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*Parent Perceptions of a Novel Health Intervention for
Neurodiverse Youth*

By: Casey Hewett

Date: May 2nd, 2019

MERRIMACK COLLEGE



PARENT PERCEPTIONS OF A NOVEL HEALTH INTERVENTION FOR NEURODIVERSE YOUTH

Parent Perceptions of a Novel Health Intervention for Neurodiverse Youth

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Background: Children with all types of disabilities are more likely to be inactive due to a variety of factors. Children with neurodevelopmental challenges such as autism spectrum disorder (ASD) and/or mental health challenges such as anxiety and depression face unique barriers to exercise, including increased demands on parenting resources. Thus there is a critical need for interventions understand parental perspectives and address such barriers in neurodiverse youth. The aim of this study was to explore parental perceptions of a novel exergaming and virtual health coaching intervention targeting neurodiverse youth, including barriers and facilitators of their children’s engagement, in order to help tailor future interventions.

Methods: Parents of three children taking part in formative research prior to a full intervention pilot were interviewed using a semi-structured interview guide. Phone interviews were recorded and transcribed without identifying information. Themes were identified during joint review of transcripts by two researchers using an adapted grounded theory approach.

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Results: Three parents of participants (1 middle school, 2 high school; 2 male) took part.

Important barriers identified included easy frustration with gaming technology, feeling defeated by game avatars, burden of coordinating participation in the intervention, and desire for different types of games (non-sporting or non-dance). Parents felt strongly that participation had improved their children's perceptions of exercise and overall exercise engagement. Suggestions for improvement included utilizing games without a competitive component, creating integrated intervention interface for parents, participants, and coaches, and using newer technologies (such as virtual reality).

Conclusions: The home-based, school-supported GameSquad exergaming intervention shows potential to improve physical activity engagement in this population, however, barriers remain that should be addressed prior to upscaling. Modifications such as integrated intervention interfaces and more diverse gaming options would help improve intervention engagement and decrease parental burden.

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Introduction

Section 1: Background:

Obesity rates have been increasing among children and adolescents in the United States. This has made childhood physical inactivity a significant public health concern especially in youth with physical, intellectual and mental health disabilities (Pitchford, Siebert, Hamm & Yun, 2016). Compared to their typically developing peers, these populations show lower levels of physical inactivity and experiences higher rates of obesity (Shields & Synnot, 2016). Children with developmental disabilities are also at a greater risk for additional secondary health conditions including type two diabetes, cardiovascular disease, cancer and arthritis (Obrusnikova & Cavalier, 2011). While considerable attention has been paid to understanding barriers to and facilitators of physical activity in children with physical and intellectual disabilities, less research has been devoted to children with mental health disorders and development disabilities (MHD/DD) without commensurate intellectual disabilities.

There are many factors why children with all types of disabilities are more likely to be inactive. Parents are one of the most important factors affecting physical activity in all children (McGarty, & Melville, 2018). However, this is likely to be especially true for children with MHD/DD, who are more reliant on support from others, specifically their parents, and who usually have very challenging behaviors as a result of their diagnoses (McGarty, & Melville, 2018).

Therefore, the purpose of this capstone was to evaluate the parental perceptions of a novel health intervention for neurodiverse youth¹. We examined looked at parental perceptions of programming of implementation at a school site, including barriers and facilitators of their

¹ The term neurodiverse is used rather than disorder or disability to address concerns among these populations regarding labeling.

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childrens' intervention engagement, in order to help tailor future interventions to best serve the respective settings of school-based care. We collected data on parental perceptions using interview questions developed during the original Game Squad study from which this intervention was adapted (Staiano 2018), which allowed comparison of our participants to the original, typically developing cohort. The qualitative data collected from the parents/caregivers assessed barriers and pilot feasibility for participants. It also helped better understand factors that may differ by characteristics of parental perception, child age and diagnoses.

Section 2: Literature Review Methods:

The process to collect research for the literature review started by meeting with a reference librarian to identify relevant databases and key words. The databases searched were through EbscoHost, using the following keywords: parental perceptions of children with mental health disorders, autism, ADHD, depression, comorbid prevalence, physical activity, and exercise. Other databases used were PubMed and National Institutes of Health (NIH). Articles were included if they were peer reviewed and related to the topic. There were 30 articles found from the databases. The number of articles excluded were ten because they focused just on children with autism rather than all mental health disabilities. The number of articles reviewed were 18.

Section 3: Literature on Epidemiology of Mental Health and Developmental Disabilities

Neurodiverse youth is a term used when neurological differences are to be recognized and respected as neutral characteristics as opposed to disabilities. This pertains to any individuals with mental health disorders. The term neurodiverse was also useful when working with parents to elicit their perceptions, because it captures the fact that their children are different but does not use terminology that could alienate the parents to prevent them from sharing information.

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There is a lack of studies reporting the whole spectrum of disorders comorbid to ADHD. Many studies often fail to collect data on or exclude patients with common co-morbid disorders such as pervasive developmental disorders or intellectual disability (Jensen & Steinhausen, 2015). Autism spectrum disorders (ASD) and attention deficit/hyperactivity disorders (ADHD) are among the most prevalent neurodevelopmental disorders (Thomas et al., 2018). Results from one study showed that approximately 40% of those with one class of disorder also met criteria for another class of lifetime disorder (Merikangas et al., 2010).

For the first time clinicians are now able to simultaneously diagnose ADHD and ASD, due to recent changes to the *Diagnostic and Statistical Manual of Mental Disorders*. It has been estimated that diagnosable ASD symptoms occur in up to 50% of individuals with ADHD (Thomas et al., 2018). Comorbid developmental disorders of learning have been studied less frequently and have been found to coexist in 10-92% of patients with ADHD (Jensen & Steinhausen, 2015). Comorbidity can refer to both the co-occurrence of disorders temporally separate from ADHD, called sequential comorbidity (Jensen & Steinhausen, 2015). The most frequently observed comorbidities in children and adolescents with ADHD are conduct disorders and oppositional defiant disorders. Conduct and oppositional defiant disorders are defined as a frequent and persistent pattern of anger, irritability, arguing, defiance or vindictiveness towards parents/caregivers and other authority figures (Mayo Clinic, 2018).

The empirical data collected in the United States is lacking on the prevalence and distribution of a wide range of DSM-IV mental disorders of children and adolescents. The mental health disorders that was looked at in one study consisted of anxiety, behavior disorders, mood disorders, and substance use disorders. This study collected results from surveys that concluded about one in every three to four children suffer from a mental disorder with severe

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impairment across their lifetime. Because of such a high prevalence in mental disorders, further information is necessary to establish resource allocation priorities for prevention, treatment, and research (Merikangas et al., 2010).

One article looked at the importance of further investigation because developmental disabilities make a significant contribution to overall childhood health. The study's objective was to determine the prevalence of developmental disabilities in US children and in selected populations for a recent 12 year period. The study also sought to supply critical data needed for health and educational planning. The children that were included in the study ranged from ages 3-17. The study also examined the changes in the prevalence of developmental disabilities overtime. Diagnoses, were parent reported, and consisted of: attention deficit hyperactivity disorder; intellectual disability; cerebral palsy; autism; seizures; stuttering or stammering; moderate to profound hearing loss; blindness; learning disorders; and/or other developmental delays. Prevalence of any developmental disability increased over the 12 year period. The US reported in ~1 in 6 children had developmental disabilities in the years of 2006-2008 (Boyle et al., 2011).

Section 4: Literature on Physical Activity and Benefits in Neurodiverse Children

In the United States, it has been recognized that there is a national priority on research that focuses on physical activity for individuals with disabilities, specifically in children (Martin & Choi, 2009). There are many benefits that children can gain from being physically active. Physical activity lowers secondary health conditions, improves functioning for activities of daily living, and reduces the risk of chronic disease (Martin & Choi, 2009). It is important by helping children become more physically active because of the health benefits that will potentially carry over into adulthood (Martin & Choi, 2009).

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Autism spectrum disorder (autism) is a pervasive developmental disorder characterized by deficits in social skills, communication and repetitive or restricted interests. For this reason, motor skill difficulties have received more attention in the literature, while physical activity patterns have received less. Parents of children with ASD have reported that their child's limited motor, social, and communication skills are child-level barriers to participation in physical activity participation (Must et al., 2015). More vigorous physical activity has further amplified positive behavior change in comparisons to bouts of light or moderate physical activity (MacDonald, Esposito, & Ulrich, 2011). Research has demonstrated that physical activity reduces negative behaviors and promotes positive behaviors among individuals with ASD. For example, bouts of physical activity has shown improvements of behaviors such as stereotypy, aggression, and self-stimulatory (McCoy, Jakicic & Gibbs, 2016).

Deficits in affective and cognitive functioning are common in children with ADHD. In addition to inattentiveness, hyperactivity, and impulsivity, these individuals often suffer from comorbid disorders and, in particular, from affective disorders such as depression (Gawrilow et al., 2016). Pharmacological treatment is commonly used to reduce ADHD symptoms. However, non-pharmacologic treatment methods would be preferred by parents, children and psychiatrists (Gawrilow et al., 2016). Because physical activity (PA) has been shown to improve cognitive functioning in healthy populations, it can be hypothesized that there are similar beneficial effects in children with ADHD. However, very little is known about this issue. One study outcome indicated that regular PA can be used as a complementary or alternative non-pharmacologic treatment for ADHD (Ziereis & Jansen, 2015).

Section 5: Literature on Physical Activity Perceptions and Behaviors Among Parents of Neurodiverse Children

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Physical activity has numerous physical and mental health benefits. To gain clinically significant health benefits, children are recommended to participate in moderate to vigorous physical activity (MVPA) for 60 minutes or more per day (McGarty, & Melville, 2018). Studies have shown that neurodiverse children and adolescents are not participating in the recommended physical activity per day (McGarty, & Melville, 2018). Researchers have suggested that parental support is an important factor of their children's physical activity levels (Martin & Choi, 2009). To accurately create interventions and community programs to address this health disparity, it is crucial to understand the unique correlate of physical activity for children with disabilities; specifically, those related to parental perceptions of exercise benefits (Pitchford, Siebert, Hamm & Yun, 2016).

Neurodiverse youth are more reliant on support from others, specifically parents. This brings attention to the main role parents have in promoting physical activity in their children with disabilities (McGarty, & Melville, 2018). Parents serve an important role in reinforcement of physical activity for their child, which has both direct and indirect influences on their child's physical activity behavior. Providing transportation to physical activity events is an example of direct influence of parents. Indirect influences are facilitated through attitudinal processes (Pitchford, Siebert, Hamm & Yun, 2016).

Common parentally-perceived barriers to physical activity in neurodiverse children that studies reported were inaccessible facilities and programs, non-inclusive providers, transportation, lack of relevant opportunities, and cost (Pitchford, Siebert, Hamm & Yun, 2016). The most common perceived facilitators were welcoming providers, parental support, inclusive providers, adaptable approaches and accessibility of facilities (Shields & Synnot, 2016). Parents of children with disabilities have been shown to be more protective of their child than parents of

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typically developing children, limiting the exposure to physical activity (Shields & Synnot, 2016). Being the “gatekeepers” to formal and informal activities, parents can either be a barrier or a facilitator to physical activity among children with disabilities.

One article examined the multidimensional sources of supportive parents and whether the perceptions were related to parents’ perceptions of their children’s physical ability. The parents completed scales which assessed how often they role modeled, encouraged, and enjoyed physical activity in addition to their perceptions of their children’s physical ability and relationships with peers during sports. The results reported that the parent’s support of their children’s physical activity was not dependent on how physically capable they viewed their children to be which is encouraging. The study concluded that more research still needs to be done on this prevalent topic (Martin & Choi, 2009).

Another study explored barriers and facilitators to participation in physical activity from the perspective of children with disability, their parents and sports and recreation industry personnel. The involvement of participation in physical activity by children with disability was studied through a series of 10 focus groups with significant stakeholders (children with disability, their parents and sports and recreation industry personnel). The children that took part in this study had the following types of disabilities: cerebral palsy, vision impairment, intellectual disability, developmental delay, and multiple disabilities. Results confirmed that children with disabilities’ need for early achievement of motor and social skills, the essential role of families and their need for support, and that societal attitudes continue to influence children with disabilities’ participation (Shields & Synnot, 2016).

A recent systematic review of parental perceptions of facilitators and barriers to physical activity for children with intellectual disabilities included ten studies. The review concluded that

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there is an important role in parents supporting physical activity levels in their children with intellectual disabilities. The study also reported that increasing the level of information and education given to relevant others (coaches, teachers, peers, parents of typically developing children, and staff) could be an important method of turning barriers into facilitators. Further investigation in future research needs to be done (McGarty, & Melville, 2018).

The purpose of the study *Parental Perceptions of Physical Activity for Youth with Developmental Disabilities* (Pitchford, Siebert, Hamm & Yun, 2016) was to investigate the relationship between childhood physical activity participation and the parental beliefs about the importance of physical activity among children with developmental disabilities. The primary disabilities categories the study included: intellectual, physical, behavioral, and sensory impairments. The results indicated that the parents/caregivers beliefs about the benefits of physical activity were significantly associated with the physical activity level of their child with a developmental disability. Having more positive beliefs for their children about exercise translated to higher rates of physical activity for the child. It was interesting that this study found no significant association between the severity of the child's disability and physical activity participation. Since prior studies most evidence showed that children with more severe disabilities were less active (Pitchford, Siebert, Hamm & Yun, 2016). Considering the negative effects of physical inactivity on youth with disabilities, physical activity promotion should focus on educating parents/caregivers on the benefits of physical activity. This study concluded that increasing exercise time and creating more opportunities for children with disabilities to be more active would benefit this population. (Pitchford, Siebert, Hamm & Yun, 2016).

Summary

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A review of relevant literature confirms that neurodiverse youth are at higher risk of engaging in low physical activity when compared to typically developing peers. One contributor to lower levels of physical activity among these populations may be parental perceptions of physical activity, as well as competing parenting priorities when children have special needs.

There is a lack of studies examining these issues in children with complex, comorbid diagnoses. Frequently studies tend to overlook or even exclude patients with comorbid mental health and developmental diagnoses. To improve the health outcomes for this particular population, increasing the levels of physical activity could potentially be a successful method to improve symptoms and chronic disease risk. However, it is essential to first, have a better understanding of why neurodiverse youth are generally less physically active in order to design more effective, accessible exercise interventions and community programming for these youth.

CAPSTONE STUDY

Methods

Setting and participants

This project sought to determine whether the Game Squad intervention was acceptable and engaging to children and adolescents with mental health and developmental disabilities. The GameSquad sessions consisted of challenges each week of the three games given to the children in the study (Shape Up, Kinect Sports Rivals, Just Dance 2016), along with weekly meetings with the virtual health coach with sessions lasting 15-30 minutes. The exergames were to be played by the children 3 times per week. The duration of the games were 10-20 minutes long, increasing over 4 week period. The students were encouraged to get as many steps in on days children do not exergame using non-screen activities. The intervention looked to assess the

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feasibility of implementation through a home-based physical activity program for children with MH/DD delivered with school-based support.

The school site studied in the intervention was Marblehead Public Schools. The children who were in this setting are in a program called the Therapeutic Intervention Designed for Educational Success (TIDES). This program consists of several North Shore community public school special education programs in Massachusetts. The special education program addresses comprehensive educational needs of students diagnosed with an emotional/behavioral disability. This interferes with successful independent learning in the typical education classroom.

The students had additional support through their caregivers and the TIDES program. Examines the parental perceptions of programming implementation at the school, including barriers and facilitators of their childrens' intervention engagement could be used to improve future studies. In order to help tailor future interventions, it was important to best serve the respective settings of school-based care.

Sampling

To participate in the 4-week Game Squad pilot intervention, three (n=3) participants from the school site were recruited. Three (n=3) from Marblehead Public School's TIDES program grades 7-12 and their parents/caregivers.

The recruitment process for the participants in the TIDES program was by, information and consent forms and also child assent. The forms were sent home to the participants parents via email. If needed, the parents were to receive a follow up phone call to support the completion of the online screening.

It was expected that the participants had complex mental health (MH) and developmental disabilities (DD) conditions including mood, anxiety, thought, and conduct disorders, and/or

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ASD or ADHD. To ensure participants' ability to participate/interact with the exergames, they were required to have IQs of 70 or above. The participants also needed to be healthy and free from any chronic or physically disabling conditions for which vigorous physical activity is contra-indicated or not feasible. In participants' home environment, wifi must have been available in order for the intervention to take place. The participants were then randomized to the Game Squad intervention or wait-list control group in each site. The wait-list control group will receive a shortened intervention in the summer months and all study materials.

Instruments

At the end of the intervention, an interview was organized via telephone that looked at parental perceptions and satisfaction with the Game Squad program. The interview was to extract additional information/feedback about the program including feedback on perceptions of the perceived quality of the program. Some of the interview questions were developed during the original Game Squad study (Staiano 2018), which allowed comparison of our participants to the original, typically developing cohort.

A research assistant conducted the phone interviews which took about 30 minutes. It also obtained the programs' implementation and perceived positive and negative effects on the participant. During the interview, the parents/caregiver were recorded. Once the recording was transcribed, any identifying information was removed. Then the recordings were deleted. The findings were reviewed and summarized by theme.

Themes come both from the data and from prior research from the characteristics of the situation being studied. One way to find themes is by word repetition. Words that occur a lot are often seen as being important in the minds of respondents (Ryan & Bernard, 2003). The qualitative data collected from the parents/caregivers, assessed parental perceptions of barriers,

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and whether they deemed the pilot feasible for participants. It also helped better understand factors that may differ by characteristics of parental perception, child age and diagnoses. This then allowed us to alter the study before beginning the Game Squad program in the spring.

Data Analysis

This was a qualitative study, utilizing interviews with parents after completion of the 4-week exergaming program. We used a semi structured interview guide developed after a review of the literature. Interviews were recorded and transcribed removing identifying information. Themes were inductively identified by the primary researcher with validation from a secondary researcher.

Results

Three major themes emerged from parent interviews: 1) benefits of participation, 2) challenges encountered during participation, and 3) suggested improvements to the intervention. These themes were further divided into sub-themes, and categorized as child-centered, parent-centered, or family-centered as appropriate.

Theme One: Benefits

Sub-theme: *Child Benefits*

The child benefit sub-theme was categorized into three sections. The first benefit was that the child made more of an effort to walk places. The games also showed that there was definitely effort required from the participants. The third was that the virtual health coaching sessions made the child thinking more about exercise techniques.

1. Child made more of an effort and was more aware of getting exercise
 - a. “Probably I wouldn’t say it wasn’t a dramatic increase, but we definitely made more of an effort. Our non-screen exercise was walking which where we live it’s

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pretty rigorous he walks pretty fast and there are a lot of hills and would pick up like 12 flights of stairs just with the hills in our town”

- b. “We definitely thought about it and trying to make an effort to being active.”
- c. “I would say yes, [my child] tried to walk more she and her brother did [just] dance a number of times, more than they needed to. They did that a lot but past that it was just the walking.”
- d. “I think [my child] became more aware [of exercise]. [My child] had always known that exercise was a good thing. [My child’s] father is a fanatic exerciser etc. but think it became more apparent to her by doing it sort of by having to do it and then it became I don’t that it was I don’t know if I would say fun on all of it but certainly on a lot of it and I think she became more aware that exercise was a good thing and you can do it in a fun way.”
- e. “He had a little bit of a different mindset about exercise and was more open about taken an extra step.”
- f. “Mostly because of the Fitbit he was more aware of steps and how much movement and it had him wanting to walk more rather than ask for a ride so it wasn’t like he played more sports or anything like that but he did walk more that was good but I wouldn’t say it increased as the trial went by I mean early on it was better and still likes to see his steps and the Fitbit so that was good.”
- g. “...Actually come to think of it for the just dance [game] which was her favorite she [danced] around the house sometimes, but she was doing it more. I think she was incorporating some of the moves.”

2. Games required moderate to vigorous exercise to complete

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- a. "... [The games] definitely required effort the kid was out of breath by the end of some of them which is good and what you want and his heart rate was up so from that aspect I thought it was good."
3. The virtual health coaching sessions had the child thinking more about exercise
 - a. "I think she learned about your different moves and different ways to move to get more exercise."
 - b. "[My child] asked a lot of questions about technique certainly on the weight lifting one more along those lines."
 - c. "Another thing that was good about the coaching sessions was that one week [my child] told the coach, oh I'm thinking about doing squats in between the games and [the virtual health coach] said oh that would be great, and the next time [the virtual health coach] asked if he had done it he hadn't but I think it had [my child] thinking more about exercise whether he did it or not. If anything, that's a step in the right direction."

Sub-theme: *Family Benefits*

The next benefit that was broken into at a sub-theme was the family benefits of the program.

This was separated into three categories. The first was that the journal that was given to the participants and family was very helpful. The second was that the virtual health coach was the same every week making the child comfortable knowing who they will be speaking with. The final is that to keep children motivated the parents told child that it's their job to do this.

1. Journal was helpful

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- a. “I think it was really well organized and I think everything was pretty clear as far as expectations and I think the journal was super helpful obviously without that we would have been completely lost.”
2. Helpful that the virtual health coach was the same person each week
 - a. “It was nice that it was the same person, so [my child] would know who it was going to be.”
3. When the child was frustrated the parent told child this was their job
 - a. “I told him if you want to keep this Xbox, which was his motivation in the first place, it’s your job and if you don’t do your job you’re not going to get to keep it. That was something for [my child] that kept him going through it when he was frustrated.”

Theme Two: Problems Encountered

Sub-theme: *Child & Parent Barriers*

The next theme that was examined, were the problems encountered. This was broken into two sub-themes, child and parent-level barriers. This was further broken into three categories. The first one was child avoidance, the second was technical problems with the system, and the third was difficulty interacting virtually with the coach.

1. Child waited until the last minute to play the games
 - a. “When I first heard about this study I thought oh video games he’ll be totally into it. [My child] never said once, I want to do it myself and we had to kept saying you need to do it and we tried to make a schedule and basically we really had to insist that he had to do it and if you look a lot of are times were 8pm [because he]

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waited to the very last minute and I was like they're going to know that you're waiting."

- b. "Having the weekly check ins, ... [my child] is a procrastinator. There were three challenges and then the check in and I found especially towards the end that he wasn't doing them until the day before the check ins so that was really sort of getting him to do it, knowing that he was going to have the check ins, so I don't know a way to have them spread it out more."
2. Child was frustrated when the connect system wasn't working
 - a. "Often when he would do them [he would] get very frustrated with them mostly as he said because the connect system wasn't great and so he would feel like he was doing what he should and it wasn't picking up so it was frustrating. Also you don't score or come in last but it was more just the process of trying to do the games and it wouldn't necessarily pick up what he was doing so it got to be a pain for him and he didn't necessarily like it that much after a while."
 3. Child wasn't thrilled with interacting on skype
 - a. "She's not really thrilled with interacting on skype but it was fine she did fine and [the virtual health coach] was really nice and the only thing was it took her the first week to understand the delay and timing with the skype but otherwise they got along great."
 - b. "The first time she was very nervous, so she was doing a lot of talking and I was kind of like okay you need to give space to [let the virtual health coach] talk."

Sub-theme: *Parent*

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The next sub-theme is the problems encountered by the parents. This was by far the most in depth because it was categorized into 9 groups. The parents gave a lot of great feedback in this section on what they think would have helped their child better succeed in the program.

1. Parent difficulties playing with children

- a. "...if that's really important maybe then have the coach encourage the kids to let other people play. If they haven't and he may be the only kid who hasn't let anyone else play but if [the virtual health coach] had said hey I really want your mom to play with you next time is that okay? [My child] probably would've said yes, but when it comes from me it's probably not as valuable."

2. Bad connection with the connect causing children to lose focus

- a. "I mean, I initially was a little awkward because we couldn't really see [the virtual health coach] or connect and again for a kid who literally has no patience and no attention span, stuff like that is really a barrier, he kind of turns off but we talked to [the virtual health coach] on our laptop and I think that was helpful."
- b. "The whole connect system, I don't know if other people had the same concerns, but with these kids and the frustration of that [it] is really detrimental to this program. I think had the equipment worked better, that would've made a big difference and wanting to do it and wanting to keep going and maybe saying like hey friends let's do this, but it was really just a source of frustration most of the time."

3. Child might have done more activities if it was a different time of the year

- a. "If it was a different time of year we might have made it to the pool more or done different types of exercise. [My child] doesn't do much more than hiking,

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walking, [or] swimming... We had gone to the Y gym a couple of times, [but] other than that it's not like he plays tennis or soccer, I mean I love tennis but I can't get him to play with me."

4. Parents didn't really play with their child

- a. "No, I sat there and watched and sometimes my husband would sit there too but he didn't play against any humans. Again, some kids really respond well to competition but he cowards away from competition. So, if I had played with him and he lost he probably would've cried and given up and said I always lose and why am I a loser. Things like that and we work on that he's 13 we've known this for a long time."
- b. "He never wanted to play with any of us and I sat there with him the whole time and said oh I want to try that but he would only do it himself which again is his own said of quirkiness. Most kids kind of like doing that stuff ya know. He takes it too seriously and then would feel bad if he was doing badly. We kind of tried to have him do it when his sister wasn't home and no one was around to kind of be judgy but again that's very specific to him."
- c. "No, I just watched."
- d. "I really only did in the very beginning [I played] the bowling game because it was fun and that was his favorite, [but] it really wasn't much."

5. Busy work schedules made it difficult to coordinating skype sessions

- a. "The only thing that was difficult... [is] my husband works days, and I work nights uhm sometimes he [gets] home late so sometimes we had trouble coordinating having a skype session with the coach with one of us here."

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- b. “I guess we were busier than we thought we were. It was harder than you think to fit it in. It doesn’t sound like very much but I don’t know why it was something else to remember what to do and like he’s not a kid who makes his own schedule he’s a kid we kind of have to direct a lot.”
6. Motivating the child to do the game was the main problem
 - a. “When I first heard about this study I thought oh video games he’ll be totally into it. [My child] never said once, I want to do it myself and we had to kept saying you need to do it and we tried to make a schedule and basically we really had to insist that he had to do it and if you look a lot of are times were 8pm [because he] waited to the very last minute and I was like they’re going to know that you’re waiting.”
 - b. “Our main problem was getting him to [play the games] and I don’t know if that’s always the case [for other children].”
7. The virtual health coach didn’t motivate children enough
 - a. “... [The virtual health coach] would say, oh don’t worry about if you get frustrated you don’t have to do it you can stop or go to another game. It wasn’t motivating to keep [my child] going. If anything [my child] felt like alright well I’m just not going to do it because it frustrated me.”
 - b. “[My child] is pretty confident and very good at interacting, so I think with her [the virtual health coach] could’ve maybe pushed her a little more on what she was doing and on sort of exercising.”

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- c. “I guess if there could be more motivation somehow so the kids keep up with it or do more and see if you could increase your abilities or levels overtime. I felt like that didn’t happen so much.”
8. Not much discussion on health knowledge
 - a. “I don’t think there was any discussion about health. There was nothing on nutrition or food or drinking water. I think he talked about the outside exercise a little bit but that was about it unless I’m forgetting something but that’s it for now.”
 - b. “No” – answer to question did your child gain any health knowledge.
 9. In-game avatars inappropriate for audience
 - a. “The [video game] coaching sessions were fine, [but] the computer generated [coach] was awfully fit and gung ho sometimes a little too much.”
 - b. “The actual Xbox thing itself the opponent she went against sometimes were a little too athletic and ra ra and she kind of felt discouraged is a strong word, but ya know I’m never going to beat them anyway.”

Theme Three: Suggestions for Improvements

Sub-theme: Technology Suggestions

In this section, it covers the themes on suggestions for improvements. The theme was broken up into three sub-theme categories. The first sub-theme is suggestions from parents on the technology equipment used. If they encountered problems with any of the equipment, they gave us suggestions on what might work better for their child or for children who have neurodevelopmental challenges. The parents concluded that there needed to different types of games, and new equipment.

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1. Non-sports games

a. "...The types of games they had were good and fun and I bet for most kids they're really fun but I was thinking if you had a game like one of the building or pioneering game [like Minecraft]...because those are the games that kids love or even battling dragons and sword fighting something less exercise focus and I realize that's kind of the point but to get them to exercise without them really knowing it"

2. Different equipment

a. "Often when [my child] would do them [my child would] get very frustrated with them mostly as [my child] said because the connect system wasn't great and so [my child] would feel like he was doing what he should and it wasn't picking up so it was frustrating. Also you don't score or come in last but it was more just the process of trying to do the games and it wouldn't necessarily pick up what [my child] was doing so it got to be a pain for [my child] and he didn't necessarily like it that much after a while."

b. "I think especially with kids in this group with the issues that they have that is one added frustration that hurts the program for sure."

Sub-theme: *Coaching Suggestions*

The second sub-theme was the suggestions parents made about the weekly chats, with the virtual health coach. They felt that the virtual health coaches could have been more motivating to keep the children engaged. Another suggestion made was for the virtual health coaches to encourage children to allow others to play with them.

1. More motivation

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- a. "I'm not sure we had a ton to say really so maybe if I was one of the coaches I'd ask more questions like, do you feel any different? Do you feel like it's getting easier or harder? And he would ask us if we had any questions and we would just sort of chat and it is tough [since] it's not like he really knows the kids."
 - b. "I think it was good I think my child is really hard to engage so I think he was friendly and outgoing. In hindsight I probably could've given him pointers on how to engage if he felt like he needed them, I'm not sure how he feels like if it was pretty engaging. But I think [my child] looked forward to talking to him but again he has like a 5 minute attention span he's like doing something else in the middle of it."
 - c. "[My child] is pretty confident and very good at interacting, so I think with her he could've maybe pushed her a little more on what she was doing."
 - d. "I guess if there could be more motivation somehow so the kids keep up with it or do more and see if you could increase your abilities or levels over time...I felt like that didn't happen so much."
2. Encourage children to let family/friends play
 - a. "...if that's really important maybe then have the coach encourage the kids to let other people play. If they haven't and he may be the only kid who hasn't let anyone else play but if [the virtual health coach] had said hey I really want your mom to play with you next time is that okay? [My child] probably would've said yes, but when it comes from me it's probably not as valuable."

Sub-theme: *Process Suggestions*

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The third sub-theme for this section is the process suggestions made by the parents. In the challenge booklet, it lists the games and approximately how long they should take. Parents felt that there was not enough time given for the children to do some activities which caused frustration. Another suggestion was to get rid of competitive games because children don't respond well to this. Parents also suggested that it would have been helpful if they had a practice week so they could get familiar with the new equipment. Finally, to come up with other ways to encourage the kids to continue playing the games.

1. Change time expectations

- a. "The other thing was in the beginning [the game book] says do 10 minutes, the second week was 20 minutes increasing each week, but it seemed like the amount of things you were supposed to do in the challenge was definitely way longer than the time you were supposed to do each week. So, if he was getting frustrated... do we stop because it's been 10 minutes or do we keep going because he needs to get through the challenges? That wasn't really clear and then we mentioned that in one of the [coaching] sessions and [the virtual health coach] said well it was really geared around to do it in that amount of time, but then another time he said [to] get through them as well. That was a little frustrating. If they are only supposed to do 10 minutes there should be less to do in the challenges, especially because it is broken up by the week."

2. Get rid of the competitive games

- a. "I think if there was a way to play the games where they are just looking at their own scores and their own improvements overtime. [For example] you must have been tired today you dropped ten points. That might be better for [my child] so he

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doesn't have to worry about this robot is beating me or something and I had to keep reminding [my child] it's not about winning or losing."

3. Add a practice week

- a. "I think if the program had a practice week but I felt like the first week we were still getting warmed up and figuring it out or maybe we were the only people who needed a training week but it took us a while to navigate the system although the system wasn't really working so maybe that's why

4. Other ways to encourage kids to continue to play

- a. "I'm trying to think of something other than [the games saying] yay fantastic you did well to give [the children] a feeling of pride for what they've accomplished that would be my only suggestion."
- b. "... I think you are going to struggle with some students who aren't as motivated as [my child] but I think yeah if there could be more incentive encouragement that would help."

Discussion

The purpose of this study was to examine potential benefits, barriers and suggestions for improvement among parents of children participating in a pilot exergame program. We interviewed three parents after their children completed the 4-week pilot intervention. The students had to complete the games three times per week. The students also had a set time each week to Skype with the virtual health coach, which lasted about 15-30 minutes. Along with the intervention program, students were encouraged to get as many steps in on days they did not exergame.

Benefits

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The first theme looked at the benefits of the overall program of the child and the parent. During the pilot study, parents found that the children were more aware and made more of an effort to be active. Although, parents said that this only increased by a little, it still had them thinking about exercise and taking that extra step. The non-screen time activity that the children in the study participated in the most was walking. The Fitbit in particular encouraged children because they were able to see the steps which motivated them to walk more. Parents also mentioned that some of the games played required a lot of effort. Along with being more aware of physical activity, the virtual health coaches had children thinking about exercise more. Parents said that children asked about different techniques that they had picked up from the game and utilized some around the house. Even if the child did not do that all the time, it still had the children thinking more and opening them up to different exercise techniques. Parents also thought that the Challenge Book was beneficial to have so they were able to follow through the program requirements. Another thing that parents appreciated was that the virtual health coach was the same person each week. It gave the child a chance to connect with the health coach. This also gave the health coach a better idea of the child and what they like vs do not like. To motivate their children parents told the child in order to keep the technology equipment, they have to complete the program to the best of their abilities.

Problems encountered

The biggest problems the study encountered were that children were frustrated when the connect system would not work and motivating children was a challenge. The first problem was technology issues. Children would lose focus when bad connection occurred. If the connect was not picking up the movement, it caused the child to become aggravated not wanting to continue on. The other problem was motivating the children to play the games. Because the children were

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not motivated it caused them to push off the games until the last minute when they would meet with the virtual health coach. Another common issue parents had was that they felt that the virtual health coach did not motivate their child enough. Parents reported that children were also not excited about interacting with the virtual health coach through Skype. This made the child nervous. The virtual health coaches had minimal if any discussion on health knowledge. Parents also were not involved in any game play. Some of this was due to the fact that children were too competitive not allowing parents or others to play with them. Some parents also felt that the in-game avatars were inappropriate for the audience. The avatars were very fit causing it to almost discourage the children because they felt as if they were never going to beat them or look like them. Another problem was that the pilot took place during wintertime. If it had been summertime, it would have allowed children to have more of a variety in non-screen time exercise for example, swimming, walking and hiking. This was also related to busy schedules. To coordinate Skype sessions around doctors appointments, school and parents work schedule it was challenging for parents to find one time that works for everyone.

Suggestions

The final theme found was suggestions for improvements. The parents found that the technology provided was too problematic, causing their children to become frustrated. The parents believed that by having different technology, it might benefit the intervention. Another suggestion that was addressed was that the games were too sport oriented or that the games did not interest the child at all. Not all children are interested in sports or dancing, so games need to be added to tailor all of the children's needs to ensure their satisfaction and motivation of the program. Parents mentioned that by having a game that was more of a lifestyle or fighting based game, could potentially get the child to be active without even realizing it. This would be another

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approach of how to engage children in physical activity in a fun way while also keeping them interested in the program.

The parents of the study also thought the virtual health coach was not motivating enough which caused the child to stop playing the games. Every child within this group has different obstacles they run into and the parents know their children and how to engage them to the best of their ability. However, the virtual health coaches do not necessarily know how far is too far when motivating these children. Trying to keep children on track and having them try to pay attention is a challenge itself. If the coach was unable to connect with children at any point, you could lose the child's attention. Allowing parents to suggest ways to interact and engage their child, it could potentially benefit the program. The parents believed that if the coach were to push the children a little more, it could have further motivated them to want to play the games. Parents also suggested to encourage the virtual health coach to let friends and family play. Most children in general do not like competition, however children in this particular group might have more issues when involving others.

Along with technology and coaching suggestions, process suggestions were made. Parents thought there was not enough time that was expected of the children to complete each game. In the Challenge Book, it had listed the estimated time on how long the child should play the game each week. Parents explained that having the time expectation caused frustration to their child, especially when combined with technology complications. This caused confusion to children and parents on what to do in situations like this. Having a more realistic time expectation in the Challenge Book could help the child and parent not run into a stressful situation if the child could not complete the game. Parents also made a suggestion to utilize games without a competitive component. By adding a competitive component, you are

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increasing the chance for children to become upset. Parents kept reminding their children that it is not about winning or losing, because the goal of this was to find a way to make the children in this group more active. If the child becomes frustrated that they lost, they might not want to play the game again. If there were other ways to encourage kids to play, like additional incentives, that might be beneficial, especially to children who are not as motivated as others. Another suggestion that the program should implement, is to utilize a run-in period. For parents, the first visit made was setting up the Xbox and going over instructions, which became overwhelming. Getting accustomed to new technology, meeting the virtual health coach, and running through the games might all seem clear in that minute but once they are left on their own, it can be a challenge to go through how everything works. On top of learning how everything works, many parents ran into technology problems. This interfered with days when the child needed to play the games. If we had a week to allow them to practice and get a feel for it, it could prevent future interferences.

Limitations and Future Research Directions: An important limitation was that the study had a very small sample size. However, after interviews were reviewed, we will be able to utilize the feedback assessing barriers to help tailor the future GameSquad intervention. Adding new technology such as virtual reality, developing a mHealth app, and expanding the types of games being played could help the program grow. Future research should investigate feasibility and engagement among a larger sample of youth with diverse and heterogeneous mental health disorders.

Conclusion

The home-based, school-supported GameSquad exergaming intervention shows potential to improve physical activity engagement in this population, however, barriers remain that should

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be addressed prior to upscaling. Modifications such as integrated intervention interfaces and more diverse gaming options would help improve intervention engagement and decrease parental burden.

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