with SB [36] and had adequate reliability in the current sample ($\alpha=.86$).

After-Scenario Questionnaire

The After-Scenario Questionnaire (ASQ) is a 3-item self-reported instrument measuring a user's satisfaction with a product [37]. Items are rated on a 7-point Likert scale (ie, 1=strongly agree to 7=strongly disagree). Respondent answers to the items are averaged to create a total score, with higher scores indicating higher dissatisfaction following a specific task. To the best of our knowledge, this is the first use of the ASQ with a sample of AYA-SBs. The ASQ demonstrated an adequate Cronbach alpha coefficient (.66) for this sample.

Health Questionnaire

The Health Questionnaire is a modified and abbreviated (17 out of 87 original items) version of the 1999 Youth Risk Behavior Survey by the Centers for Disease Control and Prevention (CDC) [38]. Items used for this study address self-reporting of weight, height, desire to change weight, diet, food, and exercise questions appropriate for youth with SB. Data from the Health Questionnaire include categorical (ie, "Which of the following are you trying to do about your weight? Lose weight; Gain weight; Stay the same weight; or I am not trying to do anything about my weight") and continuous (ie, frequency of behavior) variables. Responses on the Health Questionnaire were used to calculate body mass index (BMI) based on self-reported height and weight, which were calculated using the CDC BMI calculators for children and teens [39] and adults [40]. However, some missing data for BMI were anticipated, as there are

established difficulties in obtaining valid measurements of height and weight in people with physical disabilities [41]. The Health Questionnaire was administered to characterize the current health and weight management behaviors of the current sample and has previously been used in studies involving AYA-SBs [42].

Data Analysis

The demographic and SB characteristics (eg, type of SB), usability testing measurements (eg, time to complete and number of user errors), and questionnaire data were analyzed using descriptive statistics. The *t* test was used to compare differences between the first and second attempts of tasks (eg, time to complete the first food entry compared with time to complete the second food entry). All analyses were run in Statistical Package for the Social Sciences version 24 (IBM Corp), with the 0.05 type I error rate.

Results

Participants

A total of 29 participants agreed to participate; however, 1 participant only completed questionnaires as she reported feeling too overwhelmed from the card sorting task [13] to complete usability testing. Participants were primarily young adults (mean 18.11, SD 4.55), female (59%, 17/29), and non-Hispanic white (72%, 21/29), with myelomeningocele (69%, 20/29), with a lumbar (41%, 12/29) or unknown lesion level (41%, 12/29), and with a shunt (79%, 23/29). The BMI of the sample ranged from underweight to obese, with the average BMI falling within the normal range (mean 21.84, SD 4.19). It should be noted that 7 participants (24%) did not have BMI data because of difficulty in reporting current height and/or weight (obtaining accurate height and weight measurements in people with disabilities can pose challenges) [41]. The majority of the sample endorsed wanting to lose (39%, 11/28; one participant did not answer) or maintain (32%, 9/28; one participant did not answer) weight. [Table 1](#) displays the demographic, SB, and health characteristics.

Table 1. Demographic, spina bifida, and health characteristics (N=29).

Characteristics	Adolescents and young adults with spina bifida
Age (years), mean (SD); range	18.11 (4.55); 13-30
Sex, n (%)	
Male	12 (41.4)
Female	17 (58.6)
Race/ethnicity, n (%)	
African American	2 (6.9)
Asian	2 (6.9)
Caucasian	21 (72.4)
Hispanic	4 (13.8)
Other	— ^a
Spina bifida type, n (%)	
Myelomeningocele	20 (69.0)
Other	9 (31.0)
Meningocele	—
Lipomeningocele	1 (3.4)
Occulta	—
Unsure	8 (27.6)
Lesion level, n (%)	
Thoracic	1 (3.4)
Lumbar	12 (41.4)
Sacral	4 (13.8)
Unsure	12 (41.4)
Shunt present, n (%)	23 (79.3)
Full Scale Intelligence Quotient ^b , mean (SD); range	84.67 (19.51); 55-132
Personal mobile device, n (%)	
Android	10 (34.5)
iOS	18 (62.1)
Did not report	1 (3.4)
Body mass index ^c , mean (SD); range	21.84 (4.19); 14.50-32.00
Current weight change attempts, n (%)	
Gain	6 (21.4)
Lose	11 (39.3)
Maintain	9 (32.1)
No attempts to change	2 (7.1)

^aNot applicable.

^bData missing for 5 participants because of not participating in the larger camp-related intervention.

^cData missing for 7 participants because of not responding about height and/or weight.

Health Behaviors

To contextualize the usability outcomes within the sample's health behaviors, participants reported their current frequency of healthy food consumption, physical activity, screen time, and sleep. Tables 2 to 4 display the health behavior frequencies

of the current sample. For dietary behaviors, the CDC recommends a daily minimum intake of (1) 2 fruits/100% juice servings, (2) 2 and a half servings of vegetables, and (3) 3 servings of milk/dairy [43]. Consistent with previous reports of health behaviors in AYA-SBs [42], the majority of the sample reported consuming fruits/100% juice servings (86%, 23/28),

vegetables (82%, 22/28), and milk/dairy (89%, 25/28) below the recommended frequencies. For physical activity, teens younger than 18 years are recommended to get at least 60 min of physical activity daily; adults 18 years and older are recommended to get at least 150 min of physical activity weekly (including aerobic, muscle strengthening, and bone strengthening activities) [43]. Given that only (1) 21% (6/28) of the sample endorsed engaging in at least 30 min of strenuous exercise daily, (2) 14% (4/28) endorsed engaging in at least 30 min of nonstrenuous exercise daily, and (3) 4% (1/28) endorsed daily strength exercises, it is likely that the sample is falling

short of CDC recommendations for physical activity. However, falling in line with current recommendations of 2 hours or less of screen time per day [44], the majority (69%, 17/26) of the sample reported engaging in 2 hours or less of screen time on weekdays (No time: 11.5%, 1 hour: 11.5%, <1 hour: 11.5%, 2 hours: 34.6%, 3 hours: 15.4%, 4 hours: 3.8%, >5 hours: 11.5%). Finally, and contrary to previous findings of youth and AYA-SBs [42,45], exactly half of the sample endorsed typically sleeping 8 to 9 hours per night [46] and having no or very little difficulty falling and staying asleep.

Table 2. Health behavior frequencies.

Frequency of daily healthy food intake and screen time	No times	1-3 times in past 7 days	4-6 times in past 7 days	Once per day	Twice per day	3 times per day	>4 times per day
100% fruit juice ^a (%)	17.9	35.7	10.7	21.4	7.1	7.1	0
Fruit (%)	17.9	28.6	17.9	17.9	17.9	0	0
Vegetables (%)	14.3	32.1	21.4	10.7	3.6	0	17.9
Milk (%)	25.0	17.9	14.3	17.9	14.3	3.6	7.1

^aFrequencies reported from adapted version of the Youth Risk Behavior Surveillance System, as reported in the study by Kolbe et al [38].

Table 3. Frequency of physical activity.

Physical activity	0 days	1 day	2 days	3 days	4 days	5 days	6 days	7 days
≥30 min of strenuous exercise ^a (%)	7.1%	10.7	14.3	17.9	10.7	14.3	3.6	21.4
≥30 min of nonstrenuous exercise (%)	21.4	14.3	17.9	10.7	14.3	3.6	3.6	14.3
Strength exercises (%)	53.6	7.1	14.3	3.6	10.7	3.6	3.6	3.6

^aFrequencies reported from adapted version of the Youth Risk Behavior Surveillance System, as reported in the study by Kolbe et al [38].

Table 4. Sleep quality.

Ability to fall asleep	Not at all	Very little	Moderately often	Very often	Almost always
Trouble falling asleep ^a (%)	26.9	42.3	15.4	7.7	7.7
Trouble staying asleep ^a (%)	50.0	34.6	11.5	3.8	1.2

^aTwo participants did not report their sleep information.

Equipment

The majority of the sample reported using iOS (62%, 18/28) for their personal mobile devices; however, most of them denied using apps to help manage their SB in any way (75%, 21/28). Most participants completed the usability tasks on the Android mobile phone (86%, 24/28); however, 4 participants requested to use the iPad to complete testing because of vision or motor dexterity issues. Given the small sample size and uneven number in the groups, Mann-Whitney U tests were run to compare those who reported owning an iPhone with those who reported owning an Android on the task measurements (ie, completion and error rates and time to complete tasks) to ensure that the device platform did not impact the results. There was no evidence to suggest significant differences between those who owned an iPhone and an Android ($P>.09$), with the exception of time to complete the second exercise entry ($P=.04$). For this task, those who owned an iPhone (mean 38, SD 32) were significantly faster than those who owned an Android (mean 58, SD 29).

Therefore, the data suggest that it is unlikely that those who owned an iPhone were at a disadvantage if they completed the tasks on an Android device.

Usability of My Diet Coach for Adolescents and Young Adults With Spina Bifida

Completion

About two-thirds of participants ($n=20$) were able to independently complete a food entry on their first attempt (ie, pizza), with an increase in completion on the second attempt (ie, apple; $n=22$). For activity entries, about two-thirds of participants ($n=20$) were able to independently complete an entry on the first attempt, with another increase in completion on the second attempt ($n=24$). Significance testing was not performed on the completion rates because of lower than expected counts in at least one cell of the contingency table for both activities. The activity entries could be selected by the user, with the most frequently chosen activities being lifting

weights, sled hockey, and walking/running. Most participants (86%) were able to come up with their own activities without suggestions from the research or graduate assistant moderating the sessions.

Time

Participants significantly decreased their time to complete tasks across the 2 attempts for both food entries (mean time 2:00, SD 1:38 vs mean 1:02, SD :56; $P=.01$) and activity entries (mean time 1:11, SD :50 vs mean :45, SD :31; $P=.002$).

Errors and Deviations

The most common user errors involved (1) entering incomplete or inaccurate data (16 out of 112 attempted tasks, 14.3%), (2) being unsure of how to proceed to the next step without being able to recover and complete the task (ie, a *fatal error*; $n=13$, 11.6%), or (3) believing the task to be complete when it was not ($n=8$, 7%). The most common deviation was accidentally selecting an option to upgrade the app ($n=5$, 5%). There was no evidence to suggest a significant difference in the number of errors or deviations across food entry attempts (mean 2.42, SD 2.09 vs mean 1.88, SD 2.14; $P=.09$). However, a decrease in errors or deviations from the expected path across activity entries occurred (mean 1.46, SD 1.96 vs mean 0.58, SD 0.76; $P=.03$).

Usability and Satisfaction

Participants completed the SUS and ASQ following their interactions with My Diet Coach to evaluate usability and satisfaction, respectively. SUS ratings for My Diet Coach were highly variable (range 2.50-100). The average SUS rating was 64.17 (SD 29.59; a *below average* SUS score). The average ASQ rating for My Diet Coach was 5.55 (SD 1.36; total scores range from 3 to 21, with higher scores indicating greater dissatisfaction).

Sensitivity Analyses by Age

Given the wide range of AYA-SB participants (13-30), sensitivity analyses were conducted to explore any differences that were driven by age. Specifically, exploratory chi-square and t tests were conducted to compare demographic and SB-related factors, phone usage, and usability outcomes for those aged 17 years and younger ($n=17$) with those aged 18 years and older ($n=11$). There was no evidence to suggest differences in FSIQ, sex, race/ethnicity, type of SB, lesion level, shunt status, type of phone ownership, device used for testing, questionnaire responses, or any usability testing outcomes ($P_s \geq .1$), with the exception of adolescents being more likely to have successfully completed the first exercise entry ($P=.03$).

Qualitative Feedback

Although the usability tasks were audiotaped, the majority of participants did not engage in the suggested *think-aloud* method of completing tasks. Therefore, qualitative feedback occurred through responses to structured questions that were administered to all participants after completing the usability testing (please see Procedures section).

Despite the variable usability ratings, the majority of participants stated that My Diet Coach would be useful for them (64%,

18/28). When queried as to why this app might be useful, the most common response was related to the app reminding and encouraging them to change their eating and activity choices. For example:

I could see how many calories I'm burning and consuming, and balance those. I definitely see me using in the future. [17-year-old female]

[This app] would help me make healthy choices. [17-year-old female]

It would help me realize I need more fruits and vegetables. [21-year-old male]

Although the current usability testing evaluated initial learnability, qualitative feedback also suggested that learnability might improve with long-term use (eg, "It was a little tricky at first. As I used it more, it became easier to use." [13-year-old male]; "It seems pretty easy to use once you get used to it." [18-year-old female]). Suggested improvements specific to AYA-SBs included (1) tutorials (eg, "Make it more self-explanatory. Have practice stuff, give step-by-step directions to enter stuff." [14-year-old female] and "There's a lot of information in it with no instructions." [20-year-old female]), (2) fewer logging options and/or simplifying the design throughout (eg, "It's too confusing with too many steps" [17-year-old female] and "Make it easier by not making it so heavy in content and choices." [19-year-old female]), (3) more activity options for those who ambulate by wheelchair (eg, "It needs to add exercise for people in wheelchairs." [23-year-old male]), and (4) notifications to prompt use (eg, "I need reminders [to do this] on my phone...Remind me to do my exercises and eat healthy." [20-year-old female]).

Discussion

Principal Findings

The purpose of this study was to evaluate the usability attribute of learnability for My Diet Coach, a publicly available, high-quality app [18] designed for the general public, for AYA-SBs. The majority of the sample endorsed wanting to maintain or lose weight and reported dietary and exercise behaviors that fell short of the CDC recommendations [43]. These characteristics, combined with the increased risk for obesity in people with SB [3], make this app a potentially appropriate tool for aiding in weight management for this sample. The majority of the sample was able to complete the tasks of entering foods and exercises into the app, with improved performance on the second attempts for both tasks. Consistent with the hypotheses, AYA-SBs were able to complete initial tasks with the app in under 5 min [19,20] and demonstrated decreased task time on the second attempts. Despite this success, but also consistent with our hypotheses, high variability of usability was observed, suggesting that added tutorial features for users with special needs might be beneficial. To the best of our knowledge, there is no established metric for the ideal number of user errors on initial interactions with an app [47,48]; however, the error rates (1) appeared high for a limited number of required task actions and (2) raise questions about the initial learnability of this app for subsets of AYA-SBs. Finally, responses to validated usability questionnaires and open-ended

interview questions suggest variable usability for this group and also emphasize the importance of querying AYA-SBs in a mixed-methods fashion.

A user needs model for AYA-SBs was recently created for BITs aiming to improve self-management [16]. This user needs model was framed within the BIT model, which includes conceptual (*why* the BIT is needed and *how* it may achieve such aims) and technical (*what* is delivered to BIT users and *how* and *when* the delivery may occur) aspects for designing and deploying BITs [49]. In utilizing a high-quality app already publicly available (ie, My Diet Coach), this study evaluated the usability of existing BIT elements (ie, *what* is delivered) and characteristics (ie, *how* the delivery may occur) for AYA-SBs. The findings suggest that in applying the user needs model for AYA-SBs to the design of BITs specific to this population, design teams do not need to *reinvent the wheel* and create entirely new BITs for AYA-SBs (a cost-heavy venture from a financial and time perspective). Indeed, it appears that the majority of AYA-SBs in the current sample can independently learn to complete specific data entry tasks within a reasonable time frame using an existing BIT targeting weight management [19,20].

Although the current findings suggest that My Diet Coach is learnable for AYA-SBs, it also implicates personalizing existing elements and characteristics for AYA-SBs and related users (eg, youth with physical and/or motor disabilities) [16]. The evaluated elements of My Diet Coach involved active, text-based data entry. Consistent with the literature on AYAs with similar symptom profiles [16], the AYA-SB participants reported that these elements could be improved for their use by having tutorials, being simpler, and having less logging options. Possibly because of the lack of such features and/or the executive functioning problems associated with SB [23], participants also displayed several errors for a relatively simple data entry path. In addition, the entry options were not optimized for variability in accessibility (eg, for those who ambulate with leg braces or by wheelchair). Therefore, although AYA-SBs demonstrated that they are capable of using elements featuring text-based data entry, they may be unlikely to persist in using such elements in real-world conditions. Moreover, the data collected might not be as accurate as compared with the use of other means of collection (eg, voice-to-text entry or passive data collection via an accelerometer). These findings suggest that a multisensory and multimethod approach to BIT elements is likely warranted for AYA-SBs [16] but that text-based data entry is a learnable element for AYA-SBs.

Given the variable levels of impairment in motor dexterity, coordination, hearing, vision, and visuospatial processing in people with SB [23], BIT characteristics likely also need to demonstrate flexibility. My Diet Coach demonstrated multiple platform capabilities in testing, which was important and necessary for AYA-SBs (ie, participants accessed the app via an Android phone or an iPad). The text-based data entry tasks involved elements of the app that had limited graphics, which falls in line with user needs for simple and/or limited graphics [16] because of posterior attention difficulties (which impact the ability to focus and shift attention) [23]. My Diet Coach is also designed to include customized reminders around user goals (ie, “Drink water” and “Always be prepared with healthy

snacks”). This characteristic was reported as desired following testing and also falls in line with the user needs model [16]. However, it was not evaluated in this study. Therefore, the design characteristics of My Diet Coach appeared to align well with the needs of AYA-SBs, but future research will need to evaluate how usable such characteristics are when users are confronted with other common tasks (eg, interacting with notification reminders).

The majority of participants were able to complete the tasks and stated that the app would be personally useful. However, questionnaire responses were not indicative of high usability and satisfaction, and the majority of the sample reported that they do not use apps to manage their SB (75%). These discrepancies may have multiple explanations. First, young people with SB have variable cognitive profiles, with many falling within the category of having a mild intellectual disability [2]. The differences between qualitative and quantitative feedback may reflect the importance of feedback methods when assessing AYA-SBs. It also highlights the need for continued validation of usability measures for individuals with disabilities and/or special needs. Second, AYA-SBs may use technology less frequently and/or in selective ways compared with the general population [50]. It is likely that BITs may sound appealing in theory but are anticipated to have multiple barriers (being unintuitive, not specialized for the needs of people with SB, etc) or are in conflict with time already allotted to TV viewing or social networking [3,13]. Finally, it is possible that participants believed that the app had been developed by those conducting the usability testing. Therefore, qualitative feedback may have been driven by a desire to please the evaluators.

Limitations

This study builds upon previous work establishing the importance and feasibility of conducting usability testing with AYA-SBs [51,52]. However, the findings should be considered in light of specific limitations. First, the sample was recruited from the YMCA-sponsored Camp Independence [24-26]. The sample consisted of a wide age range of AYA-SBs who have the support and ability to attend a sleep-away summer camp session and who were also primarily non-Hispanic whites. More usability testing of apps for self-management is required, targeting AYA-SBs with greater diversity and within more *real-world* conditions. Second, testing was focused solely upon data entry of monitoring behaviors that are common in weight management strategies (ie, food intake and physical activity monitoring). Furthermore, the usability tasks were designed to be brief (ie, 4 entry tasks that took an average of about 2 min per task), so as to not keep participants from the activities of the camp for a significant amount of time. It is unclear how the current findings extend to (1) the entry and monitoring of other behavioral change strategies, (2) long-term use, and (3) other types of app elements and other apps, more generally. Third, the majority of participants reported using iOS for their personal devices, yet the majority opted to complete usability testing on an Android device. Comparisons of usability outcomes across these 2 groups did not suggest a disadvantage for iPhone users. However, to avoid this confound in future research, facilitating acclimation to the operating system before usability testing would be ideal. Finally, it is unclear if the presence of the

research/graduate assistants facilitating the testing sessions had any impact on performance.

Conclusions

For clinicians and engineers designing BITs for pediatric and AYA populations, the findings of this study suggest that it may be possible to iterate from existing technologies to personalize apps for specific populations. Doing so may decrease both the

financial and time burden associated with designing and building a new technology. However, the use of appropriate user-centered design principles and the use of formative usability testing is still critical [49,53]. Indeed, AYA-SBs were able to learn how to complete specific tasks independently on a weight management app, but design changes consistent with previously proposed user needs are still recommended [16].

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Conflicts of Interest

None declared.

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Abbreviations

- ASQ:** After-Scenario Questionnaire
 - AYA:** adolescents and young adults
 - AYA-SB:** adolescents and young adults with spina bifida
 - BIT:** behavioral intervention technology
 - BMI:** body mass index
 - CDC:** Centers for Disease Control and Prevention
 - FSIQ:** Full Scale Intelligence Quotient
 - SB:** spina bifida
 - SUS:** System Usability Scale
 - YMCA:** Young Men's Christian Association
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Original Paper

Virtual Reality Support for Joint Attention Using the Floreo Joint Attention Module: Usability and Feasibility Pilot Study

Vijay Ravindran¹, BS; Monica Osgood², BA; Vibha Sazawal¹, PhD; Rita Solorzano¹, MA, CCC-SLP; Sinan Turnacioglu¹, MD

¹Floreo Inc, Washington, DC, United States

²Celebrate the Children, Denville, NJ, United States

Corresponding Author:

Sinan Turnacioglu, MD

Floreo Inc

1875 Connecticut Ave NW

Washington, DC, 20009-6046

United States

Phone: 1 2402449473

Email: sinan@floreotech.com

Abstract

Background: Advances in virtual reality (VR) technology offer new opportunities to design supports for the core behaviors associated with autism spectrum disorder (ASD) that promote progress toward optimal outcomes. Floreo has developed a novel mobile VR platform that pairs a user receiving instruction on target skills with an adult monitor.

Objective: The primary objective of this pilot study was to explore the feasibility of using Floreo's Joint Attention Module in school-aged children with autism in a special education setting. A secondary objective was to explore a novel joint attention measure designed for use with school-aged children and to observe whether there was a suggestion of change in joint attention skills from preintervention to postintervention.

Methods: A total of 12 participants (age range: 9 to 16 years) received training with the Joint Attention Module for 14 sessions over 5 weeks.

Results: No serious side effects were reported, and no participants dropped out of the study because of undesirable side effects. On the basis of monitor data, 95.4% (126/132) of the time participants tolerated the headset, 95.4% (126/132) of the time participants seemed to enjoy using Floreo's platform, and 95.5% (128/134) of the time the VR experience was reported as valuable. In addition, scoring of the joint attention measure suggested a positive change in participant skills related to the total number of interactions, use of eye contact, and initiation of interactions.

Conclusions: The study results suggest that Floreo's Joint Attention Module is safe and well tolerated by students with ASD, and preliminary data also suggest that its use is related to improvements in fundamental joint attention skills.

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KEYWORDS

autism spectrum disorder; interpersonal skills; virtual reality, instructional

Introduction

Background

Autism spectrum disorder (ASD) is a heterogeneous neurodevelopmental condition characterized by variable degrees of impairment in social communication and restricted and repetitive patterns of behavior [1]. Prevalence rates of ASD have increased over time but show significant variability

worldwide. In the United States, 1 in 40 children carries a diagnosis of ASD according to a 2016 survey of parents [2].

Although much attention has been paid to the pathogenesis and diagnosis of ASD, there remains a clear need for effective support for the core symptoms of ASD. Ideally, implementation of such supports during childhood will lead to optimal outcomes in adult life.

The economic impact of supporting individuals with ASD can be substantial for children with ASD. In the United States, the

national cost of supporting children with ASD is estimated at US \$61 billion in total [3], and in the United Kingdom, services and support are estimated at over £25 billion each year [4]. Special education expenses account for a large percentage of this estimate. Per year, the economic impact of supporting the health care and education needs of children with ASD has averaged more than US \$17,000 per child. Students with ASD incurred higher school costs than their peers without ASD [5].

In addition to educational needs, students with ASD can require significant therapeutic support during their years in school. A survey of special education data noted that services included speech language therapy for 66.8% to 85.2% of autistic students, whereas 34.6% to 44.6% of students had behavioral services in place. This study noted that the significant number of students receiving speech language and occupational therapy was “consistent with the severity of communication impairments and with the pervasive effects of ASDs on activities of daily living” [6].

Optimal outcomes at as young as 8 years of age have been described for children with ASD who had initially been diagnosed before 5 years of age, with a percentage no longer meeting diagnostic criteria for ASD and having no significant differences in functional skills from peers without a history of ASD [7]. Individuals with such optimal outcomes were noted to have milder social symptoms than others who maintained a high-functioning ASD profile into young adulthood.

Children with ASD present with a range of social communication symptoms, including deficits in receptive and expressive language development, response to name, eye contact, appropriate use of gestures, and imitation skills. Joint attention, in particular, is a foundational social communication behavior that is often impacted during early development in children with ASD. Joint attention is a skill that involves responding to bids for attention as well as being able to initiate bids for attention. Older children with ASD who exhibit more developed language skills were noted to have shown better joint attention in early childhood [8]. Conversely, impairment in joint attention in early childhood is related to limited language development by school-aged children with ASD [9]. Joint attention is seen as a pivotal skill for the development of more advanced communication and social skills [10-13]. The ability to initiate joint attention in children with ASD is related to enhanced social interaction competence [14]. As such, joint attention has been studied as a target for interventions in children with ASD [11,15,16]

Given the increasing prevalence of ASD in the population, the impact of persisting problems in social communication, daily living skills, and the high societal costs associated with supporting individuals with ASD, it is critical, and timely, to develop innovative means of delivering opportunities for learning to affected children. Among a range of approaches, technology has been suggested and long researched (since the 1970s) as a potentially good fit for ASD populations. As such, and along with advances in virtual reality (VR) technology, head-mounted displays (HMDs) and virtual environments now offer new opportunities to design opportunities to target some

of the core needs associated with ASD and promote progress toward optimal functional outcomes.

VR has been defined as a form of technology that presents a user with the opportunity to interact with computer-generated content while simultaneous engagement with the real world is limited [17]. This means that when a user puts on a pair of goggles, she will have the opportunity to see, hear, and manipulate an environment that is completely different from her real environment. When a virtual environment is created to meet the needs of a particular user, the user’s attention can be directed to specific elements by highlighting important information and filtering out extraneous information. Strickland described several elements of VR that were particularly relevant to meeting the needs of individuals with ASD, including a primary visual and auditory world that fits the typical learning preferences of this population, safe learning situations to repetitively practice daily living skills, and modification of the virtual environment to support generalization [18]. Immersive mobile VR utilizes a smartphone that is placed in an inexpensive headset and can provide an accessible and affordable experience. Furthermore, when the image that the user is seeing can be made visible on a tablet, an adult can provide monitoring, supervision, and coaching to support skill development. Virtual environments can provide engaging activities that cannot be offered in typical real-world therapy contexts, such as interaction with exotic animals or lessons that place users in scenarios that are difficult to replicate over multiple therapy sessions. This can serve as a powerful way to support learning in individuals with ASD.

VR has been actively studied for use in various aspects of health care, including health care provider training [19], pediatric pain distraction (eg, Smileyscope [20]), and stroke rehabilitation [21]. Its application has also been investigated to support mental health conditions, laying the groundwork for research on the potential benefit of VR for individuals with ASD.

Existing research compares VR exposure for social anxiety disorder with traditional in vivo exposure [22]. Both in vivo and “in virtuo” treatments were effective, but VR was much more practical for therapists. In another study, cognitive behavioral therapy (CBT) treatment for panic disorder that included a VR component was as effective as traditional CBT treatment, but the therapy that included VR required fewer sessions [23].

VR treatment was as effective as traditional CBT for treatment of arachnophobia in children [24], although there was some concern that children were more afraid of virtual spiders than real spiders. One way to address this concern is to let children know ahead of time what they are going to see in the virtual world, such as only characters of normal size, with no supernatural abilities.

Participants in a randomized controlled trial who received VR-based exposure therapy for posttraumatic stress disorder (PTSD) were helped more than those who received traditional PTSD treatments [25]. PTSD symptoms were measured using the Clinician-Administered PTSD Scale.

One reason for considering VR as an approach is in part due to positive results from previous research—they have shown

promising outcomes. Researchers at Politecnico di Milano have undertaken a pilot study using supervised low-cost VR via Google Cardboard on a small sample of 5 children with varied developmental disabilities including ASD [26,27]. The results have been promising. The children in the study accepted the Google Cardboard headset, and therapists found the therapy easy to use and beneficial to their clients. The therapeutic content is a storytelling app that requires the user to maintain eye contact with a virtual character for the story to continue, thus developing attention and engagement skills.

In another pilot study, 29 adults with ASD used an HMD (Oculus Rift), first for 10 min, and then possibly for a longer session at a later date [28]. Although the content was not therapeutic, it was entertaining and offered similar physical effects to the proposed theoretic content. A recent systematic review by Bradley and Newbutt noted the limited scope of existing research and the need for more robust ongoing investigation in the potential of VR HMDs for learning in individuals with ASD [29].

Another recent study asked 3 children (aged 10-13 years) with ASD using an HMD to improve social understanding and social skills [30]. These participants used the VR-based therapy once per week for 6 weeks. All subjects completed all sessions, and therapists report that the treatment modality was motivating. All subjects showed improvement with regard to targeted behaviors at the end of the study.

In all VR-based therapies, there is the potential for unwanted physical side effects from being in a virtual environment. These side effects are similar to motion sickness or simulator sickness and are often called cybersickness. Symptoms include dizziness, nausea, eye strain, and fatigue. Best practices for clinical trials involving VR-based therapy include informing users about potential risks, monitoring users as they use VR, informing users how to minimize side effects, and designing VR environments to prevent as many causes of sickness as possible.

In practice, VR therapy for anxiety disorders involves limited amounts of VR exposure spread out over a suitable length of time, and side effects are not a problem for most patients. However, it should be noted that individuals with autism often have comorbid sensory processing disorders, which can increase or decrease the likelihood of unwanted side effects. Newbutt et al found that only 4 of their 29 participants with ASD dropped out due to cybersickness [28].

To better understand the ability of children with ASD to tolerate VR using modern HMDs and to assess for the occurrence of adverse effects related to VR use, the authors developed an exploratory study evaluating the safety and feasibility of the Floreo VR platform.

Objectives

The primary objective of this pilot study was to determine feasibility for using the *Floreo Joint Attention Module* to support joint attention skills in a VR setting in students with ASD

attending a special education school. Safe use, potential adverse effects, and tolerability of Floreo's VR software by school-aged participants were of particular interest in conducting this pilot study. A secondary objective was to explore the changes in participant joint attention skills over time by using a novel joint attention assessment for school-aged children. This was an open-label pilot study with no control group.

Methods

Participants

Eligible participants were recruited from the student population at Celebrate the Children school. Celebrate the Children is a private special education school. The school's mission highlights the use of state-of-the-art interventions to support the learning needs of children with social and communication challenges such as seen in ASD. Because this pilot study focused on the feasibility of using the Floreo Joint Attention Module as an educational support and as an element of the normal summer camp curriculum at a special education school, it was deemed to be exempt from review by an Institutional Review Board. Instead, the initial pilot proposal was reviewed by an outside consultant with direct feedback incorporated in an edited and updated version of the protocol that was used for the pilot study.

Potential participants were identified by Celebrate the Children staff. Families were sent a SurveyMonkey questionnaire to collect demographic and health information to determine eligibility based on inclusion and exclusion criteria. SurveyMonkey, which was also used to collect pre- and postsession information throughout the pilot, is Health Insurance Portability and Accountability Act (HIPAA) compliant for confidential management of protected health information.

Inclusion criteria consisted of an age between 7 and 18 years and diagnosis on the autism spectrum (or any diagnosis of ASD, autistic disorder, Asperger syndrome, pervasive developmental disorder, or pervasive developmental disorder, not otherwise specified). Exclusion criteria were history of seizures or known photosensitive response on electroencephalogram, migraines, vertigo or other serious balance disorder, or psychosis or other disorder disrupting the ability to distinguish reality from nonreality. In addition, families were also asked about their child's expressive communication level, augmentative and alternative communication techniques, prescribed and over-the-counter medications used, vision screening, problems with vision, use of corrective lenses, and history of problems with VR and 3D entertainment (Table 1).

Participants ranged from 9 to 16 years of age. Consistent with broader ASD demographics, 10 of the 12 participants were male. Nearly half of the participants were described by their caregivers as pre- or nonverbal, and another third were described as minimally verbal. Three-quarters of participants made use of some form of alternative augmentative communication (Table 2). All subjects were able to follow simple verbal directions.

Table 1. Characteristics of pilot study participants (N=12).

Characteristics	Value
Age (years), mean (range)	13.5 (9-16)
Overall participation, n (%)	12 (100)
Gender, n (%)	
Male	10 (83)
Female	2 (17)
Caregiver-rated verbal skills, n (%)	
Verbal	3 (25)
Minimally verbal	4 (33)
Pre- or nonverbal	5 (42)
Alternative augmentative communication used, n (%)	
Yes	9 (75)
No	3 (25)
Medication use, n (%)	
Yes	6 (50)
No	6 (50)
Corrective lenses, n (%)	
Yes	5 (42)
No	7 (58)
EEG^a performed in the past, n (%)	
Yes	7 (58)
No	5 (42)

^aEEG: electroencephalogram.

Table 2. Forms of augmentative and alternative communication used (N=12).

Communication approach	Value, n (%)
Pictures or symbols	3 (25)
Communication book or board	2 (17)
Electronic communication	7 (58)
AAC ^a app	2 (17)
Keyboard or letterboard	3 (25)
American sign language	1 (8)
Picture exchange communication system	1 (8)
Facilitated communication	4 (33)
Rapid prompting	3 (25)

^aAAC: augmentative and alternative communication.

Of note, for 2 of the participants, baseline responses indicated that the participant regularly took prescribed or over-the-counter medication and that the participant would be on the same medication schedule over the summer, but details were not provided on the specific medications taken.

For informed consent procedures, parents of eligible participants were sent consent and assent forms via DocuSign. A phone call was arranged to discuss the study with a parent and the eligible

participant, to answer any questions and to obtain the participant's assent. Parents and eligible participants sent back signed consent forms through the confidential DocuSign process. Assent was obtained in person by study staff during the initial study visit. In addition to the consent and assent forms, families were also provided a child-oriented brochure, in comic book form, about VR, how to experience it, and possible side effects.

To explore this pilot study's primary objective of the feasibility of using Floreo's Joint Attention Module with school-aged children with ASD, data collection focused on reports from school staff serving as monitors for the study participants during the VR sessions. In addition, evidence of physical side effects, discomfort, and distress was reported as well by monitors to explore the safe use of Floreo's module. The secondary objective of the potential impact of the Floreo VR experience on participants' joint attention skills was assessed through a novel play-based behavioral assessment, as described in further detail below.

Teaching Approach

The Floreo Joint Attention Module is software that offers a supervised VR experience for individuals with ASD. Floreo's module provides a 3D immersive scene for Google Cardboard-compatible smartphones and a supervisory overview that can run on smartphones or tablets. To use the software, a monitor, who can be a therapist, teacher, or parent, places the smartphone into a Google Cardboard-compatible VR HMD and then assists the individual with ASD in putting on the HMD. The monitor guides and supervises the user on a device (tablet or smartphone) paired with the user's device over a network connection (Figure 1).

The instructional content consists of a Joint Attention Module including separate learning cards addressing specific subskills necessary to develop appropriate joint attention behaviors. Each learning card consists of a VR environment in a safari-themed setting, complete with animals designed to draw the student's attention when necessary. Users proceed through learning cards sequentially to achieve the set goals related to the demonstration of target joint attention subskills. An avatar in the virtual environment initiates and responds to joint attention bids and can also verbally prompt the user when needed to make further

progress through a learning card to achieve goals. The monitor tracks the student's engagement and progress through each learning card and provides redirection and feedback as necessary. The monitor's display provides a broader view of the learner's display along with a control panel that allows the monitor to select options and guide the learner through a lesson (Figure 2; a video of the monitor view of the Joint Attention Module is presented as Multimedia Appendix 1).

In this pilot study, the Floreo Joint Attention Module was implemented in a special education setting by a school staff member working with a student during summer camp.

Participants were engaged in 1 to 2 VR episodes per session. Each VR episode lasted no more than 5 min, with a break in between the episodes for at least 3 min. Sessions occurred 3 days per week, with at least 48 h between sessions. A total of 14 VR sessions were completed over a 5-week period.

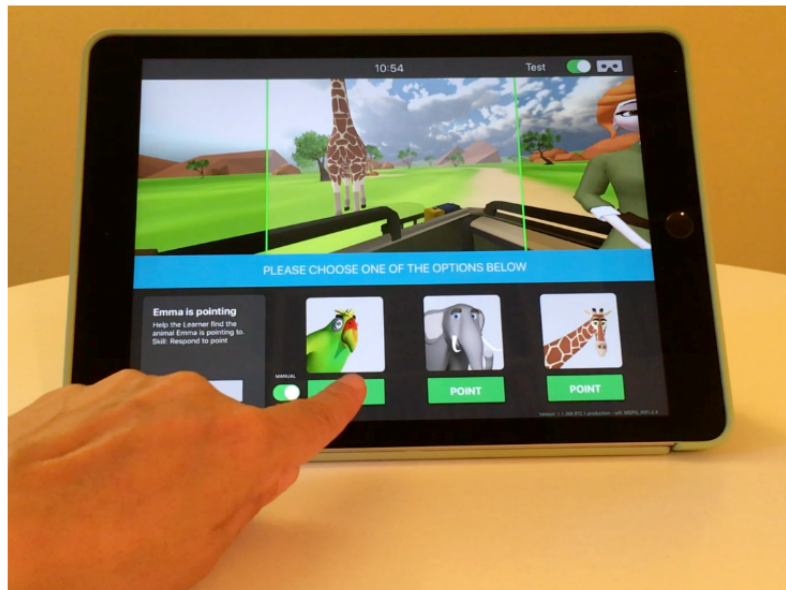
Floreo's team members conducted training with designated monitors in preparation for the pilot study. This was done on-site at Celebrate the Children school and included a presentation by Floreo's team members as well as opportunities to practice using Floreo's platform with feedback from Floreo's staff. Objectives of the pilot study, benefits of targeting and training joint attention skills, content of the Joint Attention Module Learning Cards, detailed instructions on the use of the Floreo platform, and the overall structure of the curriculum including pre- and postsession questionnaires were covered in the on-site presentation.

Prior to the first VR session, all participants underwent a joint attention assessment to capture their existing status of joint attention behavior. This assessment was a novel measure developed by the study team to directly assess joint attention skills in school-aged children (details of the assessment are available from the authors upon request).

Figure 1. The monitor uses an iPad to supervise the Floreo session with a learner.



Figure 2. An example of the monitor's view of a Joint Attention Module learning card.



A review of the joint attention and social communication measure literature revealed several challenges with the incorporation of existing measures in intervention research. At a high level, a recent review of social communication behavioral measures that might be used for treatment endpoints in ASD found that there were no measures appropriate to use without conditions [31]. Some of the measures reviewed were initially developed as screens for ASD-associated behaviors, such as the Social Responsiveness Scale) and the Autism Spectrum Rating Scales. Other measures included in the review are broad in scope, assessing either adaptive behaviors as a whole or a range of ASD-related behaviors, such as the Vineland Adaptive Behavior Scales, the Adaptive Behavior Assessment System, the Pervasive Developmental Disorder Behavior Inventory, and the Autism Diagnostic Observation Schedule (ADOS). The Communication and Symbolic Behaviors Scale (CSBS) and the Early Social Communication Scales are only appropriate for use in infants and toddlers, or young children with delayed communication skills. The CSBS in particular is only normed up to 2 years of age.

Another recent review of approaches to assessment of minimally verbal school-aged children with ASD found that measures addressing intentional communication “required high levels of expertise to code and interpret” or were “informal and nonstandardized” [32].

Of note, the Brief Observation of Social Communication Change has been developed based on social communication behaviors rated in the ADOS, and research is being conducted on its utility in clinical trials [33].

Bean and Eigsti published a joint attention measure for school-aged children and adolescents [34], but the elements of this measure did not map well with the objectives of our Joint Attention Module. In addition, there had been no further research on this scale at the time, and so the team made the decision not to use this particular measure.

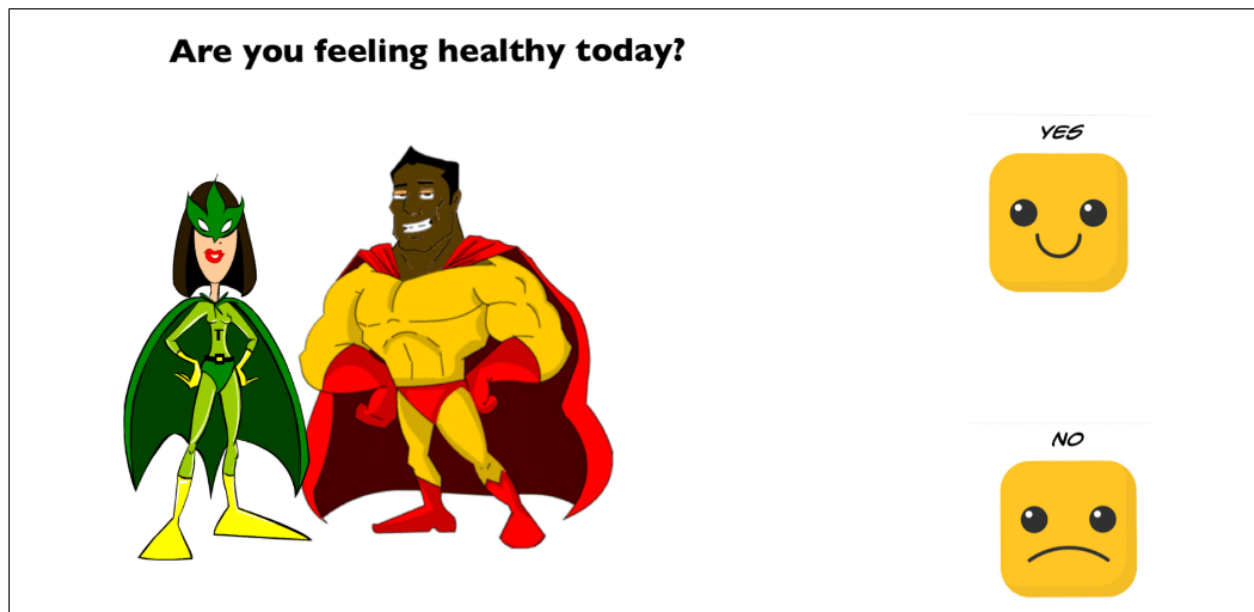
For purposes of this initial pilot study, the team instead decided to develop a novel joint attention assessment that could be

administered quickly, included play-based activities appropriate for school-aged children, and focused on the key joint attention behaviors targeted in Floreo’s VR Joint Attention Module. This measure was modeled after the joint attention measure found in the CSBS [35]. It was geared toward teenage students with limited verbal skills and needs in social reciprocity. The measure was designed to measure the instances of joint attention (specifically shifting eye gaze between a toy and a play partner) and used age-appropriate appealing toys (cause and effect and sensory toys as well as one that allows for turn taking games). It should be noted that while this measure assessed joint attention, this skill does not exist in a vacuum, but as a component of a socially reciprocal interaction, and so the assessment included other features of social reciprocity. In scoring the measure, the team looked for instances of social reciprocity (initiating, responding, continuing conversation beyond 2 turns, commenting, questioning, requesting, protesting, and refusal), response to greeting, shifting eye gaze in response to a point, and instances of prolonged eye contact toward a person or an object. Notes were taken on affect and mood during video review.

This joint attention assessment was then repeated by the same examiner, a speech language therapist, 4 weeks after VR sessions had concluded.

All VR sessions began with a greeting by the monitor, an employee of Celebrate the Children who was trained by the Floreo staff to use the Joint Attention Module. Participants then completed a SurveyMonkey questionnaire, the “Pre-session Check,” with written and visual components that inquired about general health status, balance, sleep, and interest in continuing with Floreo (as a means of verifying consent to participate in the Floreo app experience; sample image shown in Figure 3). The monitor then set up the Floreo system on an iPad used by the monitor and a phone used by the participant inside the HMD. The HMD was cleaned if necessary. The participant then put the HMD on and the monitor checked that the HMD had been put on correctly.

Figure 3. A question from the Pre-Session Check with written and visual components.



The first session consisted of 1 learning card episode to help participants orient themselves to the VR environment. At subsequent sessions, participants were given the opportunity to engage in 1 or 2 VR episodes per session. Investigators were told to stop therapy if the participant appeared to be experiencing or reporting any side effects. Prompts for side effects included preference for looking at the corners of the screen, change from standing to sitting or vice versa, fidgeting, changes in breathing pattern, sweating, verbalizing their distress (if possible), or holding hands to the head. Participants proceeded through a consistent schedule of Joint Attention Module sessions (Table 3).

In general, monitors were encouraged to have participants progress through learning cards in a sequential manner, from Learning Card 1 to Learning Card 6, but they were given the flexibility to adapt the learning card sequence as deemed appropriate for individual participants' needs. For example, if a participant seemed to get more frustrated with the demands of a given learning card, the monitor could return to an earlier learning card for the next episode. In this particular study, the monitors maintained the recommended schedule of sessions to support participant progress through learning cards.

Table 3. Joint Attention Module experience schedule.

Session number	Learning card number	Learning card name
Session 1	Learning Card 1	Explore
Session 2	Learning Card 2	Who made that sound?
Session 3	Learning Card 3	Watch me go
Session 4	Learning Card 3	Watch me go
Session 5	Learning Card 4	Emma is pointing
Session 6	Learning Card 4	Emma is pointing
Session 7	Learning Card 4	Emma is pointing
Session 8	Learning Card 5	Emma wants to look too
Session 9	Learning Card 5	Emma wants to look too
Session 10	Learning Card 5	Emma wants to look too
Session 11	Learning Card 6	Get Emma's attention
Session 12	Learning Card 6	Get Emma's attention
Session 13	Learning Card 6	Get Emma's attention
Session 14	Learning Card 1 plus 1 Learning Card of the participant's choice	Explore plus any of the above

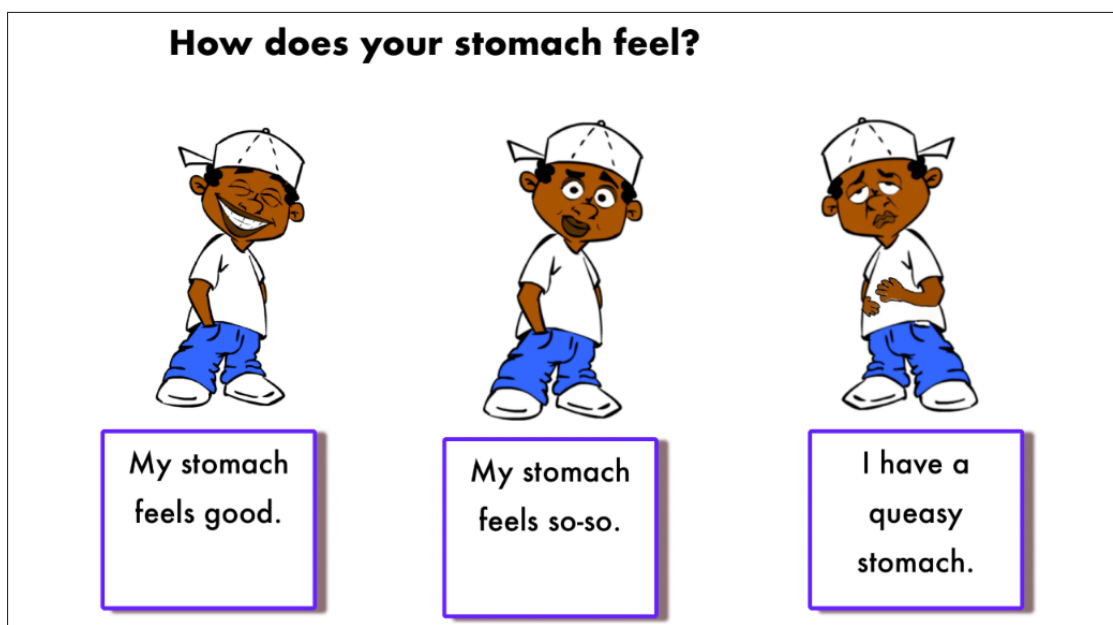
After each session, participants completed a SurveyMonkey questionnaire, the “Postsession Check,” with written and visual components that inquired about the level of alertness, eye discomfort, clarity of vision, headache, stomach ache, balance, and enjoyment of having used Floreo platform (sample image shown in Figure 4). The monitor also completed a SurveyMonkey questionnaire asking about participant’s tolerance of the HMD, perceived enjoyment of the VR session, any indication of negative side effects, and perceived value of Floreo VR sessions for the participant. (Survey questions are available from the authors upon request.) The questions addressing tolerance, enjoyment, negative side effects, and value

of the Floreo experience offered “Yes” and “No” answer choices. The final question on the monitor survey was a request for qualitative feedback on the participant’s experience and any additional information related to the VR session.

In addition, a short, simple hand-eye coordination activity was offered to participants after the VR session to support reorientation of their eyes to the real world. Participants then returned to their regularly scheduled day camp activities.

Data collected throughout the study was reviewed daily by study staff to explore the safe use and acceptance of the headset and Floreo VR experience by study participants.

Figure 4. A question from the Post-Session check with written and visual components.



Results

Virtual Reality Session Feedback

Overall, 14 Floreo VR Joint Attention Module training sessions were conducted over a 5-week period. Participants attended 80.3% (135/168) of sessions. Participants were able to complete 97.6% (164/168) of VR sessions attended. Incomplete sessions only occurred on the first day of the pilot, and afterwards school staff introduced acclimating strategies that helped ease the participants into the VR sessions, so all participants were able to complete sessions for the remainder of the study.

With regard to monitor survey data, a number of surveys were not completed because of participants’ absence during the pilot study period. One participant lost his glasses after the first 5 sessions, and, after a discussion between Celebrate the Children personnel and the Floreo team after 2 sessions of variable participation, he was not permitted to continue using Floreo VR for the final 7 sessions. In total, between participants’ absence and missing monitor surveys, the Floreo team received 79.1% of the total possible number of surveys (133 sessions with

completed monitor surveys compared with 168 total sessions conducted).

In summarizing monitor survey responses, several questions were left incomplete on postsession monitor surveys, affecting totals for the 4 key safety and usability questions.

Monitor surveys were analyzed to determine the percentage of “Yes” responses out of the total number of surveys received across all sessions (Table 4). Results indicated that 95% (126/132) of the time participants tolerated HMD use. Participants were rated by monitors as seeming to enjoy Floreo VR 95% (126/132) of the time. Negative side effects were described 9% (12/129) of the time. Ill effects that were described in open comments included participants bothered by the headset on 8 occasions, restlessness on 7 occasions, eye rubbing on 2 occasions, and fatigue on 1 occasion. Of note, 1 participant experienced 4 of the episodes of restlessness and another participant experienced 2 of the other restlessness episodes. In addition, 1 participant experienced 4 of the “bothered by headset” episodes, and another participant experienced 2 of the other “bothered by headset” episodes. Monitors rated Floreo VR sessions as valuable for participants 96% (128/134) of the time.

Table 4. Monitor survey responses.

Postsession monitor survey question	Surveys received (N)	Response (yes), n (%)
Did the participant tolerate wearing the headset today?	132	126 (95)
In your opinion, did the participant enjoy their VR ^a session?	132	126 (95)
Did you notice any signs of negative side effects?	129	12 (9)
So far, do you think the Floreo sessions have been valuable to the participant?	134	128 (96)

^aVR: virtual reality.

Despite the challenges some participants faced tolerating the HMD and VR experience on the first day of the study, following the acclimatization procedures implemented by Celebrate the Children personnel no participants dropped out of the study because of either intolerance of the HMD or VR environment, or secondary to side effects.

Participants completed the presession surveys at a 100% rate, and the postsession surveys showed a 98% completion rate. However, upon review and comparison with monitor survey responses, participants' responses were determined to be inconsistent that led the team to question the reliability of the responses.

Qualitative monitor feedback was positive based on survey results during the study and also in a poststudy debriefing. Monitors noted progress in participants' ability to utilize the app and increased comfort with the equipment. Monitors also saw the Floreo platform as having "a real potential to help our kids on the spectrum...definitely something that kids need..."

Joint Attention Assessment

Each participant's pre- and post-Floreo joint attention assessments were recorded. Video recordings for individual participants were later reviewed and coded by the Floreo team's speech language therapist to document the number of occurrences of specific joint attention behaviors. These

behaviors included the following: looks at activity/object; shift eye gaze; initiate requests; respond to requests; participant initiates interaction; participant responds to interaction; direct eye contact (participant initiated); follows a point; and points.

Lack of eye contact could not be attributed to lack of engagement with the activities in most cases. Overall, all the participants were either highly engaged or intermittently engaged with one or more of the activities. If a participant showed a lack of interest in one of the activities, it was abandoned for another activity. The level of involvement of 2 of the participants decreased somewhat during the posttest. In both of these cases, the participants were reported to have had some difficulty readjusting to the school setting. Additionally, the posttest for 1 participant was shortened to about 6.5 min as the individual appeared to be experiencing some anxiety during the assessment. In one instance, the participant seemed to become somewhat more engaged in the activities during the posttest.

In evaluating the results of the joint attention assessment, a meaningful difference was determined to be a change of more than 2 instances of a behavior between the pretest and the posttest.

Analysis of the pre- and post-Floreo joint attention assessment results showed that 10 out of the 12 participants demonstrated improvement in 1 or more key areas (total number of interactions, initiating interactions, and eye contact; [Table 5](#)).

Table 5. Change in scores of key behaviors on the joint attention assessment of pre- and post-Floreo Joint Attention Module experience.

Participant	Total number of interactions			Use of eye contact			Initiation of interactions		
	Prestudy (n)	Poststudy (n)	Change	Prestudy (n)	Poststudy (n)	Change	Prestudy (n)	Poststudy (n)	Change
1	9	13	4	1	0	-1	1	0	-1
2	10	14	4	1	2	1	2	1	-1
3	17	14	-3	8	1	-7	1	3	2
4	47	54	7	21	37	16	9	10	1
5	18	24	6	3	0	-3	4	6	2
6	43	76	33	22	57	35	9	12	3
7	14	14	0	0	2	2	5	4	-1
8	10	30	20	2	20	18	0	8	8
9	29	47	18	14	32	18	11	35	24
10	25	20	-5	4	10	6	6	11	5
11	24	32	8	20	27	7	0	6	6
12	23	29	6	10	16	6	13	12	-1

All interactions that were associated with specific types of communicative intents were counted and divided into 4 groups depending on whether the interaction included associated eye contact and/or intentional verbal/vocal components. The 4 groups included the following: interaction with eye contact and a verbal/vocal message, interaction with eye contact but without accompanying verbal message, interaction without eye contact but with verbal/vocal message, and interaction without eye contact and without verbal vocal message. Analysis indicated that 9 of the 12 participants (75%) showed an increase in the number of total interactions from pretest to posttest.

Another key behavior assessed by the team was eye gaze shift between an item or event of interest and a communication partner, outside of any other communicative act (such as requesting, gaining attention, responding). Of the 12 participants (58%), 7 demonstrated an increase in eye contact during interactions from pretest to posttest, and 4 of these individuals (33%) showed a pronounced increase in eye contact.

In addition, 5 of the 12 participants (42%) demonstrated an increase in instances of initiation of interactions from pretest to posttest.

In general, no meaningful increase was observed in requesting or in responding to requests between pre- and posttest.

Discussion

Principal Findings

In this study, Floreo collaborated with the special education school Celebrate the Children to collect pilot data on the feasibility and safety of using Floreo's mobile VR platform for training joint attention skills in children with ASD. In addition, the pilot data obtained on a novel joint attention measure designed for use in school-aged children with ASD suggests that training with Floreo's Joint Attention Module was related to improvements in social reciprocity skills in these children. Findings from this pilot study support ongoing research on the practical use of this platform and on the effectiveness of the joint attention training content on social communication skills in ASD.

Floreo's intervention is an immersive mobile VR system designed to support the development of fundamental social communication skills in individuals with ASD. Other research teams have studied the use of nonimmersive VR systems on social skills in individuals with ASD [36] or have used immersive VR to target daily living skills through the use of social story-inspired systems [26].

The research team also identified several key issues related to using VR to support the developmental needs of children with ASD. One concern raised frequently by professionals and researchers was the ability of individuals with ASD and sensory sensitivities to tolerate wearing the HMD and remaining engaged in a VR experience. On the first day of the pilot study, several participants had difficulty completing the session. As a result, Celebrate the Children personnel implemented acclimating strategies to help ease participants into the VR sessions, and all participants were subsequently able to complete the remainder

of attended sessions. No participants dropped out of the study because of inability to tolerate the use of the VR headset or participation in VR training sessions. One participant lost his glasses, and study staff determined that he should not continue in further sessions because of the fact that the participant might be at a greater risk for eye discomfort and headache without his corrective lenses. Owing to both the hypersensitivities experienced by some individuals with ASD and medical comorbidities such as gastrointestinal symptoms and seizures, there were additional concerns about the health and safety issues associated with the VR experience. Side effects were noted in less than 10% of sessions. Two participants in particular had a higher incidence of side effects that included restlessness and appearing to be bothered by the headset.

Another important element of this study was the successful implementation of pre- and post-VR session checks associated with the app itself. The pre-session check-in questionnaire can be used to gauge existing medical symptoms that might have a negative impact on the user's VR experience, as well as to confirm readiness to engage in the VR experience. The post-session questionnaire serves to capture symptoms that may have developed as a result of VR use, as well as to rate the user's level of engagement and enjoyment of the VR session. In surveys completed after working with participants, monitors at Celebrate the Children provided positive feedback regarding the feasibility of using Floreo's Joint Attention Module. In a high percentage of sessions, monitors reported that participants were able to tolerate the VR headset and seemed to enjoy using Floreo VR, and monitors also responded that the VR experience was valuable for participants.

A secondary objective of this study was to evaluate the feasibility of using a novel joint attention measure to rapidly assess the status of participants' joint attention skills before and after the VR support program. As noted above, there are no widely used measures available for focused assessment of joint attention skills in school-aged children. As improvement in this particular set of skills is the ultimate goal of using the Joint Attention Module in children with ASD, the study team wanted to begin an exploration of the effectiveness of this support in the target population. A review of the video-recorded pre- and postprogram joint attention measures suggested that conducting 14 sessions of VR-based joint attention skill training over 5 weeks was related to a higher total number of social interactions, more eye contact during interactions, and more episodes of initiation of interactions on the part of participants.

Limitations

Several limitations should be recognized in this pilot study. First, the study team did not compare the experience of using Floreo's VR Joint Attention Module with a control group of same-age peers receiving typical types of support at the school's summer camp or no specific social communication support. The primary objective of this pilot study was to explore the safety and feasibility of the use of Floreo's module by the target learner population, and further research was planned to specifically evaluate the effectiveness of the Floreo platform on social communication skills that will incorporate a control condition. Second, although the study team attempted to elicit

direct feedback from participants after each session, questionnaire responses were not consistent with what was noted by monitors or other observers. In addition, many participants' limited communication skills impacted their ability to independently complete the surveys. Therefore, the team focused on monitor feedback to generate an impression of the participant experience of using Floreo's module. On the basis of the paucity of published research on joint attention measures for school-aged children available at the time of initial study planning (as described in greater detail in the Methods section), the team developed a novel joint attention assessment for use in this study. Since the completion of this pilot study, new research has been published providing further support for the use of the Joint Attention Protocol in school-aged children [37], and the team plans to use this measure in future research studies. In addition, the study team will consider more optimal approaches to ensuring independence and validity of usability responses in participants with limited communication skills or

mild-to-moderate intellectual disability in future research study design.

Conclusions

Overall, the results from this pilot study are extremely promising for the potential of Floreo's module to be well received and used by individuals with autism and the therapists, teachers, and parents working with them. This introduces a new and innovative mechanism for providing support for social communication skills in individuals with ASDs. The long-term vision is for the Floreo VR platform to be used to develop a diverse set of lessons designed to teach a variety of skills in individuals with autism and other developmental disabilities. The Floreo app, designed to be used with the smartphones and tablets that are already accessible in many homes, classrooms, and therapists' offices, along with a low-cost HMD, can help reduce the costs and facilitate access to support for individuals with ASD and their caregivers.

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Conflicts of Interest

VR is the chief executive officer and cofounder of Floreo, Inc. VS is a cofounder of Floreo, Inc. RS and ST are employees of Floreo, Inc.

Multimedia Appendix 1

Video of the monitor view of the Joint Attention Module.

[MP4 File (MP4 Video)18134 KB - [pediatrics_v2i2e14429_app1.mp4](#)]

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Abbreviations

ADOS: Autism Diagnostic Observation Schedule
ASD: autism spectrum disorder
CBT: cognitive behavioral therapy
CSBS: Communication and Symbolic Behaviors Scale
HMD: head-mounted display
PTSD: posttraumatic stress disorder
VR: virtual reality

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Original Paper

A Parenting Behavior Intervention (the Strengthening Families Program) for Families: Noninferiority Trial of Different Program Delivery Methods

Karol Linda Kumpfer^{1*}, PhD; Jaynie Litster Brown^{2*}, BA

¹Health Sciences Center, University of Utah, Salt Lake City, UT, United States

²Strengthening Families Program LLC, Salt Lake City, UT, United States

* all authors contributed equally

Corresponding Author:

Karol Linda Kumpfer, PhD

Health Sciences Center

University of Utah

5215 Pioneer Fork Rd

Salt Lake City, UT, 84108

United States

Phone: 1 435 740 1453

Email: kkumpfer@xmission.com

Abstract

Background: The Strengthening Families Program (SFP) is an evidence-based parent training and youth life skills and drug prevention program traditionally delivered in group settings. Families attend parent and youth classes conducted by trained facilitators. Recently, a 2-disk home-use DVD series was created with the same SFP skills as the group classes for parents and the youth to watch together at home. Additional lesson material was added that included healthy brain development, school success, anger management, dangers of alcohol and drugs, and mindfulness. The SFP DVD reduces SFP delivery costs for agencies and logistic burdens to families. Creative applications of the DVD include holding SFP DVD family discussion groups of multiple families and using SFP DVD video clips as part of a shorter 10-week group class version for parents and the youth.

Objective: This study aimed to examine three different DVD implementation scenarios using a noninferiority trial, contrasting target outcomes with an age-matched sample culled from a national norm database of families who completed a standard SFP 14-week class.

Methods: The partial eta-square was used to compare effect sizes between the different delivery modalities for relevant programmatic outcomes. We adjusted the effect sizes by demographic measures to determine whether there were site-specific features influencing program outcomes.

Results: For the unadjusted effect size comparisons, 13 of the 15 indicated that the home-use DVD outperformed group norms with an average 0.13 effect size estimate difference across the comparisons (28% improvement in the effect size for DVD condition). Comparisons of the home-use DVD condition with the mixed DVD use conditions showed no discernable pattern where one condition consistently outperformed another. Adjusted effect sizes still reinforced the superiority of the DVD conditions; however, there was some shrinkage in the effect sizes as expected with the inclusion of relevant covariates.

Conclusions: The home-use DVD shows that it is possible to effectively deliver an affordable family-based intervention using alternative technology outside of the traditional group-based class format. In almost all of the comparisons, the DVD conditions outperformed the group norms, underscoring that low-cost DVDs or viewing the videos on the Web may provide a useful surrogate for costly group-based formats. Future studies may want to improve on the quasi-experimental design by examining programmatic differences based on delivery format using a randomized controlled trial, thus strengthening the causal framework regarding program effects. In addition, the assessment protocol relied on retrospective reporting, which, although this can limit response shift bias, does not separate data collection in time as with a true pre- and posttest design.

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KEYWORDS

parenting; youth drug prevention; family skills; DVD; Strengthening Families Program; internet; noninferiority trial

Introduction

Background

Adolescence is a critical period of brain development, with a vulnerability for neurotoxic substances, such as alcohol and drugs [1,2], and a high risk for addiction [3]. However, in the 2018 Monitoring the Future survey, 30% of 12th-grade students reported drinking [4]. Parenting skills and youth drug prevention programs have, therefore, become a widely used antidote to youth alcohol and drug use. Several reviews have shown this modality of prevention to be effective following rigorous efficacy trials conducted by independent research teams in different settings and with different populations [5-7]. The Strengthening Families Program (SFP) offers parenting skills training in combination with youth life skills and drug prevention. It is an evidence-based family skills training program with consistent evidence of effectiveness obtained from randomized controlled trials (RCTs) and quasi-experimental replications spanning >30 years [8]. The program's theoretical base is the tested Social Ecology Model [9] detailing mechanisms through which risk and protective factors contribute to adolescent drug use and delinquency [10]. SFP harnesses the vital role played by parents in the socialization of their children [11,12]. Hallmark features of SFP family skills training include reinforcing the need for loving family bonds, setting clear rules against antisocial behavior, and ensuring that parents supervise their child's activities. These skills help prevent rule transgressions and avoid instigation of delinquency through the formation of deviant peer bonds.

SFP was originally tested and found effective in a 4-condition dismantling RCT with substance-abusing caretakers of children aged 6 to 11 years [13,14]. This original RCT found that combining parents, family, and children's skills training produced the best results. In its traditional group-delivered instructional format, the highly structured program usually begins with dinner and involves 14 weekly sessions, with separate 1-hour skills training sessions for the parent and youth followed by a joint family skills practice session. Delivery is conducted by gender-balanced and culturally sensitive family coaches who are trained to teach and reinforce newly acquired skills. Cost to deliver the 14-week program is about US \$1000 per family, depending on personnel fees and the amount spent on attendance incentives (eg, food and transportation).

The program has been tested with parents with children of varying ages [15,16] in urban [17] and rural populations [18,19] and demonstrated to be culturally sensitive for most groups and local customs [20,21]. International applications have included effectiveness trials conducted in Ireland [22] and Thailand [23]. A shorter, 7-session version, the Iowa SFP (ISFP 10-14) was created for low-risk families as part of a collaborative partnership with Dr. Kumpfer and investigators at Iowa State University and has been tested in several randomized trials in Sweden [24,25], Poland [26,27], Italy [28], Germany [29,30], and England [31,32].

Recently, to improve dissemination or *scaling out* prevention programs [33], an 11-lesson home-use DVD video series (SFP DVD) targeting families with children aged 7 to 17 years (SFP 7-17) was created for parents and youth to view together at home [34]. The 2-disk set, with an alternate Spanish audio track, is marketed at US \$5 through a nonprofit foundation, with discounts for orders over 100 copies. In addition, the DVD is made available through internet streaming for families to view for US \$5 per year [35]. The SFP DVD set includes handouts in both Spanish and English that can be printed off the disks themselves or downloaded free from the internet.

The SFP DVD was designed specifically to target key risk factors that contribute to youth substance use and teaches skills in bonding, setting boundaries, and parental monitoring. It included new material on healthy teen brain development, an animation of how neuroplasticity works through repeated and reinforced practice, tips for achieving school success, a kinesthetic tool for anger management, and brain scans from respected scientists showing the harms of alcohol and drugs. Mindfulness training was added to the SFP DVD in 2017 to help improve emotional regulation in parents and the youth who suffered adverse childhood experiences. It also teaches social skills that the youth need to resist negative peer influences, including how to say *no* to harmful things and still keep their friends.

Repetitive skill practice is an essential component of the SFP curriculum, and viewers are routinely invited to pause the DVD at key intervals and practice the skills they just learned. Each week, the parents and youth are given skills to practice and fun family goals to work toward. The SFP DVD thus offers a fairly complete package of family relationship tools that are targeted to reduce risk factors and increase protective factors related to substance use and delinquency.

Converting a group-based program to a video or DVD delivery format presents several logistic and methodological challenges. For instance, although the DVD provides greater program implementation fidelity, it does not involve group discussions that increase buy-in and foster problem solving. Similarly, the DVD does not include a family coach or facilitator to provide reinforcement and encourage practice—all considered essential active ingredients of the SFP program. Furthermore, the SFP DVD instructional modality departs from the traditional delivery methods that train the parents and youth separately for the first hour, followed by a joint skills practice session in the second hour. The ability for families to discuss their respective approaches to parenting and child management is another core active ingredient that contributes to the success of SFP.

Practicing skills, receiving immediate feedback, and learning about the different contexts of how skills can be used all foster behavioral improvements for both the parent and child. This raises the question of whether a joint parent-youth skills training program could work using video instruction with parents and the youth simultaneously engaging and observing the other during their instruction.

Contrasting Delivery Modalities

This study compared outcomes from the standard group-based facilitator-led approach to various mixed uses of the SFP DVD using a noninferiority trial [36]. In contrast to the traditional *superiority* trials that use a placebo control condition (ie, minimal contact or an attention control), noninferiority trials are meant to compare interventions where the emphasis is on showing that a new treatment is *no worse than* a standard treatment, which in this case is the existing SFP 14-week group format. Noninferiority trials are usually implemented in the pharmaceutical industry where a drug treatment is contrasted with another that has already been shown to be effective; however, the second drug offers some amelioration of side effects or improved pharmacokinetics. The basic concept of this type of trial mirrors the present context where an intervention (standard SFP) has already been proven effective, but the second one (SFP DVD) offers some improvement in delivery and is more cost-efficient.

The focus here is whether the DVD can produce effects comparable with (or no worse than) the group-based program. As the DVD is more cost-effective, convenient to use, and has broader dissemination capability, it is valuable to test the performance of this delivery modality in comparison with the traditional group-based instructional methods. Before presenting the empirical findings, we first briefly discuss the theoretical rationale behind the SFP program, including discussion of the program's active ingredients. We then describe the different settings where the SFP DVD has been implemented since its creation in 2012. We conclude by presenting empirical findings based on analyses contrasting the different delivery modalities.

Theoretical Framework

The SFP is based on Family Systems intervention theories elaborated by Bowen [37], who observed in his clinical study that children's problems were often rooted in the way parents dealt with or treated their children. The skills training format was influenced by the behavior change techniques of Skinner Operant Conditioning [38] and confirmed by Bandura Social Learning Theory, cognitive behavioral theories, and self-efficacy theories [39]. Teaching parents to use positive reinforcement (attention and praise) for wanted behaviors and ignoring unwanted behaviors were adapted from Patterson Cognitive Behavioral Change theories and skills training methods developed to reduce psychopathology in children and families [40,41]. These explanatory systems are then integrated with therapeutic skills-based techniques, including interpersonal and cognitive problem-solving methods [42] and relationship counseling strategies [43].

Patterson coercive family processes theory of delinquency and antisocial behavior [44] provides a social-interactional perspective highlighting the vital role family dynamics play in socializing the child for both pro- and antisocial behaviors. According to this perspective, various social-interactional contexts, mainly occurring in the home, can promote *coercive processes* that enmesh the parent and child in maladaptive patterns of behavior [45].

The cycle often begins with harsh and inconsistent discipline of a difficult child, followed by lax parental supervision and the inability of parents to socialize the child into adopting prosocial behavior. The child responds to the harsh environment by aggressively acting out in an effort to coerce the parent into submission, setting into motion a recurrent pattern of maladaptive parenting practices and hostile communication. To avoid further conflict, the parent often withdraws or, through frustration, chooses to disregard the child's need for training rather than confronting additional hostility. These early patterns of problem behavior continue when the child enters school, where he or she transfers the negative behavioral interactions learned at home to their teachers and peers. This often contributes to rejection by the norm-following peers, leading the affected child to gravitate to deviant youth, who positively reinforce and shape their maladaptive behavior [46,47]. Their negative behavior increases levels of conflict in the home, which results in lower levels of parent-child involvement, which is related to poor parental monitoring and association with deviant peers [48].

Breaking this cycle requires training the parents to more effectively manage their child by spending quality time together doing fun activities, praising positive behaviors, using improved communication skills, setting expectations, and inculcating positive values. Parents also need to establish clear standards of behavior; give mild, consistent consequences for misbehavior; and monitor their child's activities and peer relations [49,50].

The importance of parental influence in children's behavior is supported by the statistically tested causal model using Structural Equations Modeling (SEM). This SEM-tested causal model found that 3 family cluster variables—family attachment or bonding, communication of positive family rules against substance use (boundaries), and parental supervision—were the most critical in protecting the youth from substance abuse [8]. These family-focused interventions proved to be particularly effective in reducing behavioral health disorders, drug use, and intermediate risk factors, such as conduct disorders, aggression, and family conflict. They also improved protective factors, such as social competencies, peer resistance skills, family and school bonding, school performance, and family organization and cohesion [17]. Similar SEMs have been tested for school failure, delinquency, teen pregnancy, and alcohol and drug use with similar results [51].

Active Ingredients

SFP lessons begin with skills to reduce hostility and create warm, loving relationships between the parents and child. The parents learn and practice nurturing skills, including one-on-one playtime (allowing the child to choose the activity), giving positive attention through daily looking for and complimenting the good and avoiding criticism; engaging in pleasant communication, including active listening and validating each other; eliminating communication boulders (eg, yelling, swearing, and sarcasm); and learning to have fun weekly family meetings.

Later, skills involving boundary setting are introduced, with each family making their own personal family rules with input from their children. A reward system is set up for following

house rules. This lays the foundation to introduce the skill of positive discipline that involves teaching and rewarding the behaviors parents want, with each family (parents and their children) deciding on fair, mild negative consequences that will be delivered calmly and consistently for misbehavior.

The lesson material on problem solving, stress reduction, thinking ahead to stay out of trouble, anger management, school success, substance use education, and parental monitoring follows. Finally, family traditions, values, and community service are introduced, with encouragement for children to become a positive agent of change.

Skills training for children parallels the parent lessons, with additional emphasis on emotional regulation and self-management skills, peer drug refusal and social skills, and the importance of choosing prosocial friends.

The core active ingredients of SFP can be administered in varying dosages, allowing a service provider (eg, family service agency) to choose the level of intervention according to the risk levels of individual families. Lower dosage versions, including the SFP DVD and 10-session group classes, are used for *universal* prevention with low-risk families. Higher dosages are used for *selective* and *indicated* prevention and treatment in high-risk families with at-risk youth, delinquents on probation, or child maltreatment cases, with trained family coaches often delivering the SFP DVD in-home to those most at risk.

Methods

Strengthening Families DVD Program Delivery Methods

Although the SFP DVD was created primarily for home use, various implementation strategies have evolved to include creative, off-label ways to incorporate the DVD. Table 1 shows the different settings where the SFP DVD has been implemented. Of these, 3 strategies involving the SFP DVD are the focus of the present analyses: (1) home-use with *no family coach*, (2) viewing the SFP DVD as part of a family discussion group, and (3) shorter 10-week SFP 7-17 group classes for parents and the youth that also included DVD video clips.

Although worthy of mention, the remaining venues listed in the table are not examined in the effect size (ES) comparison because they differed in the assessment protocol (using an abbreviated survey) and study design (true pre-posttest rather than a retrospective design) or delivery method (to parents via middle school health class assignments that required viewing only 3 lessons—the Introduction and lessons 8 and 9). The 3 primary settings examined in this paper (DVD at home, DVD family discussion group, and parent-youth classes plus DVD clips) all used a quasi-experimental design with retrospective pre-post reporting and are briefly described here.

Table 1. A total of 5 settings that utilized the Strengthening Families Program DVD for family-based prevention.

Setting, Study Method (year)	Study design	Sample number ^a	Retention ^b	Recruitment method	Implementation information
Home-use DVD					
Families viewed DVD at home with no coach—2 rounds (2012)	RPP ^c	55	27 (23); 34 (32)	Letters mailed by school to parents asking to view	SFP ^d DVD mailed to families in the Salt Lake City School District who volunteered to watch the DVD and take a Web-based survey in exchange for donated prizes; parents took a standard SFP survey via SurveyMonkey; challenges ^e —finding volunteers to watch the DVD lessons
Asian Indian families viewed DVD at home—no coach (2013)	RPP	26	28 (26)	Flyers in Indian stores and temples	Asian Indian families watched the DVD at home and took a paper-and-pencil survey; contacted via flyers at Indian grocery stores; challenges—parents not home, getting parent consent forms signed when delivering DVD to each family
DVD family discussion group					
Open Classroom Elementary School—Library (2013)	RPP	9	9 (9)	Parent Teacher Association newsletter and flyers at school	School counselor invited parents to attend; 9 finished a 10-week class and took a paper-and-pencil survey; parents eager to come and learn
Road Home homeless shelter (2013)	RPP	11	11 (11)	Notices posted in Road Home shelter	11 single mothers and children finished the course; others found housing and left before the course ended; additional nutrition information included
Washington County Youth Crisis Center (2014)	RPP	9	9 (9)	Flyers posted in schools	Held in Hurricane, UT ^f ; money for dinners from Youth Crisis food budget; gave staff time off during workday to teach SFP class at night
The Journey (2015)	RPP	16	16 (10)	Youth in detention; parents came to Friday night class	Parents and their delinquent child who was in custody watched DVD as a group; the youth returned home for the weekend, and then received visit at home from an SFP coach to practice new skills
Strengthening Family Program class plus DVD clips^g					
UT-Salt Lake City group classes, 2 sessions—spring and fall (2013)	RPP	29	8 (8)	Flyers and phone calls	Program taught by college student interns; food and evaluation funded by University of Utah grant
UT-UVU ^h intern classes (2013)	RPP	115	19 (13), 6 (6); 5 (5), 27 (27); 8 (8); 8 (8); 10 (10)	Middle school counselors advised parents to attend	SFP for families with children aged 7-17 years classes taught 3 times a year by UVU student interns at multiple sites; schools asked families to attend because of child behavior issues; food donated by a local church
UT-Payson City (2014)	RPP	11	11 (11)	Flyers posted at schools	Classes funded by the city council; participants self-selected to attend; had a waiting list of parents to attend
TX ⁱ -Conroe—Spanish (2016)	RPP	24	24 (13)	Church flyers	All Spanish speaking; held at a church; the pastor wanted all families to attend at once; hired extra coaches to teach; church members made food
NV ^j -Reno—Boys and Girls Club ^g (year 1; 2016)	TP ^k	32	— ^l	Flyers at Boys and Girls Club	Taught at multiple sites; used a shorter 48-question survey that was mailed to agencies and analyzed by an independent evaluator
NV-Reno—Boys and Girls Club ^g (year 2; 2018)	TP	98	—	Flyers at Boys and Girls Club	Waiting list for families to attend; surveys analyzed through Gravic Remark system
View DVD in-home with family coach					

Setting, Study Method (year)	Study design	Sample number ^a	Retention ^b	Recruitment method	Implementation information
North Carolina agencies (year 1; 2017)	TP	56	—	Family coaches taught SFP via DVD, in-home training, and counseling program	Year 1: SFP taught as part of in-home intensive therapy program to low-functioning families in 7 behavioral health agencies in North Carolina; Brilliance Analytics pre- and post surveys mailed to clients with self-addressed stamped envelope for return mail
North Carolina agencies (year 2; 2018)	RPP	47	—	Same as above	Year 2: same survey questions in a new format; scanned into a computer and analyzed through Gravic Remark software system
View DVD in-home as school health class assignment					
Salt Lake City School District ^m (2012)	Mixed	364	—	Middle school health teachers gave parents SFP DVDs with an assignment to watch 3 lessons with their child and fill in and return home worksheets	Students received the DVD in the 7th grade health class; mandatory homework to watch 3 lessons with parents (Introduction and lessons 8 and 9) and take a brief pre-post survey; a year later, those students took the Student Health and Risk Prevention ⁿ survey in the 8th grade; students who had an assignment to view the DVD said that parents talked to them more about alcohol, tobacco, and other drugs and checked up on them more than students who did not receive the DVD; 8th grade binge drinking rates also declined by 50% in the school district; Bach Harrison conducted analyses

^aNumber of families initially enrolled.

^bNumbers in parentheses indicate the final tally of parents who provided a pre- and posttest and completed the course.

^cRPP: retrospective pre-posttest.

^dSFP: Strengthening Families Program.

^eChallenges depended on experience-level of family coaches and site coordinator; first year challenges (except for church group and court-ordered families) were mainly getting enough people to attend.

^fUT: Utah.

^gSFP 7-17 for families with children aged 7 to 17 years; group classes are 10 weeks long versus 14 weeks for regular SFP group-based, facilitator-led classes. Facilitators showed clips of the DVD during class, showing examples of skills they were teaching.

^hUVU: Utah Valley University.

ⁱTX: Texas.

^jNV: Nevada.

^kTP: true pre- or posttest; studies using TP or mixed design were not used in the effect size analyses.

^lNot applicable.

^mAnalyzed by an independent evaluator.

ⁿThe Student Health and Risk Prevention survey—a biannual statewide survey given to students during school in 6th, 8th, 10th, and 12th grades—used items from Monitoring the Futures survey.

Home-Use DVD

The first efficacy trial of the home-use DVD required the families with children aged 7 to 17 years to view the 11 SFP DVD lessons and participate in a confidential Web-based survey in exchange for entering into a drawing for valuable prizes donated by local merchants. A total of 61 families with children from 3rd to 12th grade volunteered to watch the 11 DVD lessons. The DVD was mailed to the families to view at home together. Of them, 55 families completed the DVD lessons and took the regular SFP retrospective pre-post survey on the Web.

The results of the survey were compared with a shorter, updated 10-week version of the group class that included video clips taken from the SFP DVD. This was titled *SFP 7-17*, and the

classes were taught in the evenings at 2 Salt Lake City elementary schools by the University of Utah graduate student interns. A randomized block design was used with all 6th and 7th grade schools. Schools characterized by few risk factors for substance abuse were put into a group and those with multiple risk factors were placed in another group. From these, we randomly selected a school that was a relatively high-performing school, whereas the other was a Title 1 school, with 90% of the students receiving free or reduced-price lunch. A majority of the Title 1 school parents spoke Spanish, so the parent training classes were taught in 2 groups—1 in English and 1 in Spanish. The youth preferred to be taught in English, and the family practice session was taught in both languages with the help of translators. At the end of the 10-week class, parents in both

schools completed the regular SFP paper-and-pencil retrospective pre-post survey (in English or Spanish, depending on preference).

A second trial of the home-use DVD involved Asian Indian families who were experiencing acculturative stress arising from differences between their strict, authoritarian rearing conditions in India and their US-born children growing up in a more liberal, westernized society. Inclusion criteria required that parents (1) were born and raised in India and had children aged between 7 and 17 years who were born and raised in the United States and (2) agreed to watch the 11 DVD lessons and pause and practice the skills where indicated. A total of 28 families volunteered, and 26 finished the DVD lessons and took a paper-and-pencil version of the retrospective pre-post survey. The results of the Asian Indian survey were compared with the SFP 7-17 10-week group class version, with video clips taken from the SFP DVD. The classes were held in the evenings at local middle schools and taught by the Utah Valley University sociology student interns.

DVD With Family Discussion Group

Given drastic budget cuts, family service agencies began to use the SFP DVD as a cost-effective means of delivering SFP skills. Instead of hiring 6 staff members to teach the parent, teen, and child lessons, they gave 2 regular staff people time off during the week and had them come in 1 evening a week to act as a family coach as they led the SFP DVD family discussion group. They paused the DVD at set intervals, asked discussion questions, and had the parents and youth do *practice walk-throughs* of the skills they were viewing. We have included 4 settings that involved the SFP DVD shown in a group format: an open-education learning environment that took place in an elementary school, a homeless shelter, a crisis center, and a mixed residential and outpatient youth detention facility. In all cases, several families watched the DVD as 2 facilitators paused it where indicated, asked discussion questions from the SFP DVD discussion guide, and led the parents and youth in joint skills practice. In the residential setting, the youth in custody at the facility were taught skills from the DVD during the week. On Friday evenings, their parents visited the facility, watched the DVD in a group setting with their youth, and practiced the skills with them. At the end of the 11 lessons, all parents in their respective groups took the regular paper-and-pencil retrospective pre-post survey.

Families Participated in Strengthening Families Program 7 to 17 Group Classes and Viewed DVD Clips

The 10-week SFP 7-17 group class curriculum teaches the same skills as the regular SFP 14-week lessons, with a slight variation in the order they are presented. Additional DVD course material was added on brain development; parental involvement via pleasant personal conferences; apologies and forgiveness; anger management; harms of alcohol, tobacco, and other drugs; and mindfulness to stop automatic negative thoughts. The SFP 7-17 lessons, which follow the same order as the SFP DVD, use video clips from the DVD to demonstrate the skills being taught.

Since 2013, classes have been offered in the evenings in various community settings, including family service agencies, churches,

and schools. SFP 7-17 includes separate 1-hour classes for parents, teens, and children plus a joint family practice session in the second hour. The sessions last 10 or 11 weeks, compared with the regular 14-week SFP group class.

Strengthening Families Program Group Norms

The group norms chosen for the noninferiority trial comparison came from a database of over 6000 families who had previously taken the SFP 14-week group classes and filled out a retrospective pre-posttest. A sample of 473 representative families were randomly chosen from a variety of sites based on similar demographics (ages of the children) and the proximity of the classes to the dates corresponding to the DVD implementation. Owing to the diversity of sites where the group norm families attended the classes, it is not possible to determine implementation issues at the sites. However, retention at the group norm sites varied between 80% and 95% across the 14 weeks, depending on the teachers' experience levels and buy-in from program directors.

Measures

The SFP assessment protocol uses reliable scales that, in the interest of time and reducing participant burden, are abridged versions of psychometrically sound assessments. Estimates of internal consistency presented here are based on the group norms sample with the exception of the covert aggression scale, which is based on a larger study conducted in Ireland. A total of 5 multi-item scales assess parenting-related skills including parental involvement (eg, "I talk to my youth about his or her plans for the next day or week"; $\alpha=.75$), parental supervision (eg, "I know where my child is and who he/she is with"; $\alpha=.70$), parenting efficacy (eg, "I handle stress well"; $\alpha=.75$), positive parenting (eg, "I praise my child when he/she behaves well"; $\alpha=.79$), and parenting skills (eg, "I use physical punishment when my child will not do what I ask"; $\alpha=.64$). Items for the parenting skills, parental supervision, and positive parenting scales were taken from the *Kumpfer SFP Skills* instrument [52], and parental involvement items were taken from the *Alabama Parenting Scale* (APS) [53,54]. Recent psychometric evidence confirms the reliability of shortened scales from the APS [55,56]. In addition, 4 abridged scales were taken from the *Moos Family Environment Scale* [57,58] to assess family cohesion (eg, "I enjoy spending time with my child"; $\alpha=.75$), family communication (eg, "We hold a family meeting weekly"; $\alpha=.69$), family conflict (eg, "Our family argues a lot with each other"; $\alpha=.87$), and family organization (eg, "We go over schedules, chores, and rules to get better organized"; $\alpha=.71$).

Items assessing cognitive, affective, and behavioral facets of depression were taken from a survey instrument used to evaluate the *Good Behavior Game*, a school-based intervention to reduce aggression, delinquency, and drug use [59]. The items were originally culled from the *Child Depression Inventory* [60,61] and the *Child Behavior Checklist* [62,63]. Parents rated their children's mood and emotional tone with 6 items (eg, "My child looks sad or down"; $\alpha=.64$), making sure to simplify the wording for families with language or education barriers. A 6-item scale was used to assess covert aggression (eg, skipping school or breaking rules; $\alpha=.69$), and separately, another

6-item scale assessed overt aggression (eg, hitting or fighting; $\alpha=.75$). All scales were adapted from the Parent Observation of Child Adaptation (POCA) scale [64]. The POCA assesses how the child conforms to the family social world (ie, their aggressive and disruptive behavior) and is a modification of the Teacher Observation of Classroom Adaptation–Revised questionnaire [65] assessing a child’s performance on core classroom tasks (ie, accepting authority, social participation, and concentration) and their social adaptational status. The teacher rating instrument was developed originally as part of the Woodlawn, Chicago, early behavior management intervention study [66] and then later used in evaluating the *Good Behavior Game* intervention [64,67].

A 9-item scale assessing social behavior (ie, cooperation, assertion, responsibility, and self-control; eg, “My child plays well with other children”; $\alpha=.79$) was taken from the Social Skills Rating Scales [68,69]. We used a 12-item scale to assess family strengths and resilience (eg, “We show that we care for each other in our family”; $\alpha=.90$), developed as an abridged version of a performance checklist used in child abuse and neglect cases [70,71]. Parents were also asked to evaluate their child’s past month use of alcohol, cigarettes, marijuana, and prescription medication drugs both before (eg, “In the 30 days before the SFP class, how many times do you think your child used the following”) and again after the exposure to the SFP program (now). These scales were taken from nationally representative epidemiological surveys targeting the youth [72] and are based on counts. For all of the scales, the study calculated average scores for the parent, child, and family outcomes.

Analysis Methods

A statistical analysis was performed comparing the ES of the 3 SFP DVD conditions to the group norms. The statistician compared site characteristics using chi-square tests for categorical and analysis of variance (ANOVA) for continuous measures. The ES estimates (partial eta-square) for the outcomes were calculated using a within-subjects repeated measures of ANOVA (the interaction of time by condition was tested) [73–75]. This is an appropriate choice of ES when the designs being compared are similar. To avoid issues with power, we bundled several of the *off-label* settings into 3 distinct groups based on the delivery method (group 1 delivered the DVD entirely at home, group 2 included families that viewed the DVD as part of DVD family discussion groups, and group 3 attended SFP 7-17 group classes and viewed DVD video clips).

He then compared the resulting 3 conditions to the traditional facilitator-led SFP 14-week group format (group norms). Following standards for noninferiority trials [36,76], he used an equivalence margin based on the null hypothesis, stating that the DVD conditions would be no worse (or better) than 10% difference in ES estimate compared with the group norm condition. This level for the margin of equivalence was set because we expected all forms of the treatments to be at least similar.

Results

Site Comparisons

A total of 711 participants were divided among the 4 conditions: group norms (473), home-use DVD (81), family discussion group (39), and SFP 7-17 class with DVD clips (118). ANOVA was used to compare the 4 different conditions on demographic factors, including the age of the parent and child, and chi-square tests were used to compare the conditions on race and family status (eg, single parent, 2 parents, joint/shared custody, foster care, relatives, and other). Percentages below for race categories across all 4 comparison conditions were based on the 677 out of 711 participants who marked the “race” category. They included African American 21.1% (143/677), Asian 12.6% (85/677), White 32.8% (222/677), Hispanic 26.6% (180/677), and a mixed group comprised of Native American, Hawaiian, Pacific Islander, and Alaskan natives 6.9% (47/677).

Significant condition differences were observed for race ($X^2_{12}=219.0$; $P<.001$). In the group norm classes the greatest percent were African American families 31.3% (142/453) compared to Hispanic families 26.9% (122/453, White families 21.9% (99/453), Asian families 12.4% (56/453), and the mixed-race group 7.5% (34/453). In the home use DVD group Whites were the highest at 58% (47/81) followed by Asian 34.6% (28/81), Hispanic 7.4% (6/81), with African American and mixed race groups not represented. In the DVD family discussion group Whites were 39.3% (11/28), mixed race 32.1% (9/28), Hispanic 25% (7/28), and African American 3.6% (1/28). Asian was not represented. In the SFP 7-17 classes with DVD Clips Whites were 56.5% (65/115), Hispanics were 39.1% (45/115), mixed race 3.5% (4/115), and Asian 0.9% (1/115). African American was not represented. There were no significant differences in the gender of the parent filling out the survey ($X^2_3=3.84$; $P=.28$) or the gender of the target child ($X^2_3=6.47$; $P=.09$).

Comparison of family status was significant ($X^2_{15}=25.42$; $P=.045$). There were 242 single parents in the sample. 78.5% (190/242) were in the group norms; 10.7% (26/242) were in the SFP 7-17 classroom with DVD clips condition; 8.3% (20/242) were in the home-use DVD condition; and 2.5% (6/242) were in the DVD family discussion group condition. There were also no foster care children in any condition other than group norms; but that imbalance may reflect the recruitment strategies more than anything.

Parents were much younger in the family discussion group (mean age 26.8 years), compared with the remaining groups ($F_{3,610}=8.52$; $P<.001$; mean age 40.7, 39.3, and 39.5 years for group norms, home-use DVD, and classroom with DVD clips, respectively). Children were also significantly younger in the family discussion group ($F_{3,636}=18.78$; $P<.001$; mean age 10.89 years), compared with the other 3 conditions (mean age 13.74, 13.15, and 12.77 years for group norms, home-use DVD, and SFP 7-17 classroom with DVD clips, respectively).

A comparison of income across the 4 conditions was found to be significant after conducting the nonparametric Kruskal-Wallis

test (ie, a 1-way ANOVA, $H_3=65.575$; $P<.001$). Home-use DVD families reported the highest average income (US \$51,220, SD US \$57,872) compared with SFP 7-17 classroom with DVD clips (US \$44,876, SD US \$38,790), family DVD discussion group (US \$42,342, SD US \$24,778), and group norms (US \$27,878, SD US \$25,911).

Effect Size Estimate Comparisons

[Multimedia Appendix 1](#) shows the unadjusted ES comparisons for group norms versus the 3 DVD conditions. Notably, none of the group×time interactions were significant. Of the 15 comparisons for the SFP outcomes, 13 favored the DVD with larger ES estimates.

As seen in [Multimedia Appendix 1](#), the average ES difference between group norms and the home-use DVD condition was 0.13. The margin of equivalence favored the home-use DVD with the ES at least 28% larger by comparison (family communication favored the group norms). The largest ES overall for the home-use DVD condition was observed for family strengths/resilience (0.76 vs 0.65 for home-use DVD and group norms, respectively) followed by family organization (0.73 vs 0.64). Interestingly, the smallest ES was for youth alcohol and drug use (0.20 for home-use DVD and 0.01 for group norms), which may reflect the low perceived levels of child drug use in this sample.

ES comparisons for the other SFP DVD use conditions were in some cases somewhat larger in magnitude, compared with the home-use versus group norms comparison. For instance, the average ES difference for the DVD family discussion group compared with the group norms was 0.16, and the average margin of equivalence was 31% larger for the DVD family discussion group condition, compared with the group norms. Individual ES comparisons showed the largest ES for the DVD family discussion group condition was for family strengths/resilience (0.79 vs 0.65 for group norms), and this effect was also larger than the other conditions as well (0.76 and 0.70 for home-use DVD and SFP 7-17 classroom plus DVD Clips, respectively). Social behavior (0.74), parenting efficacy (0.73), family communication (0.72), and family organization (0.72) also had relatively large ES compared with group norms (0.34, 0.56, 0.66, and 0.64, respectively).

The same comparison for the SFP 7-17 10-week classroom version that included DVD clips indicated an average ES difference of 0.09 and an average margin of equivalence of 23%. The largest magnitude of individual ES was for family organization (0.72) and communication (0.71), both of which were larger in magnitude compared with the group norms (0.64 and 0.66, respectively) and the home-use DVD.

Adjusted Effect Size Analyses

It is conceivable that site-specific variability may influence scores within each condition and thus contribute to ES differences. This variability can arise from differences in the composition of the participants at each site. To test the effect of intersubject variability, we computed adjusted ES, modeling the influence of demographic measures (eg, adult and child gender, age, and race and family income). [Multimedia Appendix 2](#) shows the results of the ES comparisons with the adjustments

conducted with forward inclusion and modeling first-order interactions. As depicted, there was some shrinkage in the ES as the additional measures accounted for demographic variance. However, the overall consistency of the findings did not change, reinforcing the superior effects obtained with the DVD conditions.

Discussion

Principal Findings

This study provides initial evidence that the SFP DVD provides a useful surrogate for the traditional group format that uses a facilitator, which was how SFP was initially developed. For a variety of reasons, many families find it difficult to maintain their attendance at the various sites where SFP is traditionally delivered. This has been a consistent and well-noted issue associated with offering any parenting skills training program [77,78]. Parents are busy with work, caring for their children, and handling chores crucial to their survival. Many families, faced with hectic schedules, afterschool activities, and other competing interests, find it difficult to attend a 2-hour family-based skills training for 10 to 14 weeks that requires transportation to and from the facility. With the advent of the SFP DVD, parents and their children can have access to the program content, modified slightly, in an alternative setting—one of which does not require attendance per se in a fixed edifice or a labor-intensive group delivery format. Furthermore, they can review the SFP skills as often as necessary at home.

The results of the noninferiority trial show that the home-use DVD was superior to the group norms in all but 2 of the 15 comparisons. The superiority exceeded the benchmark of 10% set a priori before the trial commenced. The 2 outcomes that failed to exceed the group norms were family cohesion (which had identical ES) and communication (change in ES=0.03). Both of the other 2 DVD conditions had ES larger in magnitude for these 2 outcomes compared with the group norms. In this respect, we were able to demonstrate that using the same experimental design and generating partial eta-square statistics to create a common metric for study comparison, the DVD conditions produced superior effects to the traditional group-based format.

Although we computed ES based on a within-subject design, intersubject differences based on sample composition can also influence ES computations. This arises because the computation of the ES in an ANOVA framework utilizes the sums of squares, which is inextricably tied to the raw mean scores. Taking this into consideration, we computed adjusted ES for each condition, controlling for demographic characteristics of the sample. The adjusted ES left the same impression as the unadjusted, that is, all the conditions with the DVD outperformed the group norms. The margin of equivalence favored the home-use DVD and the DVD family discussion group at relatively the same magnitude as the unadjusted calculations.

Comparatively speaking, although most of the DVD conditions outshone the group norms, there were several SFP outcomes that produced less than optimal ESs. This observation is guided

by general standards for Cohen d and takes into consideration how the partial eta-square converts to Cohen d [79]. The benchmark numbers suggest that an ES equivalent to $d=0.2$ is small, $d=0.5$ is moderate, and $d=0.8$ is considered large [74]. If the ES is 0.5, as it was in many cases here, the families improved a half standard deviation over time. Smaller effects (eg, $d=0.2-0.4$) mean that the family did not improve as much (with ratings obtained from the parent's perspective only). In summary, across the different comparisons, there were several ESs that were relatively small, including family conflict, depression, and covert and overt aggression. A pressing question, then, is why these ESs are smaller in magnitude and tied to this concern, what contributes to the differences in program outcomes?

The strength of SFP is its focus on improving parenting skills (which increased to a considerable degree) and its carryover effect on youth behaviors. The inclusion of aggression and depression scales, although not primary outcomes, are intended to foreshadow what may happen when family dynamics improve following program exposure. This view is consistent with a developmental cascade model suggesting that behaviors in a domain can sequentially influence behaviors in a different domain through spreading activation effects and because skills for both the parent and child invariably emerge from a common foundation [80-82]. Thus, activation of negative behaviors at home can *spread* to school or adversely affect peer relations both within and across time, setting into motion developmental pathways that foster maladjustment in multiple domains. The risk-factor model and social transactional perspective underlying SFP integrates this approach, suggesting that coercion and poor parenting skills in an area (eg, boundary setting) can *cascade* and influence other behaviors (eg, family bonding), upsetting the balance of family dynamics. Improvements in the way parents discipline or set boundaries, for instance, can have repercussions on family bonding or monitoring in a positive way by bringing the family closer, improving parent-child communication, and lessening the impact of negative behaviors.

Accounting for Delivery Format Differences

There were other instances where the home-use DVD did not produce larger ES compared with the group norms; and the SFP 7-17 groups classes with video clips outperformed them all. It is possible that without a family coach or facilitator to monitor, encourage, and correct their skill practice, families deeply embroiled in conflict have more trouble changing communication patterns, especially in a short amount of time. For these families, certain behaviors may be intransigent, and efforts to change these highlight the benefits of having a family coach who can provide skill reinforcement to instigate behavior change. Yet, the majority of comparisons reinforced that ESs for the DVD conditions surpassed the group norms.

The superiority of DVD outcomes may be affected by the enriched content that was added or demographic differences, as parents in the home-use DVD condition had higher income levels and the functional ability to gather their children to watch the DVD and practice the skills at home. Higher levels of functionality can include more time spent bonding and watching the SFP videos and discussing their content. In addition,

watching the DVD at home allows families to pause the instruction, practice skills, and review sessions multiple times at their own convenience and pace. This provides a customized delivery not available with classroom-based instruction, where pace is dictated by the facilitator and the group dynamic. The ability to customize presentation could help offset 2 recurring problems in family-based prevention, including attrition and engagement [83].

When adjusted, the ES comparison indicated some decrement in program outcomes. Clearly, factors related to the demographic composition of these families had an influence on their mean scores to the extent that there was some small shrinkage in the ES as seen in [Multimedia Appendix 1](#). Overall, the DVD conditions had more families improving on the 15 outcomes.

Limitations

There are several limitations to this study worth noting. First, all of the studies included in the ES comparisons relied on retrospective pre-post reporting, thus eliminating any passage of time between assessments. There are advantages and disadvantages to this type of reporting method because it relies on *retrospective* recall of skills and behaviors that can be tarnished by memory. However, in a design that uses a true pretest separated in time from the posttest, parents are prone at baseline to evaluate themselves in a glowing light and consider themselves more effectively skilled. This personal evaluation changes dramatically when the same parent sits through the SFP lessons, learns new skills, and realizes they had less than optimal parenting skills at the beginning. As a result, the retrospective pre-post format allows parents to answer how they are currently parenting at the conclusion of the study and then *reflect* back on their earlier parenting skills and evaluate the improvements made following exposure to course content. This is one of the strengths of retrospective pre-post techniques [84], as it helps participants to generate an internal *standard of comparison* by asking them to address their parenting skills looking back over a few months' time and compare them to their parenting skills after program exposure. This technique provides an anchor for the parent and avoids any *response-shift bias* as a threat to internal validity, which may provide a more accurate assessment [85].

In comparing the group norms to the DVD conditions, we set the margin of equivalence at 10%, which is an arbitrary benchmark value. However, setting an even stricter level of scrutiny for the null, for example, 20%, would still have produced evidence of noninferiority for the DVD conditions. Despite noninferiority trials having their limitations [86], they can still be used, as is the current case, for illustrative purposes to show that a novel implementation strategy is no *worse* than an effective treatment control. Future studies may want to rely on RCT designs to strengthen causal inferences about program effects.

We also did not control for numerous factors that may contribute to the differences in study outcomes, including family risk factors, compliance with the study protocol, attrition, and measurement error. Facilitators in the group norms and DVD conditions can introduce variance into the equation, affecting program adoption and fidelity in ways that we did not account.

Moreover, the sampling mechanisms were nonrandom, and this could lead to bias in the ES estimates. Given that randomization was not used in any of the trials, intent-to-treat analyses were essentially moot.

Conclusions

Even with these noted limitations, there is a tremendous need to train parents and their children with appropriate evidence-based skills to avoid alcohol and drug use, as well as other delinquent behaviors. On-site classes are the standard

effective mode of instruction; but they can never meet the rising demand because of higher costs and reduced prevention budgets. Marrying technology with primary prevention appears to be the most viable way to offer skills training to enough parents and their youth to make an appreciable difference in decreasing delinquency and youth alcohol and drug use. The SFP DVD offers an engaging and inexpensive way to bring evidence-based programs to scale to reduce adolescent behavioral problems and social costs.

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Conflicts of Interest

Authors KLK and JLB have a financial interest in the Strengthening Families Program (SFP) group-based facilitator-led 7-17 lessons being tested in the research. They receive financial remuneration from facilitator training, sales of the curriculum, and evaluation contracts. Neither party has a financial interest in the SFP DVD, which belongs to the Strengthening Families Foundation—a 501 (c)3 not-for-profit corporation. All profits from sales of the SFP DVD belong to the Foundation and no proceeds from its sales are distributed to the authors. None of the statistical analysts who worked on the SFP DVD project have any financial interest in the SFP DVD.

Multimedia Appendix 1

Table 2. Comparison of Strengthening Family Program (SFP) group norms with 3 SFP DVD conditions.

[PDF File (Adobe PDF File), 272 KB - [pediatrics_v2i2e14751_app1.pdf](#)]

Multimedia Appendix 2

Table S1. Comparison of unadjusted and adjusted effect sizes for Strengthening Families Program (SFP) Noninferiority Trial.

[PDF File (Adobe PDF File), 203 KB - [pediatrics_v2i2e14751_app2.pdf](#)]

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Abbreviations

ANOVA: analysis of variance

APS: Alabama Parenting Scale

ES: effect size

POCA: Parent Observation of Child Adaptation

RCT: randomized controlled trial

SEM: Structural Equations Modeling

SFP: Strengthening Families Program

SFP 7-17: Strengthening Families Program for families with children aged 7 to 17 years

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