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A Swimming Program for Children with Autism Spectrum Disorders: Assessing Critical Parameters from Caregivers' Perspectives


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Cover Page Footnote

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Abstract

One in 54 individuals is diagnosed with autism spectrum disorders (ASD). Swimming can impact the physical and mental well-being of persons with ASD, which in turn may improve their caregivers' well-being. The purpose of this qualitative evaluation study is to assess the necessity, acceptability, feasibility, fidelity, and beginning effectiveness of a 12-session swimming training program (STP) at an indoor university pool designed to teach persons with ASD how to swim, and to teach caregivers precautions for safety around water. Participants included 7 boys, and 3 girls with ASD [mean age 7.05 years (SD 1.17)] and their caregivers. Results indicated that caregivers reported a need for this STP and the content was appropriate. Participants indicated the instructors' creativity and patience as well as social interaction were the most interesting/acceptable part of the STP. The number of lessons and length of the STP were considered appropriate. Evaluating these critical parameters of the STP from caregivers' perspectives was essential as this will likely influence their future participation in swimming programs.

Keywords: swimming programs, autism spectrum disorders (ASD), caregivers

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition that impacts children's socialization, communication, and behaviors (American Psychiatric Association, 2013). The diagnosed prevalence of ASD has tripled over the last two decades (Centers for Disease Control and Prevention, 2018). One in 54 individuals is diagnosed with ASD (Centers for Disease Control and Prevention (CDC), 2018). ASD impacts the health of a whole family because of the stress of accessing supports for a child with ASD (Karst & Van Hecke, 2012). Research has shown that persons with ASD themselves may experience anxiety and depression which in turn can elevate the caregivers' depression and vice versa (Almansour et al., 2013; Strang et al., 2012). In addition, they experience a range of co-morbid physical disorders including obesity (Curtin et al., 2014), constipation, hyperactivity, and sleep disturbance (Johnson et al., 2015). One of the main characteristics of ASD is impaired social interaction and communication (American Psychiatric Association, 2013). Physical activity such as swimming could benefit children with ASD. In fact, previous research has shown that swimming holds potential for child social improvement (Pan, 2010).

Swimming is an important part of a healthy lifestyle and has many benefits. Aquatic activity is whole body exercise that has a beneficial impact on stress level, muscle tone, endurance, weight management, and overall physical and psychological well-being (Becker & Cole, 2004). Research shows that swimming can improve sleep and mood (Botonis et al., 2019; Johnson et al., 2019; Mische et al., 2017). Swimming is soothing and calming for the sensory system of a child

with ASD (Mische et al., 2017). Learning how to swim at an early age and learning about water safety helps prevent drowning (Denny et al., 2019).

Research shows that drowning is a leading cause of death in children with ASD (Alaniz et al., 2017). According to the National Autism Association, accidental drowning accounted for approximately 90 percent of total U.S. deaths reported in children with ASD ages 14 and younger between 2009 and 2011 (National Autism Association, 2018).

According to the American Academy of Pediatrics, most children can learn how to swim by four years of age (Denny et al., 2019), however traditional swim lessons are not tailored to the needs of children with ASD. Previous research provided preliminary evidence that children with ASD can improve water safety skills, which are important for drowning prevention in as few as 8 sessions of intervention (Alaniz et al., 2017).

Swimming can also improve a child's challenging behaviors, social behaviors, and enhance their overall physical well-being (Fragala-Pinkham et al., 2011; Johnson et al., 2015). With the overall goal of improving parent psychological health and decreasing child challenging behaviors, our research team developed, and pilot tested a 12-lesson swim training program (STP) (Johnson et al., 2021). Results of the study (n=10) were improved scores for parent anxiety, psychological wellbeing and parent positive thinking, and decreased challenging child behaviors (Johnson et al., 2021).

One of the nursing research priorities in recent years has been to test interventions that guide practice (Aranda, 2008; Zauszniewski, 2012). Researchers have pointed out that before randomized controlled trials can take place, the examination of critical parameters are required so effectiveness can be established (Bennett, 2005; Zauszniewski, 2012). Researchers have argued that the implementation and sustainability of an intervention depends upon assessing other parameters from intervention recipients. In other words, unless the recipients perceive the intervention as appealing, convenient, meaningful, necessary, and beneficial, they likely will not adapt it, resulting in interference with their optimal health (Zauszniewski, et al., 2018; Zauszniewski, 2012).

Therefore, the purpose of this qualitative evaluation study is to examine six critical intervention parameters, namely its *necessity*, *acceptability*, *feasibility*, *safety*, *fidelity*, and *beginning effectiveness* of the swimming training program (STP) designed to help children with ASD and their caregivers.

The Intervention Parameters

The *necessity* parameter refers to whether caregivers of persons with ASD believe that they and their care-recipients need intervention (Bekhet, 2017; Bekhet, & Nakhla, 2019; Zauszniewski, 2012). Previous research showed a discrepancy in some cases between what the care providers and the care recipients believe as a necessary intervention; therefore, it is important to assess the necessity parameter from recipient's perspectives (Zauszniewski, 2012).

The *acceptability* parameter refers to whether the participants believe that the intervention is appropriate for them. This includes gaining the participants' perspectives regarding the least and the most interesting part of the swimming intervention as a part of assessing their willingness to participate in the intervention (Bekhet, 2017; Zauszniewski et al., 2018; Zauszniewski, 2012).

The *feasibility* parameter of an intervention refers to whether the participants believe that the intervention is manageable and practical for them. This includes the time commitment involved with the intervention, recruitment and the challenges associated with the intervention (Bekhet, 2017; Zauszniewski et al., 2018; Zauszniewski, 2012).

The *fidelity* parameter of an intervention is defined as a competent delivery of the intervention that adheres to a prescribed protocol. This includes adherence to the goals and strategies of the intervention and whether the recipients experience the desired gain or change as a result of the intervention.

Although intervention effectiveness can be assessed by experts or observers, the *effectiveness* parameter also can be evaluated by intervention recipients (Bekhet, 2017; Zauszniewski et al., 2018; Zauszniewski, 2012). The *safety* parameter requires that the intervention not cause physical harm or psychological distress to the intervention recipients; this can be determined by the recipients and by the observations made by interventionists. Zauszniewski (2012) argued that the effectiveness of the intervention alone might not be enough for subjects to be motivated for performing an intervention if it is unacceptable or unsafe from the care recipients' perspectives. The same is true if it is effective but the care recipients perceive it as not needed. Therefore, assessing the critical parameters, namely *necessity*, *acceptability*, *feasibility*, *safety*, *fidelity*, and *beginning effectiveness* are essential to inform the next steps that must be taken before effectiveness of the STP can take place.

Method

Participants and Recruitment

Participants in this pilot study included 10 children with ASD and their primary caregiver/parent. Inclusion criteria for children included being an English-speaking child diagnosed with ASD between the ages 5.5-11 years at the time of the intervention. Inclusion criteria for caregivers included being an English-speaking primary caregiver of a child diagnosed with ASD and willingness to be present in the pool area, i.e. be present in the swim deck for the entire swim lesson. Parking was provided close to the pool to facilitate participation. No one was excluded based on race, gender, or socioeconomic status.

Approval for the study was obtained from the University Institutional Review Board. Participants were recruited in three ways: (1) Via the Marquette University Interdisciplinary Autism Consortium (IAC); (2) Via the IAC in-house prior participant list, which contains approximately 300 families, who consented to their name remaining on this in-house list in order to be contacted for future research opportunities; (3) Participants were also recruited with the assistance of the executive director at the Autism Society of South Eastern Wisconsin, and (4) IRB approved flyers at a local Autism conference for parents of children with ASD.

Setting, Procedure, and Data Collection

The STP took place at the university's indoor pool. The 25-yard-long pool has private change rooms, floatation devices, and pool toys. There was a private room for consenting participants and holding the focus group. The qualitative data concerning the six intervention parameters were collected within one week after the STP. Prior to the STP, caregivers who completed the first set of baseline questionnaires in the larger study received a \$35 gift card. Participants then received a \$60 gift card after the first 6 lessons and another \$60 gift card after completion of the post questionnaires and focus group, after the last 6 lessons.

Swimming Training Program (STP) Description

The STP included a swimming program of 12 sessions (half hour per session) over twelve days for children with ASD to teach them how to swim, and to teach caregivers precautions for safety around water. The STP was standardized across subjects, meaning that training was delivered by the same three swimming instructors and through the presence of at least one PI in all 12 sessions. The sessions were tailored to meet the baseline swimming ability of each child, however, steps in the intervention followed the Aquatic Skills checklist (ASC) (Alaniz et al., 2017) which is based on water competency skills outlined by the American Red Cross for all participants (Denny et al., 2019; Quan et al., 2015). Autism strategies for teaching included laminated photos of expected swim

activity. Communication between the instructor and the child utilized applied behavior analysis (ABA) method, the gold standard for autism interventions (Martin & Dillenburger, 2019) ABA follows a 3-step approach to communication: (1) antecedent, (2) behavior, and (3) consequence. For example, the instructor will state “do this” while demonstrating how to enter the pool, or blowing bubbles in the water, then waited for the child’s response and rewarded appropriate responses with the phrase “good job.” Training and debriefing were provided by the PI to the three instructors to ensure that the STP was standardized across subjects. These private swimming lessons were provided on a one-to-one basis with each child having their own swimming instructor. Two children were in the pool at a time for a total of 10 children who participated in this pilot intervention study.

One swimming instructor with previous experience working with children with ASD was hired. In addition, two lifeguards employed by the university with previous experience teaching swimming lessons were present during the STP. Their roles involved teaching the children with ASD how to swim under the guidance of the experienced swimming instructor. Also, a research assistant was hired to be present during the swimming lessons and was responsible for taking attendance at the swim sessions. The research assistant also taught the caregivers precautions for safety around water prior to the actual lessons and took notes about the progress of the children during the swim sessions.

Research Design

The research design is a descriptive qualitative study that evaluates the six intervention parameters for the STP from the perspective of the parents. A focus group was hosted for the 10 caregivers of the children with ASD following the 12-session swimming program intervention. The children in the larger study who were part of the STP (see Table 2).

The intervention parameters were measured and evaluated from the caregivers’ perspectives. The focus group research questions included assessing the swimming program intervention parameters namely: necessity, acceptability, feasibility, fidelity, beginning effectiveness and safety from caregivers’ perspectives (Bekhet, 2017; Zauszniewski, 2012) (See Table 1 for the focus group questions).

Table 1

The focus group questions (Zauszniewski 2012; Bekhet & Nakhla, 2019; Musil et al., 2015)

Question Number	Question	Parameter
1	Do you think that you and your child needed this swimming program to learn how to swim and be safe around water? Explain why?	Necessity
2	Do you think that other children with ASD and their caregivers need this swimming program to learn how to swim and be safe around water? Explain why?	Necessity
3	What part or parts of the swimming program were most interesting?	Acceptability
4	What part or parts of the swimming program were least interesting?	Acceptability
5	What part(s) of the swimming program was the easiest?	Feasibility
6	What part(s) of the swimming program was/were the most challenging?	Feasibility
7	Do you think that the number and length of the sessions were appropriate in terms of time commitment?	Feasibility
8	Were you able to learn all parts of the swimming program?	Fidelity
9	What would have helped you to learn it better?	Effectiveness
10	What part (s) of the swimming program were most and/or least, distressing or uncomfortable?	Safety
11	Do you have any concerns that you would like to share?	Safety

Analysis

Content analysis was used to answer the qualitative questions related to the six intervention parameters namely: necessity, acceptability, feasibility, fidelity, safety and effectiveness of the STP. The process of content analysis consisted of reading the transcripts, coding the data, and identifying the themes in each participant's response, then finding out the congruent themes across participants (Graneheim & Lundman, 2004). The credibility and trustworthiness of the findings were achieved by independent coding of the data by the researchers, and then by meeting and comparing the responses in person until a consensus was reached on the themes

(Glaser, 1992; Struebert & Carpenter, 1999). Saturation was achieved as there was redundancy and no new themes arose from the participants responses.

Results

The mean age of the 7 boys and 3 girls who participated in the STP was 7.05 years (SD 1.17). Details about the demographics of the children and their caregiver are detailed in Table 2.

Necessity of the Swimming Training Intervention

During the focus group, caregivers indicated that they needed intervention. Examples of the caregivers' responses included "I would say definitely this program was beneficial because it was individual, one-on-one, which is not easy to find and I feel like the instructors were very, very patient" and "Yes, my son has zero fear of the water and usually heads straight to the deep end, where one of us would have to be in the water with him at all times."

Participants believed that other caregivers and their children could benefit from the STP intervention. One participant indicated "I think definitely, yes... just from my experience taking (the name of her son), he loves water, but he doesn't understand danger." The participant shared her recent experience at a local water park saying: "He jumped into the deep end and you have all the lifeguards running...it really freaks out not only the parent but the siblings." Another participant shared her point of view "I think one of the things that is also beneficial is the fact that we're also giving a program that is so needed in communities of color... We already know that the higher number of kids who are dying because of drowning that are on the spectrum... a lot of the times are kids of communities of color and that's a huge concern because statistically speaking in general the kids who learn how to swim a lot less tend to be from communities of color."

Table 2
Demographics

Item	N (%)
Gender of Child with ASD	
Male	7 (70)
Female	3 (30)
Child Age (years) (SD) (Min-Max)	
Mean=7.05 (1.167) (5.5-9)	
Gender of Parent	
Female	10(100)
Parent Age	
25-34	1(10)
35-44	8(80)
55-64	1(10)
Parent Race	
White (non-Hispanic)	4 (40)
Hispanic	3(30)
Asian/Pacific Islander	1(10)
African American	2(20)
Parent's Level of Education	
9 th grade-11 th grade	1 (10)
Some college	1 (10)
Associate Degree	1 (10)
Bachelor's degree	4 (40)
Graduate degree	3 (30)
Family Income	
\$21,000 - \$40,000	4 (40)
\$41,000 - \$60,000	4 (40)
\$100,000 and above	2 (20)

Acceptability of the Swimming Program

Participants indicated the instructors' creativity and patience as well as social interaction and sharing among kids with ASD were the most interesting (acceptable). The ability to learn how to swim was also identified as the most interesting. All parents reported that all their children were able to float and tread water by the end of the program. Examples included: "the most interesting was the level of creativity the instructors had with trying to get (name of her child) to try different techniques and learn how to be safe in the water... from throwing the ducks out to putting the rings under the water... it was just a lot of creativity things I would've never have thought of... she has been in semi-private classes before

with four kids to one instructor and they didn't try any of those things. So just to see that creativity and again that patience was just amazing, and I think it just made me feel more comfortable than I was in the previous class that she took part in." Two participants stated: "I was most interested in (child's name) learning how to swim and kick properly," and "Kids are really learning here."

The least interesting part of the intervention identified by participants was lack of firmness or lack of reinforcement from the instructors in dealing with the challenging behaviors of the children with ASD in the water that might impact their ability to learn how to swim. One participant stated, "My kid needs a lot of reinforcement to stay with the plan and so I felt like there were times that they let him get away with what he wanted." Another participant shared her experience, saying: "When you're raising an African American child that has any type of disability especially that can't be seen like autism, I can't afford to coddle him. I have to have a firm voice with him... I have to let him know that I'm serious." Another participant pointed out that boundaries are needed for all children not just children with ASD, she said: "But isn't that what all kids need? Right, they need those boundaries they need that structure, so our kids are really no different than that and I think that sometimes people sort of make that assumption...so it's like, no pity." Another participant stated that firmness along with support are needed. She said: "I think there's a way to have that firmness but still give them the support and the security in the water because I know a lot of them are afraid."

Feasibility of the Swimming Program

All caregiver participants completed the 12 sessions intervention program except two participants; one attended 10 sessions and the other attended 11 sessions. The one who attended ten sessions had to work those two days and the other caregiver participant who attended 11 sessions had a doctor appointment for her child that was not possible to reschedule. Seven caregiver participants attended the focus group, and three caregivers came at a different time individually to answer the qualitative parts related to the intervention parameters due to conflicting schedules. Challenges caregivers reported included finding babysitting for the other kids so they had to bring the other kids with them, and the other kids wanted to join the swimming program and envied the children with autism, which put also pressure on the caregiver. One caregiver stated: "Yes, that was happening with my daughter...she actually told me I want to have Autism ...she wanted to go in the water, she's been struggling so much she's like almost the same age and she goes... 'I wanna have autism'." Another caregiver stated: "When you have other siblings it's like okay well if you don't have anyone to watch them during the day or during that short time what do you do with them? Because of course you can't take a two year old in and say no you can't get in the swimming pool, like... no that's water and I can get in...so that was a little bit of a challenge."

Safety of the Swimming Program

There were no reports by the caregiver participants that they perceived any aspect as stressful or uncomfortable and there was no need for medical or psychological referral. One caregiver participant shared her experience as being stressed in the beginning of the program but then she felt safe with the reassurance she received from the PIs and the lifeguards. She said, “I think at the beginning everything for me was stressful as I don’t know how to swim, but the friendliness and the reassurance from you (PI) helps a parent out.” Also, as a part of the safety assessment, caregiver participants were asked whether they had any concerns that they would like to share. One participant stated, “Concerns? No, I think you guys hit it right on.” Another participant stated, “I don’t think it’s a concern that I have necessarily but I’m just curious on how my child would have reacted if I was not directly in the area.”

Fidelity of the Swimming Program

In this study, delivery of the STP was standardized across subjects through the training that was delivered by the three swimming instructors and the presence of at least one PI in all 12 sessions. Fidelity was evaluated by asking caregivers whether they believed that their children were able to learn all parts of the swimming intervention and whether they believed that they learned safety around the water. Caregiver participants indicated that they were able to learn all parts of swimming intervention and one indicated that “she is not sure.”

Effectiveness of the Swimming Program

Many caregiver participants stressed the importance of having a checklist and interaction with the child in the water. Participants indicated that it would be helpful to get a checklist of what went well with their children and what needs to be improved at the end of the 12 sessions. One participant suggested that it would be more helpful if they were to get a checklist after each session. One participant said, “I think even just at the end of each lesson ...kind of tell the parent this is what we worked on today... this is what she’s doing great with... this is what she might need a little help with.” Another participant stated that it would be helpful if they can get into the water in even one or two sessions to learn more. One participant stated, “I understand in this situation wouldn’t be appropriate but maybe as a follow up... being able to get into the pool with the kiddo and practice some of those things with them. So, just as a follow up maybe one or two sessions to just get in there and try to practice those things.” One caregiver stated, “A checklist...maybe have that one or two sessions where we can actually interact, because like I said some parents don’t know how to swim...so some of the moves you’re saying I have no idea, that’s like foreign language to me ...so I wouldn’t even know where to begin... I don’t even know how to float so... to know some of those things.” One caregiver indicated that her son would need repetitions, so more lessons would be better. One

caregiver stated: “(the name of her son) needs time and repetition, so more lessons would help but it is difficult to make that time commitment.” Another caregiver stated that it is optimal if you give the caregiver an option to get into the water with the child. She said: “Provide the parents with an option if they want to jump into the water and learn with the kid. Because I know that not everyone would be comfortable doing that, just like me.”

Discussion

This is the first study to examine six critical intervention parameters of a swimming training program designed to help children with ASD and their caregivers: namely the necessity, acceptability, feasibility, safety, fidelity, and beginning effectiveness. These six intervention parameters provided a framework for evaluating the STP intervention. Results indicated that caregivers reported a need for this STP and the content was appropriate. Participants indicated the instructors’ creativity and patience as well as social interaction were the most interesting/acceptable part of the STP. The number of lessons and length of the STP were considered appropriate.

The ten caregivers who participated in the study felt a need for this swimming training intervention for their children with ASD and for themselves to learn about safety around water as indicated by their narratives. This finding is in accordance with the American Academy of Pediatric Technical report on the prevention of drowning (Danny et al., 2019), which specifically highlights the increased risk for drowning for children with autism as compared with typically developing children. Caregivers also indicated that they believed that other caregivers of persons with ASD need the swimming training intervention. This finding is consistent with previous research indicating a need for private swim program with an instructor skilled in communicating with children with ASD (Mische-Lawson, & Little, 2017).

For the effectiveness parameter, caregivers indicated that the presence of a checklist would help them know what to work on with their children in the future. In fact, this is in accordance with the American Red Cross swimming program recommendation of skills checklist (Quan et al., 2015). Parents commented that they wanted to be in the pool with their child during the swimming lessons in order to improve the effectiveness of the swimming program. It should be noted that there is a gap in the evidence on swimming interventions for children with ASD that include their parents in the swimming pool while they learn how to swim. In a recent systematic review of the literature from 11 studies utilizing applied behavior analysis approaches for water safety interventions for children with ASD (Martin, & Dillenburger, 2019), only one study included a sibling or peer as a participant in the study along with the child with ASD, but none included parents (Chu, & Pan, 2012).

For the acceptability parameter, the content of the program was considered appropriate. The participants indicated the instructors' creativity and patience, as well as social interaction and sharing among kids with ASD, were the most interesting/acceptable part of the intervention. The ability of children with ASD to learn how to swim was also identified as the most interesting. Caregivers indicated that the number and length of the swimming training intervention program was appropriate. Indeed, evaluating these critical intervention parameters of the STP from caregivers' perspectives is essential as this will likely influence their future participation in swimming programs, which will in turn impact their care recipients, i.e., children with ASD, physical and mental health. Yet, some caregivers had suggestions for improvement. This finding is consistent with past research that recommends video modeling for swim training for children with ASD (Yanardag, et al., 2013).

Limitations

Limitations of the study included that ASD was by parent report only and we did not confirm the diagnosis. Another limitation is that the severity of ASD was not measured in this study, which might have impacted the caregivers' perception. In addition, we did not offer childcare services, which may have prevented some caregivers from participating in the study. Also, limitations of the study included the small sample size; the study included only 10 children and the majority were boys. Although the participants were from a variety of ethnic backgrounds, the study required all of them to be English speakers, which prevented non-English speakers from participating. However, it should be noted that this is the first study intended to inform a larger randomized intervention study.

Participants provided many thoughtful recommendations for improving STP, that should be included in future research. Future research might include childcare services for siblings and a checklist indicating the child's daily progress in swimming skills acquisition. Future research might also include social script foreshadowing behavioral expectations for children during swimming lessons to mitigate child challenging behaviors to help with on task behavior (Vandermeer, et al., 2015). Future research should consider a comparative study of child behavioral outcomes with one group including primary caregiver in the pool with their child versus child only swim program. Future research should consider measuring improvement in sleep given the fact that trouble sleeping is an issue with children with autism (Devnani, & Hegde, 2015) and some of the parents reported that their children slept better after swimming.

Thus, this pilot study makes an important contribution to research by demonstrating how assessing six critical parameters are important for future development and refinement of the swimming training intervention program. This

framework provided a structure to the evaluation process, which is essential for the swimming program designed to improve the physical and mental health of children with ASD and their caregivers. Having established the six intervention parameters for this swimming program in the study reported here, examination of effectiveness of the swimming program intervention is the next step in the development and refinement of the swimming intervention.

Conclusion

The purpose of this qualitative evaluation study was to examine six critical intervention parameters, namely its *necessity*, *acceptability*, *feasibility*, *safety*, *fidelity*, and *beginning effectiveness* of the swimming training program (STP) designed to help children with ASD and their caregivers. We found that caregivers liked aspects of the program that helped their child and learn how to tread water and float in 12 lessons. Future research is needed utilizing enhancements to the swim intervention in a randomized control trial. Evaluating these critical parameters of the STP from caregivers' perspectives will likely impact participation of children and parents in future swim programs.

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