Examining the Experiences of Parents and Caregivers of Children with Autism Spectrum Disorder around Aquatic Environments

by

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The above committee determined that the thesis is acceptable in form and content and that a satisfactory knowledge of the field covered by the thesis was demonstrated by the candidate during an oral examination. A signed copy of the Certificate of Approval is available from the School of Graduate and Postdoctoral Studies.

Abstract

Through transcendental phenomenological qualitative research we investigated the experiences of parents and caregivers of children with ASD when accessing water environments. Semi-structured individual interviews were used to collect data with 12 parents (N=12). Results were grouped into two clusters. Experiences and perspectives on aquatic environment and recreational swimming included the themes: safety is the priority, attraction to water, acceptance of children with ASD in aquatic environments, and therapeutic benefits. Experiences and perspectives on swimming lessons included the themes; making lesson accessible, teaching methods, teach the teacher, and the impact on pride, independence, and normalcy. Findings suggest participation in water activities has a positive effect on children with ASD. Enrollment in swimming lessons can promote safe encounters with water for children with ASD. Parents identified barriers to accessing aquatic programming. Recommendations are provided for improvements to current swim programming and other aquatic environments.

Keywords: autism spectrum disorder (ASD); aquatic; water; parent; swimming lessons; phenomenology

Author's Declaration

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Larissa Lobo

Statement of Contribution

Dr. Serene Kerpan contributed to the design and methodology of this study and applied for ethics approval.
As first author, my contribution was recruitment of participants, collection and analysis of the data, and writing of the thesis.

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List of Abbreviations

AD – autistic disorder

ADHD – attention hyper deficit disorder

APA – American Psychiatric Association

ASD – autism spectrum disorder

CDC – Centers for Disease Control and Prevention

CDD – childhood disintegrative disorder

DSM-III – Diagnostic and Statistical Manual of Mental Disorders, 3rd edition

DSM-III-R – Diagnostic and Statistical Manual of Mental Disorders, 3rd edition, revision

DSM-IV – Diagnostic and Statistical Manual of Mental Disorders, 4th edition

DSM-IV-TR – Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision

DSM-5 – Diagnostic and Statistical Manual of Mental Disorders, 5th edition

MLP – most-to-least prompting

NAA – National Autism Association

NASS - National ASD Surveillance System Report

PDD – pervasive developmental disorder

PDD-NOS – pervasive developmental disorder, not otherwise specified.

Chapter 1. Introduction

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition comprised of persistent challenges or delays in two categories: social interaction and communication; and restrictive/repetitive behaviours (American Psychiatric Association (APA), 2013). ASD is currently one of the fastest growing neurodevelopmental disorders worldwide affecting approximately one in 66 children aged 5 to 17 years old in Canada (National ASD Surveillance System Report (NASS), 2018). This translates to an average prevalence of about 1.5% in developed countries (Baxter et al., 2014). ASD is about four times more prevalent in boys than girls (NASS, 2018; Centers for Disease Control and Prevention (CDC), 2020). It has been reported that individuals living with ASD are about three times more likely to suffer from unintentional injury mortality compared to the general population (Guan & Li, 2017b). Drowning is a major cause of unintentional injury mortality for children with ASD, along with asphyxiation and suffocation (Forde et al., 2020; Guan & Li, 2017b; Shavelle et al., 2001). About half of children with ASD have tendencies to wander, often termed elopement, so they are more likely to find themselves unsupervised near water, unknowingly putting themselves at risk (Anderson et al., 2012; Forde et al. 2020; Rice et al. 2016). From 2009 to 2011, 91% of total U.S. deaths for children ages 14 and younger living with ASD was attributed to accidental drowning preceded by child elopement (National Autism Association (NAA), 2012). In another study by the NAA (2017), accidental drowning accounted for 71% of deaths of individuals with ASD between 2011 and 2016.

In Canada, we are surrounded by water. Our communities are often centered around lakes and rivers. Swimming is a favoured leisure activity for children with and

without disabilities (Alaniz et al., 2017; Mactavish et al., 2000). Many children on the ASD spectrum enjoy swimming, comparably more than their peers, which may preface from strengths associated with repetitive tasks (Eversole et al., 2016). However, the characteristics of ASD, water safety challenges, and alarming mortality statistics may lead parents and caregivers to hesitate or refrain from entering aquatic environments with their child(ren) living with ASD (Grosse, 2014; Guan & Li, 2017a). This may impact the experiences children with ASD and their parents and caregivers have around aquatic environments through limitation or avoidance of activities around water. This is an important aspect to look at as family members are usually the primary support for individuals with ASD (Lord et al., 2020). By better understanding the experiences from a parent/caregiver perspective, there may be opportunities to increase water safety and enjoyment for children living with ASD.

Specialized aquatic programs are available for the ASD community; however, little is known about the benefits or challenges associated with these programs outside of the intervention environment or how they affect the experiences of families caring for children with ASD. The available evidence does indicate that children with ASD improve swim skills through aquatic programming (Alaniz et al., 2017; Caputo et al., 2018) however, little is known about whether this transfers to other aquatic environments. Nor is it known whether it affects the experiences of families with children with ASD by possibly reducing fear and anxiety, and increasing enjoyment and use of environments with water present.

The experiences and perspectives of parents and caregivers has yet to be explored in the effects of swimming lessons and water safety for children living with ASD which

could provide more opportunities for water activities that children with ASD enjoy. As a researcher that has worked in aquatics for several years to actively decrease injury mortality, I have seen first-hand the need for more information to improve the efficacy and accessibility of swim lessons. My lived experience in this field has informed this research and the questions that guide it. By better understanding the experiences of parents/caregivers in regards to having their children in water environments and their beliefs about the efficacy of water safety lessons for their children, interventions can be tailored to meet the needs of families. This may help families of children living with ASD feel more comfortable if they choose to engage in aquatic environments.

1.1 Statement of Purpose & Research Questions

This research will explore the experiences of children living with ASD and families in relation to aquatic environments from the parent/caregiver perspective. It aims to understand the role of aquatic programming when engaging in aquatic environments for these families and how existing programs can be optimized to provide more favourable outcomes.

The questions that frame this study are:

1) What type of experiences do parents/caregivers and their children living with ASD have when engaging in aquatic environments?

2) Does engaging in, or not engaging in, regular or specialized aquatic therapy programs have any effect on the type of experiences parents/caregivers and their children living with ASD have around aquatic environments?

3) What do parents and caregivers need from swimming lessons so that their families and child(ren) with ASD can be more comfortable when participating in aquatic environments?

Chapter 2. Literature Review

2.1 History and Epidemiology of Autism Spectrum Disorder (ASD)

The complex neurodevelopmental disorder was first clinically described by Leo Kanner in the mid-20th century in his paper "Autistic Disturbances of Affective Contact" where he observed 11 children who exhibited an inability or delay in social interaction and relation, physical and verbal repetitions, and were overly sensitive to noise disturbances (Kanner, 1943). He indicated in his article that the children's behaviour was a result of an obsession with systematic routine that if broken, the child would become distraught beyond a normal capacity (Kanner, 1943). He classified these behaviours as autistic traits and likened the characterization to basic schizophrenia adopting the term 'infantile autism' (Kanner, 1943). The word 'autism' originates from 'autos', the Greek word meaning 'self' to define a 'withdrawal from reality' (Mukherjee, 2017; Nazeer et al., 2019). It was coined in 1912 by Eugen Bluler to describe what he suggested was a childhood form of schizophrenia (Blake et al., 2013). Frequently throughout the 1920s and 1930s, autism was used as a subcategory of behavioural traits of schizophrenia patients that did not exhibit manifestations of positive symptoms such as hallucinations (Blake et al., 2013; Tsai & Ghaziuddin, 2013; Nazeer et al, 2019). However, as autism has been researched over the years, the disagreement in the definition of autism has led to the separate entity of ASD and not at all linked to schizophrenia (Nazeer et al., 2019). Not long after, in 1944 an Austrian physician Hans Aspergers described similar characteristics of difficulties in social interaction coupled with repetitive behaviours which he termed 'autistic psychopathy' (Nazeer et al., 2019; Tsai & Ghaziuddin, 2013). Lorna Wing, an English psychiatrist, amended this term to be Asperger's syndrome

which could potentially be a mild form of autism (Wing, 1981). She was one of the first to advocate that autism itself should be considered on a spectrum instead of single entities (Wing, 1981).

Autism was officially classified as a separate neurodevelopmental disorder in the 1980s in the Diagnostic and Statistical Manual, 3rd edition (DSM-III). It was categorized under pervasive developmental disorder (PDD) with multiple subtypes such as infantile autism or childhood-onset PDD (APA, 1980). In the DSM-III-Revised (DSM-III-R), all subtypes were diminished into two classifications: autistic disorder (AD) and pervasive developmental disorder not otherwise specified (PDD-NOS) (APA, 1987). With the release of the Diagnostic and Statistical Manual, 4th edition (DSM-IV) and DSM-IV-Text Revision (DSM-IV-TR), PDD was used as the overall classification with five subcategories: AD; Asperger's syndrome; Rhett's syndrome; childhood disintegrative disorder (CDD); and PDD-NOS (APA, 1994). All of these conditions have similar characteristics and with the recent publishing of the Diagnostic and Statistical Manual, 5th edition (DSM-5), these disorders have been combined into the umbrella term of autism spectrum disorders (ASD) (APA, 2013). These developments occurred over time as a result of research-informed practice and better understandings of the developmental condition (Bent et al., 2017). This change was encouraged with intent to bring clarity to the diagnostic criteria, such as the use of Autism Diagnostic Observation Schedule, and its application of what defines autism spectrum disorders (Bent et al., 2017).

With the numerous alterations in the classification of autism leading up to the DSM-5, the prevalence rate can be difficult to track for rates in the population. The current prevalence worldwide falls around 1% (Lord et al., 2020). Developed countries

sit higher at around 1.5% (Baxter et al., 2014) which is consistent with the CDC's estimates in their 2016 report (CDC, 2020). This is quite a dramatic increase from the CDC's first report of the prevalence of ASD sitting at 0.66% (CDC, 2007). These increases of ASD in the population may be attributed to advancements in screening processes to identify individuals earlier, coupled with more accurate diagnoses descriptions with the most recent DSM-5 (APA, 2013). ASD is identified in males more often than females with a ratio of 4:1 (CDC, 2020). This may be due to females exhibiting less noticeable characteristics or camouflaging their traits associated with ASD by using 'masking', or the mimicking of normal interactions (Hodges et at., 2020). ASD is observed in all racial and ethnic backgrounds, but seems to be identified more often in people of Caucasian descent (CDC, 2020; Hodges et al., 2020). Reasons for the uneven distribution amongst ethnicities and cultures may be due to the inability to access adequate health care services or stigma (Hodges et al., 2020). With a substantial amount of the population being affected by ASD, either through diagnosis or taking care of someone living with ASD, it is imperative that research continues to explore opportunities to optimize the life experiences and provide support systems for those living with ASD.

2.2 Etiology

The cause of ASD is thought to be multifactorial in nature from a collective of genetic, biological, and environmental factors (Lyall et al., 2017). ASD was once viewed as a condition that affected a specific brain region or system but is now regarded as a disorder that stems from overall brain re-organization during early development (Lord et al., 2018). However, the understanding of ASD's etiology specifics are still unclear. With

several proposed causal factors with multiple combinations, the main consensus regarding ASD is that there is no single genetic irregularity that is sufficient alone to cause ASD (Chaste & Leboyer, 2012; Lai et al., 2014). Currently, there are genetic variants and gene mutations that have been identified as risk factors that contribute to the development of ASD. This notion of genetic risk factors was brought on through the diagnosis of other conditions, like fragile X syndrome and tuberous sclerosis, in which ASD is a secondary comorbidity to the individual (Lord et al., 2018).

Originally more importance was put on genetic factors, however with the alarming increase in the prevalence of this disorder, researchers have put more emphasis on risk from environmental factors (Posar & Visconti, 2017). Environmental factors that are linked to ASD are widespread and there are several environmental factors that have been identified to be linked to the development of ASD. For instance, prenatal and perinatal factors such as maternal gestational diabetes and maternal bleeding during pregnancy can increase the risk of a child developing ASD (Chaste & Leboyer, 2012). It has also been documented that advanced maternal age and maternal dietary habits can also increase the risk of ASD (Lord et al., 2018). Mothers over 40 years and non-optimal pregnancy conditions such as metabolic issues, hypertension, or infection can be risk contributors (Lord et al., 2018). Lastly, environmental pollutants such as heavy metal toxins and air pollution have become a topic of debate on their role in the development of ASD (Lord et al., 2018).

Regardless of the etiology, early diagnosis is key to accessing therapies to help manage the characteristics associated with ASD. Children who are lower on the ASD spectrum may be diagnosed earlier as characteristic traits are generally more noticeable

(Lyall et al., 2017). The earlier in life that children can be diagnosed, the faster interventions can be introduced to support them.

2.3 Core Characteristics and Traits of the ASD Spectrum

From a clinical standpoint, ASD is characterized and diagnosed through its observable traits. It typically manifests as a deficit in communication or social interaction viewed as a delay in development compared to the normal progress of a child at a given age (Bhat et al., 2014; Harrington & Allen, 2014). It is recommended that the DSM-5 be used along with other diagnostic and screening tools to determine diagnoses and severity (Lobar, 2015). The current gold standard for diagnosing ASD is the Autism Diagnostic Observation Schedule (Ozonoff et al., 2005). Although ASD in children typically manifests as challenges with communication, social interaction, and repetitive behaviours (Anagnostou et al., 2014), it may also present difficulties in gross and fine motor skills (Landa & Garrett-Mayer, 2006; Lloyd et al., 2011).

Children start showing characteristics of ASD around their toddler years, typically when challenges in communicative abilities become apparent, but they can be noticeable as early as infancy dependent upon the severity (Lyall et al., 2017; Mukherjee, 2017). As ASD is now seen as a spectrum condition ranging in severity rather than a number of separate conditions, the characteristics associated with this disorder can differ immensely between individuals. The characteristics affecting an individual living with ASD that fall under each of the two core domains may drastically vary. The first category that shows a disruption of social function can have a significant impact on the communication skills of the individual and their ability to interact with others (Lyall et al., 2017). For example, a delay in speech or being non-verbal, minimal eye contact, and poor nonverbal

communication would be manifestations of atypical development of a child, pointing towards a diagnosis of ASD (Goldson, 2016). Other abnormalities such as inappropriate or lack of response to social cues and social-emotional reciprocity, difficulty in language comprehension, non-verbal communicative behaviours, and inadequate ability to develop and maintain relationships can become discernible as the child gets older (Lord, Elsabbagh et al., 2018; Mukherjee, 2017). The other domain of repetitive/ restrictive behaviours creates a vast amount of characteristics that an individual with ASD can experience. It manifests in an individual through any of the following: echolalia, inflexible adherence to routine, repetitive motor movements or vocal commands, and restrictive fixated interests (Lord et al., 2018). In addition to these characteristics that cause social disruptions in the lives of individuals living with ASD, it has been noted that up to 90% of individuals diagnosed with ASD can experience disturbances in sensory experiences that can affect any or all of the five senses (Robertson & Baron-Cohen, 2017). This can make it tough for families to engage in aquatic environments as enclosed aquatic facilities often are sensory overwhelming with loud noises and crowding.

Approximately 10% of individuals diagnosed with ASD have savant skills in which they have increased IQ and can be extraordinarily gifted in areas such as the arts and music (Bhat et al., 2014). Furthermore, approximately 70% of individuals diagnosed with ASD are also challenged with other physical and/or intellectual comorbidities (Bhat et al., 2014; Caputo et al., 2018). The most prevalent co-occurring psychiatric condition is attention hyper-deficit disorder (ADHD) affecting up to 70% of individuals with ASD (Lai et al., 2014). Mood disorders, such as anxiety and depression, are also commonly documented comorbidities in this population (Lord et al., 2018). Physical comorbidities

that are prevalent in this population include epilepsy, sleep problems, and gastrointestinal issues (Harrington & Allen, 2014).

In addition to the above characteristics and co-morbidities, it is also noted that this population tend to develop maladaptive behaviours such as self-harm and aggression as a deflective response (Guan & Li, 2017b). Social disruption can cause many individuals living with ASD to have trouble forming meaningful relationships outside their dependent circle (Goldson, 2016). In many severe cases, individuals may need around the clock supervision as characteristic and behavioural traits can be unpredictable. In order to provide the most beneficial support and therapies for individuals living with ASD, it is important that the individual's specific characteristics be considered. Some may do well in certain instances when others may need extra accommodation and support to have a positive experience. The type of support and social systems that are provided for this population can greatly affect their overall experiences and outcomes (Smith et al., 2013).

From a clinical standpoint the recognition of the challenges that children with ASD and their caregivers face is important. However, all children, including those with ASD, have a combination of strengths, struggles, interests, and personality traits (Clark & Adams, 2020). While children with ASD are a heterogeneous group, some intellectual strength associated with children with ASD are open-mindedness, creativity, happiness, thankfulness, joy, and a love of learning (Carter et al., 2015; Kirchner et al., 2016). While this is not a comprehensive list of the strengths of children with ASD, and strengths occur in all domains including, physical, emotional, and intellectual, it is important to note that children with ASD cannot be solely identified by the challenges they face.

2.4 Mortality Risk for Children with ASD

As characteristics of ASD can be highly restrictive and affect communicative efforts, children with ASD are at an increased risk for possible injury and mortality (Grosse, 2014; NASS, 2018). Guan & Li (2017a, b), found that this population is at a dangerously high risk for mortality, estimated anywhere from two to tenfold times higher compared to the rest of the population. One of the highly associated tendencies within this population is elopement and wandering off into unsupervised areas (Anderson et al., 2012; Grosse, 2014). Elopement is defined as a dependent person who withdraws from supervision of their caretaker by wandering or running away that could lead to potential danger or harm of the individual (Anderson et al., 2012). Although the term can alter slightly in definition, generally the tendency to run from safe spaces and/or adult supervision is categorized as typical toddler behavior. However, in the ASD population, this tendency to elope can occur throughout childhood and well into adolescence (Anderson et al., 2012).

This creates a major safety risk as children with ASD are often attracted to bodies of water due to its glistening properties (Grosse, 2014); this, with the addition of unsupervised engagement, can put children with ASD easily in harm's way. In a study done on unintentional drowning deaths in the ASD population, the results revealed wandering was the number one activity that led to accidental drowning accounting for 73.9% of incidents (Guan & Li, 2017b). Because aquatic environments are considered high-risk, many parents choose to refrain from engaging in water activities due to the elevated dangers associated with taking a child with ASD around water (Alaniz et al., 2017).

2.5 Challenges for Parents and Caregivers of Children with ASD

The challenges that ASD presents not only affect the experiences of the individual living with ASD, but can impact the experiences of their parent(s)/caregiver(s) (Benson, 2006). Despite the many joys that come with parenting a child, there are many stressors associated with taking care of a child living with ASD that can negatively impact their family. The challenging behaviours and needs associated with ASD can be a significant source of stress which can extend well into adulthood (Smith et al., 2013; Benson, 2006). As many require lifelong care, the task of caregiving does not diminish as the individual ages. Parents of children with ASD are at an increased risk for the development of mental and/or physical health issues (Marsack & Samuel, 2017). The level of severity of a child's diagnosis of ASD is positively correlated with the amount of stress parents and caregivers experience (Lyons et al., 2009). A large amount of caregiver time is put towards the demands of aiding a child with ASD, which can cause competing child rearing demands and inhibit their self-care. This can lead to an increase in psychological distress and poor psychological health (Marsack & Samuel, 2017). Often times, families with children with ASD will focus their attention on engaging in activities restricted to the child with ASD's area of interest (Lee et al., 2009). Additionally, literature suggests that mothers experience more stress than fathers of children with ASD and that the behaviours that children with ASD exhibit are the principle stressors (Johnson et al., 2011).

Interventions that support both the child and the parents/caregivers are crucial to increase the overall experiences for families with children living with ASD. Many of the challenges can be lessened through the introduction of support systems and therapies to

help mitigate the characteristics of ASD and reduce the stress associated with caring for a child with ASD (Johnson et al., 2011). As these interventions become more advanced and tapered to the population's needs, they become not only beneficial to the child living with ASD, but also benefit the parents and caregivers (Gray, 2006). When a child living with ASD has increased skills to be more independent, they develop stronger cognitive and social skills to help navigate daily life (Johnson et al., 2011). This can provide parents and caregiver with the confidence to bring their child into different environments that may have been inaccessible before, thus potentially increasing the experiences of not only the child with ASD, but also for parents and caregivers. Thus, it is important that interventions developed to support children living with ASD are done so with the input of parents and caregivers. At the same time, the needs of parents and their experiences have to be considered when designing interventions for the ASD community; when a parent or caregiver has better familial experiences the level of care they can provide for the child living with ASD increases (Johnson et al., 2011).

Previous qualitative research on the opinions of parents of children with ASD indicate the growing need for an inclusive setting for their child that promotes physical activity (Schleien et al., 2014). There are some studies conducted on specific types of recreational programming that may be beneficial for children with ASD, however the main perception of parents seems to be the overall lower participation rates compared to neurotypical developing peers (Potvin et al., 2012; Schleien et al., 2014). An inclusive setting for this study is defined as an environment that encourages participation regardless of background or ability. For aquatic programming in specific, this can range in accommodations to allow children with ASD to participate without unnecessary

limitations. For example, lessons can be altered to modify evaluate criteria, instructor-to-class ratio, and sensory nature of surroundings without alienating families.

2.6 Aquatic Interventions

Aquatic based therapy is used to provide therapeutic means to managing challenges associated with ASD, building on the strengths of the child, as well as to initiate skill acquisition and increase swimming ability. Swimming is a favoured leisure activity among children with and without disabilities alike (Alaniz et al., 2017; Mactavish et al., 2000). Children with ASD benefit from learning swimming skills and basic water safety in a sensory positive surrounding with a private instructor (Caputo et al., 2018; Chu & Pan, 2012).

As the behavioural characteristics of children with ASD can be unpredictable, many are excluded from participating in regular swimming activities due to the potential for injury or death by drowning (Grosse, 2014). To combat this, many aquatic programs have been developed to allow these students to participate in swimming and build aquatic skill acquisition in sensory environments developed for children living with ASD. These programs are not only important to building swimming skills for children living with ASD, but can be crucial in helping them understand the dangers around water and how to be safe when engaging in water environments. With the high drowning mortality rate in this population, specialized swimming programs are essential to ensure that children with ASD are able to participate in swimming activities in a safe manner (Grosse, 2014; Pan, 2010). Due to the importance of water safety and the many benefits from swimming, a considerable number of studies have been conducted on this topic.

Alaniz and colleagues (2017) conducted a pilot study examining the effectiveness of an aquatic group therapy intervention for improving water safety and social interaction in children with ASD. Their results concluded that group aquatic therapy can improve water safety skills in children with ASD of all severity levels. Results also indicated that children with higher-functioning ASD may improve their aquatic skills in as little as 18 to 36 hours of instruction (Alaniz et al., 2017). Lastly, group aquatic therapy was found to be beneficial at indirectly improving social skills and reducing anti-social behaviour (Chu & Pan, 2012; Pan, 2010).

Caputo and colleagues (2018) conducted a study testing the effectiveness of a multisystem aquatic therapy (MAT) intervention for children with ASD. MAT consisted of three phases, (i) emotional adaptation, (ii) swimming adaptation, and (iii) social integration with the first two delivered once a week individually and the third is carried out twice a week in small groups (Caputo et al., 2018). They utilized the Childhood Autism Rating Scale (CARS). The study found that emotional response, adaptation to change, and activity level had significant improvements in the intervention group compared to the control group where there was no significant change (Caputo et al., 2018). They also noted significant improvement in daily living skills and adaptive behaviours measured through the Vineland Adaptive Behaviour Scale (VABS).

Ennis (2011) performed a study researching the effects of a physical therapy-directed aquatic program for children with ASD. This program consisted of two separate ten-week aquatic therapy program sessions inclusive of family participation. The intervention was assessed through the Water Orientation Test of Alyn to determine aquatic skill improvement (Ennis, 2011). They also used Pediatric Quality of Life

Inventory to address interactional and behavioural changes for the families. The resulting outcomes were that the children with ASD that participated in the study all increased their water-based skill level and family questionnaires showed quality of life improvement (Ennis, 2011).

Pan (2010) investigated the efficacy of a ten-week aquatic exercise program for children with ASD in respect to their swimming ability. The researcher utilized the Humphries Assessment of Aquatic Readiness and a single-blind design to gauge aquatic skill level and improvement over the course of the intervention. The end result revealed that the children in the study improved aquatic skill as well as reduced antisocial behaviour (Pan, 2010; Bremer et al., 2016). Through parent interviews it was also noted that children's self-confidence as well as athletic and social performances had increased with the children asking to participate in activities that were previously avoided (Pan, 2010). A subsequent study performed by Chu & Pan (2012) tested the effects of sibling-assisted aquatic programs on interaction behaviours and aquatic skill for children with ASD. Their results yielded positive effects that the sibling with typical development helped garner better outcomes for the child with ASD, namely physical and social interaction. The program was deemed beneficial for all siblings, whereas the child with ASD received familial support and assistance and both the child with ASD and their typically developing sibling were able to enhance aquatic skill level (Chu & Pan, 2012).

Another type of instruction, known as 'most to least' prompting (MLP) was tested on children with ASD to see if it works in an aquatic setting. MLP is used as a common method of teaching children with ASD movement skills (Yanardag et al., 2014). It works through starting with increased assistance and slowly removing prompts until movements

become more independent (Yanardag et al., 2014). Researchers sought to see if the use of MLP in an aquatic setting would result in similar results. Yilmaz and colleagues (2010) conducted the initial study based solely on testing the effects of MLP when teaching basic swimming skills to children with ASD which yielded positive results. Yanardag et al. (2014) later tested MLP for advanced movement exploration for children with ASD which supported the former study also resulting in increase of aquatic skill retention.

Vonder Hulls and colleagues (2006) surveyed clinicians who utilized aquatic means to provide therapy for children with ASD for their opinions on the advantages and disadvantages of its use. The survey's data revealed that the clinicians who completed the survey believed that water therapy was beneficial at increasing aquatic skill performance, concentration, and balance. It was also noted that children were less likely to perform self-stimulating behaviours as a result of participation in aquatic therapy and all children enjoyed engaging with water recreationally (Vonder Hulls et al., 2006).

Finally, Mische Lawson et al., (2019) recently conducted a study on the swimming experiences of children with ASD and their families. The study spoke to both parents and children together and asked them questions about water activities that the family had engaged in. The results showed emerging themes of safety, swimming preferences, swim skills, characteristics of ASD and barriers/challenges that had a significant effect on the family's experiences with swimming. This study emphasized the importance of caution around water and the safety aspect in regards to the unpredictable behaviours and elopement of their child with ASD (Mische Lawson et al., 2019). Findings were also congruent with other studies that many families had close calls with potential drowning situations, but the more lessons that the child had, the more

comfortable the family was around water (Mische Lawson et al., 2019). This article lays a good foundation for this study to build off of and provides the opportunity to fill in perspectives and gaps that have not been looked at yet.

The benefits of enrolling in aquatics lessons, physical and psychological, have been researched extensively. Evidence suggests that children across the spectrum of ASD can benefit from aquatic lessons (Alaniz et al., 2017). Interventions can also benefit their overall development when they are tailored to individuals with ASD (Bremer et al., 2014). Most research on these programs has focused on skill acquisition, and indicates that aquatic skills improve for children with ASD of all severities (Alaniz et al., 2017; Caputo et al., 2018; Pan, 2010). Yilmaz et al. (2004) also noted that there were increases in balance, agility, muscle strength, and cardiovascular fitness. Another benefit of these programs is that they reduce social isolation by allowing children with ASD to engage in an environment enjoyed by many children, which may increase their experiences around water while promoting social interaction opportunities (Grosse, 2014).

The implementation of these programs may also have a large impact on the families of children living with ASD. Due to the nature of this specific neurodevelopmental disorder, water related activities or being near water is high-risk. Parents may avoid engaging in aquatic environments with their families as it can be perceived as too dangerous of a setting for a child with ASD (Grosse, 2014). Through the use of appropriate swimming interventions catered to the ASD population, this fear may be mitigated and decrease the amount of risk and stress that families encounter in water environments (Caputo, et al., 2018). However, the experiences and perspectives of parents and caregivers has yet to be explored in the context of swimming lessons and

water safety for children with ASD and their families. By better understanding the experiences of parents and caregivers in regards to having their children in water environments and their beliefs about the efficacy of swimming and water safety lessons for their children, interventions can be tailored to meet the needs of families and improve the experiences for children living with ASD and those who care for them.

2.7 Gaps in the Literature

The current literature indicates that aquatic interventions are beneficial for aquatic and social skill acquisition for children with ASD. However, information is missing on the family dynamic and how these aquatic lessons integrate into the everyday lives of families with children with ASD and potentially aid or restrict them if they choose to engage in other aquatic environments. Parents and caregivers are stakeholders of aquatic lessons for their children with ASD; it's an opportunity to learn survival skills which could help their child in an emergency. There is limited information on their thoughts and opinions on swimming lessons and what they feel is working or needs to be included. Parent experiences on swimming with their child with ASD has been researched in one qualitative study (n=12) (Mische Lawson et al., 2019), but has not connected the piece of creating better swimming opportunities for these families. It is important to identify what is being retained from these lessons, if any, and what transfers to other environments. This is especially important to note in this population as many children with ASD struggle with generalization which could hinder them from connecting skills learned from lessons into other aquatic environments. The ASD spectrum is vast in terms of characteristics and behavioural traits (Lord et al., 2018). It is probable that one type of lesson does not work for all children with ASD.

2.8 Significance of the Study

Many families may not be comfortable in aquatic settings and avoid entering these environments. Little has been done to understand the multi-faceted barriers that might prevent them from enjoying these activities if they want to participate. By examining the experiences of parents and caregivers and their opinions on aquatic environments, we can gain insight into their perceptions of their comfort and ability to bring their child living with ASD to an aquatic environment. This study is beneficial in understanding the preclusion of injury mortality in this population by looking at past experiences shared by parents and caregivers. Through investigating the perceptions of parents and caregivers who have, and have not, had their children in aquatic interventions, a better understanding of the perceived efficacy in these programs can be understood. This information from stakeholders could be key to identifying useful learning strategies that are suitable to children with ASD. This may lead to the ability to enhance aquatic interventions for children with ASD. Subsequently, this may also lead to opportunities that in turn enhance the ability of ASD families to enjoy aquatic environments with reduced fear, leading to an improvement in overall experiences.

Chapter 3. Methodology

3.1 Qualitative Research

Research within the qualitative realm incorporates an interpretive or descriptive approach to allow for a strong understanding of individuals and their behaviours (Denzin & Lincoln, 2011). Qualitative studies employ theoretical frameworks to understand a phenomena or social issue (Creswell, 2013). There are several important components that fuel robust qualitative research, with the researcher being a key instrument in adequately connecting the pieces and providing insight to the phenomenon (Creswell, 2013; Creswell & Creswell, 2018). Though the researcher may be used as a pathway of getting the information out, the relative meaning should come solely from the participants of interest and their unique perspectives on a topic (Creswell & Creswell, 2018). Utilizing interactive methods of data collection, such as interviews, allows the researcher to not only gain insight into the thoughts of the individuals, but also observe the auditory and visual aspects that can emphasize behaviour towards important elements of the overall picture.

A qualitative approach was chosen for this study to explore the lived experiences of parents and caregivers with children with ASD. Qualitative methodology guided my efforts in investigating the phenomena and provided the groundwork of the philosophy that directs the study. It has been noted that qualitative studies may be the optimal approach when investigating families with children with ASD due to the ability to observe complex issues through -rich description (Cridland et al., 2015). Qualitative research aims to empower individuals to share their story and be heard (Creswell, 2018), this research serves to empower parents and caregivers of children with ASD by

discussing and bringing importance to their experiences. It was important to highlight and encompass the capabilities of children with ASD to provide a strength-based outlook during throughout the study (Tesfaye et al., 2019). By assessing this phenomenon, it created an opportunity to learn about the lived experiences of these parents and caregivers as well as provided a foundation of information for future programming and/or opportunities for children with ASD.

3.2 Phenomenology

A phenomenological study provides a deep understanding of a human issue or phenomenon experienced by several individuals; it an often-favored approach to understanding human experiences (Creswell, 2013). This methodology supports the investigation into the meaning people give the experiences they have, instead of looking solely for explanations. Phenomenology gives insight through descriptive, interpretive, and reflective inquiry (Morse & Field, 1995). With background roots deep in philosophy, phenomenology draws on the works Edmund Husserl, a German mathematician, who focused on observation through intentionality, or directed awareness towards a phenomenon whilst acknowledging and separating preconceived opinions (Reiners, 2012). Husserl is credited with contributions to the science of psychology through the development of phenomenology (Padilla-Diaz, 2015). He critiqued psychology in the development of phenomenology, postulating that human perception is subjective (Padilla-Diaz, 2015).

3.3 Transcendental Phenomenological Approach

This phenomenological study took a transcendental phenomenological approach where the researcher attempted to separate themselves from their bias and see the data

through the participant's perspective (Creswell, 2013; Moustakas, 1994). When utilizing transcendental phenomenology, no assumption or scientific theory should inform the inquiry, instead, the focus should be on what is given directly to the researcher (Creswell, 2013; Moustakas, 1994; Neubauer et al, 2019).

This specific approach focuses on the notion of epoche to acknowledge the experiences of the investigators that may influence the study (Creswell, 2013). Through transcendental phenomenology we developed textual (what) and structural (how) descriptions of the lived experiences of families with children with ASD to provide a rich understanding of this phenomenon (Creswell, 2013). The textual description provided an illustration of the phenomena whereas structural description built upon it and seeked to tangibly express the essence of the phenomena (Patton, 2002). When using transcendental phenomenology, the goal is to stray from prejudgments as much as possible and use systematic qualitative procedures to combat the initial bias of a given phenomenon (Moerer-Urdahl & Creswell, 2004). This systematic procedure is discussed at length in the data analysis section below.

Phenomenology enables qualitative researchers to capture the essence of an observed practice or issue (Morse & Field, 1995). Phenomenological reflection is guided through four existentials: lived body (corporeality), lived time (temporality), lived space (spatiality), and lived human relation (communality) (Morse & Field, 1995). These existentials are aspects of life, or categories, in which all humans have experiences in regardless of background. They serve as a foundation for reflection in the research process and a way to structure questions. It is accepted in phenomenology that

individuals' experiences differ substantially in how they are perceived over time and by different people (Morse & Field, 1995).

3.4 Epoche and Bracketing

Bias should always be addressed in qualitative studies, as researchers bias can occur quite easily, especially if the researcher is very invested in the topic of interest. To combat this, there are many tools that researchers can use to minimize the chance for bias by disclosing their opinions and thoughts on a topic. Positionality is used to state the researcher's viewpoint within the social and political context of the study (Coghlan & Brydon-Miller, 2012). This is used to inform readers of the direction that the study is being conducted from, not to negate the resultant data (Throne, 2012). Positionality is important to disclose as it affects every aspect of the constructed study (Coghlan & Brydon-Miller, 2012). In phenomenology, bias and positionality are encompassed in epoche and bracketing.

A phenomenological approach aims to cease judgement about what is real, creating a natural observation of reality, a cessation Husserl coined 'epoche' (Creswell, 2013). This is used to reduce researcher's bias and is often paired with bracketing. Epoche is generally described as the process of separating personal experiences or opinions of the researcher from the study, which should be taken into consideration throughout the research process (Bednall, 2006). Epoche is a dynamic, continual process of setting aside assumptions. On the other hand, bracketing is similar in acknowledging the opinions of the researcher, but is utilized mainly before and during interpreting any sets of data so as to not interfere with the results (Bednall, 2006). Epoche and bracketing

are often used interchangeably as they work toward the same goal of strengthening the trustworthiness of the study.

Within the phenomenological research community there is much debate on bracketing. Concerns surround how to bracket, when to bracket, and if bracketing is even a worthy undertaking (LeVasseur, 2003). The question that vexes many is whether a person can ever be removed from their understanding of the world based on their personal history and knowledge (LeVasseur, 2003). LeVasseur (2003) reconciles this disagreement by proposing that researchers should think of bracketing as bringing an attitude of curiosity into our work, as when we become curious we assume we do not know or understand something and we suspend our theories and prior knowledge. This suspension does not last for long periods of time, it is more a momentary suspension, in which new impressions flow in, and are then met with our pre-conceived notions (LeVasseur, 2003). But it is those moments, and then the time in which the new and old meet that provide the researcher with trustworthy data (LeVasseur, 2003; Shenton, 2004).

How to bracket and when to bracket is another concern in phenomenology (LeVasseur, 2003). For this study I took an approach of active and reflective meditation centered on questions related to this work posed by my supervisor (Moerer-Urdahl & Creswell, 2004). The questions that framed this reflective process were: 1) What is your experience in aquatics? 2) What is your experience with children with ASD in aquatics? 3) What do you feel when you teach children with ASD in an aquatic environment? 4) What do you think a parent of a child with ASD would feel in aquatic environments? I wrote a positionality letter for my supervisor, excerpts from this letter are synthesized

below. The only instructions were to write freely and to not be inhibited by thinking "I should not write that":

I was interested in aquatic directed research as I have several years of experience teaching aquatic lessons. I currently work at a private swim school as a supervisor and train instructors and lifeguards. Although this is a part-time job, I have stuck with it as I truly enjoy teaching and I am a strong believer that all children, with or without disability, should be exposed to water safety skills as early as possible. Learning to swim is quite different from other type of lessons that are typical for children. It doesn't take much for an accident to occur. I am too familiar with cases of children being left attended and falling in pools of water, or boating accidents that could have been prevented had adequate safety measures been in effect. It is so important that children not only know how to swim, but also know what to do and why they should be cautious around water.

My experiences in aquatics have vastly differed from place to place, I have worked for municipal community centers as well as private schools. I find that private schools tend to take on a more in-depth learning approach where kids can not only learn but advance their skill levels to exceeding expectations. Municipal seems to take on more of an evaluative approach as class sizes are larger with a shorter amount of time; you don't have much time to teach and practice. I personally like the low ratio classes as you not only get to teach the children, but actually form relationships and get to know them so they feel comfortable with you. I find that is where the most progress happens, especially when a child fears

certain aspects of swimming. It is one of the most fulfilling moments when one of your students finally lands that dive or can now perfectly execute their breaststroke.

Teaching children with ASD is comparably different from teaching typically developing children. It largely depends on where they are on the spectrum. I have students that are high functioning and are totally fine in regular classes where I just need to be aware of certain individual needs. On the other hand, I have students that are part of our swim plus program where it is just myself and them in the pool so the lessons are carried out in sensory positive environments without any triggers or distractions. I have not been teaching swim plus for long and I find that I learn something new every time I teach a lesson. Not all children with ASD present the same needs, so the biggest challenge is shaping your lessons into ways that work for that child. For example, one of my students who does private lessons dislikes putting his eyes on command, however if you give him a task, for example retrieve a ring, he will do it with a smile. He is very goal-oriented and actions have more meaning and must be purposeful. There are always alternative methods of teaching a skill and finding the one that works is key. There are some children with ASD who are very accustomed to their routines, certain things must be done in order, or they have attachments to numbers or letters that guide their actions. Regardless of how they learn and what pace, these lessons make a big difference in these children's lives, even if they just remember that the instructor needs to get in first before they can and build from that. It is a major milestone for little accomplishments for children with ASD and celebrating each one is also part of the process. Comfort is a huge part of these lessons. This can be a challenge again

depending on the severity of the child's diagnosis and social preferences. I personally have not had any kids that we had to help warm up to the water, but that is usually the first step especially with an instructor who is a stranger. It can also be difficult to form a relationship with a child if they are non-verbal due to a lack of communication. Again, there are different ways of combatting this. I generally talk to my students and they will either repeat specific words or point to things they want to do. Additionally, I have a coworker who has picked up basic American Sign Language (ASL) in order to communicate with some of her non-verbal students. It really falls back on getting to know your student and what works. Something I learned early on was to be extra careful of your tone. Something as simple as 'don't do that' can evoke a negative response. It quickly became, 'should we be doing that?' and we figure out together what is appropriate to do in the pool and what is not. It's a very different experience, but opens up a new perspective and multiple methods of teaching that I never thought to use before.

All these learning curves help not only with myself, but with the parent as well. Often with children with ASD, I will follow up with the parents to get feedback or give updates on their child's progress. Sharing what works and what does not on both our ends can aid in figuring out what is best for their child. Many parents take their child to swim lessons not only to learn to swim, but to be safe around water and it is no different with a child with a disability. Parents want to be able to take their children to aquatic environments to enjoy aquatic activities. I feel that without these lessons many parents would feel hesitant to take their child with ASD to a beach or pool as it can be overwhelming on the senses. However, the other concern

is the risk of the child not understanding the dangers of water and how to be safe in aquatic surroundings. Adding that children with ASD are generally drawn to water and the chance of elopement, I think it might make it increasingly difficult and even create too much fear for parents to comfortably bring their child to such an environment. The risk may be perceived as too high; as the last thing any of these parents want is for their child is to have a negative or even a traumatic experience.

3.5 Procedures

For this study I collaborated with Grandview Children's Centre, in Oshawa Ontario. Grandview Children's Centre is a not-for profit organization. It is an independently operated treatment facility to support the lives of children with special needs and their families. Among the many services they offer, therapeutic aquatic recreation provides the opportunity for children with special needs to learn and improve activity specific skills in a sensory positive environment. Grandview Children's Centre aquatic program is provided in partnership with the City of Oshawa. They are one-on-one Red Cross swim lessons offered at a reduced rate taught by City of Oshawa swim instructors.

To develop this study, Dr. Meghann Lloyd introduced Dr. Kerpan and I to the Clinical Manager at Grandview Children's Centre. We discussed my area of interest and experience and felt that a study of aquatics would benefit Grandview as an organization and provide parents in the Grandview community an opportunity to share their experiences, perspectives, and needs.

Recruitment for this study was sought using advertisements through Grandview's official website and social media outlets facilitated by Grandview staff. On the recruitment material parents and caregivers were informed that what they shared would

be confidential and their data would be de-identified before Grandview Children's Centre viewed the results. This may have assisted in recruitment as parents may have been wary of sharing, especially on questions pertaining to ways to improve the aquatic therapy program at Grandview Children's Centre.

Parents and/or caregivers of children living with ASD that were interested in being a participant in the study contacted me through email or phone call. Interested participants were asked screening questions about their child living with ASD to determine eligibility for the study (refer to appendix A).

Parents whose children met the eligibility requirements to participate in the study were contacted to set up a date and time for the interview. On the day of or prior to commencement of the interview, parents that participated were asked to provide consent to participating in the study and to have the interview recorded for analysis purposes.

Ethical approval was obtained from the Ontario Tech University's Research Ethics Board. Subsequently, ethical approval was also obtained from Grandview Children's Centre. All parents signed consent form prior to the commencement of data collection. Participants who volunteered for the interview were informed they could withdraw from the study at any time without prejudice or penalty. Confidentiality and the protection of the participant's identities were assured through de-identification of data results. No names or other means of identification were used in this thesis or in any publications. Participants were informed that there are no penalties or benefits for participation. All data is secured by Dr. Serene Kerpan for five years after completion of this study.

3.6 Participants

The sample population included participants of children with ASD who had a variety of swimming experiences. Parents or caregivers were eligible for the study if the parent(s) was the primary caregiver of a child with ASD. The number of participants for phenomenology is often 3 – 15 (Padilla-Díaz, 2015). However, this is dependent on saturation, when no new ideas or information are presented (Ness, 2015). More participants came forward than we were able to interview. Participants were selected with differing ages, experiences, and exposures based on answers to eligibility questions to try to capture all contrasting experiences. No participants came forward that had no prior/current swimming experiences. Participant information and child information can be found in Table 3.1.

As discussed in the previous section, Grandview Children's Centre supported this project by aiding with recruitment and helped guide the study design.

Table 3.1 Demographic Information.

#	Relationship to Child	Age, Sex of Child(ren) with ASD	Description of Child's Needs Provided by Parent	Aquatic Lessons Experience
1	Mother	5 years, girl	High functioning, independent with minor assistance.	Less than 1 year
2	Mother	14 years, boy	Independent with minor assistance.	5+ years
3	Mother	16 years, boy	Significant assistance required for most tasks.	5+ years
4	Mother	6 years, boy	Moderate functioning, assistance required for many tasks.	3 years
5	Mother	4 years, boy	Significant assistance. Non-verbal.	Less than 3 years
6	Mother	3 years, twin girls	Independent for their age.	About 1 year for both
7	Mother	2 years, boy	Independent for their age.	1-2 years
8	Mother	7 years, boy	Independent with minor assistance.	About 4 years
9	Mother	9 years, boy	Significant assistance required for most tasks.	5+ years for both children
		15 years, boy	Independent with minor assistance.	
10	Mother	13 years, boy	High functioning.	5+ years
11	Mother	20 years, boy	Independent with minor assistance.	5+ years
12	Mother	10 years, boy	Moderate functioning, assistance required for many tasks.	3 years

3.7 Data Collection Methods

3.7.1 Materials The materials required for this study were the interview guide, Otter recording software for transcription of interviews, and Nvivo software for organizing coding schemes for data analysis.

3.7.2 Individual interviews An interview guide was created (appendix C). Individual interviews were chosen as the method of data collection because it maintained confidentiality and provided participants an opportunity to express their honest opinions and experiences with aquatic programs. Interviews also allowed the researcher to capture behaviour and emotion of the participants towards the given topic that would otherwise be missed using another method of data collection. The interview guide was semi-structured with open-ended questions. A semi-structured interview guide was chosen as it gave direction on what information is required for the research, but provided room for extension of knowledge and encouraged the participants to elaborate where they felt necessary; this is crucial in phenomenology (Creswell & Creswell, 2018). The guide was pilot tested with a parent of a child with ASD and no changes were necessary to the interview questions.

One interview was conducted at a library and all subsequent interviews were held over the phone to comply with social distancing guidelines that came into effect during data collection. Interviews lasted between 25-55 minutes in length. Every interview was recorded with Otter software. Participant recruitment and interviewing ceased at the point of redundancy (N=12). Redundancy is when enough data is collected that patterns and relationships are emerging and new themes are not surfacing (Patton, 2002).

3.8 Data Analysis

Data from the interviews were transcribed verbatim after completion. Transcripts were analyzed for themes using NVivo. This was done by first uploading a transcribed interview to NVivo. Before starting coding, transcriptions were read multiple times to understand the answers from participants. Then horizontalization of data occurred wherein all pertinent phrases were identified, listed, and were presumed of equal value with regard to the intentions of the participants (Creswell, 2013; Padilla-Diaz, 2015). Nodes were created to generate overall themes that emerged from multiple excerpts identified from horizontalization. All references to a specific theme were then coded individually under the relevant node. Themes were discussed among my research supervisor and myself to solidify significance. This process repeated until data saturation occurred and no new ideas were presented. From the confirmed nodes, textual descriptions were then produced with the addition of "ad verbatim" quotations which were the foundation of the resultant structural definitions (Padilla-Diaz, 2015). Finally, a thematic analysis was conducted with the resultant information to identify patterned meaning across the dataset.

The quality of research produced through qualitative means is constantly under scrutiny. Rigor in research is paramount to prevent flaws during all stages of the qualitative process (Morse & Field, 1995). Lincoln and Guba (1985) originally described four criterion to evaluate trustworthiness: truth value, applicability, consistency, and neutrality, believed to be appropriate for both quantitative and qualitative research. These were established over the controversy of lack of control over the validity and reliability of findings in qualitative research (Morse & Field, 1995). Subsequently, Shenton (2004)

describes four similar criterion for trustworthiness to acknowledge that are directly relevant to qualitative endeavors: credibility, transferability, dependability & confirmability.

Credibility is likened to the internal validity of the study. It evaluates the congruency of a studies findings with reality and the studies ability to measure what it is intended to (Shenton, 2004). It was my responsibility as primary student researcher to provide the most precise perspectives of the parents of children with ASD that I interviewed as accurately as possible (Morse & Field, 1995). Credibility is enhanced through the adoption of research methods that are well established; the development of early familiarity with the topic of the research and the people/organizations involved, peer scrutiny, member checking, thick description, and training to support honest answers from participants. I am very familiar with aquatics training, and work in an ASD aquatics environment, which allows me emic knowledge of the topic under study. I went interview training with my supervisor and have taken an advanced qualitative methods course to acquire interviewing skills. After I analyze preliminary results, my work will undergo peer scrutiny. Peer scrutiny is when a peer or supervisor with experience in the research area reviews the findings and provides questions and critique to the original analysis to strengthen the results (Shenton, 2004). Lastly, my thesis was written using thick descriptions which is when the author provides background information important for understanding the meaning of data and provides the significance of the data in interpretation. The writing intimately describes the research, how it was undertaken, and the results with great attention to detail (Shenton, 2004).

Transferability is defined as the extent to which findings of a study can be utilized in other settings and is likened to external validity (Shenton, 2004). As qualitative research has many specified conditions limiting, it is near impossible to conclude application of all findings to other settings (Shenton, 2004). However, by providing adequate thick description of the phenomenon of inquiry, it grants readers a deeper understanding in which they may compare the conclusions of the study to their own similar or contrasting experiences (Shenton, 2004). As indicated above, my findings were written in thick description to afford the reader the ability to determine if the findings "ring true" and might transfer to their setting.

The notion of confirmability describes the level of objectivity in a study (Shenton, 2004). The research findings need to be the experiences and ideas of the participants, not the preferences or ideas of the researcher. Qualitative researchers should strive to produce robust and accurate findings. However, it is recognized that researcher's bias will always be present to some extent (Shenton, 2004). This concern was mitigated in my work through the admission of my beliefs and assumptions, which was done through bracketing. By addressing my own experiences and setting them aside, I set out to produce findings from the experiences of parent and caregivers of children with ASD without including my own perspective on the phenomenon. As I conducted the interviews and wrote my field notes I engaged in the process of epoche, constantly reminding myself to listen with an open mind and not allowing my biases to infiltrate what I ask and what I write. When I engaged in data analysis, I reviewed my bracketing writing exercise at the beginning of each data analysis session and at the end of data analysis with my supervisor. A careful audit trail of decisions made and analysis procedures as well as

truthful recognitions of the limitations of the study also bolstered the confirmability of the study (Shenton, 2004).

Lastly, dependability refers to the ability of a study to be reproduced and maintain similar results (Shenton, 2004). It is similar to reliability, with the difference being that the work provides the reader the opportunity to repeat the study with the understanding that the results will be different because the study is done at a different time, with different people, and in a different place (Shenton, 2004). To do this, my thesis had explicit and clear writing on research design and implementation, detailed sections, data collection methods, what was done in the field, and reflective appraisal of the research, evaluating the effectiveness of these processes (Shenton, 2004).

Chapter 4. Results

The results of this study have been categorized in two clusters: Experiences and perspectives on aquatic environments and swimming, and Experiences and perspectives on swimming lessons. Within each of these clusters are themes, and sub-themes. Table 4.1 contains the themes for each cluster. The tables at the beginning of each thematic section contain the themes, sub-themes, and sub-theme examples.

Table 4.1 Results Clusters Breakdown

Themes for Cluster 1: **Experiences and Perspectives on Aquatic Environments and Recreational Swimming**	Themes for Cluster 2: **Experiences and Perspectives on Swimming Lessons**
Safety is the Priority	Making Lessons Accessible
Attraction to Water	Teaching Methods
Acceptance of Children with ASD in Aquatic Environments	Teach the Teacher
Therapeutic Benefits	The Impact: Pride, Independence, and Normalcy.

4.1 Experiences and Perspectives on Aquatic Environments and Recreational Swimming

4.1.1 Safety is the Priority

Table 4.2: Theme Breakdown: Safety is the Priority

Sub-Themes	Sub-Theme Example
Parental Fear	*"…if he falls in water by chance, I don't want him to drown…"*
Necessity of Swim Lessons for Survival	*"… you need to learn to swim in case something happens."*
Impaired Ability to Perceive Danger	*"…it's very scary that she has no fear."*
Supervision	*"I never leave my child alone…"*
Lifejackets	*"…it's just that extra layer of protection…"*
Types of Aquatic Environments	*"…it's a containment issue."*

This theme discusses the emotions parents experience in relation to their and their child's experience in aquatic environments and participant's experiences and beliefs about water safety. In the interview's participants spoke of the necessity of swim lessons, children with ASD's impaired ability to perceive danger, and parent's thoughts about supervision around water, lifejackets, and types of aquatic environments.

In this study participants indicated that they were fearful of their child drowning and experienced a high level of stress because of this. *"I know drowning is the number one cause of death in this age group. So it's a bit stressful, I just wanted to get him swimming or be able to float, as soon as I possibly could" (P7).* For children with ASD, learning how to swim and being exposed to the water was seen as a necessary survival skill, even if it's difficult for them. *It's not for leisure in my mind. For her it's leisure, for me it's strictly safety, you need to learn to swim in case something happens" (P1).*

Another parent stated, *"When he was younger, my husband wanted us to give up on swimming lessons because it was such a struggle. But with access to water all summer I couldn't let it go because with our lifestyle he needed to be able to at least swim to survive" (P2).* This was echoed by a participant who stated *"I need him to learn swimming, in case sometimes he goes for swimming or when he grows older also, if he falls in water by chance, I don't want him to drown, I want him to learn how to save himself" (P4).*

Many parents felt that their child with ASD did not have the ability to perceive danger or have a lack of fear when it comes to many situations, including water surroundings. *"Her perception with danger is impaired… the ocean we went to on vacation, she went right in and the waves are huge and she's two years old, they could just sweep her away so it's very scary that she has no fear"(P1).* Another parent explained, *"Yeah he'll climb on anything and jump off… he doesn't really have a sense of like, if I do this, I might get hurt. It's just like that looks fun, I'm going to just do it" (P5).* One mother stated, *"I would say before he was before he hit about nine years old, it was always scary. He had that carelessness about him, wouldn't watch where he's walking you might fall in" (P2).*

Many caregivers identified that these fears stemmed from unpredictable behaviors that children with ASD sometimes exhibit and added that many elope or have tendencies to seek out water. A parent explained, *"Don't trust them to know what is or isn't safe, because I think one is still pretty fearless when she shouldn't be" (P6).* This was echoed by another participant, *"I do think safety is huge because most of them are runners, when he was younger and we just had to, kind of, nip it in the butt and just constantly repeat*

the same thing; no running on the deck, no running into the water" (P3). The lack of environmental understanding was explained by this participant *"He could very well just get it in his head that you know what I'm just going to jump in this deep end and I'm going to be fine. So there's that lack of understanding that the environment may be dangerous" (P5).*

Some behaviours that children with ASD exhibit around aquatic environments also cause concern for parents of children with ASD. *"My child has always likes the sensation of his face being under the water. Sometimes it would seem like it was a little bit too long under the water… he's freaked out a lot of people doing that" (P2).* Another parent explained, *"It's almost as if there was like this gravitational pull to water like he always wanted to go up to touch it. …When he was younger, maybe one or two [years old], he probably would have just walked right in to a pool or any body of water and just jumped into it" (P8).* Another mother spoke of her child loving being in the water so much it didn't matter the conditions to him, which was troublesome. *"I can't go to the trailer and check on it in March or April, to see how it's doing …because if I do, he'll want to go in the lake" (P10).*

Parents shared that they were so concerned about their child's safety that they did not feel comfortable allowing anyone else take their child around water. *"I've always been a little bit apprehensive about family members taking the kids swimming without me. I think it's just because I know that parents tend to be a little more vigilant when it comes to watching [their] kids when they're at a pool" (P8).* A mother reaffirmed this, *"I don't let anyone else take her because I don't trust people in that they don't realize how impulsive she is that she could at any time be a flight risk of running along the water, or*

doing something dangerous on deck" (P1). This participant indicated they felt the same about others supervising their child, *"I don't think I would let anybody take him at this time…not that I don't think people would [take your eyes off the child], but I don't think they would do it at the same level obviously as a parent" (P7).* Another mother added that this fear hindered her ability to enroll her child in independent swimming lessons at a younger age explaining, "*her first real lesson she was five because I was scared of letting her be [alone] with an instructor" (P1).*

When it comes to supervision, parents agree that they'd prefer themselves to supervise their child, but added eyes of lifeguards do help them feel more secure. *"Now we go to the pool [on vacation] because we know there's lifeguards around the outside edge of the pool. …I know that the lifeguards are always watching right so yeah I guess that makes me a little more comfortable than going to beach" (P3).*

Parents commented that their children with ASD would miss events or not go to the beach/pool if there was not adequate parental supervision for their children, especially if they have multiple children. *"Say I know it's just going to be me with the kids...If I know I'm going to be alone we would choose to maybe do something at home with like a little kiddie pool or sprinkler or something of that nature, instead of doing like an outing because…one of us has to be 100% focused on him" (P5).* Another mother explained that going to aquatic environments was a two parent outing, *"Right. So if both parents are on board then I feel more comfortable but if it's just myself I'm not comfortable" (P1).* The general consensus for supervision is that parents require one person to be solely focused on their child with ASD to avoid any potential adverse situations. One participant

clarified, *"I never leave my child alone. One person always has to be watching him just to be sure" (P12).*

The result of the impaired sense of danger coupled with worrying about their child's safety led many parents to adopting a lifejacket always approach when their child was anywhere near water. *"I think that it's a smart thing for a child to have a lifejacket on if they're anywhere near water, because it's just that extra layer of protection…like he knows that if he's going to go anywhere near water he grabs a lifejacket, that's the only way he goes in" (P8).* This was echoed by another parent, *"I always have him in in like a life jacket when we're around water. So just making sure you always got that on. Then you know kids sometimes they'll try and take it off… you have to be really firm with him, that if you take it off you're not allowed in the water" (P5).* Another parent explained they kept their child in a lifejacket until they were almost a teenager, *"Honestly, he was 12 years old when I would let him not where his lifejacket on a beach. Like if we were on a beach everybody's got a lifejacket on" (P2).* Many parents believe this is a must for all kids until an adequate level of swimming ability has been attained. *"We do go on vacations every year, we are near an ocean or pool all day long and she has her lifejacket on. I will not take it off and now she at the age like I don't need that and she always rips it off and then I panic like you need it even if she thinks she knows how to swim. She just doesn't get it" (P1).*

Parents added that the environment that they were going to makes a big difference. Many parents said they were more comfortable at pools than beaches due to the more controlled surroundings and extra supervision. *"With the lake it's different, when we go on a holiday to the beach with it not being supervised and it being open and*

he won't put a lifejacket on, there's always somebody in the water with him because of that fear that you don't know how deep it is and there's undercurrents" (P11). A mother indicated they felt similarly, *"I take him swimming all the time at the pool like it's not a problem. But the thing with the cottage, I thought it was supposed to be relaxing being by a massive lake with him, but it's not relaxing" (P7).*

Some parents explained how the open area posed a boundary concern for their child if they were prone to eloping. *"I think if we're obviously in a contained environment like my backyard where I'm sitting right there and I see what's happening it's probably easier than a beach, because if he decided to take off and run right, it's a containment issue" (P3).* This idea was reiterated, *"When you're at a pool that is a constraint area, but when you do the same thing in a lake it's an opening area right. So you can't see the boundaries like that, okay you just have to swim in this place, but not outside there" (P4).* A participant also explained that they liked pools with certain features that enhanced their feelings of safety, *"If there's a place that doesn't have like a safe, like sort of like a preschool toddler area [or] designated area where I would feel he would be safe… I won't go there just because he could run off" (P5).*

4.1.2 Attraction to Water

Table 4.3: Theme Breakdown: Attraction to Water

Sub-Themes	Sub-Theme Example
Touch Sensory Attraction	*"…she just has to touch it."*
Visual and Auditory Sensory Attraction	*"It's fun, it's flashy…"*
Calming Effects of Water	*"Nothing comforts him more..."*

A theme that emerged from the interviews was that children with ASD had an attraction to water. This theme contains data that highlights the parents' perspectives that water attraction is sensory related and involved touch, along with auditory and visual stimulation. Participants also felt that water provides a calming effect to their child with ASD.

Most parents said their child had some level of fascination with water. The majority of parents when asked whether it was more than neurotypical children, responded yes. One mother compared her experience with her 2 children; one neurotypical, one with ASD, *"She seeks out water all the time… [my other child] knows that's danger, don't go near there ...she [my child with ASD] just has to touch it"(P1).* Other parents explained that their child with ASD could be fascinated for hours washing dishes or playing in a little fountain. One mother explained her experience, *"Wherever we are, she gravitates to water for sure. Whether its rivers, lakes, pools, ocean, taps, like that's kind of not really water, but you know, any water... puddles, like it's crazy"(P1).*

Every parent thought the reason for the water attraction was sensory. Parents stated that touch was the primary sense that gave rise to the fixation. They *needed* to touch the water, stick their hand in, or feel the water all around them. One mother shared, *"I think it's sensory for him, he loves playing with water and we catch him, he goes into the bathroom and fills the sink and take cups of water and plays with water constantly. If you put him in a bathtub, he will play happily for, if you let him… for hours" (P5).* Another parent suggested an explanation, *"…it's probably a sensory thing, I would say water attracts them because it's a sensory thing, because when you're in the water, it feels like something's hugging you…because it's all around you… It's pressing against*

your skin" (P10). Other parents agreed with this idea sharing their experience, *"I think for him it's a sensory like the sensation of being in the water. Like, he likes to be completely in the water like 100% submerge" (P2).*

Other parents felt that the reason for the attraction was the sound and the look of the water, *"It's fun, it's flashy, it's kind of like especially in pools the color of it right…whether it's the waves, whether it's the movement, that's just something he's always liked" (P3).* Other parents linked the look and the sound to a calming effect, *"It looks really nice you know the light shines off of it in an interesting way so you know that could literally be even the sound that it might make, I don't know if it's just one of those, it seems calming almost"(P8).*

The water sensory experience for children with ASD was seen as very positive for most participants. Families tend to utilize their child's attraction to water to benefit them therapeutic reasons. One mother suggested, *"It's definitely a fixation, but it's not one that we dwell upon because he's getting exercise, it relaxes him and there's so many positives for it that for us it's a motivator" (P10).* Another mother agreed but added, *"I don't see the attracted to water... as a negative thing, I think it's a good thing for him. That's the place where he feels most at peace" (P11).* Some mothers shared how their child reacts to water, *"Nothing comforts him more than being in a bath or something like that. He loves playing with water" (P12).* Similarly, another mother said, *"I don't know how to explain it because he can't explain it, he just, he usually says he just feels so relaxed when he is in there" (P11).* One mother used their child's attraction to water as a means to putting him to sleep, *"When he was kid, it was really difficult to put him asleep, sometimes it took two, three hours…So when I was washing him [with water] in my lap, he would fall*

asleep" (P12). Another parent spoke of what she felt was the physiological explanation for the relaxation that occurs in water *"... it has to do with the whole resetting through the proprioceptors. I think that they instinctively know that it will give them that mental reset that they crave" (P9).*

4.1.3 Acceptance of Children with ASD in Aquatic Environments

Table 4.4: Theme Breakdown: Acceptance of Children with ASD in Aquatic Environments

Sub-Themes	Sub-Theme Example
Bullying, Teasing, & Judgement	*"...a lot of people in the world are very judgmental."*
Avoidance of Aquatic Environments	*"...he's more of a target, so it's not a successful situation."*
Lack of Understanding of ASD	*"A combination of them being uncomfortable and them not knowing."*
Sensory Positive Environments	*"A lot of pools are very very echoey..."*
Parent and Sibling Protection	*"I'm protecting him...."*

This theme explores different types of situations and interactions parent's experience in aquatic environments and how they are handled. These include: bullying and judgement, avoidance of aquatic environments, others lack of understanding of ASD, sensory positive environments, and parent and sibling protection.

Many parents discussed the unwanted attention, bullying, and teasing children with ASD experience when engaging in aquatic activities. *"You're always apprehensive because you know as an ASD Mom, you have the issue that a lot of people in the world are very judgmental" (P5).* Participants commented this extends to almost any environment, but with aquatic environments usually having more triggers, it happens

more often. *"[During] regular swimming lessons, the looks and the stares that these kids get, and even the bullying in the change room that these kids face by other parents is disgusting" (P10)*. One parent shared a malicious comment, where another parent said to their child *"this is why we behave so we don't act like him" (P10).*

Parents will not go to areas if they feel there may be potential for harassment. *"If there's like a lot of like teenagers I tend to avoid, mainly because they can get quite mean. They usually look for somebody to pick on and for some reason it's usually my son" (P2).* Many other parents shared similar stories, *"We avoid any city pool on a PA day or a vacation day or anything that's going to be extremely busy, because of the fact that some kid out there will start picking on him…he sticks out more, not in our eyes, but in other people eyes so he's more of a target. So it's not a successful situation" (P10).* They will also tend to avoid if they know it may have triggers for their child. *"If somewhere is really super busy… just the sensory issues and the overload, it's not good. It can cause a lot of stress and meltdowns, just him being uncomfortable with the situation so we'll avoid places like that" (P5).*

Parents felt that there was a lot of ignorance when it came to comments spoken by other parents. One participant shared that it might be due to*, "a combination of them being uncomfortable and them not knowing" (P11).* Parents explained it was easier to access aquatic environments if it was more accepting atmosphere. *"You definitely feel more comfortable when you're in a quieter environment where there's not a lot of people or you happen to be maybe at an event for kids with autism or special needs, where you're around a whole bunch of families that understand you and understand what you're going through. It's a lot more accepting" (P5).*

Parents stressed the need to be vigilant with their child and have back-up plans should the environment not be conducive to their child's safety. *"If it's just leisure time be mindful to give him a time if you start seeing the pools really starting to get busy. That's where we usually redirect and I'll go over to the edge of the pool and say okay buddy, you have 10 minutes left" (P10).* Parents will tend to avoid crowded places and places that are not sensory appropriate for their child. A couple mothers explained their experiences, one explaining: *"It's more the other people and he's not comfortable with the crowd so if it's super busy. We just keep going and find something else to do" (P2).* Another mother shared her thoughts on this, *"I think it really depends on the environment like if you're at a really busy beach or waterpark. You're definitely apprehensive when you first arrive because I don't know how he's going to react to this environment so you almost expect the worst and hope for the best" (P5).* A different mother explained the effects an enclosed aquatic setting has on their child, *"A lot of pool areas are very very echoey. So I find that for them auditory wise if it's super crowded it's hard, at a beach or a waterfront if it's super crowded I find it's not as hard for them. I think for them it's more of an auditory sensory issue." (P9).*

Fortunately, there are factors that help ease concerns around unacceptable behavior and comments from others. One parent explained their role to support their child, *"I'm protecting him if we're around other people because not every person is understanding" (P9).* Many other parents and caregivers shared this sentiment as well. It was also noted that older siblings were a protective factor for children with ASD providing more comfort in aquatic environments. Some siblings watch over them, making sure no one is giving them a hard time and other siblings provide guidance with

tasks and comfort. *"He's very much a mimicker. So he will watch what his siblings do, and try and copy it. I had [his sister] in [swim] lessons in the same timeslot. So I think it helps with the routine of going in and out, because he's watching his sister. It does ease the transitions" (P5).* Another mother shared similar experiences, *"Having a sibling is one more big reinforcement there, because sometimes if he is not doing something we can tell him okay look how she's doing it because it's monkey follows monkey right…So, if he doesn't like to go in water, and my daughter also goes in the water with him, he gets motivated okay she can do it then I can do it" (P4).* Parents want their child to fit in and be accepted for who they are in aquatic environments. One mother explained, *"don't treat them differently, it's not a big deal. [It] has less to do with aquatics and more to do with wanting to ensure the acceptance of my child regardless of the situation" (P9).*

4.1.4 Therapeutic Benefits

Table 4.5: Theme Breakdown: Therapeutic Benefits

Sub-Themes	Sub-Theme Example
Opportunity to Exercise	*"It's exercise that's not hard for them…"*
Tool for Stress Relief	*"It's like water provides a reset for them…"*
Informing Families on the Benefits of Water Activities	*"…flyers and program guides don't touch on that"*

The therapeutic benefits of water activities, particularly swimming or just being immersed in water was a theme that emerged in this study. Topics that fell under this theme were: providing an opportunity for their child to exercise, a tool for stress relief, and educating parents on therapeutic benefits for their child.

Parents noted that the opportunity to exercise without them getting overwhelmed by competition or not being able to participate in certain activities was beneficial. *"It's*

exercise that's not hard for them. Like you can swim for two hours in the water, and you can still come out alright, but if I put him on a bike for two hours he would probably be gassed. So it's a different type, it's relaxing for them, it's very calming" (P10).

Many parents spoke of the water as a tool for their child to help relieve stress. One mother spoke of using water as a strategy to soften oncoming frustration or potentially triggering information. *"I think when he's in water, he just seems like a different kid like he is totally relaxed, at home, at ease. It's easy to talk to him when he's in the water. So even when I had to break difficult news to him, I would take him to the pool and tell him that so he was better able to process that kind of information when he was in the water than when he was out" (P11).* Other mothers shared similar experiences of using water as a tool to prevent potential meltdowns. *"It's almost like being in the water provides a reset for them emotionally. They're calmer afterwards, it completely vents them out and they are able to focus better whenever they're struggling… we hop in the pool for 30 minutes or 45 minutes…and they're better able to handle the same situation that was frustrating them prior to the pool." (P8).* Another participant added, "*I find he needs it [being in water] two to three times a week because it's the one thing that helps him besides exercise with stress management" (P11).* One mother offered this explanation of why this occurs, *"…I think that it stops all of the excess stimuli, for just a moment, it's perfectly soothing and calming and I think they know that and that break from the excess stimuli allows them to go back into the world again afterwards and feel refreshed like they're capable of dealing with the stimuli again"(P9).*

There are multiple benefits of engaging in water and swimming, but some parents advised that not everyone may know this. Many parents enroll their child in swimming

lessons for safety and swim ability. However, it is important to highlight the other benefits a child with ASD is getting when they are in the water. One parent explained that not enough parents know this and that is can be challenging to pick between activities for their child. She proposed, *"I think explaining to parents, specifically those with ASD, the benefits, mentally and emotionally of the water would be really beneficial because when I see flyers and program guides [they] don't touch on that. So it just looks like one more thing to have to try and convince your child to do if your child's maybe reluctant, well what's the point… No parent wants to do the hard thing if there's no benefit for their child." (P9)*

4.2 Experiences and Perspectives on Swimming Lessons

4.2.1 Making Lessons Accessible

Table 4.6: Theme Breakdown: Making Lessons Accessible

Sub-Themes	Sub-Theme Example
Location of Aquatic Facility	*"…it's kind of far…"*
Availability and Timing of Lessons	*"…they only offer special needs swimming on certain nights…"*
Cost of Lessons	*"…they are so expensive…"*
Class Ratio and Pool Environment	*"…the instructor said she needs one-on-one…"*
Promotion of Available Supports	*"…I didn't know there was any…"*

This theme comprised of the logistical barriers parents faced when enrolling their child in aquatic lessons including: location of aquatic facility, timings, availability, costs, class ratio, pool environment, and promotion of available supports.

Location was a barrier identified by some participants. While most participants resided in Oshawa, there were a few that lived further away from specialized facilities like Grandview. The distance to facilities that have aquatic programming for children with ASD and the timings that the lessons are available made enrollment an issue. "*I would love to put him in a specialized program, but right now we live in Pickering and Grandview only operates out in Oshawa and getting out there for us, it's a transportation thing" (P5).* Similarly, another mother said, *"We haven't done Grandview cause it's kind of far. So we do town of Ajax swimming" (P8).*

The timings that lessons are available is also a barrier to accessing swim lessons. Many parents shared their experiences, *"The only time that special needs swimming is offered is Thursday night at dinnertime at five o'clock and that's for eight kids. I think there might be Saturday morning, so two days a week and a total of 16 kids with special needs, that's it, can go through the city" (P10).* Another mother mentioned, *"We've been very lucky, but I know sometimes it's hard because they only offer special needs swimming on certain nights…So if you're looking for after school swimming there's only a certain block of time that's available for so many people" (P3).* Another mother shared timing restraints with scheduling, *"Probably timing, just because of where it is. By the time I would get home from work and to be able to get him out to Oshawa like during rush hour, it wouldn't be feasible. I wouldn't even be able to get them there [in time]" (P5).* Another mother also added scheduling issues with other responsibilities, *"I work full-time I'm a teacher. So I find a lot of the programs for his age group are during the day. So that is a barrier" (P7).*

In addition to the location and timing of lessons being an issue, the availability of specialized lessons greatly affected participants and their child(ren) with ASD. *"There are very few classes, if there are ten regular classes, then [specialized lessons] only have two or three classes [available]. Kids with any special needs have many other therapies. It's very difficult to accommodate that time" (P4).* Another participant shared her thoughts, *"You could sign up for swimming one-on-one private session at a different time but that's not guaranteed that you're going to get somebody who has specifically worked with kids that have special needs" (P3).* Parents are forced to anticipate signing up the moment registration opens as there are multiple families vying for the few available slots. One mother explained: "*I literally set an alarm to sign up like the second it opens. I know it's really hard to get private lessons through the community center unless you're like one of the first people to sign up" (P6).* Others also mentioned experiencing this,*"It is difficult to register for that kind of stuff you've got to be on the ball to get into most of those lessons… they fill up very quickly" (P1).*

Another barrier that was spoke about several times was the cost of lessons. Many parents remarked that classes are expensive. One participant explained, *"Cost can be issues sometimes because the private lessons are obviously expensive" (P12).* Another mother shared, *"Cost is a factor, because it's very expensive especially if there's days that you don't even get to utilize the full lesson" (P10).* It can be tough for parents to justify enrolling their child in lessons, when the surrounding can potentially be sensory inappropriate and cause the child to not actually participate in their lesson. Children with ASD may need some extra time to understand ideas and concepts or learn skills, it can add to the costs of these lessons. One participant whose child with ASD is enrolled in the

lifeguarding courses explained: "*I find them a bit frustrating because they are so expensive. There's pretty much no way he's going to pass on the first go because it goes so quickly through the material. And it's, you know, $300-400 each time" (P2).*
Moreover, if parents choose to enroll their child in specialized lessons or private lessons, they are more expensive compared to regular lessons with multiple children in a class. *"So versus $98 for 10 classes. It's $305. So it's harder for people whose kids need the one-on-one, the fees are quite expensive. That kind of puts a damper on whether or not you want to continue" (P1).*

Many parents reported that in private (one-on-one) swim lessons for their child with ASD were more successful. *"The one on one helps him better focus and better listen and somehow better absorb what's going on, instead of being in a group" (P3).* One mother shared their experience with regular swim lessons, *"We ended up having to do group lessons because we couldn't afford to do private or semi-private and it was painful.* Another mother shared her experience with regular lessons, "*He was in every level for so long because he wasn't getting any extra support in the pool" (P2)*. Many other mothers experiences similar situations, *"He was not being able to get that kind of attention [one-on-one] that he would actually really require to really hone those skills in a regular program" (P8), "That [regular swim lessons] wasn't successful. The instructor said she needs one-on-one. She's still too distracted, she needed that ongoing support" (P1) and "He was able to get through more lessons doing private than he was doing group" (P10).*
One mother shared of her experience and how they solved this issue, *"When he was around Swim Kids 5 [level], he was stuck there for a long time, over a year. My husband and I basically had to make the decision that one of us had to go to the pool with him*

every week and practice and work one on one with him ourselves. But it seemed to give him that little bit of a boost that he was able to then move ahead" (P2).

The pool environment that the class takes place in can also be a barrier to children with ASD accessing swimming lessons. Some children with ASD may be more successful in sensory positive environments. *"We have done swimming at Legends [pool in Oshawa] where they had one instructor per child, but they were also in a group of like eight. And it was very challenging because of all the noises. So you're putting a child with sensory issues in the same class, as much as its one on one, with eight other kids that could scream or splash in a small confined lane. So, it was not successful at all" (P10).* The provision of additional support was also seen as important to accessibility.

Unfortunately there can often be a lack of information or sharing of information on what supports are available. Without this, children with ASD could be missing out on support systems that could be beneficial to their progress in swimming lessons. One mother shared her frustration about not knowing extra support was available because it was not advertised, *"A friend of mine told me about it a couple of years ago, but by then [my child] was already swimming. So, when he was younger that definitely would have been beneficial... I didn't really know there was any [additional supports] until two years ago, so the whole time that he was young I had no idea. I don't think that people know that they can get additional support in the pool for swimming lessons" (P2).*

4.2.3 Teaching Methods

Table 4.7: Theme Breakdown: Teaching Methods

Sub-Themes	Sub-Theme Example
They Can Learn: Instructional Time, not Playtime	*"…he was just playing, he wasn't learning anything…"*
Focus on Safety	*"There is not enough emphasis on water safety"*

Learning Types for Children with ASD from the Parent Perspective	*"…what works for one, doesn't work for the other…"*
Using Visuals	*"…showing them, rather than telling them…"*
Repetition and Breakdown of Skills	*"Kids on the spectrum really need constant repetition…"*
Using Positive Reinforcement	*"…they would reward him for the in-betweens…"*

Parents had several opinions and suggestions regarding teaching approaches and discussed what worked well for their children. Parents discussed: emphasis on instructional time and their child's capabilities, how children with ASD learn from the parent perspective, using visuals, repetition and breakdown of skills, and use of positive reinforcement.

Parents voiced concerns that they felt their child's abilities were not being realized because instructors did not push them to progress because they think that they cannot do it. "*They don't push very hard, they were too soft with him. As soon as [my child] started crying or refusing to do something, they gave up really fast without trying. They would be like okay then let's leave it and we can play a little bit. Most of the time [my child] was just playing, he wasn't learning anything and that's why we gave up" (P12).* Parents felt their child's instructional time looked more like just playtime. *"It almost makes me think that they think that kids, not just kids with ASD, but kids with any disability aren't capable of doing the skill-based stuff, and that is something that's always really bothered me about the adapted lessons around here…this is not really teaching him anything" (P8).* One mother explained, *"[My child] likes playing in the water, so*

that part is really good. Seeing him enjoying himself is fine. But when I see there is no progress, that part is a little bit frustrating" (P12). Another mother shared, *"I really wish that the adapted programs around here could be more skill based. You pay three times more for the private [lessons] than we would for say the adapted ones. If that option was there, I would put them back in adapted lessons no problem at all" (P8).*

Almost all parents shared that safety was an essential aspect of swimming to work on with their child and crucial to include in lessons. *"The whole purpose of doing lessons is so that the kids learn to be safe around water" (P3*). They want them to be able to enjoy water and it can be fun, but understand that you need to participate in a safe manner. Basic skills that a child with ASD may struggle with like getting in and out of the pool are not being incorporated according to some parents. *"There is not enough emphasis on water safety, it should be more geared around what to do on how to save themselves, and how to react. And there's not enough emphasis on that in swimming lessons at all. It's now like a five minute out of a whole six lessons… That's something that we've had to spend a lot of time on because it's not taught in the lesson" (P10)*. Many parents voiced concerns that there isn't a focus on what to do in an emergency. Many parents mentioned a few physical skills they believed were essential to their child surviving should an accident occur. *"The number one thing is literally how to float and how to tread water, to keep them afloat. I think that's probably one of the most important skills. [My child] learned if he did fall in the pool or if he did get caught out a little deeper into the water, he could learn to stay afloat if he got in trouble" (P3).*

Participants had similar ideas and perspectives on how to teach their child with ASD. However, parents did acknowledge that the characteristics of ASD vary

dramatically from child to child which means that while some methods may work for some children with ASD, it may not be appropriate for all. *"It's amazing to me, he's got so many friends with ASD that I've met over the years and one is not the same as the next. What works for one doesn't work for the other, but there are some similarities" (P11).* Participants believed that children with ASD do not necessarily learn the same way as neurotypical children and require more time and support to understand water safety and develop an awareness around water. *"They don't learn like the average kid, it needs to be more intensive" (P3).* One mother suggested why they learn differently and the extra explanations are necessary. *"We assume that it's just a lack of social capabilities, but we don't realize that it's actually a lack of understanding of the social mores and norms and why they're there in the first place" (P9).* This idea was particularly important to parents given the potential danger of water. *"They maybe need to sit with the child and show [them] like when you fall in the water this is what happens and you can't breathe, because they don't know why you're saying this is dangerous. They have no clue what drowning looks like or what this means" (P1).*

Parents shared methods that have been beneficial for their child, for example visuals and physical direction seem to help many children with ASD, especially those who may be non-verbal. One participant suggested, *"Roleplay, showing them, rather than telling them. Let's pretend you just fell in the water, they're visual right. Let's practice, if we're in a panic situation; do we know how to take our life jacket off? Showing them you have a whistle on your life jacket, what's the whistle for? Because telling them or giving them a piece of paper and showing them the rules is not going to be beneficial for them at all" (P10).* Another parent suggested another medium to teach,

"He's incredibly visual. I didn't really even see it with the adaptive lessons either but I think visuals that were laminated that they could use in lessons could definitely be something that a parent could actually easily take and use in other settings as well and that like outside of swimming lessons. Just even safety rules for the pool, I think there are a few of those that do transfer over to other situations as well so visuals would be really nice" (P8). Other parents agreed with this, *"I would say visuals. I think my son probably would have been okay without them, but I just know so many kids that require them, like pit cards" (P11).*

Another method that came up multiple times from parents were that skills needed to be broken down into more manageable steps, otherwise it was hard for their child to understand what was being asked of them. *"I explained to the instructor how they had to break things down. You know into smaller steps, that he was more visual at that stage of learning, and gave him some examples like you know they were open to working on it and they got better" (P11)*. One mother shared a positive experience with this, *"The respite workers are fantastic… they know that with both boys, you have to explain why, why does it matter that we do this? Why is this important? No, we cannot ignore this rule because of XYZ. Talking to them having those conversations, instead of just being like, No, don't do that, why because I said so, that does not work at all" (P9).*

Additionally, extra time to go over skills and purposeful repetitive practice made a huge difference in their learning ability. *"I think it's just the constant repetition, like he used to even just wander into the street, because he's not looking where he's going. He wants to get wherever so he's just wandering out. It pushes constant repetition of the safety aspects of things" (P2)*. One mother shared her thoughts on this, *"Kids on the*

spectrum really need that constant repetition and very chunked very small [tasks]…they pick one thing and they just keep working on it, so they kind of get a grasp, and then they move on to the next thing. I think that's made a world of difference for him learning safety skills" (P3).

A teaching and coaching method that was mentioned multiple times by parents was the use of positive reinforcement and incentives. One mother shared, *"I would say the positive reinforcement he got when he did do things correctly. They would break it down and then they would make sure he, they would reward him for the in-betweens. They had certificates and awards they would give him, even for those smaller things which really helped" (P11)*. Other mothers agreed with this idea, *"The reinforcement, like if you do this in the water then you will get to go on this slide. So that motivates the kids right. We all know that without motivation, mothing can be done. So that reinforcement is needed" (P4).*

In contrast, another mother shared her frustrating experience of what happens when positive reinforcements are not incorporated: *"[My child] had to do level 5 and I'm not exaggerating when I tell you this, 13 times. Do you know how discouraging that is for a child with special needs, who was so motivated to want to get that badge but because he couldn't do one of the kicks or something. I finally had to pay for a level 4 badge which he already had and just ask them, I know he's a level 5, can you please give him a level 4 badge, just so that he will come back. They don't care that it says level 1,2,3,4,5,6, they just want to go and swim. You got to give them something to motivate them to keep going" (P10).*

4.2.4 Teach the Teacher

Table 4.8: Theme Breakdown: Teach the Teacher

Sub-Themes	Sub-Theme Example
Instructor Training	*"…what are they doing differently?"*
Handling Adverse Situations	*"…strategies on how to deal with it…"*
Forming Connections with Children with ASD	*"Working with their personalities…"*

Another theme that dovetails with the instructional methods theme is the training of instructors. Parents voiced that instructors did not have enough specialized teaching training, were missing an emphasis on safety/survival skills in their swim lessons, and lacked competencies to handle unexpected adverse situations and form connections with their child with ASD.

When asked about their child's swim programming experiences, parents commented on the training of the instructors. Instructors are trained to teach neurotypical children, the parents explained, which may not be effective when teaching children with ASD. One participant explained, *"You need to have staff that understand a little bit about the spectrum in order to be able to teach and how best to teach the skills you want for kids on the spectrum because it's a different type of learning" (P3).* Other mothers voiced that they experienced similar situations, *"They're not trained to work with ASD children, they're just swimming instructors… now it's one on one, it was adapted, it's just meaning that they can focus for half an hour now on one child, but what are they do differently?" (P1).*

Many parents suggested that instructors should receive training or a module to understand the characteristics of ASD if they are going to be teaching children with ASD.

"I feel like they don't even maybe know what autism is, maybe all the instructors who are teaching adapted should take a course on autism or cerebral palsy or whatever student they are having [going to teach] (P1). Parents that had enrolled their child in specialized lessons found that the training instructors did receive for teaching children with ASD wasn't always helpful for their child's learning. *"When we first started with them, I had to sit down with the instructor. Because although I had been told they've been trained. There were things they were doing in the lesson that I could tell he wasn't understanding" (P11).* Caregivers did understand with typical programs that, *"knowing more about dealing with kids with ASD is a pretty big ask, that's not something your average teenage swim instructor is going to have knowledge of" (P7).*

Swim instructors not having appropriate training and the competencies to work with children who have ASD has made it difficult for parents who are trying to find appropriate programming for their child. *"We've been told it's not a good fit or my child said I'm not going back that kid screams too much or he's loud too much. [My child] had instructors that don't understand autism because as much as they put instructors through the city one to one with them, they're not specialty trained at all" (P10)*. Parents did feel private lessons were better however, they felt it was better due to the intimate nature of the instruction, not that the instructor had increased training. ***"****It's one on one now, it's easier because I'm spending my time with you [a child with ASD] but they maybe need to be trained on autism or disabilities. They're still teaching the regular program to a typical kid when now there's a child that's not neurotypical trying to put the same information to let them learn the same skill, maybe they're not capturing it" (P1).*

Parents responded that along with instructors having minimal, if any, training on how to teach children with ASD, they were most unprepared for how to deal with a child who was having an adverse response to stimuli. One mother explained, *"If they have somebody who is more knowledgeable about the condition of these kids, a little bit of you know behavior therapy. So they are not scared of them crying or refusing to do something [a skill]" (P12).* Other parents explained this is imperative to teaching children with ASD, *"…and how to deal with him if he gets upset…basically the learning and strategies how to deal with it…that's the most important thing, which I see most of the people don't know how to do" (P4).*

Another participant explained that individual lessons were good, but still lacked in directive teaching methods that helped guide children with ASD. Being able to connect with the child individually was seen as important. Instructors need to be taught that all children with ASD are different. *"Working with their personalities and working with what helps them. I feel like I do that in every situation not just aquatics. The only difference with aquatics is increased safety until I know they either understand the rules, or have the skills to navigate the situation by themselves should there be an emergency" (P9).* Parents also explained that not only was it difficult to find a compatible instructor, but keeping it consistent was just as difficult and would hinder progress of the child. *"We would go through patches where we might have the same teacher for about a year and then that teacher would leave and then we'd get another one…then we would have to start back at the beginning again" (P11).*

4.2.5 The Impact: Pride, Independence, and Normalcy

Table 4.9: Theme Breakdown: The Impact: Pride, Independence and Normalcy

Sub-Themes	Sub-Theme Example
Proud Parent Moments	*"…he's very accomplished in the water…"*
Water's Impact on Child's Independence	*"…gave him the ability to know he can do something…"*
Water's Impact on Daily Routine	*"…everything revolves around swimming."*
Water's Impact on Self-Regulation and Social Skills	*"…you have to be able to follow some instruction…"*
Parent Perspectives on Being Comfortable around Aquatic Environments	*"…it helped him and me become a little more confident…"*

This theme explores parent's feelings and thoughts about the impact of swimming lessons on their child. This theme includes proud parent moments, waters impact on child's independence, daily routine, self-regulation and social skills, and parent's feelings and comfortability around aquatic environments.

Participants spoke of 'proud parent moments' when they celebrate the swimming accomplishments of their child. *"As a parent I could say that it's a proud moment, because he did work so hard and he had to work so much harder than the other kids. And now where he's moving on to bronze cross, I think that's pretty huge" (P2).* Another parent shared, *"For me, it's a sense of being proud because he's very accomplished in the water. I don't have to go in the water, it's not something that I have to stand on top of him. He has more independence in the water" (P10).*

Parents felt the swimming skills their children gained through instruction helped their child fit in and experience activities that other children enjoy. *"I kind of like the fact*

that he's doing whatever kids do. It makes me feel like he's just like everybody else in that sense that's a typical Canadian, doesn't matter everybody goes to the beach or the pool, it's a thing we could do as a family" (P3). Parents also added that being involved in aquatic activities gave their child a sense of independence, something they were able to accomplish on their own accord. *"It helps give him the independence and the ability to know that he can do something. We always can find a positive when it's related to water. Whether it's wow he swam for 45 minutes and he didn't get upset or, while you were in the pool and played with so and so you did well talking to them or using your words or you know what you were upset but how you handled that was fantastic" (P10).* Parents spoke of many other indirect skills that their child with ASD was able to pick up on while in swim lessons. *"I would say absolutely because they learn the scope of independence, which helps them in everything they do. And independence is always a good thing, because they have to be try to be independent, whether it means going to the washroom or feeding yourself, which is all skills that are not easy with an autistic child" (P10).*

Parents did report that their child with ASD and their fixation with water did impact them. This included how it impacted them as a parent and caregiver for their child and how it impacts the family dynamic. One mother shared how her boys' love of swimming helped with their hygiene. *"Getting them interested in swimming can sometimes help with poor hygiene, which is often a difficult one for people that are autistic. Because you have to shower before you get in the pool and then after the pool. I love my boys. I also know how well they're willing to actually to bathe or shower without the pool, because I'm seeing that right now from three weeks of the pool being closed" (P9).*

In contrast, another mother added how the need for swimming in their life impacts them as a family. *"We live at the pool all summer, it makes it very difficult to plan other things. For us, it changes our life because he loves swimming so much, in the fact that he just wants to do it all the time… everything revolves around swimming" (P10).*

Parents also stated that children were more aware of themselves and their abilities. One mother explained, *"Thinking to even like going on vacation is best fit against the lessons, it has just made him more aware of the water and what he's capable of doing knowing that, yeah I think I would say more cautious" (P8).* Other participants shared things they observed, *"From the swim team, he learned about pacing…you don't want to go in and burn all your energy in the first five minutes so making sure that you pace yourself so that you can complete the task" (P2).* Another parent added to this sharing her children were not only more aware, but learned to be more in control of their emotions thought engaging in water activities. *"It's not a skill per se, but it's a knowledge that they can find peace and stillness within themselves that allows them to work through the sensory overload that causes meltdowns a little bit easier. They know that it's reachable. So then the meltdowns are a little less scary because we can work through those, even if we can't get into an aquatic setting right away because they know what peace and stillness feels like. It's hard to help guide someone towards peace and stillness if they've never experienced it" (P9).*

Another parent explained the social benefits their child received from swim lessons. *"He knows actually to work with other people, other than his family. So it's generalized. It's not limited to working with only that person in the pool, but it takes him,*

and he understands that he has to work with other people also outside the world" (P4). Other parents spoke of increased listening skills, *"You have to be able to follow some sort of instruction right. You have to be able to respond to that instruction. And what's appropriate behavior in a setting like that. So yes, I would say those things started when he started his swimming lessons" (P11).* Similarly, another parent suggested, *"Safety situations listening, maybe a little bit better at listening and safety situations because he learned to listen around the pool area" (P3).*

Many parents believed that exposure to water was positive and came to embrace it, *"I feel like there's a combo of exposure to different aquatic environments, but those exposures have also kind of gone hand in hand with instruction to teach him. Safety skills around water, which then led to my more comfort with those different environments. I don't think one of them is separate from the other" (P3).* Parents did state that the more their child participated in water activities such as swimming lessons and being able to expose their child to different aquatic environments, the more comfortable they felt taking their child to an aquatic environment. One mother explained the effect this had, *"Having him in lessons definitely helped. It helped him and me become a little bit more confident in his ability to actually stay above water" (P5).* Another mother shared, *"I think when he was smaller, and we realized that he was very attracted to water, we tried to [avoid water environments], but then I realized that might not be the best thing to do. I think exposing him was actually the best thing" (P8).* Another parent voiced her intentions, *"My goal is to let her learn how to swim, because I know she's such a seeker for water and aquatic environments. So if she knew how to swim that would make my life a little easier that she did fall somewhere into a water she would be safer" (P1).* Another

parent shared, *"We take him more to public swimming because we feel more comfortable, especially for my husband…now that he's been exposed more to aquatic settings" (P7).*

Chapter 5. Discussion

The purpose of this study was to speak to parents who care for children with ASD to investigate their experiences and perspectives on aquatic environments. This project was guided by three questions:

What type of experiences do parents/caregivers and their children living with ASD have when engaging in aquatic environments?

Does engaging in, or not engaging in, regular or specialized aquatic therapy programs have any effect on the type of experiences parents/caregivers and their children living with ASD have around aquatic environments? And,

What do parents and caregivers need from swimming lessons so that their families and child(ren) with ASD can be more comfortable when participating in aquatic environments?

Through the use of a semi-structured qualitative interview guide, our participants were asked to express their thoughts and perspectives. This study was analyzed through a constructivist lens meaning that the perspectives of participants interviewed are subjective and based off their own experiences that they are reflecting upon. While many ideas may be similar for many parents who care for children with ASD, it may not be applicable to all families. Each family knows their own child best, however this may give families ideas for opportunities to look into if they choose to participate in aquatic environments.

5.1 Experiences and Perspectives on Aquatic Environments and Recreational Swimming

5.1.1 Safety

Given the attraction to water and associated risk, parent participant's top priority around water was making sure their child was safe. Parents had strict rules regarding supervision and having their child in aquatic environments. These findings are similar to Lawson et al. (2019) and Schleien et al. (2014) who found parents of children with ASD's vigilance around water was a result of their understanding that their child's behaviours are unpredictable and the increased danger these environments present.

Almost all parents in the current study had implemented a 'lifejacket always' approach when first coming into contact with water with their child with ASD. This continued until they felt comfortable with their child's skill level and ability to be safe. Many participants suggested that this was a great way to make sure a child can be safe around water and provided an extra level of protection which is congruent with the best practice guidelines found in Grosse (2014). Parents also felt lifejackets were helpful if their child with ASD was prone to eloping or if they went to an uncontrolled environment such as a lake or ocean where boundaries were not clear. These findings support practical advice to parents and caregivers who are starting to navigate aquatic environments with their child with ASD or to practitioners who work with families with children with ASD.

In this study parents were asked, "What would you tell someone who takes your child to an aquatic environment?" Some participants answered this question firmly stating they would not allow their child to go to an aquatic environment with someone else due to the risks. They preferred themselves or their spouse to take their child with ASD swimming so the parent can personally supervise them. However, some parents did allow respite workers to take their child with ASD swimming. This is similar to the

findings of Lawson et al. (2019), their participants had stated they felt uncomfortable with less than two people supervising their child with ASD around water. Participants in the studies by Lawson et al. (2019) and Schleien et al. (2014), and the current study spoke to the importance of constantly watching their child with ASD to prevent accidents.

In contrast, Casey and colleagues (2020) found that parents in their study believed that learning swimming skills through swim lessons was a more important factor than adult supervision, in regard to their child being safe around water. This was a worrying finding for the authors as they noted that best practice guidelines (Grosse, 2014) recommends consistent supervision of children with ASD rather than relying on a child's swimming proficiency (Casey et al., 2020).This current study further supports the guidelines and evidence that supervision around all water is crucial for children with ASD.

Some participants also discussed the ratio of parents to children being a barrier to accessing aquatic activities. Parents felt that if their child was younger or had not developed the skills yet to be safe around water, one parent's attention had to be exclusively focused on their child with ASD. That meant that if their family had multiple children and not enough supervisees, they chose not to go to aquatic environments resulting in missed opportunities. This was similar to the findings of Lawson et al. (2019) whose parents of children with ASD also felt uncomfortable taking multiple children to an aquatic setting by themselves. In the current study, parents of older children with ASD felt more comfortable taking their children with ASD to aquatic environments or allowed

family members or respite workers to take their child swimming as they developed their understanding of rules around water and physical skills to keep them safe.

This sole responsibility affected that parent's role as caregiver as they felt that they were required to be present in order for their child to participate in aquatic activities, which added to the caregiver burden that participants experienced. Social support and having others help care for a child with ASD has shown to be a highly protective factor for mental health and contributes positively to quality of life and experiences of parents of children with ASD (Pozo et al., 2014; Vasilopoulou & Nisbet, 2016). When parents feel the need to be the sole supervisor of their children in aquatic environments, they may experience higher levels of stress, isolation, and loneliness, which may contribute to lower quality of life (Schleien et al., 2014). Future research should examine how to support parents in aquatic environments and perhaps how to educate others to support parents in this responsibility given the high desire of many ASD children to be in water.

Parents compared the experiences of going to what they conceived as a controlled area such as a pool versus going to an uncontrolled area such as lakes or oceans. Parents preferred pools with defined boundaries over other settings. For some it was a containment issue, if their child with ASD had unpredictable behaviours or commonly eloped then it could easily become an issue if their child were to react to a trigger. Some parents also preferred pools over lakes because there were no undercurrents or waves and they could see the bottom of pools. Parents may prefer the more controlled environment of pools to increase safety and ease their own stress with having lifeguards present. Future research should investigate environments and perceived safety of these environments as factors that impact the experiences of parents of children with ASD.

5.1.2 Attraction to Water

Parents were aware of the danger water possessed for children with ASD. Parent's realization of their child's attraction to water combined with the characteristics of ASD made parents more vigilant with their child in aquatic settings due to fear. Many participants shared stories of experiencing stress or anxiety in relation to their child's safety because they were drawn to water and did not fully understand the potential dangers of water. This aligns with the findings of Lawson et al. (2019), which found parents were concerned for their child's safety due to their attraction to water, in addition to other common characteristics like eloping and unpredictability. Murphy & Hennebach (2020) and Grosse (2014) also corroborated this finding as they found children with ASD who do not recognize the dangers of water may try to engage unsupervised without considering the consequences.

This concern was also brought up by Debbaudt (2002) in his book *Autism, Advocates, and Law Enforcement Professionals; Recognizing and Reducing Risk Situations for people with Autism Spectrum Disorders.* He expresses that children with ASD usually have a fixation with water and often do not understand the dangers associated with engaging with water. He explains that this coupled with the tendency to elope can and has resulted in fatal situations. Many community websites for families with children with ASD also mention individuals with ASD can be attracted to water and provide safety tips for families to prevent opportunities for accidents (The Importance of Water Safety: Tips and Tools, 2018).

Participants in this study had great concern with the unpredictable behaviors associated with the characteristics of ASD and their child's attraction to water. The

majority of participants felt their child with ASD was attracted or had a fixation to water on some level. For some, this became more apparent as the child got older. This was consistent with Nagib & Williams (2016), who found that a fascination with playing with water was a common trait for children with ASD, categorizing it under obsessive behaviours. Instances of individuals with ASD's with an attraction to water have been reported in several other studies for both children and adults (Williams et al., 1980; Smock Jordan & Turns, 2016; Lawson et al., 2019; Forde et al., 2020).

Participants in the current study felt that this fixation was due to the sensory properties of water which provided stimuli that intrigues and comforts children with ASD. Out of all the senses, touch was the most common suggestion of what sensory stimuli prompted children with ASD to want to interact with water. However, the auditory and/or visual aspect of water were also identified as attractive stimuli as well. The reasons as to why children with ASD are attracted to water is not extensively researched or identified in the DSM-5. However, an attraction to water seems to be a generally accepted trait of individuals with ASD as it is often referenced in papers that compare ASD to other neurodevelopmental conditions such as Angelman Syndrome (Steffenburg et al., 1996; Peters et al., 2004). As several participants expressed that their child had a definitive attraction to water, further investigation into this phenomenon and the effect this has on the daily life of families with individuals with ASD should be considered.

5.1.3 Acceptance of Children with ASD in Aquatic Environments

Parents of children with ASD in this study were protective of their child as they knew many people did not understand their situation or understand some characteristics

of ASD. Parents spoke of multiple incidents involving bullying or judgements from other children or their families in aquatic environments. Stares, glares, and judging sometimes made aquatic environments a place of distress for these families. This made many parents hesitant to go to pools or to the beach because of the possibility of reactions from other people which they did not want their child to have to endure. Parents understood that their child may respond to unexpected triggers or things may not go as planned and their child has a meltdown, but the added worry that their child would be subject to bullying or harassment through no fault of their own while trying to enjoy water activities left many to avoid accessing these environments at specific times. This was consistent with the findings of Ludlow and colleagues (2012) that reported parents of children with ASD were consistently dealing with reactions from others in public venues of all types, not just pools, who assume their child is just acting out and their parenting was then being questioned.

Many parents in the study described feeling emotions such as guilt and embarrassment when dealing with incidents regarding perceived judgements (Ludlow et al., 2012). The stigma around ASD these parents experience created a sense of heightened awareness for parents because they felt they had to be on guard at all times. Most parents preferred to go to places where the people were more welcoming and understanding of what families with children with ASD go through. These findings are similar to Gray (1993) that noted that families that feel stigmatized may cope in different ways including avoiding certain environments to avoid judgement. This may also lead to rejection or avoidance of support systems for families that feel ostracized and do not want to bring attention to themselves or if they feel their parental competence is being

questioned (Gray, 1993). In contrast, Neely-Barnes and colleagues (2011) reported that many parents chose to use these situations to confront individuals who assumed their child was just acting out as a means of educating them on the characteristics of ASD. Parents in this study hoped that through educating others about ASD, they will in turn foster a more accepting environment in which everyone can enjoy being there, inclusive of their child with ASD.

Fixating on the challenges that children with ASD experience can be a factor that limits their opportunities (Carter et al., 2015). All children, neurotypical or neurodivergent, have strengths and challenges that they experience. It is important to highlight and build upon the strengths that a child with ASD possesses to strengthen the community support they receive instead of focusing on things they struggle with (Carter et al., 2015). A potential way to reduce judgement and bullying at pools, and help the general public see the positive traits of children with ASD might be a knowledge mobilization campaign conducted at pools. This may be an opportunity for pool users to better understand ASD, potentially leading to less judgement and bullying and a more welcoming environment for families with children with ASD. Aquatic facilities may also further support families with children with ASD through designated swim times for children and their families, and with a sensory positive setting such as dimmed lights/reduced noise.

Siblings were found to be helpful with situations where bullying or judgement might occur. Many parents who had multiple children explained how their child's siblings would help guide them if they are struggling with a task or if they sensed something was going wrong. Parents shared stories of other children who made

comments to their child and how their sibling immediately stepped in and defended them, educating the other person about ASD in the process. Siblings were also found to be helpful with routines and transitions around swim lessons for children with ASD who struggle with changing settings. For this reason, many parents chose to enroll their child with ASD in swimming lessons at the same time as their siblings. Similar findings were reported by Chu & Pan (2012) where they ran a sibling-assisted aquatic intervention and found that the child with ASD improved their social interaction and aquatic skill.

Parents spoke of being weary of the physical and social environment they were bringing their child into because their child may respond negatively to too much sensory stimulation. Parents said bringing them to a pool or a crowded beach may not result in the best experience. Many parents discussed having backup plans if their child was not doing well in a certain environment or they purposely went to these environments at quieter times of the day. Many children with ASD are sensitive to sensory stimuli and may require accommodations to be comfortable in a given environment to prevent sensory overload. Sinclair (2010) states that individuals with ASD have different ranges of sensory appropriateness and the type of sensory modality may differ between individuals (visual, auditory, tactile). This means children with ASD may be overwhelmed in environments that possess their sensory sensitivity. This finding, in combination with other research on sensory overload, may help facilities understand what families with children with ASD experience when they are exposed to sensory inappropriate environments. Moreover, research such as this should be provided to municipal leaders, and those who have influence over aquatic environments, so that pools and beaches can be adapted to be places that are supportive and accommodating of children with ASD.

5.1.4 Therapeutic Benefits

Parents spoke of multiple instances in which they used water to help their child relax when they were too overstimulated. Many parents used water as an outlet for their child with ASD when they were upset or overstimulated to provide stress relief. These findings align with Lawson et al. (2019) where the parents they interviewed reported similar experiences of utilizing water as a means of relaxation or therapeutic benefit for their child with ASD. Yilmaz et al. (2004) also provided therapeutic means by testing a hydrotherapy program that helps children with ASD ease their repetitive behaviours. Parents in the current study explained that it was almost like their child was refreshed and better able to handle things after they got to go in the pool and be immersed in the water. This was consistent with the findings of Murphy & Hennebach (2020), which systematically reviewed swimming programs for individuals with ASD. They found that children with ASD were attracted to water because of the tranquil and calming properties water provided them.

Many parents in the study realized over time the therapeutic benefits of engaging in water for their child with ASD and it led many parents not to associate an attraction to water necessarily as a total negative. Many parents said that swimming was a priority in their lives as water activities such as laps or leisure swimming provides an opportunity for exercise that aligned with their child's needs. Providing ample opportunities for children with ASD can encourage more community involvement. Parents shared stories of their children being able to freely exercise in water as it provided an easy outlet to exercise without it being too exhaustive. Parents indicated that they wanted their child to be able to participate in low weight bearing physical activity that their child enjoys to

keep them active. This may have been because water possesses properties such as buoyancy, turbulence, and resistance that can make recreational exercise easier on the body, especially for children with ASD who may struggle with fine and gross motor control (Lee & Porretta, 2013). As such, aquatic exercise interventions for physical activity are often recommended for children with ASD (Fragala-Pinkham et al., 2011). Prupas and colleagues (2006) produced similar findings explaining that children with ASD are generally more successful with water activities versus land activities as water helps alleviate difficulties with movement.

A major suggestion stemming from the parents in this study is that parents who care for children with ASD are not informed of the benefits that could come from their child participating in water activities. With the increased dangers water presents, it is understandable that swimming may not be the first activity that parents of children with ASD may enroll their child in. However, the parents who were interviewed experienced a positive effect on their home life as a result of their child with ASD engaging in water activities.

Parents experienced a vast array of situations, emotions, challenges, and benefits when they took their child to aquatic environments. Parents of children with ASD should be informed of the benefits of water activities and swimming environments should have safety procedures in place to prevent an emergency. Barriers such as social judgement and in aquatic environments need to be addressed for families to participate comfortably. Garnering a welcoming environment for families with children with ASD can have positive effects on both the child and the parent by promoting social opportunities and ease some of the stress caregivers experience (Vasilopoulou & Nisbit, 2015). Aquatic

facilities can assist in this by providing accommodations where necessary and actively fostering inclusive recreational environments.

5.2 Experiences and Perspectives on Swimming Lessons

5.2.1 Accessibility

Participants reported that many aspects of swimming lessons needed to be more accessible. There were numerous factors that parents had to consider when attempting to enroll their child into aquatic lessons. These factors included: limited availability of specialized lessons, timing, location, cost, class ratio.

Parents stated there were limited swimming lessons at specialized and municipal facilities for children with special needs. Facilities had a set number of students with special needs that could be enrolled in each session. This left parents scrambling to make sure they were first to register for the few spots that were available. A similar finding was reported by Lawson et al. (2019) where the authors identified long waitlist that left parents unable to register for swimming lessons for their children with ASD. Obrusnikova and Miccinello (2012) also observed this with the parents they interviewed stating there were not enough recreational activities that were available to them that had the appropriate accommodations. Findings suggest that aquatic facilities should work with their community to provide an increased amount of lessons designated for children with ASD to accommodate the growing need for them. This was important to parents in this study and other, and it should be considered a public health concern given the rates of drowning for children with ASD.

Timing for lessons that were available was also an obstacle for some parents. Sometimes accessing lessons, when available, did not work with families' schedules

because the parents had multiple children and scheduling conflicts. Many parents explained that because specialized swimming lessons were so limited, it became very difficult to try and fit these lessons into their schedule. This limitation meant that some families could not access lessons. This was also found in the work of Obrusnikova and Miccinello (2012), whose findings indicated that families have multiple responsibilities caring for their child with ASD and other children, and this was a barrier to participating in physical activity. Facilities should consider offering lessons at varying times of the day and/or days of the week for children with ASD to accommodate families' availability.

Cost was a large concern for many families when trying to access aquatic lessons. Pricing differs significantly from municipalities to private swim schools. The cost of specialized swim lessons for children with ASD can be expensive compared to lessons for children who are enrolled in regular programming. Specialized lessons generally cost more as they required specialty trained instructors, private classes, and designated pool spaces.

Additionally, some parents explained that as their child required more time to understand concepts and practice, this meant that they had to pay these prices even longer. It was challenging for some parents to justify enrolling their child into high-priced lessons, when the surrounding was sometimes sensory inappropriate and caused the child to not actually participate in their lesson. Similarly, if their child is not progressing at a steady pace, it can discourage parents. This was similar to the findings of Lawson et al. (2019) and Hall (2013) where their parents also stated cost as a barrier to accessing swimming lessons. Cost is a barrier to enrollment in many physical activity programs for all children (Eime et al., 2015) and this is true, perhaps to a greater extent for children

with disabilities. A systematic review by Shields et al., (2012), indicated that cost was an important barrier to physical activity participation for children with disabilities. There is no research that I am aware of that compares the cost of enrollment in physical activity programming for children with disabilities to children without, and such research would be challenging to undertake. But anecdotal evidence from parents' descriptions of cost of programming for children with ASD would indicate that cost as a barrier may be greater for the ASD community. Given the rates of drowning of children in the ASD community, swimming lesson for children with ASD should be subsidized to a great extent by municipal, providential, and federal funding. Moreover, the ways in which it is subsidized needs to be practical so as not to add to barriers of participation through excessive application processes.

Participants felt class ratio was especially important to children with ASD as they might be easily distracted by others or not have enough attentional behavior during the lessons to progress, leaving them to continue the same level for extended periods of time adding to the costs of the overall lessons. Most parents said that their child with ASD had the best experience in a private lesson where they were one-on-one with the instructor. Participants acknowledged that this was at the cost of further developing social skills because their child did not get to interact with any of the other children. However, swimming and safety skills took priority for these parents. Parents explained that group lessons were not beneficial for many children with ASD who needed the consistent support in the water to learn. Participants stated their children needed extra time and guidance in order to capture ideas and understand skills by breaking them down into pieces thus, private lessons were the best approach. Findings suggest that private and

semi-private lessons have promising results; aquatic centres and swim schools may want to consider increasing the number of lessons delivered in this manner.

Parents discussed other factors that impacted accessibility. These included pool environment considerations such as sensory appropriate environment and number of people are in the pool area. Some private pools have specialized lessons in a sensory appropriate environment, like dimmed lights, warm water, and decreased number of overall children in the pool. However, this is not widespread across all facilities that provide specialized lessons, which can lead to crowded pools with many potential triggers even if the child is enrolled in private lessons. Lesson providers should share information on number of children in the entire pool, water temperature, and lighting with potential clients so parents can make informed decisions on participating in lessons.

5.2.2 Teaching Methods

Parents in this study explained that they paid a lot of money for swimming lessons, and some felt their child was being placated and pushed aside. Parents shared examples of their child playing on mats and with toys during most of class time. Parents affirmed that the primary reasons of enrolling their child in lessons was to learn swim skills, how to be safe around water, and what to do in an emergency and that their children were not meeting these outcomes based on the learning environment and teaching methods. All of which they felt were not being focused on or given enough time. This follows the findings of Clees & Gast (1994) that explain that the preventative and reactionary safety skills that are crucial for children with ASD should be learned as soon as possible so the child is prepared should a dangerous situation occur. The parents explained they were not worried about their child passing levels, but rather that the needs

of the child to be safe around water were addressed first.

Parents said that if teaching their child got even a little difficult, like their child refused to try a skill or started crying, the instructor would give up and let the child play. This non-instruction limits the child's potential. Participants stated, instructional time should be instructional time. Research indicates that children with ASD may require an adapted swimming level progression, but that does not indicate that they are not capable of swimming and learning aquatic skills (Alaniz et al., 2017, Caputo et al., 2018; Pan, 2010). Many interventions have shown that children with ASD can become proficient at swimming.

Most parents in this study valued enrolling their child in swimming for survival readiness. They were very aware of the drowning rate for the ASD population. If not for anything else, they want their child to have the skills to act in the event of an emergency for a better chance at survival. All parents expressed concerns and ideas on how to improve lessons to incorporate more emergency skills and knowledge including spending more time talking about safety rules, roleplaying, and repetition of survival skills. Instructors are encouraged to work with families with ASD to see what their child's specific needs are when it comes to swimming lessons so that the child can be successful in aquatic environments. Swimming programs should focus on safety and survival skills for all children, especially those with ASD.

Some parents explained many children with ASD need the explanation of why a rule is important as they may not immediately understand the consequences if they do not follow the rules. It may take a little more time for children with ASD to understand why certain rules are in place or why certain lessons or skills are being taught (Klinger et al.,

2007). Some children with ASD struggle with generalization, or the ability to transfer skills from one area to another, so they may not necessarily associate 'pool safety skills' the same as 'lake safety skills' because it is a different environment (Prupas et al., 2006). This makes it essential that children with ASD are given explanations of where these skills can be used, this will support retention and help students know when to apply skills.

Future research should focus on swim safety and survival training for children with ASD. This is a clear priority for parents of children with ASD. Drowning is one of the top three causes of mortality for children living with ASD (Guan & Li, 2017b) and water survival skills are crucial. Examining barriers and strategies to provide swim safety and survival training for children with ASD within a swimming lesson environment should be explored to foster successful outcomes and reduce chances of injury mortality in this population. Testing pedagogical strategies for swim safety and survival should also be undertaken to strive towards the most beneficial teaching methods. Strength-based approaches should be taken into consideration when developing these strategies such as employing methods that can utilize a child's restricted interests or repetitive behaviours (Steiner & Gengoux, 2018).

One suggestion that came up from multiple participants was the use of visuals to teach. Many parents shared that using visuals in the learning process was very beneficial for their child with ASD, and if they felt their child did not need it, they did say that many other children with ASD may benefit from having flash cards during instructional time, especially if their child was non-verbal. Picture exchange communication system is a series of pictures used specifically for helping children with ASD communicate better

and is recommended for teaching use (Townsend et al., 2018). This may be helpful for children who are non-verbal or provide a visual when verbal articulation of a skill is not sufficient in swimming lessons (Kraft et al., 2018).

Another type of visual learning that came up was role play. By acting out scenarios with the children like an emergency drill, it helps them better connect the skill to the situation, especially if they struggle with generalization. This if often utilized as a component of Behaviour Skills Training which has shown to be an effective learning strategy for children with ASD to react to dangerous stimuli (Rossi et al., 2017). The four components of BST are: instruction, modeling, rehearsal, and feedback, which can be used to mimic emergency situations to help recall of skills (Rossi et al., 2017).

Another suggestion by parents was the need to break down skills and add more repetition to swim lessons. They stressed the importance to focus on smaller skills and master them first, before moving onto bigger skills or adding them together. This helped many of the participant's children grasp concepts and skills, stemming off a strength-based approach by utilizing repetitive behaviours (Steiner & Gengoux, 2018). This type of learning is coined 'task analysis' defined as the learning of individual skills which can later be combined to perform a sequence of movements (Gaylord-Ross et al., 1984). Breaking down skills and rules are important for children with ASD as it can separate skills into smaller manageable movements producing a more successful learning opportunity (Kraft et al., 2018). The more repetition and constant reminders, the more the children were able to remember things, many parents explained this was the way that they instilled safety rules in their child and explaining what the consequences were if the

rules were not followed. This pedagogical strategy may be very useful if used to support swimming skills for children with ASD.

One of the most important strategies that parents discussed was positive reinforcement. Parents spoke of their child not wanting to go back to swimming lessons because they got frustrated with skills that they could not master. Successful experiences were shared where the use of positive reinforcement drastically changed their child's attitude toward swimming lessons. Whether it is a sticker for completing a small skill, or a progress report that gave a great job badge, parents were quick to explain that their child did not care what the number on the badge says, just that they were being congratulated on all their hard work and celebrated for their personal achievement either through tangible means or verbal celebrations. Parents explained that this did happen, but it could be used more regularly.

Research has shown that positive reinforcement has been effective in encouraging children with ASD participate in activities (Schmidt et al., 2013). This strategy can also be combined with incentivization. For example, telling the child that if they practice the back crawl then they can do jumps off the side of the pool. This is known as a reward system where the child performs the task asked, then is rewarded with a task of preference (Kraft et al., 2018). Letting the child have an opportunity to do what they like while still getting practice time in is key with all children, but can be especially resonate with children with ASD (Schmidt et al., 2013). Future researchers should investigate into the different types of aquatic interventions available to families with children with ASD to compare approaches and resulting learning outcomes.

5.2.3 Teach the Teacher

Many parents suggested that instructors have training for teaching a child with ASD. This idea is explored by Kraft & Leblanc (2017) that researches building instructor's knowledge on teaching children with ASD. They voice a lack of knowledge for teaching swimming to children with ASD and that although there may be training programs created, they are not readily accessible (Kraft & Leblanc, 2017). Future research should consider looking further into the instructor's perspectives to investigate their barriers to teaching, if any, and developing standardized training methods to prepare instructors to teach children with ASD.

Parents felt that instructors needed to have a basic understanding of ASD to be able to teach a child with ASD. Many felt that just having a private lesson for their child with ASD was not enough. They explained there was no change in the approach with teaching a neurotypical child and a child with ASD in their experiences. Parents spoke of instances where instructors were not a great fit which hindered their child's progress or where they were asked not to come back because their child responding negatively to a trigger and they did not know the proper protocol to handle the situation. Parents explained that although they were offered private lessons to help with their child's learning, the accommodation to their child's needs were still not being met through the teaching staff. If a child with ASD is only identified through what is challenging for them, the labels placed upon them result in a limiting learning environment (Carter, et al., 2015). Instead, if instructors learn the strengths of children with ASD, they can develop them through aquatic activities and use them to learn new skills. Going into an interaction underestimating a child with ASD's ability can hinder their learning potential (Tesfaye et

al., 2019).

Participants had ideas on what training instructors should have. Instructors need to understand that children with ASD learn different, but it is important to note that not all children with ASD learn the same, just as neurotypical children do not all learn the same (Rossi et al., 2017). Parents felt that instructors need to be taught that children with ASD may need explicit explanations to understand what the possible consequence to their actions would be as they may struggle with implicit learning to understand concepts (Klinger et al., 2007). Parents explained that, the same goes for learning new skills, many children with ASD need the reasoning behind an action or skill to make it make sense to them. For example, explaining to children why they are learning to float on their back or kick their feet.

Parents suggested that swimming teachers that are a suitable for their child with ASD are harder to come by. In addition, when they find them, they are hard to keep since many are employed part-time leading to high turnover. Participants said that finding that connection with an instructor, so their child feels comfortable is essential. This corroborates the findings of Lawson et al. (2019) that stated parents value consistency, specialty training, the bond between child and instructor, and the instructor's understanding of ASD. As swim instructors generally tend to be part of a younger population, finding experienced and/or specialized instructors can be difficult. Investigating the ideas and perspectives of children with ASD, clinicians, and swim instructors may provide a variety of experiences producing valuable information that can highlight necessary adjustments to current training standards.

5.2.4 The Impact of Swimming Lessons

Parents were asked if they felt any skills their child had learned in swim lessons had an effect on their lives. Parents stated that the skills that were retained were not so much the swim skills, but the indirect life skills they acquired while taking swimming lessons. Parents explained it led them to gain more independence in and out of the water. For one mother, it meant that their child took a more independent role in getting themselves changed or going to the washroom by themselves. For others, it gave them a chance to do something the whole family can enjoy and that their child can do things any other child would like to do. This is important for many families with children with ASD, as those who struggle with fundamental motor skill acquisition are often found to have a decreased participation in physical activity (Barnett et al., 2008). This finding confirms the findings of Lawson et al. (2019) and Yilmaz et al. (2004) that swimming was a meaningful activity for families with children with ASD and enables them to participate in typical family recreational activities together.

It is important to note that while many parents had similar overall arching ideas of how to keep their child safe, there is no one size fits all for taking a child with ASD to an aquatic environment. The suggestion from parents to other parents was to figure out what works in the best interest of the child with ASD and their family. This also rings true for aquatic lessons as not all types of lessons would have the same effect on all children with ASD. Adaptations for swim lessons should be implemented on a case-by-case basis to maximize the efficiency of the lessons and build upon the teaching method that works best for the student. This would improve the inclusivity and accommodations for many children with specialized learning needs.

Despite the challenge's parents identified with swimming lessons many still felt that participating in swimming lessons gives children with ASD the opportunity to gain more autonomy. Parents shared stories of their child having more awareness around aquatic environments and being more cautious. Parents also related participation in swimming lessons with increased self-regulation, or autonomy over oneself. Swimming lessons also supported positive social skills, as children learned to work with others and better communicate and follow directions. This is important as many children can struggle with social skills (DSM-5). In a similar study that tested an aquatic intervention for children with ASD, parents reported improvements in their child's social performance and self-confidence to participate in other sports (Pan, 2010).

Parents were able to identify multiple barriers their families faced when attempting to participate in swim programming. They underlined that swimming lessons are paramount for their child with ASD to learn how to be safe around water which is consistent with the current literature (Grosse, 2014; Murphy & Hennebach, 2020, Mische Lawson et al., 2019; Ennis, 2011). Alongside providing valuable recommendations for improving aquatic programming from the client perspective, their lived experiences give rise to the challenges that families who require similar accommodations may face. Recreational physical activity inclusive of swimming should be encouraged and procedures should be investigated to make it easier for families to access these programs. Parents expressed being proud of their child for their accomplishments and not giving up. They also explained that the more their child was exposed to aquatic environments the easier it became for not only their child, but for themselves as well. Parents felt more

comfortable after they had learned the tools to help them navigate aquatic settings with their child easing their stress, citing that they experienced enjoyment in aquatic environments once their child had started taking swimming lessons.

5.3 Limitations

There were limitations to this study that are important to discuss. First, this research consisted of only participants that were mothers of children with ASD. Although recruitment was open to all primary caregivers of children with ASD, all potential participants that came forward were mothers which allowed for only the maternal point of view to be seen. The literature indicates that mothers and fathers of children with ASD have different quality of life outcomes and view experiences in parenting children with ASD differently (Vasilopoulou & Nisbit, 2016). With only mothers as participants in this study the findings may not represent all parents as fathers may have presented contrasting views. Lower participation rates in child health research from fathers than mothers is a common trend in child health research (Davison et al., 2017). Future studies should look to included paternal viewpoints by specifically seeking out and/or explicitly welcoming paternal figures during recruitment.

This study did not include any participants that had children with ASD with no formal swimming instruction experience; all parents had enrolled their child in some type of swimming lessons for at least a few sessions. By not having participants with any formal swim instruction, we may have missed valuable information on families that have no access to swim lessons and/or aquatic environments or do not participate in them. Future research should attempt to get information from these families by reaching out to communities that may not have sufficient means to access to these programs.

As there was no age restriction for the child with ASD that the parent cared for, there was a vast range of ages for the participant's children (2-20 years old). The information from parents of older children were focused on experiences about caring for a child with ASD and ideas for improvements, whereas mothers of younger children with ASD had trouble answering many questions as they were still trying to navigate the early years of being a parent to a child with ASD.

This research was intended to be done through in person interviews so personal observations could be collected. However, all but one interview occurred during the early months of the Covid-19 pandemic, in which our country was quarantining due to imposed public health regulations. Due to this the interviews were done over the phone. This may have taken away from meaningful information that could have been noted during the interview process. However, we were able to recruit all participants with relative ease and schedule interviews easier than if they needed to be in person. The phone interview process may have helped mitigate a barrier to research engagement for the parents in this study who have many responsibilities.

Chapter 6. Conclusion

Our intentions in undertaking this research was to investigate the experiences of parents and caregivers of children with ASD around aquatic environments. The lived experiences of participants shed light on parent perspectives as caregivers and highlighted the challenges and factors that families with children with ASD face around water. The findings of this research expressed the parents' general consensus on why they chose to enroll their child in swimming lessons and the resulting effects of that choice. Parents illustrated the positive effects swimming lessons had on their child's abilities in the water and in other social and physical environments and explained how water can be used as a therapeutic approach to support their child. Supporting children with ASD in these lessons promotes their autonomy and provides opportunities for independence (Tesfaye et al., 2019). Parents gave valuable information into what they need in the lessons for their child to be more successful, including: what to teach, how to teach, and what instructors should know. This research may help improve swimming programs and aquatic facilities that teach children with ASD.

The findings from this work indicate that children with ASD are capable of acquiring swimming skills, but this is not always recognized in the aquatics community. Parents found that visuals, repetition and break down of skill, and positive reinforcement were effective methods for teaching their child with ASD. Parents shared that their child was often left to play and not pushed to gain skills, or that adaptations were not in place to support their child in gaining swimming skills. This indicates that instructors or aquatics leaders may not believe that children with ASD can gain the skills needed to be competent swimmers, which aligns with a deficit model of skill acquisition for children

with ASD. When it is assumed that someone with ASD cannot do something this contributes to the lack of ability of society to envision places and roles for people with ASD (Carter et al., 2015). Through a strength based swimming education approach, where the child's strengths and challenges are encompassed in the swimming instructional plan, children with ASD will be able to gain swimming skills, continue to engage in a physical activity and sport that has many benefits, and take part in a beloved activity in Canadian society. This may lead to a greater sense of belonging and acceptance in society for children with ASD and their parents and caregivers.

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Appendices

Appendix A: Eligibility Questions for Parents/ Caregivers

1. How old is your child?
2. Does your child have a confirmed diagnoses of Autism Spectrum Disorder (ASD)?
3. Does your child have any conditions that does not allow them to engage in swimming lessons?
4. Has your child had any formal swimming instruction at any time in their life?

Appendix B: Epoche: Initial Reflection

Parents of children with ASD most likely have multiple things running through their head when it comes to caring for their child. Adding a water setting to the mix creates even more preparations as they must be extra vigilant with supervision of their child. I would imagine that if the more severe a child's diagnosis is, the more hesitant parents would be to bring their child with ASD to an aquatic environment. With typically developing children, parents are already wary of the dangers of water and set rules for their children to follow when they are participating in aquatic activities. With children with ASD, this may be a challenge as they may not understand the risk that water poses and may have a hard time following rules set in place for them. This along with the chance of elopement can cause fear for many parents that would lead them to avoid these type of surroundings all together. Many parents of children with ASD utilize swimming as a form of therapy for their child. However, these lessons are very controlled, for example warm water with a private instructor in a sensory positive pool environment. These lessons do not mimic the experience of a typical water environment. Parents bringing their child with ASD to a pool or a beach may constantly fear triggers from sensory overload that may cause their child to act out or have a meltdown. I think that parents of children with ASD do not want their child to feel excluded from participating in activities that may involve or occur around water, however they are trying to protect their child from surroundings that could provoke negative reactions. If they feel their child would not react well in these settings they would not let them engage with them. The fear of drowning or behavioural implication of their child with ASD would be far too great. They may feel more comfortable finding different outlets or altered surroundings that are better suited to their child.

Appendix C: Interview Guide

Interview Guide: Examining the Experiences of Parents and Caregivers of Children with Autism Spectrum Disorder around Aquatic Environments

Introduction

Thank you for talking with me today, I am trying to understand what it is like for you as a parent or caregiver to experience aquatic environments such as pools, lakes, and rivers with your child. When you are answering the questions, please give me as much detail as you would like so that I can really understand your perspective. Take your time and do not feel rushed. If you are having a hard time finding the words to describe your answer take a moment to think about it. There is no right or wrong answers. I am trying to gain insight into your experiences and you are the expert. I will be using an audio recorder so that I can ensure I am fully capturing what you say and so that I can be present in the conversation as opposed to frantically writing notes. As you know from the consent form, everything you say is confidential. Do you have any questions before we start?

History about child and parent

1) How old is your child?
2) How much caregiver support does your child require when participating in daily activities?
    a. Prompts: eating, bedtime/morning routines, at school, playing with others

3) Have you participated in Grandview's specialized aquatic therapy lessons or any other swimming or aquatic therapy lessons for children with ASD or disabilities before?
    a. Prompts: For how long?
    b. What type of program was it?
        i. Specifically, for children with ASD or more general?
        ii. Group or private lessons?
        iii. Location and organization?

4) If you have not had your child in swimming lessons, why not?
    a. Availability
    b. Cost
    c. Concerns over the program?
        i. E.g. Thinking it won't help, issue with how its delivered?

Experiences with Aquatic Environments

5) How often is your child exposed to aquatic environments?

a. Prompts: Pools, lakes, creeks or rivers
b. Further prompts: Birthday parties, family events, camping, walks, school outings.

6) What has been your experience having your child in or near aquatic environments such as pools, beaches, lakes, rivers, and creeks?

7) Do you feel like you avoid, or have avoided aquatic environments?
    a. Why or why not?
    b. When do you avoid and when do you engage?

8) How do you feel as a parent or caregiver in aquatic environments with your child with ASD?
    a. Positive emotions (e.g happy, proud, hope, inspired)
    b. Negative emotions (sad, nervous, angst, fear, embarrassed).

9) Do engaging in or not engaging in aquatic environments impact other members of your family?
    a. Other children?
    b. Vacations or trips?

10) What are some mechanisms, skills, or plans that have helped you navigate aquatic environments with your child?

11) What do you want others who take your child in or near aquatic environments to know?
    a. For example, teachers and field trips

12) Do you think your child with ASD is attracted to water?
    a. Have they ever been attracted to water?
    b. More so than other children?
    c. What is it that you think attracts them?
        i. Sensory: feel, sound, look.
    d. If not attracted why do you think that it is often said that children with ASD are attracted to water?

Experiences with Aquatic Programming

13) Has enrolling or not enrolling your child in lessons had any effect on your ability to take your child to aquatic settings?
    a. How or how not?
    b. How has them being in lessons or not in lessons impacted you?
        i. Positive emotions (e.g. happy, proud, hope, inspired)

ii. Negative emotions (e.g. sad, nervous, angst, fear, embarrassed).

14) If you have had your child in swimming lessons or aquatic therapy do you think the skills transferred into real life outside of that setting?
    a. Why or why not?
    b. If no, any idea what might help transfer the skills to real life?

15) Is there anything you feel should be taught in specialized aquatic lessons that would benefit families with children with ASD when engaging in aquatic environments?
    a. What has worked in your experience?

16) Is there anything else you would like to tell me about your experience with swimming programs, like Grandview, or aquatic environments in general? Remember this is a confidential interview.

Appendix D: REB Approval

Date:	*January 23, 2020*
To:	*Serene Kerpan*
From:	*Paul Yielder, REB Vice-Chair*
File # & Title:	*15747 - Examining the Experiences of Parents and Caregivers of Children with Autism Spectrum Disorder around Aquatic Environments*
Status:	***APPROVED***
Current Expiry:	***January 01, 2021***

Notwithstanding this approval, you are required to obtain/submit, to Ontario Tech Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The Ontario Tech Research Ethics Board (REB) has reviewed and approved the research study named above to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 2014), the Ontario Tech Research Ethics Policy and Procedures and associated regulations. As the Principal Investigator (PI), you are required to adhere to the research protocol described in the REB application as last reviewed and approved by the REB. In addition, you are responsible for obtaining any further approvals that might be required to complete your project.

Under the Tri-Council Policy Statement 2, the PI is responsible for complying with the continuing research ethics reviews requirements listed below:

Renewal Request Form: All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed 30 days post expiry date will be automatically suspended by the REB; projects not renewed 60 days post expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.
Change Request Form: If the research plan, methods, and/or recruitment methods should change, please submit a change request application to the REB for review and approval prior to implementing the changes.
Adverse or Unexpected Events Form: Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
Research Project Completion Form: This form must be completed when the research study is concluded.

Always quote your REB file number (**15747**) on future correspondence. We wish you success with your study.
Sincerely,

Dr. Paul Yielder
REB Vice-Chair
paul.yielder@uoit.ca

Emma Markoff
Research Ethics Assistant
researchethics@uoit.ca

Appendix E: Recruitment Posters

Contact for more information or to participate:
Larissa Lobo, Masters Student Researcher
Ontario Tech University

Email: larissa.lobo@ontariotechu.net
Text or call: 647-973-9041

Examining the Experiences of Parents and Caregivers of Children with Autism Spectrum Disorder around Aquatic Environments

We are looking for parents and caregivers of children with ASD to share their experiences, ideas, and perspectives on aquatic environments (e.g. pools, lakes) and on swimming lessons for children with ASD.

We want you to have your opinions and ideas about aquatic environments heard so that others can learn from your perspective.
Decision makers, researchers, and service providers will all be able to learn from this research which will support future projects or programs.

Interviews will be 45 minutes and take place at a location and time convenient for you.

We believe that your time and knowledge are valuable and we would like to provide you with a $50 Visa gift card for your participation.

This research has been approved by the Ontario Tech University Ethics Board and the Grandview Children's Centre Ethics Board

OntarioTech UNIVERSITY

Contact for more information or to participate:
Larissa Lobo, Masters Student Researcher
Ontario Tech University

Email: larissa.lobo@ontariotechu.net
Text or call: 647-973-9041

Examining the Experiences of Parents and Caregivers of Children with Autism Spectrum Disorder around Aquatic Environments

We are looking for **parents and caregivers** of children with ASD to share their experiences, ideas, and perspectives on aquatic environments (e.g. pools, lakes) and on swimming lessons for children with ASD.

We want you to have your opinions and ideas about aquatic environments heard so that others can learn from your perspective.

Decision makers, researchers, and service providers will all be able to learn from this research which will support future projects and/or programs.

PHONE INTERVIEWS

Complying with social distancing.
Approximately 45 minutes.

$50 Mastercard gift card for participation.

We believe that your time and knowledge are valuable.

This research has been approved by the Ontario Tech University Ethics Board and the Grandview Children's Centre Ethics Board

OntarioTech UNIVERSITY

Appendix F: Consent Form

Consent Form to Participate in a Research Study

Title of Research Study: Examining the Experiences of Parents and Caregivers of Children with Autism Spectrum Disorder (ASD) around Aquatic Environments

Principle Investigator:	**Student Investigator:**
Dr. Serene Kerpan Faculty of Health Sciences, Ontario Tech University 905.721.8668 ext 2961 serene.kerpan@uoit.ca	Larissa Lobo Faculty of Health Sciences, Ontario Tech University 647.973.9041 larissa.lobo@ontariotechu.net

Purpose

The purpose of this study is to understand your experiences with your family in and around aquatic environments and with aquatic education.

What is involved?

As a parent or caregiver, you will be asked to participate in a 45-minute interview on your experiences in aquatic environments (e.g. pools, near lakes etc.) and aquatics education (e.g. swimming lessons) with your child with ASD. We will work around your schedule for the interview.

You must be 18 years or older to participate. This study has been reviewed by the Ontario Tech University Research Ethics Board **#15747** on **January 23/2020.**

Potential Benefits and Risks:

There are no anticipated risks associated with participation in this study. The interview questions only surround familial experiences inclusive of children with ASD around water. Participants may experience unanticipated mixed emotions whilst answering questions provoking feelings such as anxiety or fear. If a participant feels uncomfortable answering any question, they may ask to refrain at any time. If an unanticipated outcome occurs, we will work with the participant to find the appropriate assistance to resolve any potential outcome effects.

The benefits likely to be gained through this research project are:

- Having your opinions and ideas about aquatic environments heard and shared so that others can learn from your perspective. Decision makers, researchers, and service providers will all be able to learn from the findings.
- Providing information that could be used to support future projects or programs.
- A $50 gift card to thank you for your participation.

Confidentiality and Data Storage:

The interview will be recorded and transcribed. Only a study number and not your name will be associated with your interview. All information you provide will be confidential. If we chose to

use a quote you have provided when we share the results we will use a pseudonym (fake name) and we will not use quotes that make you identifiable.

All information collected during this study, including your personal information will be kept confidential and will not be shared with anyone outside the study unless required by law. Access to data will be restricted to the Principal researcher, Serene Kerpan, and a student researcher, Larissa Lobo. All data will be kept on a secure computer in the office of Serene Kerpan for five years upon completion of the study. At this point all data will be deleted.

Voluntary Participation:

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind later. You can say "pass" if you do not want to answer any of the questions. This is a study conducted by Ontario Tech University, not Grandview Children's Centre, thus there will be no impact to your service at Grandview Children's Centre for participating or not participating. If you withdraw from the research project, any data that you have contributed will be removed from the study and you do not need to offer any reason for making this request.

Compensation, Reimbursement, Incentives:

We believe that your time and knowledge are valuable and we would like to provide you with a $50 Mastercard gift card for your participation. After the interview we will give you the gift card.

Sharing and Publishing the Results:

The results from this project will be made available to you through a report at the completion of the study. We will contact you when it is ready and email it to you, or drop it off if you would prefer a print copy. The results may appear in published reports such as journal articles and conference presentations.

Participant Rights and Concerns:

If you have any questions about your rights as a participant in this study, complaints, or adverse events, please contact the **Ontario Tech University Research Ethics Office at (905) 721-8668 ext. 3693 or at** researchethics@uoit.ca**.**

By signing this form you do not give up any of your legal rights against the investigator or institution, nor does this form relieve them of their legal and professional responsibilities.

Consent to Participate

I have read the form and understand the description of the research study. I have been provided an opportunity to ask questions and those questions have been answered. I can ask questions about the study in the future. I freely consent to participate in the research study, understanding that I may discontinue participation at any time without penalty. A copy of this consent form has been made available to me.

_____ _____

_____ _____

Print Study Participant's Name Signature Date

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining	Signature	Date

Appendix G: Thank You Letter

Dear [Participant's Name],

On behalf of Ontario Tech University, we want to thank you for your participation in our research study on the experiences of parents and caregivers of children with Autism Spectrum Disorder and aquatic environments. It is only with the help of volunteers like you that we can perform the essential research to continue to enhance programs for children with ASD. We greatly appreciate your willingness to meet with us to share your thoughts about your experiences, which were extremely informative and useful.

We value your participation in this research study and your willingness to share about your experience. If you have any questions or concerns, please do not hesitate to contact us. Again, thank you so very much for your time and effort that made this research study possible.

Kind Regards,

Larissa Lobo, MHSc Student

Serene Kerpan, PhD

Appendix H: Codebook

Code	Definition	Quote Example
Safety Skills	Life-saving skills and how to be safe around the water that aren't being focused on in lessons.	That definitely would be my biggest concern if we're either visiting someone with a pool or something if one of them fell in, they would have no idea how to get out. (Interview 6)
Parent Inclusivity	Education/Feedback for parents on aquatic lessons.	You know what they're doing during lessons, but I think a lot of other parents and especially parents with ASD kind of like to know things in advance so that we can prep our kids in advance, but priming thing is really important. (Interview 8)
Location	The distance facilities that offer special needs are from participant's place of residence.	I would love to put him in a specialized program but right now we live in Pickering and Grandview, they only operate out in Oshawa and getting out there for us, it's a transportation thing. (Interview 5)
Stigma	The judgement families receive based on the characteristics of ASD.	So when your child is having that meltdown, or doing something you get a lot of those stares and comments. (Interview 5)
Bullying	Teasing, picking on or otherwise unwanted behaviour received from other children.	And if there's like a lot of like teenagers I tend to avoid, mainly because they can get, you know, quite mean they usually look for somebody to take on and for some reason it's usually my son. (Interview 2)
Availability	Amount of special needs lessons available.	They have many other therapies, other activities to be so every time, it's very difficult to accommodate that time. (Interview 4)
Timing	Times during the day aquatic lessons are offered.	I work full-time I'm a teacher. So I find a lot of the programs for his age group are during the day. (Interview 7)
Cost	The price of aquatic lessons	They are trained in special needs, as well as they have children that don't have special needs, and it's all one to one private, but it's like, I think it's like $75 a lesson, like it's expensive. (Interview 10)

Swim Skills	How strokes and swimming-based drills that are being taught In lessons.	I really want my child to learn how to swim but this is not really teaching him anything. (Interview 8)
Lack of Fear	Child not understanding the danger associated with water.	They still don't fully understand the dangers and potential dangers but they understand what they're supposed to do if XYZ happens. (Interview 9)
Parent Fear	Parental emotion associated with their child and dangers of water.	Just because he's a busy boy and I'm concerned and I know drowning is like the number one cause of death, like in this age group. So, yeah, so it's a bit stressful so I just wanted to get him swimming or be able to float, as soon as I possibly could. (Interview 7)
Anxiety	Parental emotion associated with worrying about their child and dangers of water.	Because of my anxiety with worrying about her, that she's not capable of swimming and that she's not capable of making good decisions near water so. (Interview 1)
Lifejackets	Use of a lifejacket when swimming or around water.	You have to be really firm with him, that if you take [the lifejacket] off you're not allowed in the water. (Interview 5)
Sensory	The overall aspect that draws children to water.	I think for him it's a sensory like the sensation of being in the water. Like, he likes to be completely in the water like 100% submerge. (Interview 2)
Touch	A child's interest in making contact with the water.	Whereas my two year old knows that's danger, don't go near there, he just didn't go near there, she just has to touch it or something when there's water. (Interview 1)
Sight	A child's interest in the way water looks.	A sight thing like it looks, looks really nice. I think it looks really nice you know the light shines off of it in an interesting way. (Interview 8)
Sound	How noises in the setting affect a child with ASD.	And a lot of pool areas are very very echoey. So I find that for them auditory wise if it's super super crowded it's hard. (Interview 9)
Calming	The experience of relaxation in the water.	As I said, he just seems like a different kid like he is totally relaxed at home, at ease, it's easy to talk to him when he's in the water. (Interview 11)
Stress-reliever	Swimming or being in water as a therapeutic means to relieve stress/frustration.	We hop in the pool for 30 minutes or 45 minutes, and they come out and they're, they're better able to focus they're

		better able to handle things. (Interview 9)
Positive reinforcement	Rewards for accomplishing certain goals set by instructor and child.	So usually I see there is a slide everywhere in a pool but if they can be more slides or other fun things which kids can do in the water and learn also right, like the reinforcement. (Interview 4)
Lack of Motivational Tools	Nothing to encourage students to keep trying.	So there's no, there's no accommodation that way. You know, even a sticker badge, or something that says at the end of the lesson fantastic job. (Interview 10)
Training	Instructor education for teaching children with ASD	Right, like you need to maybe be more creative, or use different language or be more patient and like give them extra time like, I don't know, because they're not trained to work with ASD children. (Interview 1)
Familial Impact	How being around water affects other family members.	It does impact us because we live at the pool all summer, and it makes it very difficult to plan other things. (Interview 10)
Supervision	A parent/guardian watching over a child.	Definitely a tag team effort, you have to have like at least one adult kind of just on him the whole time. (Interview 5)
Outsider Supervision	Hesitation associated with other's supervising their child.	I just feel like someone else is not, maybe not going to watch my child as well as I would because I tend to have those eagle eyes on them all the time versus I feel like somebody else would you know they might get distracted by something else. (Interview 8)
Confidence	Belief in one's ability to do something.	It helped him and me become a little bit more confident in his ability to, you know, actually stay above water. (Interview 5)
Setting	The location the family is going swimming/engaging with water.	Not at the cottage because, you know like, I take him public swimming, don't get me wrong I'm not afraid of a water. I'm afraid of the lake. Because it's not a controlled environment. (Interview 7)
Visuals	Pictures/visual descriptions of tasks or drills for children to do during swim lessons.	He's incredibly visual. And I know that, you know, I guess, because you don't really see it I didn't really even see it

		with the adaptive lessons either but I think like even visuals that were like laminated that you know they use, they could use in lessons could definitely be something that, you know, a parent could actually easily take and use in other settings as well. (Interview 8)
Proud	Emotion parents feel associated with their child in swim lessons.	That I think that, like, as a parent, I guess I could say that it's a proud moment, because he did work so hard and he had to work so much harder than the other kids. (Interview 2)
Promotion of Support Available	How accessible information is for parents with children with special needs.	I don't think that people know that they can get additional support in the pool for swimming lessons. I don't know if it was an option when he was younger for us, for the inclusive programming. I didn't really know there was any until like two years ago so the whole time that he was young, I had no idea. (Interview 2)