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Lessons learned from a blended telephone/e-health platform for caregivers in promoting physical activity and nutrition in children with a mobility disability

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Abstract

Background: Children with physical disabilities report higher rates of sedentary lifestyle and unhealthy dietary patterns than non-disabled peers. These behaviors can increase comorbidities, caregiver burden, and healthcare costs. Innovative interventions are needed to assist caregivers of children with physical disabilities improve health behaviors.

Objective/Hypothesis: The purpose of this pilot study was to test the usability and preliminary efficacy of an e-health and telecoaching intervention compared to telecoaching alone.

Methods: Parent/child dyads (n= 65) were randomized into either the e-health and telephone group (e-HT) or the telephone only group (TO). All participants received regular calls from a telecoach, and the e-HT group received access to a website with personalized weekly goals for diet and physical activity, and access to resources to meet these goals. At the conclusion of the intervention, participants in the e-HT group were asked to complete a semi-structured interview to discuss the usability of the e-health platform.

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Results: Fifty of the 65 randomized dyads (77%) completed all baseline measures and had at least one intervention call. Forty families (80% of those that started the intervention) completed the study (50% spina bifida, 24% mobility limitation, diagnosis not reported). Age of the children ranged from 6–17 years old. Both groups had high adherence to scheduled phone calls (e-HT (n=17): 81%, TO (n=23): 86%); however no significant differences in dietary intake or physical activity were seen within or between groups. Primary themes to emerge from qualitative interviews were: the platform should target children rather than parents, parents valued the calls more than the website, and schools need to be involved in interventions.

Conclusions: E-health interventions are a promising way to promote healthy behaviors in children with physical disability, but technology must be balanced with ease of use for parents while also engaging the child.

Keywords

e-health; physical activity; healthy eating; mobility limitations

INTRODUCTION

Youth with physical disabilities are at higher risk than peers without a disability for unhealthy lifestyle behaviors including physical inactivity and poor dietary intake. These behaviors are likely to exacerbate the movement-based activity limitations associated with their disability, increase the need for medical services, and limit or restrict participation in socially engaging community activities.^{1,2} Unfortunately, the significant physical and motor limitations that accompany a child's physical disability greatly limit his/her opportunities to participate in socially engaging home, school, and community-based activities.^{1,3} Children with disabilities are much less likely to participate in school-based or community-based health promotion activities and are far more likely to be sedentary and eat poorly.^{4–10}

There are several possible reasons for this health disparity. First, many parents who have a child with a physical disability (e.g., spina bifida, cerebral palsy, spinal cord injury) do not have the resources or capability to find programs that meet the physical needs of their child. While a few communities offer a special recreation or peer mentoring program for youth with disabilities, even when these services are available their infrequency (e.g., offered 1 or 2x/wk at times that may not fit within the family member's schedule) limits their utility as a weight management strategy.¹¹ Second, many if not most school-based programs do not provide the same level of opportunity to participate in recess and physical education. Class sizes are too large for children with physical disabilities to receive specialized attention and equivalent levels of physical activity time as non-disabled students, physical education teachers often have little or no background in adapting programs for these children, and adaptive equipment is often nonexistent.¹² Third, the built environment is often inaccessible to children with physical disabilities. In a report published by the Government Accountability Office (*Students with Disabilities: More Information and Guidance Could Improve Opportunities in Physical Education and Athletics*),¹² youth with disabilities were found to have much lower rates of participation in physical education and sports compared to non-disabled children. Finally, many families who have a child with a physical disability bear the stress of providing the child with medical support, assisting with activities of daily

living, managing medications, overcoming inaccessible environments, and finding appropriate transportation. These critical life issues often override the need for their child to be physically active, eat properly and manage weight.

The social, physical and mental health issues that many children with physical disabilities are already exposed to are further compromised by the additional health condition of obesity.¹³ The epidemic of childhood obesity observed in non-disabled children is even a greater health concern in children with disabilities. In nearly every published paper since 1990,^{14–28} children with disabilities were reported to have two to four times the rate of obesity compared to children without disabilities. Chronic and secondary conditions associated with obesity in children with disabilities have the potential to undermine physical independence and community participation, and as children transition into adolescence and adulthood, may incur substantial health care costs to treat and manage these conditions.²⁹

The challenge in promoting health and weight management among children with disabilities and their caregiver is finding cost-efficient, technology-driven innovative solutions that can assist family members in overcoming such barriers as lack of knowledge on how to get their child more physically active and eating more nutritious foods, and having greater access to qualified health professionals who understand how to tailor appropriate physical activities for children with disabilities. Currently, there are no customized electronic health promotion/weight management delivery systems to help family members who have a child with a disability improve the child's physical activity and nutrition behaviors. For this reason, we developed the Personalized On-line Weight and Exercise Response System (POWERS) to assist families with children with a physical disability to gain education, resources, and social support specially tailored to the needs of their family.

POWERS is a web-based telecoaching system that combines digital health resources and human interaction to achieve diet and physical activity behavior change using a personalized approach. The POWERS platform was designed by an interdisciplinary team including a physical medicine physician, disability health expert, health behaviorist, dietician, adapted physical activity expert, and information communication technology specialists. After the initial development, the platform was refined through expert interviews with pediatric physical medicine physicians and nurses, adapted physical activity providers, and parents of children who have physical disabilities. The interviews covered all aspects of the platform, including the overall presentation of the platform (i.e. color scheme, content layout), terminology, resources provided, content provided, and ease of use of the platform. After all each phase of interviews, revisions were made to the platform.

The purpose of this study was to conduct a usability and feasibility study of the completed POWERS platform compared to a telephone only intervention for caregivers who had a child with a physical disability. We hypothesized that caregivers having greater access to customized e-health resources within the POWERS platform would have higher engagement and retention in the study. The secondary aim of this study was to explore changes in health behaviors between those who receive the POWERS telehealth intervention and those who received only telephone support. We hypothesized that access to the POWERS platform

would result in improved physical activity and nutrition behavior uptake among the children compared to guidance through the telephone only.

METHODS

The study was conducted between April 2015 and June 2017 at the University of Alabama at Birmingham (UAB). This study was a collaboration between UAB, Children's of Alabama and Lakeshore Foundation, a large nonprofit organization that provides exercise and fitness programs to people with disabilities and was conducted as part of the UAB/Lakeshore Research Collaborative. The research protocol was approved by the Institutional Review Board at UAB and all participants gave written informed consent (parents) and written informed assent (children).

Participants.

Participants were parents who had a child ages 6–17 years old with a lower extremity mobility disability. Children had to have the ability to use hands and arms for exercise, not be currently enrolled in another health promotion or weight management program, and report sedentary lifestyle for the previous 6 months as measured by weekly level of structured physical activity. Children with spinal cord injury had to be at least 12 months post injury. Families were excluded if the child had cardiovascular, respiratory, or renal disease, had dietary or exercise restrictions/monitoring caused by conditions such as Chiari II, or had a current pressure ulcer. Parents had to be at least 19 years old, able to converse and read English, and have high-speed internet access in the home.

Screening and Randomization—Participants were recruited from the pediatric rehabilitation medicine clinics at Children's of Alabama, the membership database of Lakeshore Foundation, and membership database of the Spina Bifida Association of Alabama. Families self-referred by calling the phone number on the study advertisement, or were identified by clinic staff. Once identified, research staff conducted an eligibility screening interview, either by phone or in person during the clinic visit. Physician approval was obtained to verify there were no dietary and exercise restrictions or other contraindications for participation. Once physician release was obtained, an appointment was scheduled for baseline data collection and randomization. If the child was referred during a clinic visit, and the physician signed approval during the visit, baseline data collection and randomization took place during that visit as well. Families were instructed to complete all questionnaires online prior to the first coaching call.

Families were randomly assigned to either the e-health group (telephone + POWERS website) or the telephone only group with a 1:1 allocation. Because the primary goal of this study was to examine the feasibility of the POWERS platform, the primary outcome variables were adherence and study completion. Outcomes of diet and exercise behavior change were considered exploratory variables. Since children with physical disabilities typically encounter more barriers to exercise than children without disabilities and given the remote nature of the intervention, we decided to use a conservative estimate of 0.70 for acceptable adherence rate.

Pilot Intervention—At baseline, each participant completed a Health Appraisal Profile (HAP), which included questionnaires related to health conditions, disability, environmental characteristics related to food and activity (e.g., access to resources for healthy food and exercise, typical food preparation roles in the home), and psychosocial variables (e.g., readiness for change and barriers to change).

e-Health + Telephone (e-HT). The e-HT group received access to an online platform referred to as POWERS (Personalized Online Weight and Exercise Response System). POWERS was developed specifically for families with children with physical disabilities for use in this and future studies. This is the first study exploring the usability of this platform. POWERS is a web-based telecoaching system that combines digital health resources and human interaction to achieve diet and physical activity behavior change using a personalized approach. POWERS identified potential goals for diet and physical activity changes based on participant responses to the HAP. Participants then worked with their telecoach to refine the POWERS-generated goals. Coaches offered behavioral strategies and resources for meeting each goal, and these were delivered via the POWERS platform. Participants received weekly phone calls from the telecoach for the first 6 weeks of the study and every other week during the second 6 weeks, and had access to the POWERS website throughout the intervention.

e-HT Dietary recommendations. Parents were given goals for the child's intake in each of 6 food groups: fruits/vegetables, grains, protein, dairy, fats, and desserts/junk foods. Goals were based on the [MyPlate.gov](https://www.myplate.gov) recommendations for children in the target age group. [MyPlate.gov](https://www.myplate.gov) food group recommendations are based on the 2010 Dietary Guidelines for Americans and are categorized by a person's estimated calorie needs.³⁰ After reviewing the recommended goals, the participants' individual dietary goals were negotiated between the coach and parent. Parents could choose to start with the recommended goal if they felt it was achievable, or they could start out with a smaller dietary change than the recommended [MyPlate.gov](https://www.myplate.gov) recommendation if they felt their child was not ready for a more challenging dietary goal. Parents were also given the option to focus on only 1 food group, or all food groups, depending on their child's level of readiness to change, perceived barriers, and accessibility to resources.

Parents were given instruction on what constituted a serving for each food group, as well as proper methods for measuring foods. Additionally, they received feedback on the nutritional quality of foods in each food group during telecoaching sessions, and received instruction about foods that should be served more or less frequently (e.g., adding more whole wheat grains and lowering consumption of refined grains). Parents were asked to record their child's daily intake of each food group on the POWERS website.

e-HT Hydration recommendations. All participants received a daily hydration goal that recommended drinking 8 glasses of water or other non-caloric, non-caffeinated beverages/day.^{31,32} Lower water consumption has been found to be associated with poor diet intake and physical inactivity. Focusing on water and other non-caloric beverages has been recommended as a way to increase overall healthy eating patterns.³³ As with other goals, this recommendation could be lowered initially to accommodate baseline hydration patterns

as well as bladder/bowel control plans. Parents were asked to track the participant's water intake throughout the day on the POWERS website.

e-HT Physical activity recommendations.: Physical activity goals were set at 60 minutes per day based on CDC guidelines for youth of 60 minutes per day of physical activity.³⁴ Each participant's individual goals were tailored to their baseline activity level and physical ability. Given the challenges associated with regular amounts of physical activity of this magnitude, most of the participants began with goals lower than 60 minutes per day. The telecoach and the parent decided on an acceptable initial goal, and participants were encouraged to gradually increase their exercise minutes to the 60-minute recommendation by the end of the intervention. Participants were not given a prescriptive exercise program to follow, rather they were encouraged to increase daily play time and find enjoyable activities like pushing their wheelchair through a park. The telecoach provided ideas of activities on the POWERS platform, and provided links to recommendations for adaptive exercises and activities via a resource list found on the National Center on Health, Physical Activity and Disability (NCHPAD, www.nchpad.org) website. Parents were asked to record the number of minutes of activity their child accumulated each day on the POWERS platform.

e-Journaling.: Parents were asked to record the child's physical activity and daily food and water intake on the POWERS website. Physical activity was entered as minutes of structured activity accumulated each day. Food was recorded as number of servings of each food group, and water was entered as number of 8 oz. glasses consumed each day. The daily journals were used by coaches to review progress toward the goals, as well as a means of increasing participant awareness of intake and progress toward goals.

Telephone Only (TO) Group.: Participants randomized to the TO group received phone calls from the telecoach at the same frequency as the e-health intervention group but did not have access to the POWERS website. During these calls TO participants were provided with information on accessing nutrition and physical activity recommendations and resources for meeting these recommendations through the NCHPAD website. All of the resources provided to both groups of participants were available on the NCHPAD website, but participants in the TO group were not provided with a hands-on demonstration of how to use these resources and no individualized goals or recommendations were given by the telecoach.

Measures

Height and Weight.: In children who were able to stand, height was measured using a wall-mounted stadiometer. Segmental height was measured with the child in a supine position for those unable to stand. Weight was measured on a digital wheelchair scale. Participants' weight was measured while sitting in their wheelchair, and then the chair was weighed alone. Weight was derived as the weight of the child and chair minus the weight of the wheelchair.

Dietary Patterns.: Food intake was measured using a food frequency questionnaire.³⁵ Parents were asked how often the child ate a variety of foods within the categories of dairy,

fruits, vegetables, eggs/meats/fish, cereals/breads/starches, beverages, and sweets/baked goods/miscellaneous. Responses options included: Never, less than once/month, 1–3 times/month, once a week, 2–4 times/week, 5–6 times/week, once a day, and two or more times daily. Food frequency questionnaires have been found to be valid and reliable in both adult and child populations.³⁵

Physical Activity.: Parents completed a physical activity questionnaire that consisted of recording the number of days/week and minutes/day their child engaged in a variety of activities within the categories of exercise or leisure activity, household activities, outdoor chores or work, and physical or occupational therapy sessions.

Feasibility Measures.: Number of individuals screened, enrolled, and completing the program were recorded to measure the feasibility of recruiting and retaining an adequate sample in larger future trials. Adherence to the intervention was measured as phone calls completed with the telecoach for both groups, and number of days of journal entries for the e-HT group.

Data Analysis.: Data analyses were performed with the IBM SPSS software, version 23 (IBM, Armonk, NY). Descriptive statistics including frequency distributions, means, and standard deviations were calculated for participant characteristics. Independent sample t-tests were used to assess if differences in physical activity, fruit and vegetable consumption, change in weight, and intervention attendance were statistically significant between the two groups. The level of statistical significance was set at $\alpha=0.05$.

Qualitative Analysis.: Upon completion of the intervention, all participants in the e-HT group were asked to complete a semi-structured interview to discuss their experiences with the program. The interview questions focused on aspects of the POWERS website that were helpful and those that needed refinement. Additionally, participants were asked to give their opinion on the helpfulness of the coaching calls. Interviews were conducted by a research staff person who was not involved in the intervention implementation and responses were recorded on a standard template. Participants in the e-HT group who withdrew from the study were also invited to complete an interview, and these interview scripts included additional questions related to aspects of the intervention that may improve retention. Research staff who were not part of the qualitative data collection reviewed interview responses to analyze the findings for emerging themes. To ensure rigor, investigators applied Braun and Clarke's stages of thematic analysis.³⁶ Using this process, question responses were organized after reading participant responses multiple times. Next, preliminary codes were generated by chunking together meaningful data, ascertaining the key concepts which would later be formed into themes. Preliminary concepts were then arranged, combined and split to develop overarching themes.

RESULTS

Participant characteristics are presented in Table 1. Sixty-five parent/child dyads were initially consented and randomized and a total of 50 participants completed baseline measures (Fig 1). Female parents were the predominant group (90%) participating in the

intervention. The predominant disability groups were spina bifida (50%) and mobility limitation (24%, diagnosis not reported). The majority of participants (82%) used some type of assistive or mobility aid.

Forty parent-child dyads (80% of those with baseline measures) completed the study (Fig 1). Ninety-two percent of TO dyads completed the study, compared to 67% in the e-HT group (Table 2). The most common reasons stated for drop-out among both groups were death or illness in the family (n=4) and the child being non-cooperative with health changes (n=2); however some participants were lost to follow-up with no specific reason for withdrawal noted (n=3). There was no significant difference in coaching calls completed between groups. Participants in the e-HT group completed a mean (SD) of 7.31(1.62) phone calls (81% of scheduled calls), and the TO group completed 7.81 (1.89) calls on average (86% of scheduled calls). All participants in the e-HT group had at least one day of journaling for water and food intake (mean (SD) days of journal entries: water: 46.1 (30.9), food: 45.6 (30.8)), and all but one had at least one physical activity journal entry (mean (SD) days of activity entries: 42.1 (29.4)). Twenty-six percent (n=15) of participants entered at least one weight over the course of the intervention (mean number of weights entered: 2.9 (3.1)).

There were no significant within or between-group differences in change in weight, fruit or vegetable intake, or physical activity levels (Table 3). Both the e-HT and TO groups increased weight over the course of the intervention (e-HT: 3.04 kg, TO: 2.07 kg). The TO group had an increase in mean minutes of physical activity compared to e-HT group (e-HT: −.59 min/week, TO: 16.52 min/week) although this difference was not statistically significant. In the e-HT group, 35% of children reported increases of physical activity over the course of the intervention (range: 10–100 min/week), while 47% reported no change and 17% reported a decrease in activity (range: 30–230 min/week). In the TO group, 43% of children increased their physical activity over baseline (range: 20–210 min/week), 35% stayed the same, and 22% of children reported decreases over baseline (range: 30–150 min/week). The number of families reporting at least daily fruit intake decreased in the e-HT group and stayed the same in the TO group (eHT: n=3, 17.7% at baseline, n=1, 5.9%, at follow up; TO: n=3, 13% at both time points); while the number of families reporting at least daily vegetable consumption stayed the same for both groups (eHT and TO groups: both n=1, 5.9% at baseline and follow up).

Twenty parents (62.5% of those randomized e-HT group; 12 completers, 8 non-completers) completed qualitative interviews. Qualitative analysis highlighted a number of benefits of the intervention, barriers to completing the study, and refinements that could improve the program.

Perceived benefits of the program.

When asked to describe the perceived benefits of the intervention, participants most frequently noted the *accountability that came with the coaching calls*. Participants reported that the phone calls increased their perceived accountability to follow the program and offered an important support system for setting goals for their child. There were mixed responses to the ideal frequency of coaching calls, with many responding that the every-other week calls allowed for more scheduling flexibility. However, all participants noted that

they were more likely to get off track with the behavior change plan when calls decreased in frequency.

While the participants overwhelmingly reported that the POWERS website was user-friendly and easy to navigate, they noted that the *coaching calls were the most motivating factor* of the intervention. Many participants acknowledged that even if they logged in to the website infrequently, they felt it was important to make scheduled calls.

Participants also noted the *increased awareness that came from journaling*. A few participants kept paper-based journals or used a mobile app and transferred information to the POWERS website daily or weekly, but noted that regardless of how the journals were kept, the act of recording water, food, and physical activity was beneficial for behavior change.

Perceived Barriers of the program.

The most commonly cited barrier to completing the program or making scheduled phone calls was the *lack of time* and *busy family schedules*. Many participants noted that managing multiple medical appointments for the child, along with schedules of other family members, made the intervention feel like “just one more thing to do.” Several families also reported that other issues including bladder and bowel management also took a lot of time and became a higher priority during the course of the intervention. Among those interview participants who did not complete the study (n=8), *lack of interest from the child* was also a commonly cited barrier, although this was not reported among those who completed the study.

The final theme to emerge related to barriers was the *impact of schools*. Many parents reported difficulty knowing what their child ate at school and all activities they engaged in at school, which resulted in difficulty journaling school-based food and activity. Caregivers suggested involving schools as part of future interventions to help fully track diet and exercise, as well as reinforce dietary and activity goals.

Recommended refinements to the program.

Two notable themes emerged specific to potential refinements to the POWERS website. The first was the need for increased *engagement with the child*. Caregivers noted that for their child to change his/her behavior, he/she should be directly involved with the program rather than the intervention being directed at the parent. Many caregivers also noted that their child was hesitant to change behaviors and became “bored” with the new foods and activities after a few weeks. Suggestions were made to offer age-appropriate content as well as adding a game component. One caregiver noted the site needed to be “flashier, like the games they play.” Several caregivers (20%) noted that the ribbons and incentives were a motivating factor for the child, but were not enough for long-term engagement.

The second theme was the *accessibility of the website* itself, as well as the resources relayed from the coach. Many participants noted that they would be more likely to use the platform if it were presented as a mobile app rather than a website, or at a minimum include an app component for journaling. Similarly, many participants reported finding the website

resources including shopping guides and recipes helpful, but requested that the coach email the resources to them so they could print them out to use while shopping.

DISCUSSION

This study pilot tested a newly-developed blended electronic and telephone health coaching platform for parents of children with mobility disability. Using a mixed methods approach, we explored feasibility of retention and adherence, as well as behavior changes between treatment groups; and used qualitative inquiry to further understand usability of the POWERS e-health platform among those in the e-HT group. Findings from this study advance our understanding of potential future communication strategies for targeting families of youth with disabilities. While the e-HT group engaged with the e-health platform, they did not make significant changes in their health behaviors, indicating that refinements in technology delivery are needed. Specifically, qualitative results indicated that more engagement with the technology by the child is needed, and less interaction was desired by the parents. These results provide evidence that more dynamic, interactive engagement with family members, particularly focusing on the child and his/her interest level, may be an alternative approach to our study design. This may indicate an opportunity to directly apply behavior change theories such as Social Cognitive Theory, which focus on the importance of reciprocal relationships by targeting both the child and the parents for shared learning experiences.³⁷

Although more interactive methods are needed to engage children, more traditional methods of communication may be sufficient for parents who felt the website added demands to their already busy schedules. Parents in the qualitative interviews indicated they valued phone calls more than the e-health platform, which might explain why no difference in behavior change was found between groups. This finding was supported by the high adherence to phone calls, with both groups completing over 80% of all scheduled calls. Although the POWERS platform provided individualized goals and resources, it did not add to the benefits of the phone calls, or to providing the resources in the self-directed method presented to the control group. This is an interesting finding, and provides potentially valuable insights into how to best reach parents of children with disabilities. Many parents noted that their schedules are already full with school and medical appointments for their child, as well as caregiving responsibilities associated with their other children and family members. This may be a key reason for the high dropout rate in the e-HT group, and reflects the fact that many of those participants who withdrew specified participant burden as their reason for withdrawal. While the resources on the e-health platform were noted to be helpful, many noted that more traditional methods including email would be more user-friendly for conveying this information. Providing a weekly call, along with email for resources, may result in less technology but more utility for the demands of this population. Additionally, time was noted as a barrier for both those who completed the intervention and those who withdrew. This included both the time it took to interact with the website for journaling and searching for resources, but also for the phone calls. This finding points to a potential solution for implementing more asynchronous communications with coaches and automated data collection methods including wearable technology.

Another key finding was that parents felt that programs for promoting better health in their child should include the school system. Children with disabilities often have an individualized education plan (IEP) that could include physical education and nutrition goals and be supervised by the physical education or special education teacher. In the same way that goals and objectives are established for academics, many children with disabilities who are predisposed to higher rates of obesity, physical activity and poor nutrition¹¹ need a set of health/wellness goals in their IEP that address these critical issues. Additionally, parents found it difficult to journal foods consumed at school, so having schools partner with parents to assist with journaling food and activity could help improve adherence.

Our findings are in line with a growing body of literature that indicates parents are open to and accepting of digital health interventions to help them deal with a range of childhood illnesses and lifestyle behaviors. While this is the first known study targeting parents of children with a mobility disability, a small but growing number of studies have been published examining feasibility and preliminary behavior change outcomes among parents with children with other conditions including cancer, mental health conditions, substance abuse, and chronic kidney disease.^{38–42} In many of these studies, parents reported acceptability of the web-based interventions and many noted they found the material helpful, but none have reported significant change in parental or child behavior. This underscores the need to find digital interventions that are beneficial in providing resources and supporting engagement, while balancing the time constraints and mental fatigue experienced by caregivers.

There are limitations of this study that should be noted. First, this study included a small sample size with a short-term intervention; however, because the primary purpose of the study was to determine the usability of the POWERS platform, a small, short-term study was valid. The small sample size may have influenced the lack of change seen in both diet and physical activity behaviors. For physical activity especially, a large range of scores was seen, indicating that extreme scores may have influenced the findings more than true change. However, due to the distribution of findings, and the exploratory nature of the analysis, it was appropriate to include all participants' results without excluding outliers. Future studies that build on these results should include larger sample sizes and longer-term interventions, which will be necessary to generalize results to a broader population. Similarly, this study included only self-report measures of behavior. Future studies will need to include more objective measures such as accelerometers as well as more specific measures of food intake (24 hour food recalls, food journals, etc.) to determine behavior change as a result of the intervention. However, commercially available accelerometers are not effective in capturing total physical activity expenditure in children who use wheelchairs. Finally, only those individuals randomized to the e-HT group were invited to participate in the qualitative follow up interview. The purpose of these interviews was to gain additional insights into the features of the POWERS platform that promoted and/or prevented engagement and behavior uptake. While we gained valuable insight into this area of the intervention, we also learned that many parents considered the coaching calls to be as important, if not more so, than the website. Given this finding, it would be beneficial in future studies to gather additional input from the telephone-only group on their experiences with the coaching calls as well.

CONCLUSIONS

There is a critical need to develop effective health promotion interventions for youth with physical disabilities that are personalized, contextually relevant, cost-effective, and culturally sensitive. As the nation targets obesity management in youth, it is important to recognize the critical need for such interventions among children with disabilities.⁴³ The current healthcare system provides little guidance in these areas to families who have a child with a physical disability and as a result, many if not most families are unprepared to manage or improve their child's health.⁴⁴ Technology-based interventions may provide a unique way to target this underserved group, and more research is needed to determine the key aspects of e-health interventions needed to maximize engagement of both children and parents. School systems might serve as active partners with parents and increase the current practice in promoting health/wellness behaviors in children with disabilities.

Disclosures:

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References

1. Murphy N, Carbone P, Council on Children With Disabilities. Promoting the participation of children with disabilities in sports, recreation, and physical activities. *Pediatrics*. 2008;121:1057–1061. [PubMed: 18450913]
2. Committee on Disability in America. *Future of Disability in America*. Washington, DC: National Academy Press; 2007.
3. Rimmer JH, Rowland JL. Physical activity in youth with disabilities: A critical need in an underserved population. *Devel Neuroreh*. 2008;11:141–148.
4. Steele CA, Kalnins IV, Jutai JW, et al. Lifestyle health behaviors of 11- to 16-year old youth with physical disabilities. *Health Educ Res* 1996;11:173–186.
5. Lollar D, ed *Preventing secondary conditions associated with spina bifida or cerebral palsy*. Washington, DC: Spina Bifida Association of America; 1994.
6. Dosa NP, Foley JT, Eckrich M, Woodall-Ruff D, Liptak GS. Obesity across the lifespan among persons with spina bifida. *Disabil Rehabil*. 2009;31(11):914–920. [PubMed: 19037774]
7. Law M, King G, King S, et al. Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Dev Med Child Neurol*. 2006;48(5):337–342. [PubMed: 16608540]
8. Schoenmakers MA, Uiterwaal CS, Gulmans VA, Gooskens RH, Helders PJ. Determinants of functional independence and quality of life in children with spina bifida. *Clinical rehabilitation*. 2005;19(6):677–685. [PubMed: 16180605]
9. Short K, Frimberger D. A review of the potential for cardiometabolic dysfunction in youth with spina bifida and the role of physical activity and structured exercise. *Int J Pediatr*. Online pub, 6 14, 2012.
10. Rimmer JH. The conspicuous absence of people with disabilities in public fitness and recreation facilities: lack of interest or lack of access? *Am J Health Promot*. 2005;19(5):327–329, ii. [PubMed: 15895533]
11. Rimmer J, Rowland JL, Yamaki Y. Obesity and obesity-related secondary conditions in adolescents with disabilities. *J Adolescent Health*. 2007;41:224–229.
12. Government Accounting Office. Students with disabilities. More information and guidance could improve opportunities in physical education and athletics. In:2010:GAO-10-519.

13. Rimmer J, Yamaki K, Davis B, Wang E, Vogel LC. Obesity and obesity-related secondary conditions in adolescents with Intellectual/Developmental disabilities. *J Intell Dis Res*. 2010;54:787–294.
14. Chen A, Kim SE, Houtrow AJ, Newacheck PW. Prevalence of obesity among children with chronic conditions. *Obesity*. 2009;18:210–213. [PubMed: 19521350]
15. Rimmer J, Yamaki K, Davis B, Wang E, Vogel LC. Obesity and Overweight Prevalence in Adolescents with Disabilities. *Prev Chronic Dis*. 2011;8:1–6.
16. Bandini L, Schoeller DA, Fukagawa NK, Wykes LJ, Dietz WH. Body composition and energy expenditure in adolescents with cerebral palsy or myelodysplasia. *Pediatr Res*. 1990;29:70–77.
17. Bandini LG, Curtin C, Hamad C, Tybor DJ, Must A. Prevalence of overweight in children with developmental disorders in the continuous national health and nutrition examination survey (NHANES) 1999–2002. *J Pediatr*. 2005;146(6):738–743. [PubMed: 15973309]
18. Reiner T, Dobe M, Winkel K, Schaefer A, Hoffman D. Obesity in disabled children and adolescents. *Dtsch Arztebl Int*. 2010;107:268–278. [PubMed: 20458368]
19. De S, Small J, Baur LA. Overweight and obesity among children with developmental disabilities. *J Intellect Dev Disabil*. 2008;33:43–47. [PubMed: 18300166]
20. Sukanya D, Small J, Baur LA. Overweight and obesity among children with developmental disabilities. *J Intell Dis Res*. 2008;33:43–47.
21. Emerson E. Overweight and obesity in 3- and 5-year-old children with and without developmental delay. *Public Health*. 2009;123(2):130–133. [PubMed: 19147165]
22. Holtkamp K, Konrad K, Muller B, et al. Overweight and obesity in children with Attention-Deficit/Hyperactivity Disorder. *Int J Obes Relat Metab Disord*. 2004;28(5):685–689. [PubMed: 15024399]
23. Lam LT, Yang L. Overweight/obesity and attention deficit and hyperactivity disorder tendency among adolescents in China. *Int J Obes (Lond)*. 2007;31(4):584–590. [PubMed: 17211443]
24. Simeonsson RJ, McMillen JS, Huntington GS. Secondary conditions in children with disabilities: spina bifida as a case example. *Ment Retard Dev Disabil Res Rev*. 2002;8(3):198–205. [PubMed: 12216064]
25. Luke A, Roizen NJ, Sutton M, Schoeller DA. Energy expenditure in children with Down syndrome: correcting metabolic rate for movement. *J Pediatr*. 1994;125(5 Pt 1):829–838. [PubMed: 7965444]
26. Stewart L, Van de Ven L, Katsarou V, Rentziou E, Doran M, Jackson P, Reilly JJ, Wilson D. High prevalence of obesity in ambulatory children and adolescents with intellectual disability. *J Intell Dis Res*. 2009;53(10):882–886.
27. Curtin C, Anderson SE, Must A, Bandini L. The prevalence of obesity in children with autism: a secondary data analysis using nationally representative data from the National Survey of Children's Health. *BMC Pediatr*. 2010;10:11. [PubMed: 20178579]
28. Papas M, Trabulsi JC, Axe M, Rimmer JH. Predictors of obesity in a US sample of high school adolescents with and without disabilities. *J Sch Health*. 2016;86:803–812. [PubMed: 27714868]
29. Steele CA, Kalins IV, Rossen BE, Biggar DW, Bortolussi JA, Jutai JW. Age-related health risk behaviors of adolescents with physical disabilities. *Soz-Praventivmed*. 2004;49:132–141. [PubMed: 15150865]
30. Agriculture USDo. Dietary Guidelines for Americans 2010, 7th ed In. Washington, DC: US Government Printing Office; 2010.
31. Popkin BM, D'Anci KE, Rosenberg IH. Water, hydration, and health. *Nutrition reviews*. 2010;68(8):439–458. [PubMed: 20646222]
32. Electrolytes IoMPoDRIf, Water. DRI, dietary reference intakes for water, potassium, sodium, chloride, and sulfate. National Academy Press; 2005.
33. Park S, Blanck HM, Sherry B, Brener N, O'Toole T. Factors Associated with Low Water Intake among US High School Students—National Youth Physical Activity and Nutrition Study, 2010. *Journal of the Academy of Nutrition and Dietetics*. 2012;112(9):1421–1427. [PubMed: 22749261]
34. U.S. Department of Health and Human Services. 2008 Physical Activity Guidelines for Americans. Washington, D.C.: U.S. Department of Health and Human Services;2008.

35. Hu FB, Rimm E, Smith-Warner SA, et al. Reproducibility and validity of dietary patterns assessed with a food-frequency questionnaire. *The American journal of clinical nutrition*. 1999;69(2):243–249. [PubMed: 9989687]
36. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77–101.
37. Bandura A Health promotion by social cognitive means. *Health education & behavior: the official publication of the Society for Public Health Education*. 2004;31(2):143–164. [PubMed: 15090118]
38. Voepel-Lewis T, Tait AR, Becher A, Levine R. An interactive web-based educational program improves prescription opioid risk knowledge and perceptions among parents. *Pain management*. 2019;9(4):369–377. [PubMed: 31215347]
39. Hollis C, Falconer CJ, Martin JL, et al. Annual Research Review: Digital health interventions for children and young people with mental health problems – a systematic and meta-review. *Journal of Child Psychology and Psychiatry*. 2017;58(4):474–503. [PubMed: 27943285]
40. Tu AW, Watts AW, Chanoine JP, et al. Does parental and adolescent participation in an e-health lifestyle modification intervention improves weight outcomes? *BMC public health*. 2017;17(1):352. [PubMed: 28438202]
41. Devine KA, Viola AS, Coups EJ, Wu YP. Digital Health Interventions for Adolescent and Young Adult Cancer Survivors. *JCO clinical cancer informatics*. 2018;2:1–15.
42. Geense WW, van Gaal BG, Knoll JL, et al. Effect and Process Evaluation of e-Powered Parents, a Web-Based Support Program for Parents of Children With a Chronic Kidney Disease: Feasibility Randomized Controlled Trial. *Journal of Medical Internet Research*. 2018;20(8):e245. [PubMed: 30068502]
43. Newacheck PW SB, Shonkoff JP, Perrin JM, McPherson M, et al. An epidemiologic profile of children with special health care needs. *Pediatrics*. 2007;102:117–123.
44. World Health Organization. World report on disability. In: http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf. Accessed August, 15, 2011.

Fig. 1.
CONSORT flow diagram.

Table 1:

Participant Characteristics (n=50)

	Total Sample		Telephone and Internet (n=24)		Telephone only (n=26)	
	n (%)	Mean $\pm$ SD (Range)	n (%)	Mean $\pm$ SD (Range)	n (%)	Mean $\pm$ SD (Range)
Parent's gender						
Male	5 (10%)		3 (12.5%)		2 (8%)	
Female	45 (90%)		21 (87.5%)		24 (92%)	
Child's gender						
Male	21 (42%)		9 (37.5%)		12 (46%)	
Female	29 (58%)		15 (62.5%)		14 (54%)	
Child's age (years)		11.3 $\pm$ 3.3 (6–17)		11.7 $\pm$ 3.1 (7–17)		10.9 $\pm$ 3.6 (6–16)
Child's Primary Disability						
Spina bifida	25 (50%)		10 (42%)		15 (58%)	
Cerebral Palsy	7 (14%)		4 (17%)		3 (11.5%)	
Stroke	1 (2%)		1 (4%)		0 (0%)	
Other	12 (24%)		7 (29%)		5 (19%)	
Did not respond	5 (10%)		2 (8%)		3 (11.5%)	
Child used assistive device or mobility aid	41 (82%)		18 (75%)		23 (88.5%)	
Function limitations						
<u>Arm</u>						
Full function	39 (78%)		18 (75%)		24 (92%)	
Partial function	8 (16%)		6 (25%)		2 (8%)	
<u>Leg</u>						
Full function	22 (44%)		11 (46%)		11 (42%)	
Partial function	22 (44%)		12 (50%)		10 (38%)	
	6 (12%)		1 (4%)		5 (19%)	
On a bladder/bowel management program	22 (44%)		9 (37.5%)		13 (50%)	
Parent's highest level of education						
Less than high school	6 (12%)		3 (13%)		3 (11%)	
High school	13 (26%)		5 (20%)		8 (31%)	
Some college	10 (20%)		5 (20%)		5 (19%)	
College/University degree	15 (30%)		7 (30%)		8 (31%)	
Graduate/professional education	6 (12%)		4 (17%)		2 (8%)	
Parent's employment status						
Full time	15 (30%)		8 (33%)		7 (27%)	
Part time	10 (10%)		5 (21%)		5 (20%)	
Student	6 (12%)		1 (4%)		5 (19%)	
Retired	3 (6%)		2 (8%)		1 (4%)	
Unemployed	16 (32%)		8 (33%)		8 (31%)	

	Total Sample		Telephone and Internet (n=24)		Telephone only (n=26)	
	n (%)	Mean $\pm$ SD (Range)	n (%)	Mean $\pm$ SD (Range)	n (%)	Mean $\pm$ SD (Range)
Annual household income						
<\$34,999	14 (28%)		7 (29%)		7 (27%)	
\$35,000–\$74,000	19 (38%)		7 (29%)		12 (46%)	
>\$75,000	7 (14%)		2 (8%)		5 (19%)	
Did not know/Did not respond	10 (20%)		8 (33%)		2 (8%)	
Parent's marital status						
Married	28 (56%)		13 (54%)		15 (58%)	
Never married	13 (26%)		5 (21%)		8 (31%)	
Separated	2 (4%)		2 (8%)		0 (0%)	
Divorced	6 (12%)		4 (17%)		2 (8%)	
Widowed	1 (2%)		0 (0%)		1 (4%)	

Table 2:

Intervention adherence

	Telephone and Internet	Telephone only
Completed intervention (n, %)	17 (53.1%)	23 (70%)
Phone calls attended (mean, SD) [range]	7.31 (1.62) [3–9]	7.81 (1.89) [3–9]
Days with journal entry (mean, SD) [range]		
Food	45.6 (30.8) [1–90]	NA
Water	46.1 (30.9) [1–90]	
Physical Activity	42.1 (29.4) [4–90]	
Weight	2.9 (3.1) [1–12]	

Table 3:

Change in weight and behaviors after 12 weeks of intervention (completers only)

	Telephone and Internet (n=17)	Telephone only (n=23)
Weight (kg; mean, SD)		
Baseline	53.22 (30.51)	50.47 (27.29)
Follow-up	56.26 (34.05)	52.54 (26.86)
Minutes of weekly physical activity (mean, SD)		
Baseline	27.06 (87.66)	34.78 (48.82)
Follow-up	26.47 (41.07)	51.30 (74.18)
Families reporting daily fruit intake (n, %)		
Baseline	3 (17.7%)	3 (13%)
Follow-up	1 (5.9%)	3 (13%)
Families reporting daily vegetable intake (n, %)		
Baseline	1 (5.9%)	1 (4.3%)
Follow-up	1 (5.9%)	1 (4.3%)