

# A Qualitative Investigation of Swimming Experiences of Children With Autism Spectrum Disorders and Their Families

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## ABSTRACT

**OBJECTIVE:** To understand the swimming experience from the perspective of children with autism spectrum disorder (ASD) and their families.

**METHODS:** We interviewed 12 diverse families using a semi-structured interview with follow-up probing questions related to their swimming experiences. Interviews were transcribed verbatim and coded by researchers.

**RESULTS:** Themes included family water activities, safety, characteristics of ASD, instructional methods, swim skills, swimming preferences, barriers/challenges, and benefits of swimming. Findings indicate positive experiences and skill acquisition were prevalent when instructional methods matched a child's unique needs. Parents revealed they were more confident in safety as their children's swimming competence improved. Individualized instructional methods and unique characteristics of ASD may influence perceived safety.

**KEYWORDS:** Autism, swimming, qualitative research, safety, swim instruction

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## Introduction

Children with autism spectrum disorder (ASD) are at great risk of drowning. In fact, accidental drowning because of elopement is the leading cause of death in children with ASD under the age of 14, accounting for 91% of childhood deaths in this population.<sup>1</sup> Nearly half of families with a child with ASD report their child eloped at least once at or after the age of 4. Many of these families report their child went missing long enough to cause concern and high levels of stress.<sup>2</sup> Of children who wander, 32% have had a 'close call' with drowning, as they were in or near water unattended when found.<sup>3</sup> Evidence suggests swim lessons may decrease the risk of accidental drowning in typical children by teaching skills related to recovering from a simulated fall into a pool.<sup>4</sup> However, there is limited or no evidence regarding swimming and swim lessons for children with ASD.

### *Benefits of swimming*

In addition to being a potentially life-saving skill, swimming enhances mental, social, and physical abilities.<sup>5–9</sup> A study of children with ASD who participated in an adapted swim programme showed 74% improved at least one swim level.<sup>7</sup> For example, children who began the programme with no swim experience might move from water orientation (eg, blowing bubbles, putting body parts in the water) to beginning

swimming (eg, floating with support). Parents report skills developed within the context of swimming carry over to other aspects of a child's life, such as increased strength and endurance, and decreased stereotypic movements.<sup>10</sup>

Swimming also benefits leisure engagement, which is a common concern with this population.<sup>11</sup> Children with ASD frequently spend more time engaged in sedentary leisure completed alone or in the company of their mothers,<sup>12</sup> putting them at greater risk for obesity and decreasing their exposure to important skill-building opportunities with peers.<sup>13</sup> To meet Healthy People 2020's goal to 'improve health, fitness, and quality of life through daily physical activity', establishing positive leisure habits in children with ASD is a must. Swimming is the most preferred physical activity for children with ASD as compared to being ranked 30th among typically developing children.<sup>14</sup> Although swimming requires coordinated movement, it can be learned in the absence of complex demands associated with other sports. The repetition and low social demands of swimming are compatible with the communication impairments and restrictive, repetitive behaviours that characterize ASD. Swimming provides benefits over other physical activity as the buoyancy of water supports body movement of children with motor impairments and may decrease fears of injury associated with land-based physical activity.<sup>15</sup> Water also provides consistent resistance, pressure, and temperature, which may moderate sensory arousal. Scholars, families, and professionals report



**Table 1.** Interview questions.

PARENT QUESTIONS	CHILD QUESTIONS
Can you describe your family's swimming/water activities? What does your child do during family water activities? Does your child enjoy swimming? Has your child ever had a close call with drowning? Can you tell me about your child's experience with formal swim instruction? Do you feel safe with your child around the water? Is there anything else you want to tell me about parenting a child with autism and swimming?	Do you like swimming? Have you ever gone in the water without an adult knowing? Can you tell me about your swim lessons? Do you know how to swim? Do you think swimming is the same or different for you because of your autism? Do people (swim instructors/lifeguards) do anything that makes swimming more or less enjoyable? Is there anything else you want to tell me about swimming?

Techniques used to facilitate child participation: child's communication system, visual supports (swimming pictures, happy/sad face pictures, etc), non-verbal communication (eg, gestures and pointing), moving about the room with the child, pets present during interview, parent restatement, and clarification of question/response.

children with ASD respond to sensory experiences in everyday life differently than their peers,<sup>16</sup> and the aquatic environment may be a valuable for meeting sensory needs while supporting healthy leisure engagement.

### *Research among children with ASD*

Although there are common characteristics of individuals with ASD, it is known to manifest differently in each person.<sup>17</sup> Given the unique nature of the disorder, researchers recognize the importance of investigating interventions from the perspective of those experiencing it. Little is known about swimming experiences of children with ASD and their families. Current studies related to swimming and ASD use quantitative methods to investigate the effects of swimming on various outcomes, including skill acquisition, socialization, and health outcomes.<sup>6,9,18-20</sup> A qualitative investigation exploring parents and children's swimming experiences is needed to understand beliefs, values, feelings, and motivations related to swimming. There is particular need for this, as the current literature lacks diverse perspectives. Published studies of qualitative research are limited by focusing on children considered 'high functioning' with good verbal communication skills.<sup>21</sup> This ignores the voices of an estimated 25% of children who are nonverbal, and 54% who do not qualify as 'high functioning'.<sup>22</sup> This study seeks to understand the diverse perspective of this population by exploring the swimming experience of children with ASD of all levels of function and their families.

## **Methods**

### *Phenomenological approach*

The tenets of phenomenology are founded in the ways in which ordinary people constitute and reconstitute the world of everyday life.<sup>23</sup> This approach encourages the researcher to focus on ways people interpret and treat life events as real, assuming that people may have different interpretations of the same life event. Families of children with ASD may experience the world differently than other families, thus a phenomenological approach is best for exploring how children with ASD and their families experience swimming. Phenomenology

encourages using language as a 'central medium' for transmitting meaning, so we used semi-structured, in-depth interviews to investigate swimming experiences of children with ASD and their families.

### *Participants*

Participants were recruited from a community swim programme led by faculty and students from a Midwest academic medical centre. The team provided information about the study by email to current and past participants to recruit a volunteer convenience sample. The research team also provided information about the study to families face-to-face during the programme. In effort to reach families whose children had not engaged in formal swim lessons, invitation to participate in the study was posted on a closed Facebook Autism Support Group. The first 7 families included male child participants. Researchers then purposively sampled female child participants and families with more than one child with ASD to explore diverse perspectives related to swimming experiences. The team emailed consent forms to potential participants who expressed interest in the study and scheduled a time and location for interviews. Child participants were included in the study if he or she had an ASD diagnosis, was between the ages of 4 and 17 years at the time of recruitment, had experience with swimming, and English was his or her primary language. Parent participants who spoke and understood English were included in the study if their child met the inclusion criteria.

### *Data collection*

Based on participants' availability, the research team conducted face-to-face interviews in the families' homes. Interviews consisted of separate questions for parents and children (see Table 1). Interviewers implemented a semi-structured approach with probing questions for clarification and depth of information. The research team provided visual supports (eg, pictures of swimming skills and activities) for children with verbal challenges. Families were also encouraged to utilize communication systems typically used in the household, when applicable.

### Data analysis

Interviews were recorded with Livescribe<sup>24</sup> Echo Smartpen and notebook. Members of the research team then transcribed interviews verbatim for analysis. Researchers separately read and coded transcripts to compare findings and highlight emerging themes. To ensure reliability of coding, all transcripts were coded by 2 or more researchers during the analysis. Researchers simultaneously recruited new participants and performed data analysis to inform probing questions. Data collection was discontinued when no new themes emerged, and researchers agreed saturation had been reached. To ensure trustworthiness, the research team used a constant comparative method, like the data analysis system used by Mische-Lawson et al<sup>25</sup> to investigate patient experiences with expressive art-making. Researchers created and updated a coding dictionary describing emerging themes as data were analysed. When the coding dictionary was finalized, data chunks were sorted by theme and reviewed to confirm the information fit the theme appropriately. Families reviewed (ie, member checked) themes to confirm they reflected the perspectives they had shared during interviews. Researchers documented meetings in detail to create an audit trail for transferability.

### Ethical approval and informed consent

Study activities were approved by the University of Kansas Medical Center Institutional Review Board (#00140463). Parents provided consent and children above age 12 whose parents deemed appropriate provided assent prior to engaging in study activities.

## Results

The research team interviewed 12 families comprising 28 participants before reaching redundancy in the data. Family 8 provided consent for both their son and daughter with ASD to participate in the interviews. After consenting, the parents decided their son should not be interviewed because he would perseverate on the idea of swimming and become agitated if they were unable to take him swimming after the interview. Although he did not participate in the interview, his parents shared information about his swim experiences that is included in analysis. All other children participated at least minimally in the interview process. Child participants were mostly male (n=12). More than half the families identified as white, with others identifying as Latino, Asian, African American, and multi-racial. Children were 6 to 18 years old at the time of the interviews, had varied engagement in recreation activities, and all had received therapy services (see Table 2).

This study aimed to understand the swim experience from the perspective of children with ASD and their families. Five families explicitly shared experiences about their child wandering into or near water without them knowing. Families also reported concerns with safety near water, being more vigilant

with watching children near water, or limiting water exposure to avoid the potential of drowning. Only 2 families stated they felt comfortable with their child swimming on his or her own. All parents indicated an increase in safety and a greater level of comfort with their child being in the water following swim lessons. All the children with verbal ability indicated swimming is an activity they enjoy, and parents confirmed enjoyment of the other children. Data analysis revealed 8 major themes: *family water activities, safety, characteristics of ASD, instructional methods, swim skills, swimming preferences, barriers/challenges, and benefits of swimming* (see Table 3).

### Family water activities

Family water activities emerged as a prominent theme and included swimming and water activities in which the family members participated together or individually. The interviews revealed swimming and water experiences were a meaningful activity for all the families and were greatly influenced by having a child with ASD. Families stated swimming provides them the opportunity to participate in a typical recreational summer activity together. Many parents took additional steps to ensure their children had access to pools and could successfully participate in water activities. This included, but was not limited to, providing exposure to indoor and outdoor pools or water parks, beaches, and lakes. One mother revealed her family enjoys swimming together in several different environments. 'We like to go to Great Wolf Lodge. We will go a few times a year and swim and we'll do Schlitterbahn. My kids really like water parks . . . Both of their grandparents have pools in their backyard, so in the summer they go there a lot' [P11].

Several parents reported minimal involvement in water activities, while others did not engage at all. 'We don't really do that much on the swim front' [P8]. 'It's just too difficult, it really is' [P8a]. One family discussed avoiding the pool completely due to her comfort level of being alone with 3 children, especially one with ASD. '[He] has a twin brother, and they also have an older brother who is 21 months older. So, for the first several years, I didn't, we just didn't go to the pool' [P2]. Other participants stated they avoid swimming as a family due to the parent's lack of swim skills, 'I'm a nervous wreck because I can't swim . . . I take him once a year to the YMCA in the summertime' [P12].

### Safety

Safety also emerged as a strong theme and included family fears and dangerous experiences regarding water. Parents frequently expressed the need to be intentional about watching their child when in or around water. For example, they expressed feeling uncomfortable with less than 2 adults supervising their child, or not being able to relax when their child is in the water. A mother of a 9-year-old recounted '[His father] seems to be fine kind of a distance away. Me personally, I'm like holding

**Table 2.** Demographic information.

FAMILY	PARTICIPANTS	CHILD CHARACTERISTICS
1	Mom (P1) Child (P1b)	6 years old, white with autism. Enrolled in swim lessons at the time of the interview (2 previous sessions). Received OT, PT, ST, and SPED services at school, private OT, behaviour and nutrition services. Used 2-3 word phrases and was interviewed with visual supports and parent restatement/clarification.
2	Mom (P2) Child (P2b)	12 years old, white with autism. Participated in 2 sessions of swim lessons for children with ASD, and general semi-private swim lessons. Received OT, ST, SPED, and behaviour services at school. Participated independently in the interview with minimal modifications (eg, interviewer clarification).
3	Mom (P3) Child (P3b)	9 years old, Latino with autism. Participated in 1 session of swim lessons. Received OT, PT, ST, SPED, and behaviour services at school and private behaviour services. Non-verbal and was interviewed with visual supports and parent clarification.
4	Mom (P4) Child (P4b)	18 years old, white with Asperger syndrome. Participated in 3 sessions of swim lessons. Received behaviour, psychology, and SPED services. Participated independently in the interview with minimal modifications.
5	Mom (P5) Child (P5b)	11 years old, Latino with autism. Enrolled in swim lessons at the time of the study (5 previous sessions). Received OT, ST, SPED, and psychology services at school as well as private behaviour services. Was non-verbal and participated in the interview with visual supports and parent restatement/clarification.
6	Dad (P6a) Child (P6b)	7 years old, white with autism and ADHD. Participated in 7 sessions of swim lessons. Received OT, ST and SPED at school. Participated independently in the interview with minimal modifications.
7	Mom (P7) Dad (P7a) Child (P7b)	14 years old, white with autism. Participated in 2 sessions of swim lessons. Received OT, ST, SPED, and behaviour services at school as well as private psychology and social work services. Has limited verbal responses. Participated in the interview with parental support (eg, clarification of questions, redirection).
8	Mom (P8) Dad (P8a) Child (P8b) Child (P8c)	P8b was 7 years old, Asian, female with autism. Participated in 9 sessions of swim lessons. Received OT, PT, ST, behaviour services, and SPED at school. Able to participate in the interview with parental support (eg, clarification of questions, redirection). P8c was 10 years old, Asian with autism. Participated in 13 sessions of swim lessons for children with ASD. Received OT, PT, ST, behaviour services, SPED, and psychology services privately. Was present but not allowed to participate in the interview due to potential behaviour issues.
9	Mom (P9) Child (P9b)	P9b was female, 11 years old, and multi-racial (white, Latino, and Native American). Participated in 6 sessions of swim lessons. Received OT, PT, ST, behaviour services, psychology services, SPED, and nutrition services. Was present during the interview and confirmed some of her parent's responses.
10	Mom (P10) Child (P10b)	9 years old, white with autism. Participated in 19 sessions of swim lessons. Received OT, PT, ST, SPED and behaviour services at school, and private behaviour services. Able to participate in the interview with parental support.
11	Mom (P11) Child (P11b) Child (P11c)	P11b was 11 years old, white with autism. Participated in 6 sessions of swim lessons. Receives OT, PT, ST, SPED, and behavioural support services at school. Able to participate independently in the interview with minimal modifications. P11c was 5 years old, white with autism. Participated in 5 sessions of swim lessons. Received OT, ST, and SPED services at school, and private ST and behaviour services. Participated independently in the interview with minimal modifications.
12	Mom (P12) Child (P12b)	P12b was 7 years old, African American with Asperger syndrome. Participated in 2 sessions at swim lessons. Received OT and PT and behaviour support at school. Participated independently in the interview with minimal modifications.

All children were male unless otherwise specified. All lessons were specialized for children with ASD unless otherwise specified. Abbreviations: ADHD, attention-deficit hyperactivity disorder; ASD, autism spectrum disorder; OT, occupational therapy; PT, physical therapy; SPED, special education services; ST, speech therapy.

him the whole time' [P3]. This vigilance stemmed from awareness that their child can be impulsive and unpredictable. 'If his toy floated past [into the deep end], he wouldn't think about it. He would go after the toy' [P11]. For many families, the unpredictability of their children's behaviour led to close calls with drowning. 'He jumped right into the lake and started swimming in the middle of the lake, so I had to dive into the lake after him' [P8], and another instance, 'We had called the police. They were all searching everywhere. [They] had helicopters.

He came back completely naked and just mud, filled with mud . . . I don't know where [he] got the mud' [P8]. Parents also recognized their child's affinity to water increased dangers of eloping. 'You know something could happen to her. That's my concern. Because I don't know why kids with autism love water so much, but they do, don't they?' [P9].

Parents recognized the importance of swimming and water safety lessons. 'It's a great experience for him to be able to learn the skills for survival' [P12]. Some families grew comfortable as

**Table 3.** Themes identified from family interviews.

THEME	DEFINITION	EXAMPLES
Family water activities	Family swimming or water activities and family interactions in the water, including swimming and water activities that the family participates in together or that family members participate in individually (eg, swim lessons). Includes water activities the family avoided, past experiences, and aquatic environments.	'I am just really appreciative that we learned about the program and were able to get him in and participate at the time we did . . . I mean, we were at the point of just, ya know, we just can't go . . . because it's just not safe, and ya know'. (P2) 'Well, my husband doesn't swim, so that's a bad thing'. (P4) 'All the trips we do, like we will go to the river for floating trip. And we play in the river. We go anywhere we go, I will normally pick out a hotel that has a pool. Because we want him to swim'. (P5)
Safety	Factors related to children's general safety in and around water, including elopement or fear of elopement, and close calls with drowning. Also includes parent and child comfort levels and fears, or lack thereof.	'I would want to have eyes on him all the time, I mean it may not be necessary but it's better to be safe than sorry'. (P7) 'We actually have a pond in the neighbourhood, behind that house, and we actually stopped taking walks over there'. (P11) 'I just worry about safety. I just want her to have the ability to be safe. I'm glad that she enjoys it, I'm glad she wants to be in it. But ultimately, it's about understanding I'm tired and I need to, you know, get to the edge. Or I need to get out'. (P9)
Characteristics of ASD	Challenges, strengths, and co-occurring conditions that are associated with an autism spectrum disorder (ASD) diagnosis.	'We can't control him to where he can be calm and like swim in a certain area. He has to get in or jump in. He's just hyper super hyper'. (P8) 'The developmental coordination disorder aspect tends to help us on the not being able to get out the door [to elope] aspect'. (P1)
Instructional methods	Formal and informal strategies used by swim instructors that either facilitated or hindered the child's swim experience and skill acquisition.	'You know, we tried everything, as far as ya know, what's going to help, and then we tried just private lessons with [child] only, without the other boys. And ya know, he still just couldn't concentrate . . .' (P2) 'I think he did well with a lot of hands on stuff'. (P1) 'Um he seemed to really enjoy learning something about the water and his instructor . . . he had a good bond with her'. (P3) 'The fact that I did, that we did lessons in a, in that water depth that wasn't too much but not too little'. (P2b)
Swim skills	Skills children have attained, or want to attain and are working towards through formal or informal swimming experiences.	'I learned at swimming lessons . . . is . . . I ju-jump off a little diving board . . . Yeah, I learned how to jump'. (P6b) ' . . . you know he didn't know the strokes beforehand. He picked them up quickly'. (P7a)
Swimming preferences	Individual preferences, including likes, dislikes, and sensory preferences related to swimming. Includes bath time and other experiences that provide opportunities for water adjustment/water play.	'My favourite part is running and jumping and diving board!' (P6b) 'He likes to spin around or splash some'. (P3) 'he has always loved the water, I mean, even as just a toddler, he would stand at the bathroom sink and just run the water and splash his hand in it'. (P2)
Barriers/challenges	Factors interfering with swimming including environmental, social, policy, and financial barriers.	'It would be nice if there were more spots [in the program]'. (P6) 'It wasn't in the pool, but you know in the locker room, he didn't have the best appropriate etiquette and so we stopped going'. (P7a)
Benefits of swimming	Benefits to the child, parent, or family because of participating in swimming activity.	'Because it's always a good way to relieve my stress now'. (P4b) 'I think it was also nice I got to talk to some other moms at those sessions. So, it's nice to have a group that has similar experiences'. (P4)

their children's skills improved. 'I don't want to leave him unattended, but I can walk away from the pool and come back, and I'm not scared he's gonna go under' [P10]. But with improved skill, some children experienced over-confidence. A mother of an 11-year-old girl shared, 'She feels safer now. But then with safety, there's also that concern, like, false security, you know' [P9]. She goes on to say 'I'm glad that she enjoys it, I'm glad she wants to be in it. But ultimately, it's about . . . having a healthy fear of the water. I don't want her to be fearful, but I want her to have a respect' [P9]. Parents also expressed the challenge of navigating their child's evolving needs as swim skill improved, finding a balance between vigilance and independence. 'I

wanted to get in and my husband said "Let him be! Let him be!" [P5].

### *Characteristics of ASD*

The characteristics of ASD theme captured personal traits, strengths, challenges, comorbidities, and co-occurring conditions that influenced engagement in swimming activities and the development of swimming skills. Parents described personal traits, such as extreme excitement or lack of attention, having an impact on swimming. A father expressed how his 7-year-old son's emotional reaction to water affects family swim

participation. 'Because what happens is [he] gets too excited. We have to also watch [his] excitement level, [he] gets way too excited and doesn't really know how to handle that' [P8a]. A mother shared that her 12-year-old son 'just couldn't focus and listen to directions' [P2] in describing the semi-private lessons he attended when young. Families also shared challenges associated with ASD that influenced engagement in water activities such as lack of safety awareness, poor judgement, and impaired social skills. For example, a mother of a 7-year-old described her child's difficulty with socialization stating, 'He has a hard time with other kids. Not listening and being impulsive. And jumping in' [P12]. Another parent reported a lack of safety awareness in the child. 'I don't know that he is aware of, you know, how dangerous the water is' [P7]. In addition, families identified co-occurring conditions including attention-deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), myopia, and developmental coordination disorder (DCD) as having an impact on their child's ability to participate in swimming. 'He was recently diagnosed with ADHD. Which wasn't a surprise to us, but it kinda helps, you know . . . Sometimes it was just, he could not focus, because he literally could not focus' [P6a]. Another mother reported her child's visual impairments. 'Myopia, so, she's like a minus 10. She can't see very well, and I was trying to figure that out with her swimming' [P9].

#### *Instructional methods*

The theme instructional methods is defined as methods and techniques used by swim instructors to promote skill acquisition related to water safety and swimming. Families noted the child's bond with the swim instructor and the consistency with that instructor is essential to quality instruction. A mother of 2 children with ASD shared, 'There's a personal relationship' [P8a]. Another parent stated, 'I think parents should do that, find somebody that can do it. You know the patience, having that kind of patience, you know sometimes kiddos don't respond teaching wise to their parents' [P10a]. Value is placed on the instructor's knowledge of autism, as well as other positive character traits, such as patience and kindness.

Sensory preferences and related behaviours were another important instructional consideration; strategies used by the instructors included incorporating arm weights into lessons to promote body awareness, using wet suits for proprioception and thermal regulation, and offering a variety of equipment to support instruction. Other instructional techniques to develop swim skills included hand-over-hand assistance and demonstration as effective strategies for teaching children with ASD. For example, a mother of an older boy shared of her son's instructor, 'so she would have to move his arm for him cause they can't look at something and translate it to their own body like a lot of kids can' [P4]. The physical environment of lessons can also affect swim instruction. A 12-year-old child who participated in 2 sessions of lessons expressed, 'The fact that, that, we . . . did lessons in . . . water depth that wasn't too much but

not too little' [P2b], was helpful for him learning to swim, as he was most comfortable learning in chest-deep water.

Parents stressed the importance of instructors using methods suited to their child's unique learning needs:

People who aren't exposed to autism or don't know . . . that we need to tell her one-on-one because if you [give a direction to the group] she's like 'I don't know who you're talking to'. It has to be like . . . [get up close to her and say] 'this is what we need to do'. [P9]

A mother of 2 children with ASD shared,

It's great, we have had a lot of different teachers, every single one has been wonderful. It's nice when you don't have to explain so much about autism and what works. They kinda seem to have a good idea about behavioural strategies and what works with the kids in the water. [P11]

Effective instructors supported children to work through fear and go beyond their comfort level. A mother of a 12-year-old expressed, 'So I do remember a lot of encouragement, especially when he started kind of doing, maybe the width of the pool' [P2].

In addition to one-on-one instruction, parents emphasized the importance of structure. 'I kinda like that the way Sensory Enhanced Aquatics has it set up because there's a structure to it' [P9]. Another parent shared,

His instructor right now is trying to get a little more structure and use more visual aids . . . So, it's like a little like she has like a laminated thing 'Ok we're gonna work on our stroke and this is what it looks like type of thing' or 'We're gonna dive off the side'. You know just giving him an idea. [P10]

#### *Swim skills*

Swim skills emerged as a theme closely related to instructional methods and included both desired and mastered swim skills. Parents and children identified skills learned through formal instruction or other swimming experiences. For example, a 7-year-old child that had participated in 7 sessions of lessons specified, 'I will do front crawl . . . and kick on the wall' [P6b], while a mother shared her child can now perform front glides off the wall because of his participation in swim lessons [P1]. Parents also identified progress in swim skills stating, 'He is learning strokes . . . how to breathe . . . kicks . . .' [P12]. Another family shared, 'he started wearing goggles and figured out how to hold [his] breath. So, the instructors right now are trying to get him to be able to dive off the side and work on his kicking' [P10]. In addition, parents identified their children developed safety skills through swimming experiences. A mother of a 12-year-old identified her child's ability to recognize when he was getting tired and needed to get to the edge of the pool as an important skill learned in lessons [P2]. Another family reported, 'I have no reason to think that kid can't float, he can float on his back, now' [P8].

### *Swimming preferences*

Swimming preferences encompassed what children did or did not like about experiences related to swimming, including sensory preferences, bath time, or other water activities. Children expressed a wide range of preferences, from highly active to relaxing and calm. When parents were asked what their children liked about swimming, a mother of a 9-year-old responded, 'He likes to jump off the diving board and I guess play games, real simple games . . . he will just stay in the water forever . . . he doesn't get out' [P10]. Another responded, 'He likes to splash in the water. He likes to go down slides. He just loves water. If you turn your head he's doing it all' [P12]. When the children were asked what they liked about swimming, a 9-year-old responded, 'Go on the diving board' [P10b], and a 7-year-old expressed, 'I like going on the water slide' [P12b]. When asked about dislikes, a more fearful child responded with 'The depth, and it's kind of like . . . sometimes it can be a bit deep' [P2b]. The oldest child interviewed responded with 'Well, sometimes the water is too cold and then you have to take time to warm up' [P4b]. When asked if he liked going under water a child responded, 'Nuh, uh. No' [P11b].

### *Barriers/challenges*

Barriers were identified as anything interfering with the family's ability to participate in swimming activities. Limited or inadequate resources were a common concern. Sensory Enhanced Aquatics is the only swim programme in the area offering swimming and water safety instruction for children with ASD and has a long waitlist. A father of a 14-year-old who had attended 2 sessions of specialized lessons shared registration was a barrier, 'It's just like half an hour after it's open, everything's full' [P7]. Another mother confirmed by sharing, 'We've only been able to get in one time' [P3]. Cost was also a barrier for some families. One family lamented to being unable to provide their child with various water experiences due to the lack of financial resources. 'That's why we don't go very often, 'cause it costs something' [P7].

The environment in which swim activities took place was also a barrier for some families. Several families stated they had more success with indoor lessons than outdoor. 'Outside . . . there's kids at the park and there's just a lot else going on, so it seems . . . more difficult to concentrate at the outdoor pool, just because of what's going on' [P2]. A mother of a 12-year-old also discussed environmental challenges she and her son encountered, 'The locker rooms at the community pool were a lot easier. Yeah, the high school was difficult just to get changed, in and out' [P2].

Parental stress also emerged as barrier. When asked about swimming and autism, a mother of an 11-year-old stated 'Oh is it stressful! I'm a lot more stressed than I should be . . . it's a constant stress' [P9]. Another mother [P1] discussed a specific instance of going to the pool with her friend with 2 typically

developing children. While her friend's children could have 'free reign', both mothers focused their attention on the child with autism, illustrating the vigilance parents felt they needed when their child was swimming. Another mother [P12] shared her stress may be affecting her son's swim participation. An instructor had asked her if she was ready for her son to jump off the diving board. 'I was like "I don't know 'cause I can't save him, so I'll let you make that determination." She's like "I feel like he's ready." So, it could be me holding him back, just because of my fear' [P12].

### *Benefits of swimming*

Benefits of swimming included benefits experienced by the child, parent, or family due to participation in recreational swimming or formal instruction. Benefits were vast and frequently included ideas related to social, community, parent support, relaxation, exercise, meaningful activity, and swimming as therapy. A 12-year-old boy who had participated in formal swim instruction shared, 'It's good exercise, it's fun, it's relaxing, and it also cools you down when it's hot outside' [P2b]. Parents also noted the way swimming soothed their child or was even therapeutic. 'It's something about calming the nerves when you're like in sensory overload . . . it's very soothing for them so maybe they know that, and they're just drawn to it' [P12].

Community engagement was a particularly important benefit of specialized swim programmes for children with ASD:

I think having this opportunity . . . was such a relief and weight off my shoulder because we like to be at the pool in the summertime and I wanted him to be able to swim, so having a program that is available like this . . . I am amazed by it, so thankful, so grateful that it's out there. [P10]

Parents also enjoyed the opportunity to connect with other parents of children with ASD. 'I think it was also nice I got to talk to some other moms at those sessions. So, it's nice to have a group that has similar experiences' [P4]. But the most life-changing benefit was the way swim lessons improved children's skills and parent's confidence. 'I think more communities are doing it because it works. It works. He can swim, and he is good at it. I feel confident. I don't feel like he's going to drown' [P10].

## **Discussion**

Current quantitative research shows the benefits of swimming and aquatic therapy for improving specific behaviours, skills, or health-related outcomes.<sup>5-9,18,20</sup> Utilizing qualitative methodology was advantageous for gaining the perspectives of children with ASD and their families regarding swimming experiences and provides insight into challenges and benefits associated with swimming. Safety and instructional methods, specifically individualized swim instruction, were two prominent themes

emerging from the data. Safety has long been a concern for parents due to the increased risk of elopement and drowning for children with ASD.<sup>2,4,26</sup> Perspectives gleaned from this study support this, as all families interviewed identified safety as a concern despite parents' perceiving their child enjoying swimming. Parents also cited their child's unpredictability, their tendency to elope, and their attraction to water as particularly unsettling. Many families shared experiences of 'close calls' that increased their safety concerns. These concerns limited community involvement when parents expressed reluctance in taking children to the pool without additional supports.

Furthermore, parents reported a need for constant vigilance when children were near or in the water, and children expressed varied levels of confidence in the water. Parents indicated increased safety and comfort after the child participated in formal swimming instruction; however, many families indicated their children would benefit from further instruction illustrating the need for continued exposure to water and formal swim lessons to ensure safe behaviours in and around water, and progress swim skills for this population.

In addition, families of children with ASD reported a higher level of family stress. High demands in daily life make it difficult for families to participate in activities outside of their home.<sup>2,27</sup> Leisure water activities were often sacrificed due to safety concerns, although numerous families stated they enjoyed taking their children to the pool because swimming is a typical family recreational activity. Parents expressed reluctance in taking their child to the pool without additional supports. This vigilance may increase stress for parents of children with ASD compared to parents of typically developing children, which in turn affects overall family quality of life; decreasing child and family access to social opportunities, meaningful leisure, and physical activity.<sup>28-30</sup>

On the other hand, parents reported that participating in individualized, evidence-based swim lessons, specifically designed for children with ASD, gave their child the opportunity to increase water safety skills. These lessons increased parent confidence as well as provided the children a safe activity outside the home. Instructional methods also emerged as a prominent theme in this study. Swim instruction based on evidence and the unique learning needs of this population is required to truly maximize benefit. Parents noted their children did not learn in the typical group setting, but had success when given visual supports, minimal verbal cues, and environmental/sensory modifications. This is consistent with previous research showing specialized swim instruction, specifically for children with ASD, improves swimming and water safety skills.<sup>7,26</sup> Other instructional techniques used in lessons included educating instructors on ASD characteristics, hand-over-hand instruction, providing sensory supports, using visual aids, and providing routine/structure.

Unfortunately, there is a lack of available lessons taught by instructors skilled at providing necessary environmental and

instructional accommodations.<sup>31</sup> There are more children and families wanting to participate in individualized, evidence-based programmes than there are available slots, with parents expressing frustration about long wait lists. This study provides valuable insight about parent and child experiences with swimming to guide future programme development to increase family access to swim opportunities. More programmes are crucial to meet the unique needs of children with ASD and reduce risk of drowning in this population.

### *Limitations*

While this study included 28 participants from 12 families, it only represented families who had been involved in a specialized swimming and water safety programme for children with ASD. Our study lacked the perspectives of participants unable to take part in formal swim instruction, who may have differing barriers, or no access to swim instruction for their children. Although the sample was limited to children with formal swim instruction experience, it was diverse in gender, swim experience, age, ethnicity, and communication ability.

Another potential limitation is multiple researchers conducted interviews. To ensure consistency of interviews, the team used a semi-structured interview guide and the primary investigator modelled and monitored interview techniques. In addition, the team reviewed transcripts to inform probing questions. Interviewing nonverbal or minimally verbal children with ASD had its limitations, but was critical for understanding the perspective of children with ASD. At times children demonstrated difficulties typical of ASD, including inattention, echolalia, or non-response. Researchers used visual aids and confirmed children's answers with parents when necessary. Demographic information was only provided for child participants, not parents. Although researchers observed parents to be of the same ethnicity as their children, the team did not collect additional demographics (eg, education level, socioeconomic status) about parents, which could have provided additional insight about the resources available to them. A few families did, however, have both mother and father participate in the interview. Including the male parent participants made our parent sample diverse. Finally, the qualitative methodology utilized in this study is limited to rich description and categorization of participant experiences. Exploration of the relationship between experiences and the functional levels, specific behaviours, or characteristics of the children with ASD requires both qualitative and quantitative analysis (eg, coded experiences correlated with demographic characteristics).

### *Future research*

Future research should include children with no formal swim instruction to better understand the swimming experiences of children with ASD and their families. Because this study



utilized a convenience sample, all families interviewed found formal swim instruction important and children had participated in at least one session of swim lessons. Both parent and child participants identified preferred instructional methods. Future research should seek to identify best practice instructional methods for teaching swimming and water safety to children, as well as compare different swim lesson curriculums/methods to determine which are most effective for teaching swimming and water safety to children with ASD.

## Conclusions

Our findings indicate children with ASD and their families provide valuable perspectives on swimming experiences. Families and children perceive swimming as a meaningful family activity; however, having a child with ASD makes participation in swimming challenging. Concerns with safety and limited access to resources influence engagement in family water activities. With formal, individualized swim instruction geared towards meeting the unique needs of children with ASD, children can develop skills to promote safety and comfort with water activities, thereby increasing parents' confidence with their child in and around water.

## Author Contributions

LML conceived and designed the study, trained data collectors and collected data, led analysis and interpretation, and substantially contributed to writing the paper. JDA, KC, BH, SH, JM, KN, MN and AT assisted with data analysis and interpretation and made substantial contributions to writing the paper.

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