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Swimming as an occupation for children with autism spectrum disorder: parent and swimming teacher perceptions and experiences

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School of Therapeutic Sciences
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SWIMMING AS AN OCCUPATION FOR CHILDREN WITH AUTISM SPECTRUM DISORDER: PARENT AND SWIMMING TEACHER PERCEPTIONS AND EXPERIENCES.

Research report for the degree: MSc OT

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PLAGIARISM DECLARATION



PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Bronwyn Claire Carter (Student number: 708588) am a student registered for the degree of MSc OT (paeds perception) in the academic year 2020.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

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DEDICATION

“The man who is swimming against the stream knows the strength of it”

- Woodrow Wilson

This research report is dedicated to all the swimming teachers and parents who dove into this process with me. Thank you for allowing me a window into your experiences.

ABSTRACT

Background: Swimming as an occupation for children with ASD is an unexplored field of research in the South African context. ***Aims:*** The purpose of this study was to explore the experiences of swimming teachers and parents of children with ASD in the context of swimming lessons. ***Methods:*** Semi-structured in-depth interviews were utilized and a qualitative, descriptive-phenomenological design. Colaizzi seven-step method for data analysis was utilized. ***Results:*** Findings showed that parent's often sought swimming lesson's as they perceived their children to be at an increased risk of drowning due to the characteristic features of their diagnosis. Parent's experienced swimming as a valuable and meaningful occupation for their children with ASD and experienced a number of additional benefits, such as experiences of belonging and pride, which they had not first anticipated. However, they experienced a variety of barriers to accessing this service. Swimming teacher's also derived meaning and fulfilment from providing lessons. Although their perceptions and knowledge of ASD changed and grew as they interacted more with the children and their families, they expressed a definite need for greater support and training. ***Conclusion:*** Swimming is a meaningful and valuable occupation for children with ASD and their families, but swimming teachers in South Africa are not always equipped to provide this service. Occupational therapist could play a number of different roles in supporting participation for all stakeholders.

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NOMENCLATURE

DEFINITIONS

- Occupational Justice: “enabling, mediating and advocating for environments in which all people’s opportunities to engage in occupation are just, health promoting and meaningful” (Hocking, pg 35, 2017)
- Transactionalism: “a set of philosophical tools, or a method, employed to address the complexities of human social exchange or transactions; articulated most prominently by John Dewey and Arthur Bentley” (Lee Bunting, 2016).
- This study is written using person-first language (child with Autism Spectrum Disorder) as opposed to identity-first language (autistic child). Person-first language recognizes that the child is first and foremost a person - they have a disorder, but that disorder doesn’t define them.

ABBREVIATIONS

- SSA – Swimming South Africa
- ASD – Autism Spectrum Disorder
- OT – Occupational Therapy/Therapist

CHAPTER ONE: INTRODUCTION

1.1 BACKGROUND

The need to engage in purposeful and meaningful occupation is central to human life (AOTA, 2020). This engagement can be described as a synthesis of "doing, being and becoming" (Wilcock, 1993, 1999; Hammell, 2014), the means through which our human potential can be expressed and realized. Although the form, function and meaning of occupation may vary dependent on the sociocultural context in which an individual is embedded (Dunn & Brown, 1994; Hammell, 2014), occupation can serve to transcend context, uniting people through their common need to engage. If we acknowledge that occupation is indeed central to the lives of all people, it is reasonable then to assume that all people should have the right to experience occupation as meaningful, to develop health and social inclusion through engagement in occupation and to have equal access to the occupations of their choice (Hocking, 2017; Wilcock & Townsend, 2018; Bailliard et al., 2020). However, exclusion - as opposed to inclusion - is often the experience of people with disabilities and their families when attempting to engage in meaningful occupations. Occupational injustices such as occupational alienation, deprivation and marginalization are definite experiences of people with disabilities (Wilcock & Townsend, 2018; Bailliard et al., 2020) including those with Autism Spectrum Disorder (ASD).

ASD is characterized by the DSM V as a neurodevelopmental disorder with "persistent deficits in social communication and interactions across multiple contexts combined with restricted, repetitive patterns of behaviour, interests, or activities (APA, 2013 pg 50)." Globally, there is a large body of research on and around ASD. However, very little research has tested the applicability of this greater research body within an African context (Ruparelia et al., 2016; Springer, Toorn, Laughton, & Kidd, 2013). While prevalence in South Africa is estimated to be similar to international statistics (CDC, 2018), experiences of occupational injustice appear to be amplified (Schlebusch, Dada & Samuels, 2017; Reddy, Fewster & Gurayah, 2019), with families of children with ASD experiencing significant barriers to participation and emotional distress in coping with their child's diagnosis (Lai et al., 2015; Bravo-Benítez et al., 2019).

Due to the social deficits, sensory processing differences and repetitive and restricted behaviours characteristic of children with ASD, they may find participating in the same activities as typically developing children difficult or be excluded from participation altogether. Bravo-Benitez et al., (2019) observed that families lives tend to shift to "revolve" around meeting the unique needs of the child with ASD – leading to disruption of previously valued family occupations (Bravo-Benítez et al., 2019), which may lead to occupational deprivation. They further noted that families may struggle to engage in previously meaningful occupations due to contextual barriers, such as stigma and lack of awareness within the community, making environments less accommodating to their child's unique

needs (Thompson & Emira, 2011; Schlebusch, Dada & Samuels, 2017), also representing occupational marginalization. This can lead to experiences of isolation, depression and decreased quality of life. Iadarola et al., (2019) and Lock (2010) found that having the opportunity to participate in valued family activities, especially leisure activities, can in fact be a protective factor that mediates parental stress and thereby increases family quality of life – further reinforcing the health-promoting nature of engagement in meaningful occupations, and the necessity for all people to have equal occupational rights (Werner DeGrace, 2004).

Swimming specifically has proven to be a meaningful leisure activity for children with ASD and their families. In a study conducted in the US by Eversole et al. in 2016, the activity enjoyment of children with ASD was compared to typically developing children. The research demonstrated that children with ASD enjoyed swimming significantly more than typically developing children; with swimming being rated as the fifth most enjoyed leisure activity for children with ASD (Eversole et al., 2016). Lawson et al., (2019) conducted a qualitative study aimed at understanding the experience of swimming lessons from the perspective of children with ASD and their families. They also found swimming to be a meaningful family occupation, that provided families with an opportunity to engage in a “typical” leisure activity. However, the meaning and enjoyment derived from swimming was somewhat of a “happy accident” and not the primary reason which motivated parents to take their child for swimming lessons – water safety was.

In November 2014, the World Health Organization (WHO) released their first global report dedicated solely to drowning. They reported drowning to be the third leading cause of unintentional injury death worldwide; with the highest percentage taking place in the African region, especially among young children (WHO, 2014). Specific statistics for South Africa are considered to underestimate our drowning statistics (Saunders, Sewduth, & Naidoo, 2017). Research has further shown that Autistic children are at a higher risk of drowning than typically developing children due to wandering behaviour, decreased risk awareness and being “drawn to water”; which was echoed from parent’s experiences in Lawson et al., (2019), Martin & Dillenburger, (2019) and Casey et al., (2020). Among the WHO recommendations to prevent accidental drowning, especially among children, is teaching school-age children basic swimming, water safety and safe rescue skills.

Teaching typically developing children how to swim can sometimes be a challenging activity. Teaching a child with ASD how to swim may be made even more so, due to difficulties with social and communication skills, delayed gross motor skill development, difficulty planning movements and difficulties with self-regulation (Hall, 2013; Kraft, 2019; Kraft, Leblanc & Culver, 2019; Casey et al., 2020; Murphy & Hennebach, 2020). This may be further compounded by a lack of knowledge regarding ASD and training in appropriate handling techniques (Thompson & Emira, 2011). The developing research in this field has shown that, however difficult lessons may be, children with ASD

are capable of learning basic swim skills, provided the teacher is skilled and able to utilize appropriate techniques (Alaniz et al., 2017; Kraft, Leblanc & Culver, 2019). Teachers lived experiences of teaching a child with ASD swim skills are mostly “absent” within the literature. Aside from primarily providing the child with a survival skill and the family with piece of mind, swimming lessons have also proven to have a number of other benefits.

Occupational therapists in a number of developed countries have recommended swimming and more specifically aquatic therapy for children with ASD. All studies included in a 2014 systematic review investigating the effect of an aquatic therapy program on behaviours of children with high functioning ASD (aged 3-12 years) demonstrated improvements in social interactions and behaviours (Kumar, Mortimer, & Privopoulos, 2014). These included decreased stereotypical movements, hyperactive behaviour and anxiety, with increased interaction with the environment (Yilmaz et al., 2004; Du Bois, 2011). Aquatic activities provided opportunities for social interaction and play, which facilitated language development leading to improved social engagement. (Pan, 2011; Du Bois, 2011). Parents also observed improved self-esteem through children experiencing a sense of achievement (Pan, 2012)

Despite all the benefits and meaning swimming as an occupation may offer to children with ASD and their families, it remains for many an inaccessible occupation for a number of reasons that need to be further explored.

1.2 PROBLEM STATEMENT

Overseas, organizations like Autism Swim©, offer specialized training for teaching children with ASD how to swim. Currently, there are no formally recognised training programs for swimming teachers to teach children with disabilities how to swim in South Africa. It is important to consider this in terms of occupational justice (marginalization and deprivation) and equal access/opportunity for children with disabilities and their families to engage in meaningful occupations. By depriving children of engagement in a physical, social and leisure activity such as swimming, they miss out on opportunities to feel included in their home and school environment. They are further deprived of opportunities to experience the positive physical and mental health benefits derived from physical activity and of the experience of success as a result of their engagement. In addition, swimming is a vital survival skill for all children living in South Africa (not only those with ASD), with drowning statistics being considered. Is a lack of training for teachers a barrier to their participation?

Hydrotherapy and Swimming interventions being offered by occupational therapists overseas for children with ASD have seen positive outcomes for social and communication skills, family quality of life and repetitive behaviours. As no such services are readily available/offered in South Africa, is

there the possibility, from parent and swimming teacher perspectives that there may be scope for this? What has the experience been of parents been who have taken their children with ASD for swimming lessons? Is this something we can recommend/should be offering in schools to other families of children with ASD? Should we be advocating for/involved in the development of training for swimming teachers? Or is this not a meaningful occupation for children with ASD and their families in a South African context? Ultimately, the questions of this research is, “what is the experience of parents and swimming teachers involved in swimming for children with ASD in South Africa?”.

1.3 PURPOSE OF THE STUDY

The purpose of this study was to explore the experience of parents and swimming teachers of children with ASD, in South Africa. As there are currently no formal swimming programs for children with disabilities in South Africa - it was vital to first obtain feedback from those who have/are already engaged in this context, to determine if there is future value in applying/recommending swimming for children with ASD in the future.

1.4 AIM OF THE STUDY

To explore the *lived experience* of parents and swimming teachers of children with ASD in South Africa.

1.4.1 OBJECTIVES OF THE STUDY

To understand the lived experience and perceptions of the swimming teacher in teaching one/multiple children with ASD

To understand the lived experience and perceptions of the parent of child with ASD in the context of swimming lessons.

1.5 SIGNIFICANCE OF THE STUDY

The study aims to contribute to the greater body of knowledge about ASD in Africa, more specifically South Africa. The results of the research can further promote equal access to meaningful occupations and facilitate participation in the community through engagement in occupation, specifically swimming. Furthermore, it may assist the practitioner in addressing any barriers to participation that children with ASD and their families may be experiencing. Here exists an opportunity to combine the interests/activity enjoyment of the child with ASD, with an activity that can aid in the development of social skills and improve behaviours. This research is the first step towards understanding if there is a benefit from engaging in activities in an aquatic environment for children with ASD and their families.

It can also provide the health care practitioner with insight into meaningful recommendations, which can be made to families of children with ASD.

CHAPTER TWO: LITERATURE REVIEW

2.1 OCCUPATIONAL SCIENCE

“Swimming is my passion and something that I love. Going out there in the water, it feels as if there's nothing wrong with me. I go out there and train as hard as anybody else. I have the same dreams, the same goals.” – Natalie du Toit (Paralympic and Olympic Swimmer).

2.1.1 UNDERSTANDING OCCUPATION THROUGH OCCUPATIONAL SCIENCE

The understanding that purposeful engagement in meaningful occupations can influence a person’s health and well-being, is a core belief in the practice of Occupational Therapy (AOTA, 2020). Another key belief underpinning the profession is that humans are occupational beings, and that through occupation, a person can influence and interact with their environment and vice versa (Lee Bunting, 2016). Although, culture, race, religion, gender and socio-economic status (among others) may vary, occupation is something which can transcend these defining traits, something that can bring people together toward a similar purpose and give a sense of belonging or identity (as noted in du Toit’s statement above) (Yerxa, 1998; Hammell, 2014). Occupation can be defined as anything a person wants to, needs to or is expected to do (AOTA 2020). This is obviously a broad definition with a number of arguments surrounding it (Royeen, 2002) – which serves to further highlight the complexity of this concept. Occupations are currently classified into discrete categories by the Occupational Therapy Practice Framework 4th edition (OTPF-4), but argument has been made that occupations should rather be classified based on the meaning the person derives from engaging in them (Hammell, 2018). These definitions and debates are largely set out in Occupational Science literature.

Occupational science is the study of humans as occupational beings (Yerxa, 2000). The purpose of the field is to further understand the “form, function and meaning of occupation” (Blanche & Henny-Kohler, 2000, p6) for all human beings (not only those with disabilities), with the intention of generating knowledge which can support practices in the field of Occupational Therapy (Hocking & Clair, 2011). Occupational Science is primarily concerned with understanding occupations that are naturally occurring/emergent. A transactional perspective of occupation, as discussed in occupational science literature, is one of the theoretical constructs that acknowledges the complexity of why people do the things they do and helps provide a framework to further conceptualize it (Dickie, Cutchin, & Humphry, 2006; Lee Bunting, 2016)

Transactionalism, views a person, their occupation and environment as functioning *interdependently* relative to one another and as being influenced by the socio-cultural context in which they are suspended (Figure 1). This complex, non-linear interplay helps one begin to conceptualize what motivates a person/group to make specific occupational choices. It also helps one to understand how the environment can have an impact on engagement and conversely can be changed through engagement. Core concepts within this theory include functional coordination, ends-in-view and habit. Functional coordination refers to finding a balance between elements for successful occupational participation, which is achieved through action (habits) towards an end point/goal (ends-in-view) (Lee Bunting, 2016).

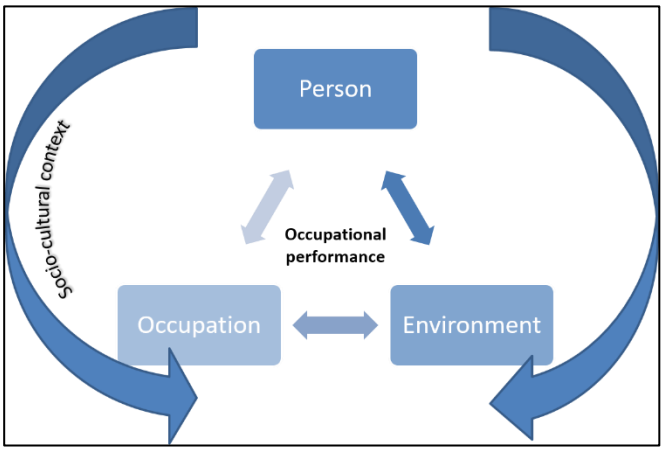


Figure 1: Transactional lens to understand occupation (Lee Bunting, 2016)

The transactional perspective offers a sensitivity to contextual features, through which occupational therapists can better understand the impact of sociocultural, economic and political factors on occupational engagement (Bailliard et al., 2020). In cases where the context or environment is limiting engagement of individuals or groups, one is further sensitised to the possibility of occupational injustice.

2.1.2 OCCUPATIONAL RIGHTS AND OCCUPATIONAL JUSTICE

A just society can be defined as one in which all human beings are treated equitably and where all people receive a fair share of societal resources (Hocking, 2017). Hocking (2017) further defines occupational justice as a process of "enabling, mediating and advocating for environments in which all people's opportunities to engage in occupation are just, health promoting and meaningful" (pg 35). Occupational justice is philosophically based on the premise that human potential is realized through doing in the real world, and that justice can only be achieved when individuals have the opportunity to do/be what they value (Bailliard et al., 2020). Occupational justice, as a facet of social justice (Wilcock & Hocking, 2015; Stadnyk, Townsend, & Wilcock, 2010), is considered part of the domain of occupational therapy because contextual factors impact participation in occupation (as described above), which is considered essential to human life (Bailliard et al., 2020).

Occupational injustices are and can be experienced at multiple levels. Individual experiences of injustice often point to larger structural/political/societal issues, and conversely broad systemic issues are frequently revealed in the day-to-day occupational lives of individuals. Occupational justice therefore stretches beyond improving an individual's skills so that they can engage in meaningful

occupations, but offers a lens through which to view restrictions on micro, meso and macro levels of policy that limit participation for individuals/populations (Bailliard et al., 2020). Concepts delineated within occupational justice sensitize researchers and practitioners to detect inequities, understand the issues perpetuating them, and provides a linguistic framework through which to guide actions for inclusion. Terms defined in occupational justice are commonly used in occupational therapy research (Benjamin-Thomas & Rudman, 2018; WFOT, 2019; Bailliard et al., 2020). Such terms include: occupational alienation (having to participate in meaningless/incompatible occupations), imbalance (being either over- or under-occupied or both), deprivation (subject to external barriers to participation in meaningful occupations), marginalization (being excluded from certain activities) and apartheid (deliberately denying access to occupations based on rules of segregation) (Hocking & Hocking, 2017).

Hammell and Iwama (2012) have argued against justice as a guiding concept because it is primarily concerned with "receiving a fair share"– not occupation. They also argue that the concept of justice alone does not provide a means of addressing injustice. In identifying injustices, one also needs to consider the complementary rights associated with them and proactive ways in which this can be used to advocate for those being treated unjustly. Wilcock and Townsend further outline a series of occupational rights, based on the premise that occupation is central to the lives of all people: that all people should have the right to experience occupation as meaningful and enriching, to develop health and social inclusion through engagement in occupation, to choose their occupations and to have equal access to the occupations of their choice (Townsend & Wilcock, 2004). Also pertinent to this research is the United Nations Convention of the Rights of People with Disabilities (of which South Africa is a signatory) – specifically the rights to participation and inclusion, accessibility, equality of opportunity and acknowledgement of the evolving capabilities of children with disabilities.

However, well written policy may be, exclusion - as opposed to inclusion - is often the experience of people with disabilities and their families when attempting to engage in meaningful occupations. This may be through ignorance, neglect or direct exclusion. One such diagnostic group, which is often subject to occupational injustice, is Autism Spectrum Disorder.

2.2 AUTISM SPECTRUM DISORDER (ASD)

2.2.1 DEFINING THE DIAGNOSIS

ASD is characterized by the DSM V as a neurodevelopmental disorder with "persistent deficits in social communication and interactions across multiple contexts combined with restricted, repetitive patterns of behaviour, interests, or activities (APA, 2013 pg 50)." Symptoms are usually present in early childhood and cause varying degrees of clinically significant impairment in social, occupational, or other important areas of functioning. The diagnosis is made when the behaviour cannot be better explained by intellectual disability or global developmental delay (APA, 2013). Globally, there is a

large body of research on and around ASD. However, very little research has tested the applicability of this greater research body within an African context (Ruparelia et al., 2016; Springer, Toorn, Laughton, & Kidd, 2013). Current statistics regarding the number of children diagnosed with ASD in the United States are estimated to be 1 in 54 (CDC, 2020). Although less research is available in South Africa, experts in the field estimate that statistics resemble those of the US (Gee, Nwora & Peterson, 2018). Issues regarding autism awareness and diagnosis are considered important in a South African context, especially in areas with poor education and lack of basic resources, where children with ASD may go undiagnosed and their families unsupported (Springer et al., 2013).

Even once diagnosed, Schelbusch, Dada and Samuels (2017) and Reddy, Fewster and Gurayah (2019) reported that South African families raising a child with ASD experience significant barriers when accessing medical, therapeutic and educational services. It is important to understand the child with ASD as functioning within a home environment, and the effects of the diagnosis on the family. Many studies have been conducted to explore parent's experiences of receiving and living with their child's diagnosis of ASD (Bravo-Benítez et al., 2019; Iadarola et al., 2019; Reddy, Fewster & Gurayah, 2019), with most describing a protracted grieving process and increased parental and family stress (Lai et al., 2015). A number of reasons have been cited for these experiences, among them symptom severity, disruption of expectations, resource limitations and financial burdens, isolation due to lack of community support, stigma/lack of awareness and support service navigation difficulties (Iadarola et al., 2019; Reddy, Fewster & Gurayah, 2019). These combined factors determine the family's experience of the diagnosis, degree of stress and ultimately the quality of life of the child with ASD.

Due to the social deficits, sensory processing difficulties and repetitive and restricted behaviours characteristic of children with ASD, they may find participating in the same activities as typically developing children difficult or may be excluded from participation altogether. This can further exacerbate parental stress, as parents grieve the loss of their "neuro-typical child" they had prepared for/expected and realize the impact of the diagnosis and symptoms on valued family roles, routines and activities. Bravo-benitez et al., and Reddy, Fewster and Gurayah (2019) describe how families lives tend to shift to "revolve" around meeting the needs of the child with ASD – leading to disruption of previously valued family occupations (Bravo-Benítez et al., 2019). Families of children with ASD are particularly at risk of experiencing occupational injustice as a result of their child's diagnosis and one means to mediate the effects of this injustice, is through therapeutic intervention.

2.2.2 OCCUPATIONAL JUSTICE AND AVAILABLE RESOURCES

Treatment strategies to promote social participation, communication and management of difficult behaviours are varied, with a rapidly growing evidence-base. According to data collected by the CDC, the prevalence of ASD has increased from 1:150 in 2000 to 1:54 in 2018 (CDC, 2020). This increase in the apparent prevalence of ASD lead to an equal increase in research surrounding potentially

effective treatment modalities. A multidisciplinary team approach is generally recommended, including speech therapy, occupational therapy, play therapy and physiotherapy (among others) (Gee et al., 2018) to enable children and families to engage in valued occupations. A variety of evidence-based models of practice and treatment strategies/approaches can be used from an occupational therapy perspective in order to manage behaviours characteristic of the condition and facilitate participation. Ayres Sensory Integration (ASI ©), ABA, TEACCH, Tomatis, and DIR/Floortime are among the more prevalent (Gee et al., 2018). However, specialist treatment is not the only option.

Naveed et al., (2019) systematically reviewed the efficacy of *non-specialist* mediated interventions for children with ASD. They cited the high cost associated with specialist treatment for ASD as creating a "treatment gap", especially in low and middle income countries (LMICs), which would include South Africa. This echoed evidence found in Ruparelia et al. (2016) and Schlebusch, Dada & Samuels, (2017) that highlighted limited access to services for children with ASD and their families in Africa and South Africa. Task-sharing has been recommended in order to bridge this gap and provide more cost-effective interventions; non-specialist mediated interventions are one such task-sharing option. Non-specialist mediated interventions are delivered by parents, caregivers, teachers or peers, with the aim of improving social skills, communication and behaviour (Naveed et al., 2019). Results of the review demonstrated that non-specialist mediated interventions for ASD were effective across a range of outcomes including child distress, communication, joint attention, motor skills, self-regulation, repetitive behaviours and parental distress and self-efficacy (Naveed et al., 2019). Physical activity and leisure-based tasks can be considered one such non-specialist mediated intervention.

The complex nature of ASD is the reason why a such broad variety of therapies exist to manage the symptoms of this disorder. Parents of children with ASD frequently seek complementary and alternative methods of treatment (such as physical activities like horse riding, swimming and kata training) to support classic approaches (Trzmiel et al., 2019). Participation in these naturally occurring activities, ie: those that would be available to neuro-typical children and families, further supports the occupational rights of families of children with ASD (Askari et al., 2015; Alaniz et al., 2017). Research conducted by Lock et al., in 2010 found that parents of children with ASD enjoyed having the opportunity to engage in leisure activities with their child and other families with children with ASD. Furthermore, they appreciated the chance to include their children or other family members without ASD. They further expressed a sense of peace at meeting many needs at once (Lock et al., 2010). Having the opportunity to participate in valued family activities was further noted as a protective factor that could mediate parental stress and increase family quality of life by Iadarola et al., (2019); however, García-Villamisar & Dattilo, (2010) noted that current research conceptualising leisure as a contributor to quality of life is limited, especially in the Autistic population.

2.2.3 LEISURE PURSUITS OF PEOPLE WITH ASD

Leisure is defined by the OTPF-4 as any “non-obligatory activity that is intrinsically motivated and engaged in during discretionary time, that is, time not committed to obligatory occupations such as work, self-care, or sleep” (Parham & Fazio, 1997, as cited in AOTA, 2020, p. 47). Leisure has been described as providing opportunities for self-exploration, to develop relationships, a sense of belonging and self-determination, as well as stress reduction (Fenech, 2008; Hammell, 2014). This occupation has also been studied in detail in positive psychology, with findings showing that it can contribute to experiencing a joyful, connected and empowered life (Iwasaki, Messina & Hopper, 2018; Chen & Chippendale, 2018). Research has also suggested that leisure can be used as a means to address social (and by definition occupational) justice (Fenech, 2008; Ikiugu et al., 2015; Iwasaki, Messina & Hopper, 2018), on the foundation that justice is achieved when individuals have the opportunity to do/be what they value (Bailliard et al., 2020). That is, through meaningful leisure participation, individuals may develop/express their identity and experience self-determination, leading them to feel empowered.

In 2015, Askari et al., conducted a scoping review of peer-reviewed studies published between 2000 and 2013, including children aged 5-17 years with ASD and describing their participation in leisure activities outside of school. Sixteen articles (out of 920) met the inclusion criteria, with the majority being descriptive of participation rather than analysing factors contributing towards it. Overall, children with ASD participated in fewer leisure activities than typically developing children, mostly at home, either with adults or on their own. Children with ASD were at higher risk of occupational imbalance, deprivation and alienation (Askari et al., 2015; Hocking, 2017).

Thompson and Emira’s 2011 investigation into parental and carer perceptions of access to leisure activities/facilities in the UK, had previously revealed a number potentially modifiable barriers to participation including, parents sense of isolation/not knowing what services were available, poor staff training and attitudes, and being unsure whether to access mainstream or special services with or without disclosure of the child’s diagnosis (Thompson & Emira, 2011). Further factors identified by Askari et al., (2015) as limiting participation included: family support, social attitudes (environmental factors), sensitivity and behavioural challenges, and communication and interpersonal relationship problems. Askari et al’s., (2015) review found that more than 60% of studies were conducted in America, indicating a need for evidence from different cultural contexts and geographical locations. Their findings further suggested that negative attitudes and lack of social supports are important environmental factors associated with level of participation and should be further addressed in research, especially as potentially modifiable factors.

Beyond the psychosocial benefits of leisure, physical and cognitive benefits have also been discussed in literature. Tanner et al. (2015) systematically reviewed the effectiveness of interventions for people

with ASD, focussing specifically on those concerned with leisure, social participation, and play. Although limited participation in play and leisure occupations should be addressed in individuals with ASD, they found that little evidence currently exists for specific interventions to improve these areas of occupation. Exercise, as a facet of leisure, was found to decrease restricted and repetitive behaviours but further research and replication of the initial results was needed. Moderate strength of evidence was found to support activity-based interventions. Stronger evidence was found to support the use of group-based social skills training, in improving social skills. Tanner et al. recommend that Occupational therapists should consider implementing multiple strategies as part of a comprehensive, interdisciplinary intervention (2015).

Reinders et al. later conducted a scoping review in 2019 examining the relationship between physical activity and social functioning for children with ASD. They concluded that there is a positive bidirectional relationship between physical activity and social functioning, with physical activity having a greater effect on social functioning than vice versa. However, this was somewhat contradicted by Howells et al. 2019 systematic review and meta-analysis on a similar topic, evaluating the efficacy of group-based organized physical activity for social outcomes in children with ASD. Their pooled statistical results revealed a non-significant effect for communication and a significant small-medium improvement in overall social functioning.

Overall, there were many limitations noted throughout the aforementioned studies, which may account for this contradiction. These included small sample sizes, few randomized control trials, lack of blinding and of standardized outcome and fidelity measures - affecting generalizability. This reflects the difficulty experienced when conducting research with this complex and diverse population (Askari, 2015., Tanner et al., 2015., Howells et al., 2019.,).

However, this evidence tends to demonstrate a positive correlation between participation in leisure activities (such as physical activity), quality of life and improvement of symptom severity for children with ASD and their families. Participation in leisure activities can lead to stress reduction, improved quality of life, improved social skills and communication and decreased repetitive behaviours ((Askari, 2015., Tanner et al., 2015., Reinders et al., 2019). Barriers to participation include factors such as social attitudes and knowledge, support structures, and severity of symptoms (communication and behavioural difficulties) (Thompson & Emira, 2011). Some of these factors are potentially modifiable (social attitudes and knowledge) and should be considered in further research, especially from the perspective of occupational justice.

A core component in the definition of leisure and occupational justice, is that it activity choices should be meaningful, intrinsically motivated and self-determined (Hocking, 2017). It is therefore important not only to understand the benefits of participation, but what activities are most motivating.

2.3 SWIMMING AND ASD

2.3.1 PERSONAL AND THERAPEUTIC MEANING AND VALUE

Swimming has proven to be a meaningful leisure activity for children with ASD and their families. As earlier discussed in the study conducted in the US by Eversole et al. in 2016, the top-ranking activities for both typically developing children and those with ASD were similar, with video games, watching TV and going to movies ranking in the top five for both groups. An interesting area of disparity among the top five most enjoyable activities was swimming. The research further demonstrated that children with ASD enjoyed swimming significantly more than typically developing children (Eversole et al., 2016). Lawson et al., conducted qualitative research in America in 2019 aimed at investigating swimming experiences from the perspective of children with autism spectrum disorder (ASD) and their families. In order to explore parents and children's swimming experiences, beliefs, values, feelings, and motivations related to swimming - semi-structured interviews were utilized. Themes that emerged from thematic analysis of transcribed interviews included: "family water activities, safety, characteristics of ASD, instructional methods, swim skills, swimming preferences, barriers/challenges, and benefits of swimming (pg 5)".

The interviews revealed that swimming and water experiences were a meaningful activity for all the families (Eversole et al., 2016., Lawson et al., 2019). Parents cited their child's unpredictability, tendency to wander off, and their attraction to water as concerning and a significant reason for taking their child for swimming lessons (Lawson et al., 2019; Casey et al., 2020). Benefits were similar to those noted in quantitative studies and included social and community participation, opportunities to connect with other parents, relaxation, exercise, safety skills, and swimming as therapeutic. Findings also indicated that when the instructional method was individualized, evidence-based and matched the child's needs, positive skill acquisition was possible, leading to an increase in parent confidence and child safety. Swimming preferences varied between children, from something activating to a relaxing and calming experience – dependent on sensory preferences. Limited resources and environmental factors were common barriers to accessing swimming lessons (Thompson & Emira, 2011; Askari et al., 2015; Lawson et al., 2019).

Not only has swimming specifically proven meaningful to children with ASD and their families but also proven to have other values. Occupational therapists in a number of developed countries have recommended swimming and more specifically aquatic therapy for children with ASD (Murphy & Hennebach, 2020). The inherent properties of water have been utilized for their therapeutic value. An aquatic environment is characterized by resistance, buoyancy and hydrostatic pressure, providing tactile, proprioceptive and vestibular input (Musiyenko, Chopyk & Kizlo, 2020). These properties may be used to facilitate postural control, muscle strength and endurance, while at the same time offering a fun and motivating environment. The sensory input may also be regulating/dysregulating, depending

on the child's specific sensory processing preferences (Musiyenko, Chopyk & Kizlo, 2020). Swimming is a life-skill and leisure activity that individuals with and without disabilities can enjoy across the lifespan (Fragala-Pinkham, Haley & O'Neil, 2011).

There is an increasing body of evidence indicating that children with ASD respond positively to aquatic based intervention (Alaniz et al., 2017; Murphy & Hennebach, 2020). All studies included in a 2014 systematic review investigating the effect of an aquatic therapy program on behaviours of children with high functioning ASD (aged 3-12 years) demonstrated improvements in social interactions and behaviours (Kumar, Mortimer, & Privopoulos, 2014). These included decreased stereotypical movements, hyperactive behaviour and anxiety, with increased responsivity to stimuli and interaction with the environment (Yilmaz et al., 2004; Du Bois, 2011). Overall, parents reported that their children enjoyed the programme and the opportunity for exercise. Parents also noted that their children demonstrated improved self-confidence, social performance and relationships (Pan, 2011; Du Bois, 2011). Aquatic activities provided opportunities for social interaction and play, which facilitated language development and improved self-esteem and awareness with a sense of achievement (Mills et al., 2020; Pan, 2012). However, in a 2017 study conducted by Alaniz et al. social skills did not respond to aquatic group therapy, contradictory to the early research, but improvements in swim skills were documented (Alaniz et al., 2017). Occupational therapists have also reported improved attention, muscles strength, balance, tolerance of touch stimuli, eye contact and social participation (Du Bois 2011; Vonder Hulls et al., 2006). Improvements in motor coordination were noted in all four studies, although this was not the core outcome being measured. (Kumar et al., 2014). However, one study not included in this review noted no statistically significant improvements in fitness (Fragala-Pinkham, Haley & O'Neil, 2011).

Although positive outcomes were noted across the research, some contradicting evidence was found for fitness (Fragala-Pinkham, Haley & O'Neil, 2011) and social skills (Alaniz et al., 2017). Limitations regarding sampling techniques, allocation of subjects to treatment groups, homogeneity of treatment groups, and blinding were also noted across the research. It may be difficult to address these areas in research due to the population of interest and the intervention administered. Furthermore, due to the broad social and behavioural impairments experienced by children with ASD there is difficulty selecting standardized outcome measures and treatment strategies across all studies – limiting generalizability. Standardised and evidence-based programs for teaching children with ASD how to swim have yet to be fully developed (Alaniz et al., 2017; Murphy & Hennebach, 2020). There also exist possible limitations in implementing the intervention in question across a variety of contexts. Access to aquatic/hydrotherapy services is likely to be influenced by local health care models of service delivery and funding arrangements. Most classes/programs were taught by health care professionals and not by swimming teachers themselves, with only two articles that were specifically written by and included swimming teachers. Swimming teacher's voices regarding their experience

are largely absent from the literature. It may also be important to consider the monetary cost to families of children with ASD, having to attend lessons with health professionals, as opposed to swimming teachers with special training in ASD, bringing us back to the usefulness of non-specialist mediated interventions and task sharing (Naveed et al., 2019). These factors need to be taken into account when considering hydrotherapy/swimming as a therapeutic option (Kumar et al., 2014).

It is clear that learning to swim demonstrates a number of benefits for the children and their families (both as a means and as an end) (Murphy & Hennebach, 2020), while not learning to swim also has its consequences - such as drowning.

2.3.2 WATER SAFETY AS A LIFE SKILL

In November 2014, the World Health Organization (WHO) reported drowning to be the third leading cause of unintentional injury death worldwide. They also reported that drowning death rates were highest in the WHO African Region, accounting for approximately 20% of global drowning, with a drowning mortality rate of 13.1 per 100 000 population, with the highest drowning rates being among children 1–4 years, followed by children 5–9 years. There is a large variation in global drowning mortality, with drowning rates in LMIC's reported to be over three times higher than those in high-income countries (Saunders, Sewduth, & Naidoo, 2017). The WHO cited lower socioeconomic status, being a member of an ethnic minority, lack of higher education, and rural populations as risk factors that increased the likelihood of drowning (WHO, 2014).

Specific statistics for South Africa are considered to underestimate our drowning statistics due to a lack of record keeping and accurate data collection (Saunders, Sewduth, & Naidoo, 2017). Across their systematic review of drowning statistics in South Africa, the highest proportion of drowning fatalities occurred in the age group 1 - 4 years, consistent with global trends. In one city-level analysis of NIMSS data (Donson and Van Niekerk's), the rate of drowning was particularly high in the city of Johannesburg (9.3 per 100 000 population), with approximately half of drowning incidents occurring in and around the home. Bodies of water common to drowning in South Africa were private and public swimming pools and buckets in low-income areas (Saunders, Sewduth & Naidoo, 2018).

As previously noted, Autistic children are at a higher risk of drowning than typically developing children due to wandering behaviour and decreased risk awareness (Murphy & Hennebach, 2020) . Furthermore, it has been hypothesized that certain children with ASD are particularly drawn to bodies of water near their homes due to the sensory qualities of water (sound and visual movement) (Guan & Li, 2017; Casey et al., 2020). Among the WHO recommendations to prevent accidental drowning, especially among children, is teaching school-age children basic swimming, water safety and safe rescue skills. Saunders, Sewduth & Naidoo also call for strategic implementation of evidence-based intervention programmes, by trained and skilled teachers, to prevent drowning in resource-limited settings such as South Africa (SA) (2018).

2.3.3 TEACHING CHILDREN WITH ASD HOW TO SWIM

Teaching typically developing children how to swim (or in general) can sometimes be a challenging activity. Teaching a child with ASD how to swim may be made even more so, due to difficulties with social and communication skills, delayed gross motor skill development, difficulty planning movements and difficulties with self-regulation (Hall, 2013). Parents also described personal traits, such as extreme excitement or lack of attention, having an impact on swimming (Lawson et al., 2019). This may be further compounded by the teacher's/instructor's lack of knowledge regarding ASD and training in appropriate handling techniques (Hall, 2013; Lawson et al., 2019) and may perpetuate occupational marginalization.

While teacher's voices are largely absent from the available research in the swimming context, their experiences in the context of teaching children with ASD in school/classroom environments has been well explored in literature. This is especially true since more emphasis has been placed on inclusive education. Available literature shows that finding effective strategies to facilitate inclusion of autistic children in mainstream classrooms has proven difficult for teachers from a variety of countries and backgrounds (Soto-Chodiman et al., 2012; Anglim, Prendeville & Kinsella, 2018; Stites, Walter & Krikorian, 2020). Teachers noted that they were apprehensive initially at the prospect of having to facilitate inclusion of children with ASD in their classroom. They related this to a lack of support, knowledge and resources on how to handle the children's behaviour and ensure a successful learning experience (Soto-Chodiman et al., 2012; Anglim, Prendeville & Kinsella, 2018; Stites, Walter & Krikorian, 2020). As a result teacher's required a high degree of self-efficacy, adaptability and creativity to enact a trial-and-error approach to teaching (Soto-Chodiman et al., 2012; Anglim, Prendeville & Kinsella, 2018). Although the classroom and the swimming pool may be two different environments, each with their own challenges, teachers in both environments are still required to facilitate learning and skill/knowledge acquisition.

Preliminary evidence from Alaniz et al. (2017) demonstrated that children with moderate to severe ASD are capable of learning swim skills. They established that skills for water safety and drowning prevention could be taught successfully after a total of 16 hours of classes. Classes were one hour with a ratio of one teacher to two children per class. Children had no previous swim experience. They were taught by an occupational therapist and speech therapist, with extensive experience in swimming coaching/instruction and treating children with ASD. Volunteer interns, who were qualified swim instructors and lifeguards, with experience teaching typically developing children were also utilized to increase the adult to child ratio and to help ensure participant safety (one per class). Despite being a trained swimming instructor, volunteers reportedly required extensive instruction from the occupational therapist (Alaniz et al., 2017). Considering the specialized experience and training of the primary instructors, it may be difficult to replicate these results across various sectors (Alaniz

et al., 2017). Research may further consider if swimming teachers could be trained to deliver this as a non-specialized intervention.

Hall further sighted that parents of children with ASD often have difficulty finding swimming lessons that cater for their child's specific needs. Several parents in his 2013 study noted that they would like their child to participate in traditional lessons but were dismayed by their previous attempts and the limited capacity of the program to provide instructional support for their child's special needs. Lawson et al. noted that from family's perspectives the instructor's knowledge of autism, the child's bond with the swim instructor, consistency with that instructor and a structured class were essential to quality instruction. (Lawson et al., 2019). The following techniques have been recommended to assist teachers: firstly, extended time and one-on-one instruction with visual supports, minimal verbal-cues, Hand-over-hand assistance and demonstration. Secondly, a routine, predictable and controlled environment was beneficial for the students in regulating sensory issues. Finally, the following teaching tools were found to be useful in improving sensory regulation, safety and comfort: wet suits, arm weights and a floating mat/platform (Hall, 2013; Kraft, 2019; Kraft, Leblanc & Culver, 2019; Lawson et al., 2019).

2.4 CONCLUSION:

Overall, this literature review concludes that although all human beings have the right to participate in occupations which are meaningful to them, they do not always have the opportunity to do so. Children with ASD and their families, due to a number of barriers, may experience occupational marginalization and deprivation. Swimming has proven a meaningful activity for children with ASD and their families in other countries. It can provide children with a survival skills and improve psychosocial and other capacities. However, teachers are not always equipped to provide a service that families feel is inclusive and accessible to them and their children with ASD – representing a barrier to occupational justice.

CHAPTER THREE: METHODOLOGY

3.1 TYPE OF STUDY/RESEARCH METHOD

Qualitative research is defined as the "study of things in their natural setting; attempting to make sense of, or interpret phenomena, in terms of the meanings people bring to them" (Denzin and Lincoln in Creswell, 2002, pg3). For the purposes of this study, a qualitative research approach was selected, with a descriptive phenomenological design. This definition was applied to the research aim/question, where swimming as an occupation for children with ASD is the phenomenon and the aim was to understand the *lived experience* of parents and swimming teachers of these children. This inherently implies measuring a subjective experience where not all the variables are known or can be controlled. (Creswell, 2007; Smith & Osborn,). As previously explained, swimming for children with ASD in South Africa is relatively unexplored phenomenon.

A paradigm is described as a basic set of beliefs that guide action (Creswell, 2007). Social constructivism combined with interpretative disability theory are the paradigms underpinning this research and have guided the actions/process of the study. Social constructivism focuses on understanding the subjective meaning of experiences to individuals within a specific context. In this case, the focus is on the subjective experience of parents and swimming teachers, in the context of swimming lessons for children with ASD. Disability theory considers the meaning of inclusion in the environment, taking into account views of various stakeholders, and considering disability as a dimension of human difference, not a defect (Creswell, 2012). The research acknowledges that for children with ASD and their families, the experience of swimming lessons may be a different one and their experience of this is valuable to promote further inclusion. Overall, complex views were obtained through broad questions and inductive reasoning to better describe the experience of parents and swimming teachers of children with ASD in the swimming context in South Africa.

3.2 RESEARCH PROCEDURES:

3.2.1 RESEARCH CONTEXT

All of the research participants reside in/work in the Johannesburg and Ekurhuleni Metropolitan Municipalities in Gauteng Province. Parents and swimming teachers were from similar socio-economic backgrounds, staying in middle/upper class suburbs in these areas. This geographical area was chosen due to convenience for the researcher (both for transport and access to the population required). Within this context there are no formally advertised swimming lesson's available for children with ASD – as swimming teachers in South Africa are not trained in this field (as previously discussed). However, there are a number of swim schools available across both the aforementioned areas of Gauteng, often with multiple swim schools in a single suburb.

3.2.2 PARTICIPANTS

1. Parents of children formally diagnosed with ASD who are participating in swimming lessons.
2. Swimming teachers who have/are teaching children with a formal diagnosis of ASD.

As childhood occupations are largely determined by a child's parents and activities in which they place value, the focus of this study is primarily on the experience of parents and swimming teachers. Children generally start learning to swim from the age of four or five years, this, combined with the communication deficits characteristic of ASD, would have made obtaining in-depth information from the children themselves difficult. Parents and swimming teachers were able to provide a depth of information regarding their own experiences in this context and their *perception* of their child/children's experiences. Participants came from a variety of cultural and ethnic backgrounds. Teachers were from similar socio-economic and cultural backgrounds to parents and children. Two teachers taught at special needs schools. These special needs schools served different population groups with one being a small, private school in Johannesburg, another being a large government school just outside of Alexandra Township. This is further laid out in the results chapter (Table 3,4).

3.2.3 SOURCING PARTICIPANTS

The researcher is a registered member of Swimming South Africa (SSA), as a Learn-to-swim (LTS) instructor. This provided the researcher with access to other registered LTS instructors through SSA, who are currently/have taught children with ASD how to swim. Swimming South Africa sent out an email on behalf of the researcher to all registered learn-to-swim instructors in the Gauteng area, inviting them to participate in the study (Appendix C). The email included the consent forms, background of the study and request for participation (Appendix A-C).

Initially responses were slow from the aforementioned general email. The researcher then conducted an online search for swimming schools in Gauteng who advertised that they offered swimming for special needs. These swim schools were contacted telephonically to introduce the research and invite them to participate. Follow-up emails were sent to those who were interested. From this, four of the six teacher participants in the research were obtained. The other two teachers responded to the original email.

At the end of the teacher's interviews, the researcher obtained permission from them to approach the parents of the children they teach. Teachers were asked to first check with parents if it was fine to pass their details along, in order to respect their privacy and autonomy. The parents who gave permission were then contacted by the researcher telephonically to ask for their feedback/participation, with similar processes followed for making contact and obtaining informed consent (Appendix A and C).

3.2.4 SAMPLE SELECTION

The following inclusion criteria were considered, within each group:

1. Parents of children (under the age of 18) who are:
    a. formally diagnosed with ASD
    b. participating/have participated in swimming within Gauteng for at least 6 months
2. Swimming teachers who have/are
    a. Registered and qualified learn-to-swim (LTS) instructors with Swimming South Africa (SSA)
    b. teaching/has taught children with a formal diagnosis of ASD within Gauteng for at least 6 months

Purposeful sampling and snowballing were used in order to obtain participants who not only meet the inclusion criteria, but who also provided rich, in-depth information regarding the phenomenon. The inclusion criteria in all categories were met by all participants. Of the 7 participants who contacted the researcher, one participant was excluded as she taught children with other special needs, but not ASD.

An approximation of sample size was (and always is) necessary for planning and development of a research protocol (Malterud, Siersma & Guassora, 2016), but simply meeting the predetermined number of interviews does not necessarily account for saturation – the data must be reviewed concurrently with collection to determine saturation (Hennink, Kaiser & Weber, 2019). Two different types of saturation have been defined in literature, namely code/thematic saturation and meaning/theoretical saturations (Malterud, Siersma & Guassora, 2016; Hennink, Kaiser & Marconi, 2017). “Code saturation may indicate when researchers have “heard it all,” but meaning saturation is needed to “understand it all.”” In this case, the focus is on gaining insight into a breadth and depth of experiences/themes in the context of swimming for children with ASD in South Africa. Saturation is reached when there is sufficient informational power to capture the range and complexity of this experience and when no new themes/ideas emerge/the same themes are being repeated (Hennink, Kaiser & Weber, 2019).

However, true measures and means of determining data saturation have been a topic of debate within the field of qualitative research, with most methods still grappling with how to make subjective observations of the researcher, objectively measurable (Malterud, Siersma & Guassora, 2016; Lowe et al., 2018; Saunders et al., 2018). Research has noted that code saturation may be reached before meaning saturation and that it is almost impossible to predict what “number” participant will share information that will add new depth of understanding to the working theory (Saunders et al., 2018). The researcher thus set out with the goal of achieving data saturation, that is the goal to “hear it all” and “understand it all” through the methods described below, but with the simultaneous

acknowledgement that true meaning saturation may be difficult to objectively and empirically claim (Lowe et al., 2018; Saunders et al., 2018).

The recommended sample size for this study was twelve participants (six teachers and six parents) (Malterud, Siersma & Guassora, 2016). Data collection and initial data analysis were concurrent to determine data saturation. The researcher reflected on interviews as they were completed to highlight any new points raised or points which were repeated. Six teacher interviews and five parent interviews were conducted. The recommended number of 12 interviews was not reached as a final participant could not be recruited – difficulty with recruiting a final parent to interview was related to timing relative to CoVID-19 lockdown restrictions and the relatively small size of the population available to the researcher. All except one interview was conducted with only one parent. For most of the interviews it was convenient for only one parent to meet due to time constraints. One interview, conducted on a Saturday, included both parents as they both expressed an interest in being present and had arranged a babysitter for their son. This still counted as only one interview, although it had two participants.

3.3 INSTRUMENTATION

The research utilized semi-structured, in-depth interviews. An interview schedule was developed as part of the initial protocol for the research study (Appendix D). The interview schedule was reviewed and refined with the help of the research supervisor, before being utilized. This form of instrumentation was best suited to the study design and allowed for a broad variety of subjective experiences in the swimming context to be explored (McIntosh & Morse, 2015; McGrath, Palmgren & Liljedahl, 2019). Questions asked in the interview were open ended, unless to clarify a specific statement made by a participant. This was to ensure that a breadth and depth of information was gained, and so as to avoid introducing bias into the study (McIntosh & Morse, 2015). Three different guiding questions were selected and structured to ensure the answers from both parents and teachers spoke back to the research aims and were formulated based on the existing literature that was reviewed in this context. Probes were used mainly in response to statements that demonstrated strong emotion or description, to further understand the experience (Adams, 2015; McIntosh & Morse, 2015; Kallio et al., 2016).

In preparation for the interviews, to ensure sound instrumentation, the interviewer practiced two interviews with another student from her same degree and reviewed these with her supervisor (McIntosh & Morse, 2015). This helped to ensure that the interviewer obtained a depth of experience, not simply a breadth. Notes were made and the interview schedule adapted again to include probes for more specific trigger words, specifically those with strong emotional connections or imagery (eg: “the lesson was *chaos*” - “Tell me more about that, what does that look like?”) (Kallio et al., 2016).

Although semi-structured in-depth interviews were the primary instrument for data collection, demographic data was also collected from participants (as outlined in appendix D) as this helps to situate the data contextually. Parents were also proud to share video's/pictures of their children either at swimming lessons, or swimming on holiday (self-initiated and without request by the interviewer). This additional multimedia data served to further embellish the researchers insight into the stories/experiences shared by parents. Each of the interviews were approximately one hour in duration.

Adjustment had to be made to the research instrumentation from face-to-face interviews, in-person, to face-to-face interviews over an online video call. The first eight interviews (five teachers and three parents) were completed face-to-face over a period of two weeks. The research was put on hold for a period of six weeks by the University of the Witwatersrand due to concerns regarding health and safety as a result of a global pandemic. Following this, the remaining three interviews were rescheduled and completed via Zoom (1) and Whatsapp video call (2), over a period of two weeks. The platform used was at the request and comfort/familiarity of the participants. A change in delivery method of the instrument was necessary to protect the health of the researcher and participants and to ensure compliance with disaster management protocol, as set out by the South African government, in the face of the CoVID-19 pandemic. This change was further approved and advised by the University Human Research Ethics Committee. It is interesting to note that although one may assume digital interviews may be easier to schedule than face-to-face, this was not the case, with all three remaining participants finding it difficult to schedule a suitable time amongst other household and work responsibilities.

Another important consideration with regard to data interpretation and this change in methodology is the establishment of rapport. Rapport is defined as an ease in interaction, or a respect established between parties allowing them to work together (Weller, 2017). This is a vital aspect of qualitative research, which enables researchers to obtain a depth of information about a person's experiences. One may assume that rapport is better established during face-to-face interviews, however, Weller (2017) found that rapport can equally be established via online video calls, provided there is a good quality video and internet connection, allowing for visible "co-presence". Participants in her research reported that although this form of interview felt less formal, it was also experienced as less daunting. Visible co-presence helped to facilitate an emotional connection that in some cases was greater than face-to-face, due to a sense of ease with the setting. For the three interviews carried out online, all three participants were at ease in their homes, they also had good internet connections and clear video calls were established. These interviews provided equal length, depth and quality to those that were conducted face-to-face, with consistent themes emerging.

3.4 PROCEDURE

The following procedure was followed in carrying out the research, in line with the methodology for a descriptive phenomenological study:

1. The research protocol was written, submitted and approved by the University of the Witwatersrand, Occupational Therapy Department for submission to the School of Therapeutic Sciences Protocol Assessors' committee
2. The protocol was then submitted to the School of Therapeutic Sciences Protocol Assessors' committee. Suggested changes were made to the protocol, following which the title was approved (Appendix E).
3. The approved title and research protocol were then submitted to the Human Research Ethics Committee.
4. Ethical Clearance Certificate (M190910) was received on 08 November 2019 (Appendix F).
5. Practice and review of the interview schedule with the research supervisor took place to ensure sound instrumentation.
6. Participants were obtained via:
    a. Swimming South Africa: sent out an email on behalf of the researcher to all registered learn-to-swim instructors in the Gauteng area, inviting them to participate in the study (Appendix D). The email included the consent forms, background of the study and request for participation.
    b. Initially responses were slow from the aforementioned general email. The researcher then conducted a search for swimming schools in Gauteng who advertised that they offered swimming for special needs. These swim schools were contacted telephonically to introduce the research and invite them to participate. Follow-up emails were sent to those who were interested. From this, 4 of the 6 teacher participants in the research were obtained. The other 2 teachers responded one week later from the original emails.
    c. At the end of the teachers interviews, the researcher obtained permission from the swimming teachers to approach the parents of the children they teach. Teachers were asked to first check with parents if it was fine to pass their details along. The parents were then contacted telephonically to ask for their feedback/participation, with similar processes followed for making contact and obtaining informed consent (appendix A and C).
7. The researcher engaged in reflective journaling throughout the interview process.
8. Transcription of interviews was concurrent with data collection and data analysis.
9. Wrote the research report, with a personal and literary rhetoric.
10. Research report submitted for examination

Voice recordings were taken during all the interviews. This facilitated better rapport between the interviewee and interviewer. Some participants were aware of the recording device for the first few minutes, but settled into relaxed conversation thereafter. Although some of the interviews were conducted online and included video, only audio recording was taken on a separate device to ensure consistency between face-to-face and online interviews. Following each interview, the voice recordings were checked for quality and backed up to electronic storage on a private, password protected Google Drive – to protect confidentiality. Thereafter they were submitted for transcription. All interviews began with a clarification of the consent process and a review of the expectations of the interview process. All participants had an opportunity to ask questions before starting (as set out in the interview schedule). The aforementioned steps aimed to ensure participant respect, autonomy and justice. At the end of all interviews, the participants were thanked for their participation, reminded of their right to withdraw at any point and asked if they would like to have access to the research results once completed – again ensuring autonomy. Although participants consented to be available for multiple interviews, this was not required as sufficient information was gathered from the initial interview with all participants. Although a distress protocol was included, none of the participants demonstrated/expressed distress during/after the interviews.

3.5 DATA ANALYSIS

Colaizzi's seven-step method for data analysis (Colaizzi, 1978) was utilized to pursue an in-depth exploration of experiences in the context of swimming lessons for children with ASD in South Africa. This method of data analysis provides explicit, sequential steps that increase the reliability and dependability of the results – enabling researchers to fully explore an experience/phenomenon (Wirihana et al., 2018).

Table 1: Colaizzi's Seven-Step Method for Data Analysis

Colaizzi's Seven-Step Method for Data Analysis (Colaizzi, 1978)	
1	Reading and rereading the transcripts
2	Extracting significant statements that pertain to the phenomenon
3	Formulating meanings from significant statements
4	Aggregating formulated meanings into theme clusters and themes
5	Developing an exhaustive description of the phenomenon's essential structure or essence
6	A description of fundamental structure of the phenomenon is subsequently generated
7	Validation of the findings of the study through participant feedback completes the analysis

To summarize, in step one, the researcher began by familiarizing herself with the transcriptions of the interviews (reading and re-reading). This steps ensures that the true essence/meaning remains at the core of the research as the researcher progresses through the steps and that participant's true meanings are not lost. Once the researcher was familiar with the transcripts, significant statements pertaining to the phenomenon were highlighted and extracted. These extracted statements were sorted into tables (see example below) to facilitate a cohesive output between steps 2 – 4. (Appendix G)

Table 2: Example of Coding Process According to Colaizzi's Method

Location of significant statement	**Significant statement**	**Formulated meaning ("Code")**	**Thematic cluster**	**Theme**
T100	"Luckily for me the very first class that I had a kid like that was one-on-one. Okay so it wasn't hard work, well it was hard work but it wasn't like I had other kids I had to worry about. I could focus on this kid"	One-on-one is useful	Groups vs one-on-one	Teaching techniques

Information regarding the participant who made the statement and any important contextual information around the statement was kept in the tables so as to ensure the meaning was not lost. Meanings were then formulated from the extracted statements and further arranged into theme clusters and then into themes. These themes were then combined to create a rich and exhaustive description of the phenomenon, which was further narrowed down to three overarching theme's – in answer to both the research aims and to describe the phenomenon in a succinct way, while still forming a relatable, understandable visual image. Once this was completed, a summary of the findings was sent back to participants for feedback (as discussed below). The data analysis was also peer-reviewed (as discussed under trustworthiness). Finally, the researcher also made use of transactionalism in her interpretation to gain an in-depth understanding of parents' and teachers' experiences.

Efforts were made throughout the study to obtain the full spectrum of views/experiences of the participants, so as best to understand the nature of the phenomenon and try to ensure data saturation.

3.6 TRUSTWORTHINESS

Epistemologically, the researcher has some knowledge and experience working with children with ASD and their families. The researcher is a trained Occupational Therapist, thus working from an Occupational Science frame-of-reference, which will influence the value placed on engagement in occupations. Furthermore, the researcher is trained as a learn-to-swim instructor with exposure to the

swimming context. The background knowledge available to the researcher enabled the researchers to engage in the research process, but can also introduce bias. For this purpose, bracketing and a number of other strategies were implemented throughout the research process to ensure credibility and confirmability.

The researcher began the process of bracketing (acknowledging her own subjective experience of the subject matter and possible biases that may arise therefrom) before beginning the protocol writing process. This continued throughout the research process and was written in a journal and discussed with her research supervisor, before interviews, during data collection and data analysis and in writing the research report (Appendix H). Other strategies utilized to ensure trustworthiness included:

1. Member checking – Colaizzi's method differs from other methods of phenomenological data analysis as it requires participants to validate findings as part of it's seven steps to ensure accuracy and credibility (Wirihana et al., 2018). A summary of the findings was sent via email to all the participants, requesting their feedback. Two weeks were given for them to review the findings and either confirm that they were a true representation of their experience or to suggest amendments. Six of the eleven participants (four parents and two teachers) responded to the email, stating that they were happy that the results were a true reflection of their experience. No one who responded disagreed with the summary or asked that any changes should be made. A follow-up email was sent to the remaining participants to allow them a final opportunity to provide feedback, however the remaining five participants did not respond.

2. Peer review – An occupational therapist and Master's student at the University of the Witwatersrand was approached to assist with the peer-review process. She read and co-coded a parent interview and a teacher interview using the same method as the researcher (as described above). Once she had coded the interviews, these codes were compared to the researcher's codes and read relative to the established theme's/categories and subcategories. Overall there were no new codes that emerged from the peer-reviewed transcripts. The co-coder confirmed that the established themes captured the essence of both interviews and that all important points had been included within the themes.

3.7 ETHICAL CONSIDERATIONS

The research study upheld the core ethical principles of beneficence, non-maleficence, autonomy and justice. All participants were informed on multiple occasions (verbally on first contact, electronically on consent form and verbally again before the interview) of what the study entailed, how their information would be used, and the possible benefits/harm of their participation in the study, before

they gave consent to participating. Permission from the chairperson of SSA was gained prior to sending out requests for participation. There were no benefits or harm experienced in participating in this study. An information sheet (Appendix C), interview and audio-recording consent forms (Appendix A and B) outlining all the aforementioned information were sent when requesting participation and details regarding the research and consent re-stated verbally before commencing the interview process.

The research participants had the right to withdraw from the study at any point in time – although none chose to do so. If they had chosen to withdraw, their data would have been excluded from the research entirely. As no-one withdrew, all interviews were included in the research. In order to maintain confidentiality, all identifying information of the swimming teacher, swimming school and parents/children was removed and participants were allocated a pseudonym by which they could be identified in the research. Transcriptions and recordings were securely stored on a password protected Google Drive (to which only the researcher had access), using only the identifying pseudonym to represent the participant.

CHAPTER FOUR: RESULTS

"Diving in" to swimming lessons for children with ASD

The aim of this study was to explore swimming as an occupation for children with ASD in South Africa, by examining parent and swimming teacher experiences separately and in combination. As there are currently no formal swimming programs for children with disabilities in South Africa, or any available research in this context – it was vital to first obtain feedback from those who have/are already engaged in this context, to determine if there is benefit derived by children with ASD and their families and if teachers feel well-equipped to provide lessons.

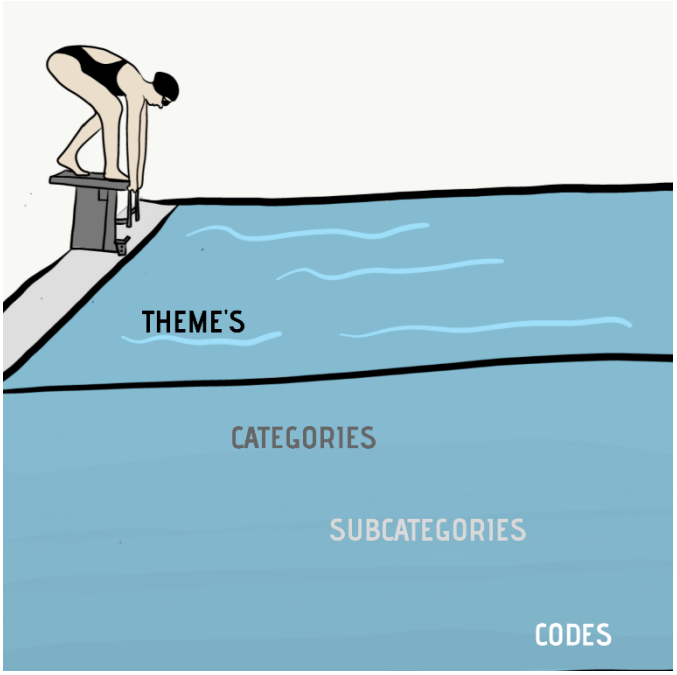


Figure 2: "Diving in" to swimming lessons for children with ASD

Three overarching theme's emerged in answer to the research aims, namely:

1. **From being thrown in the deep end to stepping up to the starting blocks** – teachers changing experiences and the nitty gritty of lessons (answering the first aim)
2. **From just keeping your head above water to making a splash and going for gold** – parents changing experiences (answering the second aim)
3. **Teamwork makes the dream work** – the relationship between parents and teachers (answering a combination of the two aims)

Overall, parents and their children experienced swimming lessons in a dynamic and meaningful way, providing them with not only a life skill, but a sense of achievement that went far beyond that. However, as much as this proved a meaningful occupation for children with ASD and their families, accessibility and inclusion emerged as a common challenge from both parent and swimming teacher perspectives. Teachers often felt thrown in the deep end initially - feeling they had a lack of training and support in this context. Although they grew confidence and skill through their experiences, they still expressed a desire to have more certainty in the service they were providing. The most important message teachers learnt from lessons was that every child with ASD is different (to each other and to typically developing children) and that your personality as a teacher and the techniques you use will influence the outcome of lessons. On the converse side of this, parents also experienced a changing context, going from "just keeping their head above water", with the focus on swimming as a survival skill, to going for gold and realizing that

swimming can have a number of different meanings for them and their children. All parents expressed a sense of fear that their child may drown motivating them to seek out swimming lessons for their child. Once their children were engaged in lessons, many parents noted that the aquatic environment was motivating for their children, giving them a sense of achievement and pride. What was initially only a survival skill gradually became a leisure activity, a form of exercise, a routine providing sensory regulation and facilitating improvements in other life areas (such as school and activities of daily living). Parent and swimming teacher relationships also had an impact on both the likelihood and success of lessons.

DEMOGRAPHICS:

All parent participants in the research study were from the Johannesburg or Ekurhuleni Metropolitan Municipalities, living in middle to upper class suburbs and coming from a variety of cultural backgrounds. All of their children started swimming lessons in their pre-school years (age 3-6 years). The majority of the children of parent participants were boys (4), with only one girl. This is consistent with the typical male to female ratio of children diagnosed with ASD (4:1) (DSM V). All of the children had undertaken at least one year of swimming lessons (table 3). The majority of teacher participants had more than 10 years' experience providing swimming lessons, with multiple additional qualifications (including SSA). One participant also had an honours degree in Biokinetics – this was also the participant with the least practical experience, but a more in depth theoretical knowledge. Teacher participants working at special needs schools (2), had taught the highest number of children with ASD. All the teachers were based in the Northern suburbs of Johannesburg (table 4).

Table 3: Parent and Child Demographics

	Child's age at time of interview	**Age when starting swimming lessons**	**Number of years in swimming lessons**	**Gender (child)**	**Socio-economic status/community setting**
P104	8 years	3 years	4-5 years	Male	Johannesburg East, Upper Class
P106	5 years	4 years	1 year	Male	Johannesburg East, Middle Class
P107-1 P107-2	5 years	4 years	1 year	Male	Johannesburg North, Middle Class
P108	16 years	6 months	15 years	Female	Johannesburg North, Upper Class
P110	5 years	4 years	1 year	Male	Johannesburg North, Upper Class

Table 4: Teacher Demographics

	Age	Years of swimming experience	Training/Qualifications	Number of children with ASD taught over years of experience	Place of work
T100	34	13 years	Learn to swim (SSA) Swim Australia Swim America Swim England Rescue Diver	3	Private swim school (Johannesburg North)
T101	35	13 years	Learn To Swim (SSA)	2	Private swim school (Johannesburg North)
T102	28	6 years	Learn to Swim (SSA) Diploma in fitness and sports conditioning	3	Private swim school (Johannesburg North)
T103	33	13 Years	Aquatots Learn to Swim (SSA)	20	Private swim school and special needs school (Johannesburg North)
T105	25	1 year	BSc Sports Science BSc (Hons) Kinderkinetics Learn to Swim (SSA) ASCA level 2	2	Private swim school (Johannesburg North)
T109	36	15 years	Swim Australia (Institute of Sports) Learn to Swim (SSA) Infant Aquatics Course (IAA – America)	15	Private swim school and special needs school (Johannesburg North)

4.1 THEME 1: TEACHERS EXPERIENCES - FROM BEING THROWN IN THE DEEP END TO STEPPING UP TO THE STARTING BLOCKS

Table 5: Theme one

Theme	Category	Subcategory
From being thrown in the deep end to stepping up to the starting blocks	Teachers' dynamic experiences	"your knees are knocking"- nervous initially
		Experience grows confidence
		Challenge accepted – excited to learn and grow
		Rewarding to build relationships and see progress
		Challenging to deal with slow progress and find a balance in handling
		Disappointment at lack of information/support available
		Need and desire for more specialized training – want to provide a quality service & have certainty in skills
	Personal presentation and traits	It takes someone special
		Patience
		Perseverance
		Observant and flexible/adaptable
		Intuition/Instinct
	Different Strokes for Different Folks	Understanding how the child perceives the world
		Respect for individuality
		Meeting the child where they are
		Observe and react
		Be aware of your expectations
		Trial and error – just wing it
	Teaching techniques (Every child is different, but some techniques are helpful for all of them)	Groups vs one-on-one
		Types of feedback: Physical guidance, demonstrations and verbal instructions
		Duration of lessons
		Use of equipment and toys
		Boundaries
		Repetition and routines
		Role of the environment in attention
		Other tricks
		Other teachers and professional support

This first category explores teacher's experiences of providing swimming lessons for children with ASD in South Africa, with some reinforcing statements provided from parents. This speaks back to answer the first objective of the research.

Teachers experienced providing swimming lessons for children with ASD in a dynamic way, going from being "thrown in the deep end" – that is feeling ill-equipped with the knowledge/training necessary to provide this service with confidence – to "stepping up to the starting blocks" - with nervousness gradually shifting towards a feeling of confidence and accomplishment. This shift was facilitated through experiential learning, where teachers learned about Autism, themselves and the importance of open communication with parents through being "thrown in the deep end".

4.1.1 Category 1: Teachers experiences in teaching children with ASD

Teachers experienced providing swimming lessons for children with ASD in a dynamic way. They expressed a sense of nervousness initially at not knowing what to expect from lessons. A feeling of being "thrown in the deep end" which was related to a lack of knowledge/information on how best to approach these children is reflected in the below statements:

> *T101: The first lesson I was extremely nervous. I'm not going to lie. So, I'd like to know how should I be talking to these kids? How do they learn? So like what ways do they learn better so that I can like implement those into my classes.*

> *T102: My first class with him… excited but nervous, excited to learn something new, learn something different… expand my knowledge as a swimming teacher and nervous because "what am I doing?" "Am I doing the right thing?" "Am I going to help"? "Am I hurting?" "Am I doing anything that's going to complicate things for him?*

> *T109: So, you know, your knees are knocking…*

However, from being thrown in the deep end initially, most teachers gradually gained confidence and knowledge through their experience. The first lesson proved to be the biggest learning curve and a sense of nervousness gradually shifted toward a sense of excitement and fulfilment – seeing the lessons as an opportunity to learn and grow. Teachers were prepared to "step up to the starting blocks".

> *T103: I think mostly excitement and it was something new and challenging. I really just went in there, thinking I have got the skill and I have got this time and I can try and use it and see how things work out.*

> *T105: …I enjoy it a lot. I love it. I think it's special. I think there's a definite opportunity for this to become a career, or a… ja. I was disappointed that it's not…*

It also became rewarding to build relationships with the children and to see the progress they made over time (both in and out the pool).

> *T103: And then from there it becomes rewarding to see them grow and to see how they actually can learn different skills and then they carry on because they want to better their*

swimming. And it becomes something that they actually enjoy. It is like a hobby. It is not just for safety anymore. It is now become part of their lives.

T105: So just for me, why I loved it so much, was I could see the personality change in them. The confidence they got towards the end. The personal connection that you make with them. They start talking to you, they just become like another kid.

As with all positive experiences, there were still challenging days/moments, especially when dealing with slow progress and in finding a balance when handling the child's behaviour (knowing am I being too firm/not firm enough).

T100: Like at the end of it you're just exhausted. You're like what am I going to do at the end of this week, it's half an hour. I don't know how I'm going to keep you focused every week. At the end of it, but you like at the same time, I'm trying to reassure the parent that this kid is going to be fine.

T103: And, ja it was about a month or a month-and-a-half where he just was not doing anything and eventually the mom was like: "Look, I mean he can swim, he is safe." and then they stopped. And for me, that was horrible because I felt like I had so much more to give.

Four out of the six teachers had 10-15 years of experience and could be considered "expert" swimming teachers based on their years of experience. The remaining two teachers, who had fewer than 10 years of experience, had additional tertiary qualifications related to sport and fitness, one with a diploma, another with BSc (Hons) in sport science – specializing in kinderkinetics. Ultimately there was also a sense of disappointment at the lack of information and support available to them in this context. Despite many years of experience and tertiary training, teachers still expressed a definite need for more specialized training that would provide them with more certainty in their skills and confidence in the quality of the service they are providing to parents.

T105: …I was disappointed that it's not [a career], and that's exactly why I'm here, to help make this happen, or ... I think more people in the field that are interested in it, so that you have someone to phone and ask, or chat about it, or more research – like you're doing – so that I can learn.

T102: …but I am not qualified for special needs, it's very difficult to find a course here in South Africa that does cater for that.

T100: It was difficult to get specific information. I found a lot of it was repetitive. If there was someone out there who actually made a good course and got it properly certified. It would be awesome to have a course to actually know how to talk to kids, how to handle them, and things like that, yes that would be awesome.

Ultimately, despite the lack of available training and resources, teachers gained confidence and learned what worked. They did this through interaction with children and their families and through employing a trial and error approach to lessons. They realized they needed to adapt and individualize their teaching methods to meet each child's specific needs, noting that every child with ASD is different. They also found that it takes a special teacher, to work with a special child.

4.1.2 Category 2: "It takes someone special" – personality and presentation

The teacher's personality and personal presentation emerged as an important element in the determination of the success of lessons.

P110: So you need to have a special person to teach them…

P108: …especially with Autistic kids, you definitely have to have a special kind of person who wants to do the teaching because you need patience and a lot of patience…

Teachers and parents highlighted some common traits which were most effective in lessons. Patience was highlighted as the single most important teacher trait, with parents and teachers noting the high level of patience it takes to work with children with ASD.

T100: You've got to be extremely patient with them, like I have a patience level like here [mid-range indicated with hand] but when I have those kids my patience level is here [higher].

P108: That's another thing; you need to be a saint because [child's name] is hard work. She is a lot of hard work. And [Teacher's name] is patiently, slowly, gently, calm voice, calm voice encouraged her to learn strokes;

P104: …have the patience to let them take their time and understand that some days is not going to be a great lesson, you know?

Perseverance was another important trait – speaking back to the difficult days experienced by parents, teachers and children – but a need to keep going to reach the goal of water safety.

T103: And now he is doing so well in the pool but it was really tough at the beginning and the dad was like "should we quit?" and I said "No, just keep going. Keep going. Keep going."

T109: Yes, it might take a bit of perseverance and you might need a few sort of tricks up your sleeve, but I honestly believe that most Autistic kids should be able to swim and be water safe

Intuition and flexibility were two other important traits, which closely relate to the above statements about "winging it" and meeting the child where they are.

T103: So I find that if you are working with those kids, you are kind of follow your gut.

T109: I instinctively know when enough is enough and how much I can get out of him.

T102: You just… all the time and every day is a new day, you never know, today is a good day; next week could be a great day, it could be an absolutely terrible day, you just never know what you getting with a special needs child, or a superhero kid. So, you just have to adapt who you are all the time; that's why this job you need to be able to adapt.

As much as teacher's personalities were an important factor contributing to the likelihood and success of lessons, they also needed to learn about each child's unique personality and how this can influence the success of lessons.

4.1.3 Category 3: Every child with ASD is different – things to understand before starting

Both parents and teachers emphasized how unique each child with ASD is, and how this can impact on the way in which they engage in swimming lessons.

T103: But I found every week just so amazing and so rewarding and getting to know the kids and each one of them is so individual that you cannot really base your approach with one child on another child because they are all so completely different.

Parent's all described their children's unique interests and personality, with no two being alike. In general, teacher's insight into ASD had developed through some informal, online research, but mostly through interaction in context. They described it as being a spectrum, with children having a range of difficulties with communication and social skills, attention (distractibility) and cognition. They

described/emphasized the features of ASD which in their experience had the most impact on their lessons and the child's skill acquisition.

> *T100: There's nothing wrong with these kids at all, you just have to find a different way to talk to them, or explain things to them, that's really all it is.*

> *T102: What I understand of it is they live in their own world, they live in their own mind, they very much live inside here and you've got to be able to get their attention.*

> *T103: ... I think I would explain it as a person's brain just wired to experience the world in a different way. So it has got nothing to do with intelligence or understanding or anything. I think it is just the way that they experience it. It is just very different to what normal kids experience or people experiencing.*

> *T109: So, you know, I guess my exposure to it is kind of a communication… the communication side obviously stands out for me.*

When reflecting on this, they identified that you needed to respect each child's individual abilities/difficulties and to manage your expectations for the lesson accordingly.

> *T105: So my expectations was, I'm going to work with what I see in the pool. I didn't expect them to perform according to what I think they should be able to do. I wanted to see what they can do…*

> *P110: …like the only way that you would break through with a kid with autism is to respect them and explain. …her [the teacher's] style and the respect that she shows the kids in the water and the child; I think it is also about the way she speaks to the kids; the trust in the eyes [referring to what makes her teaching effective].*

They noted it as being important to observe and react to the child's needs – meeting them where they are on a specific day (as this can change) and responding in a respectful and adaptable way.

> *T102: So, you just have to adapt who you are all the time; that's why this job you need to be able to adapt.*

T100: You have to look at how they come to you and go alright you cool, that's fine, we can do a lot more today, or okay today we're going to take it easier. You just have to adjust for how they're feeling that day.

Overall, teachers recommended a "just wing it" approach, stating that preparing for a first lesson with a child with ASD was difficult (and sometimes pointless), as they are each so different.

T101: I would say winging it, because you don't know until you have the kid in front of you. They are all completely different people. I guess I would just wing it.

T100: I wouldn't work out a program beforehand, there's no point in preparing anything beforehand. Wait for you to get there and work on how you react to me.

An understanding of both the child and the teacher's personality proved important contributing factors to lessons, which could be complimented by a number of practical teaching techniques that teachers found to be effective through experience.

4.1.4 Category 4: Practical teaching techniques

Through their experiences of teaching and in discussing with each other/healthcare professionals, teachers found a number of techniques useful in teaching children with ASD. Although each child with ASD is different, certain techniques proved useful for most of them. One-on-one lessons proved more effective initially and were also the preference of parents – allowing the teacher to focus her attention on just the child. However, groups also became useful at a later stage so that the child could first observe others and then participate.

P107: One on one is priority for me. That's absolute if it's not one on one I do not, I'm not interested

T100: I find those kids are better at one-on-one at first, because having friends distracts them, having other kids in the class distracts them. Once they get more comfortable with the water having a friend they can watch helps them a lot as well.

T103: with a special... like, also say a spectrum child, that is... you cannot do a group lesson. You really got to be focussed in on that one child.

Teachers also found that children with ASD needed more physical guidance/support than typically developing children. Demonstrations and verbal feedback needed to be broken down and kept very simple to be effective.

> *T105: I think presenting yourself to a child on the spectrum, just to be, I don't know, straight forward. So communication's important. Where you'd be able to give a typical child a, like a reference, or make a story, or give them content, I don't know. Like about, let's say ... more simple, more to the point, more instructive, like more definite instruction.*

> *T102: You've got to be able to get their attention by the words that you use, the tone of the voice, eye contact, touching all the time*

> *T100: So, for most kids you show them you're like, look at me, this is what we're doing and they go alright, so I got to a point where I was like alright I actually need to physically take him and this is what we do, down here, down here, and just repetition over and over. Until they go oh click and then they do it*

Learning also required a longer period of time, so slowing down during lessons and using repetition was important. Children also benefitted greatly from routine and tended to become unsettled when there was a change in routine.

> *P110: You know, that you're going to have to push the hand forward over a thousand times to make them move that hand, especially when it comes to water.*

> *T105: But with the autism, I find that repetition, repetition, repetition. So we start off with the same thing for the first month or two. It was always the same thing, we did the same couple of exercises every day and then every week or two I'd add in another exercise… But when you added it in, my word, that just threw him off completely and it was a… mess.*

There was a mixed opinion about the duration of classes, with some stating that shorter classes were better to allow for poor attention, but that longer than usual classes accommodated the repetition and slower pace.

> *T109: But with all the Autistic kids we've actually lengthened the program to six weeks and done a… made the lessons shorter. So, we've made them ten minutes instead of twenty*

minutes. And it just, yes it seems like that is a better time duration for them, just from a concentration point of view and from a learning point of view.

T105: It would take a few weeks for me to introduce a different song, or a different skill and then I'd repeat that skill, also for longer. So, I actually felt in a few lessons, that a longer lesson would be beneficial

Certain pieces of equipment proved difficult to use due to preferences of texture, but the use of some pool toys was motivating - improving attention and participation.

T103: And then the other child, just like freaked-out of a touch of the noodle, he was fine and when he touched the noodle and then he got out of the pool and he ran through the school. And it was my very first day so I ran after him in my costume.

T100: …they don't like the feeling of some things, so you'll have to adjust your program around like, holding the noodle, they won't hold until I can try and get it boat shaped in the front, they don't want to touch it with their hands, they'll push it back into their chest and leave their hands like out here.

Some teachers mentioned that a noisy, busy environment tended to lead to distractions and recommended a quiet, calm environment. Parents noted this more readily.

T105: I believe, with my whole heart, that a quieter lesson, less busy environment would have helped the girl.

P104: …So, again the size of the pool and the environment [affected learning and lessons]. It was a lot busier than before. A lot of different noises and sensory input for [child's name]'s mind.

P106: One of the things that's a problem though is if there's lots of other kids. So the one time they went swimming and there was about four little kids and [child's name] just started like screaming, but it was not like a constant scream it's like a scream like every like ten seconds or so. And I realised it was because he was so close to the other kids and I went to… and it wasn't his usual swim teacher and I went to her… I said I think you just need to swim away from the other little kids. Then when they did that though, he was fine.

Teachers all expressed the importance of having a support structure to help trouble shoot problems and come up with new techniques.

> *T103: I was very lucky because I deal with [therapist's name] who is our physio. So she has really helped me learn a lot about different kinds of diagnoses, I suppose and how you can help them in the pool.*

> *T102: …we can talk amongst ourselves and say "okay listen, I'm battling with this one." "What do you guys think?" "Did you see what he did today?" "How can we help?*

Ultimately, despite being thrown in the deep end, with little to no training or support available in the context of swimming for children with ASD in South Africa, teachers built confidence and knowledge through their experiences. They learned about the children they were teaching, themselves, their relationship with parents and the nitty gritty of providing lessons. Although they have stepped up to starting blocks, accepting the challenge of lessons, the expressed need for more support and training still exists.

To summarize teacher's experiences transitioning from being "thrown in the deep end" to "stepping up to the starting blocks", figure 3 is provided below, which offers a visual representation of their experiences viewed through a transactional lens. This will be further discussed in the discussion chapter.

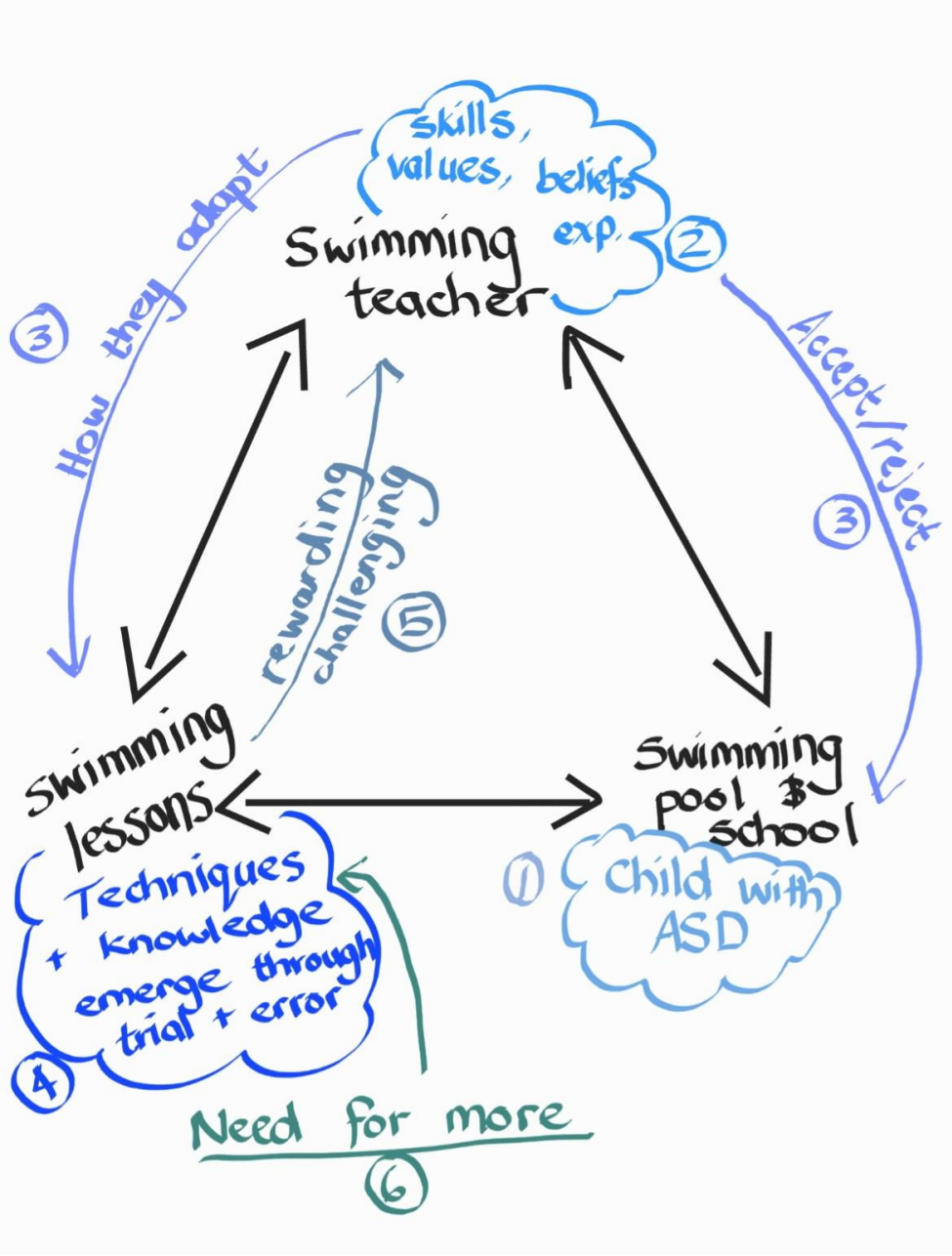


Figure 3: Teacher's dynamic experiences understood through a lens of transactionalism

Viewing teacher's experiences through a lens of transactionalism:
1) A child with ASD comes for swimming lessons
2) Based on their skills, values, beliefs and past experiences the teacher chooses to accept (or reject) the challenge of offering lessons to a child with different needs (Category 1).
3) Due to a previous lack of training – teachers rely on personality and intuition to adapt lessons to meet the needs of the child – with the overall goal of teaching them swim skills (Category 2)
4) Techniques and knowledge which can be used to help children with ASD learn swim skills emerge as a result of this interaction in context – that is through trial and error (Category 3 & 4).
5) Teachers experience either rewarding feedback from this (motivating them to continue) or negative feedback (Category 1)
6) In response to negative feedback, teachers feel the need to gain more knowledge and support from external sources, which currently aren't available to them (Category 1)

4.2 THEME 2: PARENT EXPERIENCES - FROM JUST KEEPING YOUR HEAD ABOVE WATER TO MAKING A SPLASH AND GOING FOR GOLD

Table 6: Theme two

Theme	Category	Subcategory
From just keeping your head above water to making a splash and going for gold – parents and children's changing experiences	Swimming for survival - the initial reason why parents started swimming lessons	Parent's experiences of child with water → Fear of drowning
		Children with ASD: Drawn to water
		Safety as a primary goal for parents
	The changing meaning of swimming lessons for parents and children	Love for water and swimming Swimming as a meaningful occupation
		Sense of achievement for children • Having goals • "I am capable"
		Proud to see progress
		As a parent – your child's happiness is your main priority
		There are still challenging days and difficult emotions • Seeing your child upset • Feeling judged by others
		Swimming, family time and holidays
		Opportunities for sibling interaction in aquatic environment Can be difficult to balance their needs
	The multifaceted nature of swimming → means and an end	Swimming as a leisure activity/for exercise
		Swimming as a career/productive occupation
		Swimming for sensory regulation – inherently therapeutic
		Participation in swimming led to improvements in other occupations (dressing, washing hair, social participation, school)

The second aim of this research was to understand the experience of parents of children with ASD, in the context of swimming lessons in South Africa. Parents were initially motivated to take their children for swimming lessons due to fears regarding drowning. The meaning derived from lessons shifted however, as children engaged and parents realized a number of hidden benefits from lessons. Overall, for multiple reasons, swimming proved to be a meaningful occupation for children with ASD and their families.

4.2.1 Category 1: Swimming for survival - the initial reason why parents started

Almost all the parents described an experience with their child and a body of water which lead them to become fearful of their child drowning. Most parents described their children as being especially

drawn to water. This affinity for water, combined with risk taking behaviour, impulsivity and tendency to elope made them especially fearful of their child drowning. For most parents, the initial motivation for swimming lessons was thus water safety, with swimming serving the purpose of a survival skill.

> *P104: He is fearless. It is also one of the motivating factors to get him to swim, because he didn't understand the dangers of water*

> *P106: And I know the autism kids, most of them don't, the highest percentage of them that goes missing is because they've drowned… So I thought okay let's be pro-active here, let's get him into swimming. We are always very nervous around water.*

> *P107: Just we went to a wedding, her cousin's wedding. And there was quite a strong flowing river it's a waterfall there. And [child's name] was supposed to be the little groom boy with walking … And he was not willing to walk to them, he just bolted for the river. And that gave me a massive fright. I had to run there in front of all the guests and try to get him away from this actually … And that gave me a massive fear and I said no we have to get this child, if at all he needs to know how to swim.*

> *P110: We always had the fear that the child is going to drown. And he is pre-verbal or non-verbal at times, he doesn't have the voice so the best thing is rather to get him water trained.*

As can be noted from the above statements, parents expressed a sense of fear and anxiety initially. Swimming lessons provided hope that they could somewhat alleviate that fear. However, they did not anticipate the other emotional benefits and meanings that this occupation could have for them and their children.

4.2.2 Category 2: The changing meaning of swimming lessons for parents and children

What started out as a survival skill soon became something more for parents and their children. All the parents described how their child's love for water made swimming a truly meaningful and fulfilling family occupation.

> *P108: So lovely because it's when she's less Autistic, you know? She has least of her symptoms… If you look at [child's name], she's always frowning. When she's swimming, never frowning. Look at [child's name], can you see? [showing picture of child] This is on the beach at the Valley of the Waves. See her face? Yes, and that's why we got it in the frame next to the bedside table because it's when she's at her happiest.*

Parents expressed a sense of pride and achievement at seeing their children's skills develop and in seeing them participate. They also described their children's sense of achievement – with many having sharing memorable moments of their child bringing a medal home with pride or participating in a gala.

> *P108: But I had one really good memory where [child's name], every end of the season [Teacher's name] gives them a medal, you know? That little… so now, our other daughter is a rower and we would go to Roodeplaat and (child's name) would come and if she got a medal she'd come and show us the medal. Like mom, I got gold or silver or bronze. So [child's name] obviously saw that and learnt it or visualised it. So when she came home one day she took the medal out of her bag and she put it on. She said, look! She had her medal on, her swimming medal on. That was a very good memory…*

> *P110: You know, there is maybe not a lot of things he's good at but that is, I won't say he's brilliant but you can see he's got potential. I would say, "You're going to be a big swimmer, you're going to go to the Olympics. You're going to go to all these things." …So he had his dream so you would nod and say he's going to the Olympics. He is going to swim there and all. So he is loving water.*

> *P107-1: Almost like enabling function, I think. Like he feels more enabled… It's almost if he feels more accomplished after that.*

> *T109: We handed out certificates at the end of the gala and the Head Mistress spoke after I spoke and she was just in floods of tears and she said, you know, you've got to understand that in their community these kids are seen as being special because of their sort of learning disabilities… And she said now they're special because they've got a skill that no one else in their community has got. They're able to swim.*

Teachers also noted that it was rewarding to see parents realizing their child had more potential than they may initially have thought.

> *T109: The dad actually came and watched a lesson probably a few days after that and mom was very excited and he just said, "you know, we didn't realise that he was capable of that", you know, they didn't think that he would be able to make those decisions. just seemed so amazed by that because he just said "maybe we've got to expect a little more from him because, you know, if he can make those decisions".*

Swimming was also described as a meaningful activity which siblings could participate in together – both at home and on family holidays. All but one set of parents mentioned Sun City specifically as being one of their child's favourite places.

> *P104: …Valley of the Waves. Him and his brother run towards the waves and not away from it. He loves it because I think his understanding is, it's holiday, it's family time…*

> *P106: [child's name] and [sibling's name], they can stay in the pool the entire day. They love it.*

Although the aquatic environment provided opportunities for siblings to interact, balancing their needs with lessons became tricky for some parents. Siblings skills often improved much faster, requiring them to attend a different lesson. Waiting for lessons and time constraints proved to be limiting factors to participation.

> *P104: He eventually liked it, but where the problem came in is that his lesson was a different time to his brother's, and then I would be rushing from one place to the other*.

> *P106: Yes so swimming, like with him and his sister swim together, that can be a challenge sometimes. He wants to race to the end of the pool and he wants to win. He's not going to win.*

Parents reiterated that seeing their children happy and fulfilled was their main priority – this helped them through challenging days. Difficult days involved feeling lost when seeing your child upset in the water or feeling judged by other parents/people in the pool area when your child is having a difficult day.

> *P104: So, bad memories would obviously just be lessons where he would cry to a point that made everyone else stop their lesson to see if this child was having a meltdown in the pool, and that would sadden me. There was one day I actually ended up crying at the poolside and I'm like, "I don't understand. He loves swimming. He loved it all the time. What is making him so unhappy?"*

Swimming lessons provided not only a survival skill, but a meaningful family occupation, that offered parents the opportunity to see their child fulfilled and engaging. The sense of pride and achievement expressed by parents and children, although unanticipated, motivated them to continue with lessons

and made daily life more manageable in multiple areas, such as on family holidays, and even on a daily basis at home and school.

4.2.3 Category 3: The multifaceted nature of swimming

Swimming teachers and parents spoke about a variety of other meanings and effects swimming has had for the children participating. Most parents noted that swimming has provided their children with exercise that in some cases has improved their posture and participation at school.

> *P106: And then the exercise. So even he's starting to sit normal*

> *T103: To exercise and stuff, ja so from an exercise perspective and a mobility perspective. And then it does also kind of work as therapy a because they are moving in the water and they are using all their muscles and they are being stimulated and they are following a routine and they are following instruction and all of that. So, I think the majority sign up from a safety perspective. And then from there it becomes rewarding to see them grow and to see how they actually can learn different skills and then they carry on because they want to better their swimming.*

One of the teachers spoke about two boys he had taught how to swim, who are now helping him with teaching – illustrating how swimming as a skill can become a productive occupation.

> *T109: So, yes it's been hell of a rewarding to see them kind of grow into it and develop as instructors. So they are both close to finishing school so that's also nice for them that there is some kind of career path at the end of this.*

Many parents and some teachers noted that the aquatic environment is inherently therapeutic. The sensory qualities of the water helped to regulate their level of arousal, with some attending better in the classroom after lessons or being better regulated once they got home.

> *P110: You know, with autism they can stim, those kinds of things. And those are also the things you know, that can just help them overcome those stimming behaviours dealing with them, showing them that they can do it, kids loving in the water and you know, just working and nurturing. So the swimming has really changed [child's name]'s life.*

> *P107: After Thursday when he had a swim session with [teacher's name], he is really mellowed down, toned down he is really. So Thursdays are like the best day of the week in the evenings when we see him again.*

P108: So with swimming, it's almost like the weightlessness and the lightness of the water… she senses that. It's almost like… it doesn't interfere with her sensory system integration. Yes. So, it's she's always been very sensory like I was explaining. So with water, it has this calming effect… Even though she's excited and she's like splashing or whatever, her whole behaviour is calm. And that weightlessness, that freedom of not… [child's name] is very anxious when she doesn't perform. So if she's sitting at the table doing work and she doesn't understand it or she can't get it right… So when she… in water, it doesn't matter if she can't perform because she's free… And happy, you know?

T109: The one little boy, they said turned a massive corner in the classroom within a week.

Improvements in other occupations were broad and varied. Parents noted that their child's participation in bath time, specifically being comfortable to put their head back and wash their hair, improved once they became comfortable going on their back during swimming lessons. For one parent, her child was more motivated to dress independently in order to get into her costume to go swimming. Other parents spoke about how their children were more likely to engage socially with others in an aquatic environment.

P107-1: The one also big thing which I've noticed with [teacher's name] is that he would not lie on his back in the bath time. He would not want to wet his hair and [teacher's name] actually managed him to tilt around and float on his own on his own. This is a massive thing …Because it's a no go. So it's a double positive. He enjoys the water. He's gaining something and it's got a positive effect as well.

Similar to teacher's experiences, parent's experiences have been summarized in Figure 4: *Parent's dynamic experiences viewed through a lens of transactionalism*. Overall parent's experiences of swimming lessons were also dynamic, especially with regards to their changing meaning.

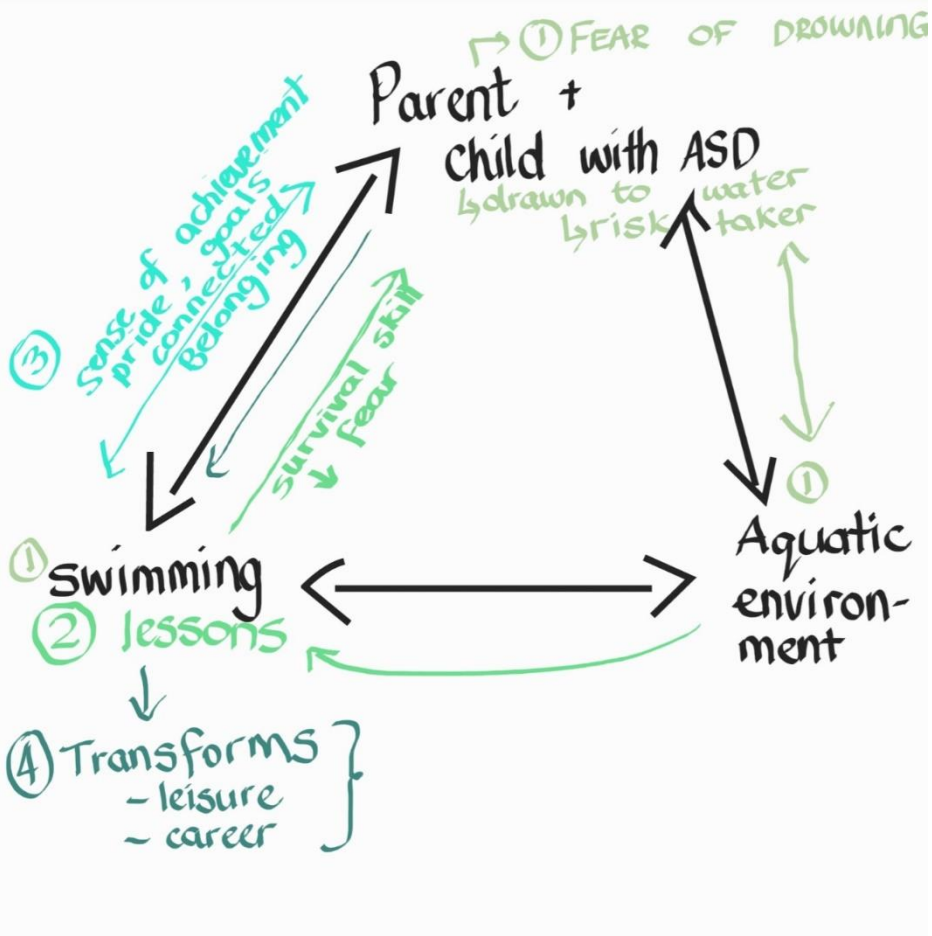


Figure 4: Parent's dynamic experiences viewed through a lens of transactionalism

Viewing parent's experiences through a lens of transactionalism:
1) Parent has a negative experience with their child in/near an aquatic environment, leading them to become fearful of their child drowning (Category 1)
2) Parents seek out swimming lessons to provide themselves with peace of mind and their child with a survival skill (Category 1)
3) Once engaging in lessons – hidden values/benefits emerge through transaction including experiencing a connection and a sense of pride and achievement (for child and parent) (Category 2)
4) What started as a survival skill is transformed and be classified in many different ways depending on the value parents and children derive from it (Category 3)

4.3 THEME 3: TEAMWORK MAKES THE DREAM WORK

Table 7: Theme three

Theme	Category	Subcategory
Teamwork makes the dream work	Parent and swimming teacher relationships	Knowing the diagnosis allows for preparation and improved lesson quality
		Parents don't always know the diagnosis
		Disclosure builds relationships between parents and teachers Working at a school for special needs was different to privately
		Not knowing can cause conflict, frustration and poor service delivery
		Parent's perspective – desire for inclusion and awareness – not always the experience

The third theme that emerged addressed teachers and parent's experiences of each other. "No man is an island" and in the context of swimming lessons parents and teachers both interact and thus influence this occupation. The first interactions tended to set the tone for the relationship – starting with disclosure of the child's diagnosis.

4.3.1 Category 1: Parent and swimming teacher relationships

Teacher's stated that parent's disclosure of the child's diagnosis greatly aided them in preparing for lessons and providing a better quality service. They expressed frustration when parents did not disclose this information, as they often become aware that a child is having difficulty in the water but find it difficult to ask the parent/broach difficulties if there is not an open line of communication. Open communication was important to teachers, but they didn't always know how to facilitate this process.

> *T102: I think a lot of the time, I think it's difficult for parents to accept what they've got, and they don't actually tell us; they not upfront with this information. And it's difficult because you need to ask, you have to ask, but you also don't want to have to bring that to the parent's attention, if they know and are denying it or if they're not quite aware yet but we can pick stuff up very quickly.*

> *T100 "I find that if they [the parents] tell me straight up there's already a relationship there because I've already gone alright that's fine, I can still do that and they're like okay cool, because I haven't gone oh, that's difficult. I'm like I'll make it work.*

T101: …so the more I understand about whatever condition you have, the better I can do my job. I feel like there's a lot of like pressure to treat your kid the exact same way I treat every other kid, which is not fair on your kid.

Some parents reflected that they had started swimming lessons before they knew their child's diagnosis and that their experience of swimming lessons became more positive once they, and the swimming teacher, knew the diagnosis. All of the parent's disclosed their child's diagnosis to the swimming teacher (if they knew it).

P104: But in [swimming school]'s defence, that was when I didn't know he was autistic so the teacher wouldn't have known either. She would have just thought it was a fussy kid coming to swim all the time. So, that was the difference. But with the [other] one - more of a satisfying feeling, because I knew they were getting taught what I wanted.

P108: Oh my gosh, there's no chaos [comparing lessons]. Before it was chaotic because it was… the aim of the lesson wasn't to teach her the stroke in the beginning, it was to teach her to allow the person to teach her, to tell her to do something and then it was chaos. It was a very stressful half an hour.

When parents did disclose their child's diagnosis, they experienced barriers to accessing services. Most parents expressed a degree of frustration when trying to find a swimming teacher/swimming school that really understood their child's needs and could provide a service to meet those needs.

P107: Well I went through the process and it was quite difficult [to find a swim school].

P104: So, it's the ignorance that needs to change and the fact that they don't understand awareness... and I think if a school actually comes out like that, it would be so great because there is a lot of special needs kids that don't know how to swim. Because they're scared. You make an environment conducive to their needs, it will be awesome.

Swimming teachers working at a school for children with special needs found the experience of lessons to be overall more positive, as they had good insight into the children's diagnosis and support from teaching staff. Similarly, parents of the children at the special needs schools also had a more positive experience as teachers were more aware and accepting of the diagnosis. Insight and support broke down barriers to participation.

*T109**: ...**because whilst you are teaching the kids you are always worried about the parent's commitment and in this case it was the teacher's commitment. I was really chuffed with the teacher's commitment*

T103: So it happens during class time. So the teachers are really supportive. They are amazing and because the kids... sorry.... ninety-nine percent of the time really enjoy swimming, the teachers are quite happy to send them to us. [laughs] It also gives them a bit of a break.

One swimming teacher, working from a special needs school sent videos to parents of her sessions – this line of communication built a positive relationship between the parent and teacher. Parents enjoyed having open communication with the teacher and felt at ease with the lessons.

T103: It is nice to have good communication with teachers and with the assistants and then with the parents. I try to communicate with the parents almost every day.

P107: It really gives me a satisfactory feel for all of this. I don't know yes, peace of mind [receiving the video's].

In other circumstances, poor communication between teachers and parents lead to frustration uncertainty and ultimately to a negative experience of lessons for the child.

P104: I had to stop because it was heart breaking to see him not enjoy something he actually loves [moving and changing swimming school].

Overall, the relationship between teachers and parent's impacts on the experience of engaging in this context and occupation for all role players. Positive relationships were those that offered acceptance (through insight) and support to parents. Teachers experienced lessons as more rewarding when they had the trust of the child and the parent and could gain insight into the child with the help of their parents and school teachers. Disclosure, while sometimes limiting participation was also the factor which was most likely to facilitate positive experiences of lessons. In conclusion, this final figure demonstrates how transactions take place between role players and that they both impact on the experience of swimming lessons (providing them and receiving them).

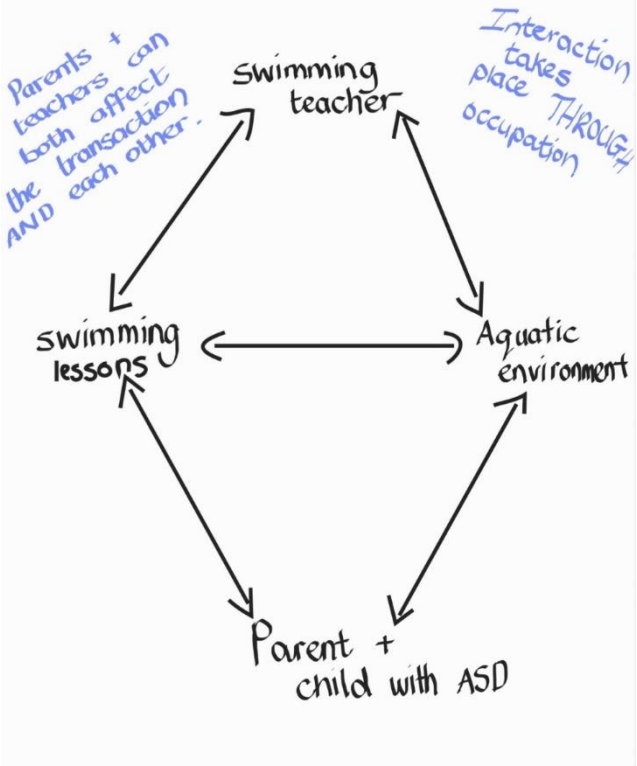


Figure 5: Teamwork makes the dream work - parent and teachers dynamic interdependence

CHAPTER FIVE: DISCUSSION

The complex, co-constitutive give-and-take between a person, their occupation and the environment is as central to human life as breathing and holds a transformative power that should be denied to no one. Children with ASD in South Africa are at risk of experiencing occupational deprivation (Schelbusch, Dada and Samuels; 2017), that is being deprived of the opportunity to engage in activities which are meaningful to them due to factors outside of their control (Wilcock & Townsend, 2004). According to the United Nations Convention on the Rights of People with Disabilities, of which South Africa is a signatory, children with disabilities, including ASD, have the right to inclusion, accessibility and equal opportunities to engage in activities which are meaningful to them (Philpott, 2018; Bailliard et al., 2020). This research has demonstrated that swimming is meaningful for children with ASD and their families. Beyond that, it has also demonstrated the transformative power of occupation for swimming teachers, parents and children with ASD in different ways. All stakeholders should have the right and opportunity to engage in this activity in a meaningful way and to experience fulfilment through their engagement (WFOT, 2019; Townsend & Wilcock, 2004), be they teachers, students or parents. However, lessons have not always proved to be equally accessible. This chapter will discuss the findings presented in chapter four. Three main themes emerged from the data that focussed first on teacher's experiences (Being thrown in the deep the deep end to stepping up to the starting blocks), then on parents' experiences (From just keeping your head above water to going for gold) and finally on their combined experiences (teamwork makes the dream work). All these themes will be discussed and interpreted using the lens of transactionalism giving rise to the rich experience of occupation.

5.1 TEACHER'S EXPERIENCES IN TEACHING CHILDREN WITH ASD

The results of this research, as they primarily speak to occupational engagement (from various stakeholder's perspectives) can be interpreted through a lens of transactionalism. When viewed through this lens, one can see that teachers experienced providing swimming lessons for children with ASD in a complex and dynamic way. For the purposes of the discussion, the researcher has chosen to intertwine the first category outlining teacher's dynamic experiences, within the remaining categories under this theme, in order to demonstrate the depth and complexity of this transaction. To begin unpacking their dynamic experience, we view the swimming teacher (person), with all their existing beliefs, values, skills and experiences that have evolved and developed over the course of their life, providing swimming lessons (occupation) to *typically developing* children, very likely in a swimming school environment, with the purpose of earning an income (ends-in-view) as seen in figure one (Lee

Bunting, 2016). One can then begin to unpack how this transaction changes when the child they are teaching is no longer typically developing, but diagnosed with ASD; examining how a change in one element of the system (in this case the “environment”), will offset the balance previously achieved between elements and result in changes in occupational engagement and other elements of the system.

When faced with this initial change, the person needs to react in order to once again achieve balance (functional coordination) and successful occupational engagement (Lee Bunting, 2016). For example, the teacher may choose not to teach the child (due to personal preference, lack of available skills/knowledge and fear of the unknown/anxiety), thus maintaining the system exactly as it is/was, or they could choose to accept this challenge and adapt to the new demands of the system. But what determines whether a teacher will choose to act in one way or another? Due to the lack of available support/training for swimming teachers in South Africa, accessibility at present appears to rely largely on personal preference (personality, beliefs and values) and the person’s goals. This affects not only the likelihood of accessing lessons but also the quality of lessons. Teachers who did accept the challenge appeared to have key traits in common.

Swimming teacher’s experiences have not been well explored in existing research in this context (Craig, 2018). All the teacher participants expressed a sense of nervousness initially due to a lack of knowledge/training that would equip them to teach not only a child with ASD, but any child with special needs (*Your knees are knocking)*. However, they also stated that although they were nervous they were excited for the opportunity to learn and grow. Teacher participants who accepted the challenge tended to display a high self-efficacy and initiative, fuelling a desire to use their skills in a new/different way. This was similar to results found by Soto-Chodiman et al., (2012), Anglim, Prendeville & Kinsella, (2018) and Stites, Walter & Krikorian, (2020), which explored teacher’s experiences in inclusive classrooms as opposed to an aquatic environment. They found that teacher’s self-efficacy influenced their willingness to adapt despite their uncertainty. This suggests that although the skill teachers are trying to impart and the environment in which they are doing so may vary, the experience, at it’s core, of teaching a child with autism is similar. Teacher’s shared experiences across contexts could be used to provide support through universality – that is knowing you are not alone in your experiences.

Beyond a desire to learn and grow, a number of common personality traits of effective teachers emerged from both parent and teacher participants’ perspectives. Teacher participants who were successful in facilitating swim skill acquisition had key characteristics in common, including patience, adaptability, intuition and observance. Interestingly, there is little

consensus in literature regarding the most valuable/most common personality traits of special needs teachers although it is widely acknowledged, both anecdotally and in research, that it takes a “special” sort of person to teach children with ASD (Polk, 2006; Kim, Jörg & Klassen, 2019). At its core, this is because personality affects how we develop relationships and our relationships influence how we experience the world. Patience, flexibility (adaptability) and intuition were also frequently mentioned in literature - amongst others (Kim, Jörg & Klassen, 2019). While it is commendable that certain teachers have made efforts to include/accommodate children with different needs, it is not just that access to this service, which fulfils a number of different meanings for children with ASD and their families, appears to be determined solely by a teacher’s personality (Bailliard et al., 2020). It is important to consider that only teachers who actually “accepted the challenge” were interviewed for this research and that it did not include the teachers who had been approached by parents of children with ASD, but who had declined to teach them for whatever reason. While it remains a teacher’s personal preference whether to work with children with special needs (or not), their personality alone should not equip them to do so. This represents a barrier to occupational justice that could lead to deprivation and marginalization of children and families (Wilcock & Townsend, 2018).

However, in a context with limited training, adaptability and intuition are indeed valuable personality traits, that appeared to enable teacher participants to respond to a variety of situations. In place of formal training and due to a lack of available resources/support, they tended to rely on their intuition and engaged in (mostly) unguided experiential learning (Kolb, 1984) – that is learning through doing – or a “just wing it” approach. This was once again similar to teachers experiences of inclusive education for children with ASD in mainstream classrooms (Soto-Chodiman et al., 2012; Anglim, Prendeville & Kinsella, 2018; Stites, Walter & Krikorian, 2020). Understood through a transactional lens, teachers through providing lessons to the child with ASD, obtained feedback and made adjustments to their habits (actions) to once again achieve functional coordination (Lee Bunting, 2016). This will change not only the way the way classes look but also how teachers experience providing swimming lessons.

The efficacy of the “just wing it” approach was not quantitatively measured through this research, however it is interesting to note that, despite teacher participants lack of “formal” training or access to information, almost all the tools/techniques that are currently supported by evidence were discovered by teacher participants through engagement (discussed below) and were noted as being useful in practice. Again, considered through a transactional lens, we can see how changes in the occupation emerge as result of changes in context and the person’s engagement in that context (Lee Bunting, 2016). Although teacher participants in this

study may eventually have gotten to the correct techniques, this again highlights issues with accessibility and occupational justice. What if teachers did not come to the right techniques through their experience? Such as was true in the case of P104, who eventually stopped her child's swimming lessons after changing teachers, because an activity he previously loved became traumatic and unenjoyable. Both Kraft, Leblanc & Culver, (2019) and Lawson et al., (2019) recommend evidence-based approaches to lessons, noting that evidence-based approaches better support accessibility, inclusion and skill acquisition. The beauty of evidence-based practice is that we don't have to intuitively hope we are doing "the right thing" every time and learn as we go, but rather that we can plan and base our actions on what has already been proven to work (Connolly, Keenan & Urbanska, 2018; Novak & Honan, 2019) – giving teachers confidence and consistency in the service they are providing (Stites, Walter & Krikorian, 2020). This is how we are able to insure inclusion and skill acquisition in a just and equitable way (Hocking, Townsend & Mace, 2019). However, in the absence of access to this evidence base, teachers in the South African context learnt on the job.

Teacher participants successful service delivery and occupational engagement relied on two components, understanding the child with ASD and from that understanding, being able to select appropriate tools/techniques when presenting lessons. For the most part, their definitions/understanding of ASD developed through interaction in context and informal, online research. They frequently defined it by the characteristics of ASD which in their experience had most impacted swimming lessons – another result of the occupational transaction. Most teacher participants were able to identify core features of ASD, defining it as a spectrum, and noting a range of difficulties including communication skills, distractibility and cognitive delays, but with most missing elements such as sensory processing differences and the presence of restricted, repetitive patterns of behaviour (Kraft, 2019) . Importantly, they identified that children with ASD were capable of learning how to swim, noting that it is important to remember that every child with ASD is different and that they needed to respect each child's individual abilities/difficulties. Successful lessons involved meeting the child where they are and responding in an adaptable way. This supports Alaniz et al. (2017) and Murphy & Hennebach, (2020) conclusions that children with moderate to severe ASD are capable of learning swim skills, provided teachers utilized individualized instructional methods that matched the child's needs (Thompson & Emira, 2011; Lawson et al., 2019). Lawson et al. also noted that from family's perspectives the instructor's knowledge of autism, the child's bond with the swim instructor and consistency with that instructor were essential to quality instruction (Lawson et al., 2019), as were the practical teaching techniques selected by the instructor.

Once again, the practical techniques teachers found useful emerged as a result of the interaction between the swimming teacher and the child with ASD during lessons and represent actions towards functional coordination. These ranged from the size, duration and setting for classes to the type of instruction given and use of equipment. Most swimming teachers agreed that one-on-one lessons are preferable as the child requires your full attention. In addition, they noted that group lessons can become useful later on as this provides the child with peers who they can imitate. This reinforces and expands on the available literature, where one-on-one lessons over an extended period of time were recommended for children with ASD (Hall, 2013; Alaniz et al., 2017; Lawson et al., 2019; Kraft, Leblanc & Culver, 2019; Murphy & Hennebach, 2020) and group lessons with typically developing peers were not frequently discussed. Most teachers also stated that longer lessons worked better as the progression of the lessons was slower – however one teacher noted that shorter lessons worked better as this compensated for poor sustained attention. All the teachers and some parents noted that skill acquisition was slower and that more lessons were required to acquire the same skills as their typically developing peers/siblings (Askari et al., 2015; Kraft, 2019). Other strategies including routine and repetition, hand-over-hand guidance and physical support with fewer verbal cues were effective strategies according to teachers practical experience and were further supported by the literature (Hall, 2013; Kraft, 2019; Kraft, Leblanc & Culver, 2019; Lawson et al., 2019). Teachers and parents in this study also emphasized the importance of a quiet, calm environment and an awareness of the texture of pool toys/surfaces and how this may impact on learning (Hall, 2013; Lawson et al., 2019). The usefulness of these techniques, as supported by the available literature, could be kept in mind when supporting teachers/developing programs in future.

The success/failure of these techniques, which represent actions toward functional coordination (Lee Bunting, 2016), affects not only the likelihood of a child's skill acquisition but also the likelihood of teacher's continued engagement in this context. Teacher participants who accepted the challenge, who persevered through chaos of the first few lessons and were gradually able to adapt and gain confidence, experienced lessons as more rewarding. Seeing progress as a result of their actions, experiencing a personal connection with the child and seeing their parents sense of pride all facilitated fulfilment for teacher participants and helped them to persevere through the challenging days (Craig, 2018). Anglim, Prendeville & Kinsella, (2018) noted that the creative ways in which teachers in inclusive education were able to adapt and still see progress, despite a lack of support, is what kept them going. This was true for teacher participants in this research as well. The implications of which are this: if we want to ensure access to swimming lessons for children with ASD and their families, it is imperative

to create environments in which teacher's experiences of seeing progress and experiencing a personal connection as a result of their actions are common place.

Although teachers may have been using the "correct" techniques intuitively, an expressed need for feedback to give them certainty to support their intuition still exists (6). There was ultimately a sense of disappointment at the lack of information and support available to them in this context. They expressed a definite need for more specialized training that would provide them with more confidence in their skills and in the quality of the service they are providing to parents. When evaluating this relative to Hocking's definition of occupational justice as being "a process of enabling, mediating and advocating for environments in which *all people's* opportunities to engage in occupation are just, health promoting and meaningful" (pg 35, 2017), we can see that teachers also have the right to experience providing lessons for these children in a meaningful way. Therefore, by providing training for teachers you mediate not only one injustice (on the part of the child and their family) but two, as you aid the teacher in participating more successfully in lessons.

It is further interesting to contrast this with the available literature in this context, where most lessons were delivered by health care professionals/teachers with specialist training/knowledge. In these studies, the need for more support was neither explored nor identified. This raises an interesting question regarding service delivery in naturally occurring environments and task-sharing. Should this be a service delivered by HCP's, or should HCP's be providing support/training to teachers, enabling children with ASD to access mainstream/existing services (Trzmiel et al., 2019; Alaniz, 2020)? Existing research would support the importance of task-sharing and integration of children and their families into already existing services. Task-sharing makes services not only more affordable but also provides families with a degree of normalcy (Kumar et al., 2014; Naveed et al., 2019). Calls for affordability and integration were echoed by parents and teachers in this study and may be an important consideration in terms of occupational justice, inclusion and accessibility moving forward. That is, swimming lessons are not necessarily a service occupational therapists (or any other healthcare professionals) need to take over/offer directly – but rather indirectly to fulfil the role of a consultant/advocate, offering support to swimming teachers to enable them to provide a more accessible service.

Overall, teachers shared experiences indicate that support from occupational therapists may be valuable in mitigating the risk of occupational injustice in this setting. Occupational therapists, in an advocacy and consultative role, can provide support and education that not only provides teachers with a greater sense of confidence in their skills but also enables

children with ASD and their families to access existing services in an inclusive way. Parents perspectives served to further support these assertions.

5.2 PARENTS' EXPERIENCES OF SWIMMING LESSONS

Swimming proved a meaningful occupation for children with ASD and their families. Parent's experiences, like teachers, were dynamic, especially with regard to the meaning derived from engaging in swimming lessons. An initial focus on learning a survival skill and "just keeping your head above water", gradually shifted towards fulfilment, pride and meaning that went far beyond that. The way in which the meaning of swimming for children with ASD and their family's changed serves to further demonstrate the transactional nature of occupation (Lee Bunting, 2016). It also demonstrates how difficult it can be to classify occupations into discrete categories, as discussed by Whalley-Hammell (2014), with swimming being categorized differently depending on the meaning the person derives from it (Wilcock & Townsend, 2019; OTPF-4, 2020).

For most parents, the initial motivation for swimming lessons was water safety, with swimming serving the purpose of a survival skill. The need for swimming lessons emerged in response to factors within the environment, with almost all the parents describing an experience where their child was drawn towards a body of water, with little safety awareness, which lead them to become fearful of their child drowning. In a qualitative study utilizing in depth interviews to establish family's experiences of swimming lessons for children with ASD in America, parents reported that their child's unpredictability, tendency to wander off, and their attraction to water were significant reasons for taking their child for swimming lessons (Lawson et al., 2019). The existing literature further supports parent's sentiments that Autistic children are at a higher risk of drowning than typically developing children due to wandering behaviour and decreased risk awareness (Guan & Li, 2017; Casey et al., 2020; Murphy & Hennebach, 2020). Water safety has been identified as an important skill for typically developing children, but the findings of this research, coupled with the existing literature, tend to suggest that it may be even more necessary for children with ASD. In its classification as a "survival skill" alone, one can see the importance of equitable access to this service. However, this research suggests that swimming lessons go beyond simply being a survival skill, in fact providing parents with a number of ends-in-view.

Once engaging in swimming lessons, a new "transaction" began to take form, one that allowed parents and children to meet multiple needs at once (Lock et al., 2010). There were a number of "hidden" benefits and factors that motivated parents and children to continue with lessons

including social, family and community participation, a sense of pride, belonging and achievement and improvements in other occupations such as school and ADLs, echoing many other findings already available in literature (Lock et al., 2010; Kumar, Mortimer, & Privopoulos, 2014; Eversole et al., 2016; Lawson et al., 2019).

Once parents were able to access swimming lessons that could accommodate their children, all the parents described how their child's love for water made swimming a truly meaningful and fulfilling family occupation. Through swimming lessons, children with ASD and their families experienced increased social and community participation, with a greater sense of ease and enjoyment on family holidays and a unique opportunity for meaningful sibling interactions. The meaning experienced by families was similar to the findings in Lawson et al, (2019) and Lock et al., (2010) and demonstrates how occupation can serve as a means to achieving a sense of belonging and connectedness, which contributes to health and well-being (Whalley-Hammell, 2014). A family's well-being directly impacts on their ability to cope with their child's diagnosis and thus also on the well-being of the child.

Finding occupations through which they can derive a sense of belonging and connectedness can be particularly difficult for parents of children with ASD in South Africa due to a lack of community insight and services that can accommodate their child (Lai et al., 2015; Schlebusch, Dada & Samuels, 2017; Reddy, Fewster & Gurayah, 2019). It can also be difficult for parents and siblings to experience connectedness to the child with ASD due to the nature of the diagnosis and its impact on social skills and communication (Iadarola et al., 2019; Reddy, Fewster & Gurayah, 2019). Swimming lessons, when they are accessible and provided with appropriate support, appear to enable parents to experience this sense of connection, belonging and well-being. Again, from the perspective of occupational justice, families should be enabled to experience this kind of meaningful engagement that can support their health and well-being.

Beyond a feeling of connectedness, parents also expressed a sense of pride and achievement at seeing their children's skills develop and in seeing them participate. They also described their children's sense of achievement and their improved self-confidence (Pan, 2011; Du Bois, 2011; Lawson et al., 2019 & Mills et al., 2020). It is further important to consider the value of this "normal" experience for parents. Parents of children with disabilities can sometimes experience a degree of "loss" as they adjust their expectations and hopes relative to their child's unique needs and can find it difficult to know what to expect/hope for in their child's future (Krishnan, Russell & Russell, 2017). Swimming lessons appear to offer an opportunity to experience hope, pride and "dreaming" as children attain this lifelong skill.

Swimming proved to be a leisure activity that individuals with and without disabilities could enjoy across their lifespan (Fragala-Pinkham, Haley & O'Neil, 2011). As this has proved a motivating occupation and environment for children and young adults with ASD, it is interesting to consider that it may provide an opportunity to earn an income at a later stage, as discussed by one of the participants. What would be classified as a leisure activity can also become a productive occupation in adulthood. This is a concept that has not been explored in literature thus far, but that reinforces the above statement that it can be considered a lifelong occupation. Beyond that, it also reinforces the idea that engagement in swimming lessons can offer both hope to parents of children with ASD, who may worry about what their children will do as adults, and a sense of belonging and connectedness.

Beyond the aforementioned psychosocial benefits for parents and their children, a number of other benefits were noted. Swimming, as a sport and leisure activity, provided children with ASD an opportunity for exercise that in some cases has improved their posture and participation at school (Lawson et al., 2019; Trzmiel et al., 2019). Although opportunities for social interaction were increased through family engagement, improvements in social and communication skills as a result of swimming were not noted by parent or teacher participants. This would support Alaniz et al., findings that social skills did not respond to aquatic group therapy (Alaniz et al., 2017) and further contradict Reinders et al., earlier findings (2017). Most parents did however observe improved quality of life and decreased symptom severity (Askari, 2015., Tanner et al., 2015., Howells et al., 2019), such as can be seen in the statement made by one participant stating "*it's when she's less Autistic, you know"* – P106. Many parents and some teachers also noted that the aquatic environment is inherently therapeutic, with the sensory qualities of the water helping to regulate their children's level of arousal. Improved regulation led to improved participation in a variety of other activities, both at home and at school, which was similar again to findings in Lawson et al., (2019) and Musiyenko, Chopyk & Kizlo, (2020). When we consider this from the perspective of transactionalism, we can see that not only the activity of swimming, but also the environment it takes place can result in positive feedback and benefits for the child and their family.

The transaction taking place has been considered from the perspective of both teacher and parent participants, but the final step in discussing this experience is considering where they overlap and how their experiences are interlinked and interdependent.

5.3 TEAMWORK MAKES THE DREAM WORK

Communication is the foundation of all functional relationships, including the parent-teacher relationship, and it is widely recognised that social support and strong relationships are protective factors which can mediate experiences of stress (Halstead, Griffith & Hastings, 2018). While perceived social support can mediate stress for parents of children with ASD,

Iadarola et al. (2019), found that misperceptions and a limited understanding of ASD in communities could have the opposite effect and exacerbate stress.

Parent participants were faced with a number of barriers when trying to find swimming lessons that could accommodate their child's needs, most notably teachers lack of awareness regarding their child's diagnosis (Thompson & Emira, 2011; Askari, 2015., Tanner et al., 2015., Howells et al., 2019.,; Lawson et al., 2019). This lack of awareness lead to either refusal to provide lessons or unproductive, distressing experiences of lessons for both the child and the parent; similar to findings made by Hall (2013) and Thompson & Emira (2011) and represents occupational injustice. This injustice is the end result/knock on of what happens if teachers do not "accept the challenge"; although the teacher's occupational engagement continues unaffected – the parent and child have experienced a limitation to their occupational engagement (Lee Bunting, 2016). By extension, they have also been deprived of the opportunity to experience positive social support and acceptance – all stress mediating factors. Should parents then pursue lessons without disclosing their child's diagnosis?

Although parents may have been more likely to access lessons initially if they *didn't* disclose their child's diagnosis, this doesn't ensure a positive or productive experience of lessons and may still limit participation long-term. Parent participants mostly felt that disclosing their child's diagnosis was important in order to ensure the service would cater to their needs, despite the possibility of being turned away from lessons. From teacher participant's perspectives, disclosure was important as they felt it built relationships and aided them in preparing and in providing a better service. Ultimately, despite the possibility of short-term, negative experiences, disclosure proved to beneficial to long term participation for both parents and teachers; supporting the recommendation made by Lawson et al., (2019) that parents should be encouraged to disclose their child's diagnosis when accessing services such as swimming lessons.

Ultimately, there is a complex interaction between all the stakeholders in the experience of any occupation, including swimming lessons and this needs to be clearly understood and considered when dealing with children with ASD. Open communication between parent's and teacher's lead to a more positive experiences and enabled more successful participation for both parties. Teachers who regularly communicated with parents were able to gain their insight (as experts on their child's diagnosis) that enabled them to provide more successful lessons. While parents had the opportunity to feel accepted and respected – and to see their child being accepted. Demonstrating once again the transformative power of occupation.

5.4 LIMITATIONS:

Having a diverse sample of individuals participate in a qualitative research study ensures the findings richer and more reliable; as such, two of the main limitations to this study were the small sample size and, given South Africa's diverse population, that the research was only conducted in the context of Johannesburg, Gauteng. This may limit the generalizability of the research to the broader South African population.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSION:

Globally, standardised and evidence-based programs aimed at teaching children with ASD how to swim have yet to be fully developed due to a number of limitations in the available research (related to the broad social and behavioural impairments experienced by these children). In South Africa, this had yet to be explored all together. The aim of this study was to explore swimming as an occupation for children with ASD in South Africa, by first gaining insight into the experiences of parents and swimming teachers. Through semi-structured, in-depth interviews, the researcher was able to begin not only skimming the surface of experience in this context, but exploring a depth of experience. By exploring parents' and swimming teacher's experiences, this study contributes a new depth of understanding in this context globally, and further tests out the applicability of existing international research in a South African context.

Swimming proved to be a meaningful occupation for children with ASD and their families – one with a diverse range of positive outcomes. It provided not only a survival skill for children (and peace of mind for their parents), but an opportunity for family engagement, to feel a sense of belonging and achievement, opportunities for sensory regulation and even improvements in objective performance of other occupations. However, there proved to be barriers to accessing this valued occupation. Due to a lack of training, support and resources available to them, teachers mostly needed to rely on their intuition and employ a trial-and-error approach to lessons. This meant that accessibility tended to rely on the teacher's personality and personal preferences. Although teachers mostly gained knowledge and confidence through their experiences, intuitively using techniques recommended in the available literature, they still expressed a desire for more specialized training that would better equip them to provide this service and would allow them to advertise and reach more families of children with ASD. A lack of insight, education and training for swimming teachers is the ultimate barrier limiting participation in this valued occupation for children with ASD and their families in South Africa.

It falls well within the scope of occupational therapy to support their occupational rights and facilitate engagement in meaningful and health promoting occupations (Bailliard et al., 2020; WFOT, 2019). Occupational therapists are therefore well positioned to support swimming teachers understanding of ASD and assist them in adapting their swimming lessons to promote and facilitate access for children with ASD and their families.

6.2 RECOMMENDATIONS FOR CURRENT PRACTICE:

When writing occupational therapy assessment reports, “swimming lessons” frequently appear as a recommendation – especially for children with gross motor difficulties such as low muscle tone and poor endurance (among others). From the experiences of parent participants, it is definitely important to consider recommending swimming lessons as a hobby/leisure activity for children with ASD – not only as it can address gross motor difficulties, but for its numerous other psychosocial benefits as described above.

However, this research also indicates that we need to think about the capabilities of the person/people who are providing the service we are recommending. We frequently provide support to teachers in mainstream and special school settings on how to better manage children’s behaviour and enable participation. As therapist’s we need to offer the same support to teachers or service providers in other settings as well. When we do this, we enable our clients to access meaningful services while simultaneously facilitating meaningful engagement for service providers, in this case swimming teachers.

6.3 RECOMMENDATIONS FOR FUTURE RESEARCH:

Future research in this field could seek to understand the experience of swimming lessons from children’s perspectives, to compliment those perspectives of parents and swimming teachers and offer further depth of understanding.

The research could also be expanded to include participants from a broader variety of provinces and socio-economic backgrounds across South Africa, in order to test out the applicability of these results relative to the broader South African population.

Future research may also test the applicability and usefulness of internationally available swimming programs for children with ASD in a South African context, helping to equip swimming teachers in South Africa with an evidence-based approach to providing lessons.

Ultimately, future research in this field in South Africa should be framed with a lens of occupational justice, with the goal of enabling both swimming teachers and children with ASD and their families to participate in a meaningful and health promoting way in an aquatic environment.

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APPENDICES

APPENDIX A - INTERVIEW CONSENT FORM



PARTICIPANT CONSENT SHEET

Swimming as an occupation for children with Autism Spectrum Disorder: Parent and Swimming Teacher experiences.

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Contact details:

Bronwyn Dudley, Principal Investigator, telephone no. 072 192 9234, or by e-mail at brondudley11@gmail.com.

Lyndsay Koch, Supervisor, by e-mail at Lyndsay.koch@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of Participant: _____
Date: _____
Place: _____
Signature or mark _____

Witnessed by:

Name of Witness: _____
Signature: _____
Date: _____

APPENDIX B - AUDIO-RECORDING CONSENT FORM

CONSENT FORM FOR AUDIO RECORDING OF STUDY PARTICIPATION

Swimming as an occupation for children with Autism Spectrum Disorder: Parent and Swimming Teacher experiences.

I hereby consent to audio recording of the interview.

I understand that:

- The recording will be stored in a secure location (password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me (or others/organizations) will be removed, I will be assigned a pseudonym within the research report.
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of Participant: _____
Date: _____
Place: _____
Signature or mark _____

Witnessed by:

Name of Witness: _____
Signature: _____
Date: _____

APPENDIX C - INFORMATION SHEETS



PARTICIPANT (PARENT) INFORMATION SHEET

Swimming as an occupation for children with Autism Spectrum Disorder: Parent and Swimming Teacher experiences.

Dear sir/madam,

I, Bronwyn Dudley, am an Occupational Therapist practicing in the field of paediatrics. I am currently completing my Master's degree in Occupational Therapy at the University of the Witwatersrand. As part of my postgraduate studies, I am completing a research project. My research is focussed on exploring swimming as an occupation for children diagnosed with Autism Spectrum Disorder (ASD) in South Africa. There is currently no research available in South Africa addressing this area, although specialized swimming lessons and aquatic therapy have been utilized for children with ASD overseas. In order to understand the value of swimming as an occupation for children with ASD, I would first like to explore the experiences of those who are already engaging in this activity, namely parents and swimming teachers. I would like to invite you to participate in this research. This will be achieved through an in-depth interview, which will be scheduled at a time and place that is convenient for both you (the participant) and myself (the researcher). Information gathered from the interview will be transcribed and analysed, and will contribute to an initial understanding of parents experiences in this context. This research may further support recommendations made by practitioners regarding possible leisure activities and may assist in addressing social inclusion of the child with ASD and support any difficulties experienced by parents in this context.

There is no harm in participating in the aforementioned research. There is no direct benefit to the research participant for participating. You have the right to withdraw from the study at any point in time. If you choose to withdraw, your data will be excluded from the research entirely. A follow-up interview may be required to clarify information after the initial interview. All personal information, which could identify the participant or the swimming school, will be excluded from the study. Direct quotes may be used from the interview, but will be referenced using an assigned pseudonym. Transcriptions and recordings will be securely stored (on a password protected computer), using only the identifying pseudonym. Once information from the interviews has been analysed, it will be presented back to you to confirm that it accurately reflects your experience. Results of the research study, once completed, will be available to you on request.

Should you wish to participate in the study, please complete and send back the attached consent form, following which a time, date and place for the interview can be scheduled. If you have any questions, concerns or clarifications before providing consent, please feel free to contact me.

Contact details:

Bronwyn Dudley, Principal Investigator, telephone no. 072 192 9234, or by e-mail at brondudley11@gmail.com.

Lyndsay Koch, Supervisor, by e-mail at Lyndsay.koch@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

PARTICIPANT (TEACHER) INFORMATION SHEET

Swimming as an occupation for children with Autism Spectrum Disorder: Parent and Swimming Teacher experiences.

Dear sir/madam,

I, Bronwyn Dudley, am an Occupational Therapist practicing in the field of paediatrics. I am currently completing my Master's degree in Occupational Therapy at the University of the Witwatersrand. As part of my postgraduate studies, I am completing a research project. My research is focussed on exploring swimming as an occupation for children diagnosed with Autism Spectrum Disorder (ASD) in South Africa. There is currently no research available in South Africa addressing this area, although specialized swimming lessons and aquatic therapy have been utilized for children with ASD overseas. In order to understand the value of swimming as an occupation for children with ASD, I would first like to explore the experiences of those who are already engaging in this activity, namely parents and swimming teachers. I would like to invite you to participate in this research. This will be achieved through an in-depth interview, which will be scheduled at a time and place that is convenient for both you (the participant) and myself (the researcher). Information gathered from the interview will be transcribed and analysed, and will contribute to an initial understanding of swimming teachers experiences in this context. This research may further support recommendations made by practitioners regarding possible leisure activities and may assist in addressing social inclusion of the child with ASD and support any difficulties experienced by swimming teachers in this context.

There is no harm in participating in the aforementioned research. There is no direct benefit to the research participant for participating. You have the right to withdraw from the study at any point in time. If you choose to withdraw, your data will be excluded from the research entirely. A follow-up interview may be required to clarify information after the initial interview. All personal information, which could identify the participant or the swimming school, will be excluded from the study. Direct quotes may be used from the interview, but will be referenced using an assigned pseudonym. Transcriptions and recordings will be securely stored (on a password protected computer), using only the identifying pseudonym. Once information from the interviews has been analysed, it will be presented back to you to confirm that it accurately reflects your experience. Results of the research study, once completed, will be available to you on request.

Should you wish to participate in the study, please complete and send back the attached consent form, following which a time, date and place for the interview can be scheduled. If you have any questions, concerns or clarifications before providing consent, please feel free to contact me.

Contact details:

Bronwyn Dudley, Principal Investigator, telephone no. 072 192 9234, or by e-mail at brondudley11@gmail.com.

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Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

APPENDIX D - INTERVIEW SCHEDULE

PARENT QUESTIONS:

Question	**Probe**	
Tell me about your son/daughter	Can start with questions like age, gender etc. to make person more comfortable, then move onto: likes/dislikes, personality and more abstract concepts if necessary	MUST GET DOWN TO DEEPER LEVEL OF WHO THEIR CHILD IS
Why did you start taking them for swimming lessons?	How did you find a swimming school? Does anyone else in your family swim?	LISTEN FOR EMOTIONAL TRIGGER WORDS
What has your experience of swimming lessons been?	What has been positive/negative? How did you find it initially? How do you think your child experiences swimming lessons? Have you noticed any changes in behaviour/social engagement?	DESCRIBE STEP-BY-STEP What does it look like? How has this changed? EXPECTATIONS VS EXPERIENCE

TEACHER QUESTIONS: (Be aware not to sound condescending – temper voice)

Question	**Probe**	
Tell me about your career as a swimming teacher?	When did you start? Why did you choose swimming? What has it been like? What do you enjoy/not enjoy about it?	STAY ON TOPIC
What do you understand about autism?	How do children with ASD behave? What do they find hard/easy? Where did you gain this understanding?	
What has your experience been of teaching children with ASD to swim?	How did you **feel initially**? How do you **feel now**? Was it **easy/hard and why**? Have you had any **support/special training**? If yes, **what was it and how has it helped you**?	LISTEN FOR **THOUGHTS AND FEELINGS** – PROBE THOSE – What did you think? How did you feel? DESCRIBE A **TYPICAL CLASS** COMPARE TO TYPICAL CHILDREN INITIAL **EXPECTATIONS - COMPARE**

DEMOGRAPHIC DATA TO BE COLLECTED:

Parent: Gender, age and race (of parent), age of child (now and when started swimming), gender of child, geographical location, has child attended therapy? profession **Swimming teacher**: Gender, age, number of years teaching, area in which they teach, experience

Setting up the interview:

“Thank you so much for agreeing to participate in my research study. When and where would it suit you to meet for the interview? The time take for the interview is not limited, but dependent on our conversation and the information you share with me. Do you have any questions regarding the study or interview process? Did you understand everything in the information and consent documents?”

At the interview:

“It is lovely to meet you, thank you so much for making the time to sit down with me for this interview. Before we start, I would just like to confirm that you are happy for me to record our interview? This is so that I can listen to you and take the most information possible away from our discussion. The interview will be transcribed afterwards, which will aid in my analysis. All personal information will be scrubbed from the transcription and replaced with pseudonyms to protect you confidentiality. The recording will be safely stored and all your personal information will be removed, to maintain confidentiality”

At the end:

“Thank you so much for your participation in my research and for sharing your experience with me. I will now transcribe and analyse the interview, on it’s own and in conjunction with other interviews. When I have finalised the results of the research, these results will be available to you on request. If you have any questions between now and then, or would like to withdraw from the study for any reason, you are free to do so.”

APPENDIX E: APPROVAL OF TITLE

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

10 October 2019
Person No: 708588
PAG

Miss BC Dudley
18 Louw Avenue
Lakefield
Benoni
1501
South Africa

Dear Miss Bronwyn Dudley

Master of Science in Occupational Therapy: Approval of Title

We have pleasure in advising that your proposal entitled *Swimming as an Occupation for Children with Autism Spectrum Disorder: Parent and Swimming Teacher Perceptions and Experiences.* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX F: ETHICAL CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Miss Bronwyn Dudley

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M190910 MED19-08-147

NAME: (Principal Investigator)	Miss Bronwyn Dudley
DEPARTMENT:	Occupational Therapy
PROJECT TITLE:	Swimming as an occupation for children with autism spectrum disorder: Parent and swimming teacher perceptions and experiences
DATE CONSIDERED:	27/09/2019
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Miss Lyndsay Koch
APPROVED BY:	Dr C Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	08/11/2019

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed September and will therefore be due in the month of September each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX G: CODING TABLES

Theme	Category	Subcategory
From being thrown in the deep end to stepping up to the starting blocks	Teachers dynamic experiences	"your knees are knocking"- nervous initially
		Disappointment at lack of information/support available
		Experience grows confidence
		Challenge accepted – excited to learn and grow
		Rewarding to build relationships and see progress
		Challenging to deal with slow progress and find a balance in handling
		Need and desire for more specialized training – want to provide a quality service & have certainty in skills
	Personal presentation and traits	It takes someone special →
		Patience
		Perseverance – tenacious
		Observant and flexible/adaptable
		Intuition/Instinct
	Different Strokes for Different Folks	Understanding how the child perceives the world (link in how teachers understand ASD from experience)
		Respect for individuality
		Meeting the child where they are
		Observe and react (linked "wing it")
		Be aware of your expectations
		Trial and error – learning as you go
	Teaching techniques (Every child is different, but some techniques are helpful for all of them)	Groups vs one-on-one
		Physical guidance, demonstrations and verbal instructions
		(Go slow and break it down)
		Duration of lessons
		Use of equipment and toys
		Boundaries
		Repetition and routines
		Goals setting and safety
		Role of the environment in attention

		Other tricks
		Other teachers and professional support
From just keeping your head above water to making a splash and going for gold – parents and children's changing experiences	Swimming for survival - the initial reason why parents started swimming lessons	Parent's experiences of child with water → Fear of drowning
		Children with ASD: Drawn to water
		Drawn to water and risk taking behaviour → safety as a primary goal for parents
	The changing meaning of swimming lessons for parents and children	Love for water and swimming Swimming as a meaningful occupation
		Sense of achievement • Having something to aim at • "I am capable"
		Proud to see progress
		As a parent – your child's happiness is your main priority
		There are still challenging days and difficult emotions • Seeing your child upset • Feeling judged by others
		Swimming, family time and holidays
		Opportunities for sibling interaction in aquatic environment Can be difficult to balance their needs
	The multifaceted nature of swimming → means and an end	Swimming as a leisure activity/for exercise
		Swimming as a career/productive occupation
		Swimming for sensory regulation – inherently therapeutic
		Participation in swimming led to improvements in other occupations (dressing, washing hair, social participation, school)
Teamwork makes the dream work	Parent and Swimming Teacher relationships	Knowing the diagnosis allows for preparation and improved lesson quality
		Parents don't always know the diagnosis
		Disclosure builds relationships between parents and teachers Working at a school for special needs was different to privately
		Not knowing can cause conflict, frustration and poor service delivery
		Parent's perspective – desire for inclusion and awareness – not always the experience

Theme	Category	Subcategory	Codes
From being thrown in the deep end to stepping up to the starting blocks	**Teachers dynamic experiences**	**"your knees are knocking"- nervous initially**	Fear of the unknown Nervous – the same as the child **Chaos**
		Disappointment at lack of information/support available	Difficult to find information specific to swimming Courses available in SA (for typical children) are very basic – not consistent/focused enough Desire for more information – not available Disappointed there are not more opportunities available for professional development
		Experience grows confidence	Fake it till you make it. The first child/lesson is the biggest learning curve Experience teaches you the skills you need Confidence comes with experience, exposure and knowledge They're not that difficult to work with once you know what to do
		Challenge accepted – excited to learn and grow	Excited – opportunity to learn and grow The more you do the more you learn Challenge accepted
		Rewarding to build relationships and see progress	It is rewarding to: See progress Experience personal connection and growth See parent's expectations change and sense of achievement/pride Hearing children's behaviour has also improved outside the pool
		Challenging to deal with slow progress and find a balance in handling	Difficult when you feel like you could have achieved more – but lessons stop Slow progress can be difficult

			Finding a balance of support vs independence while maintaining safety is challenging and important
		Need and desire for more specialized training – want to provide a quality service & have certainty in skills	No formal disability training or course available in SA A hands-on course would be valuable (not just theory) Want to trust that the process you are following will work – what you offer parents is genuine. Desire to do more as autistic children are drawn to water. Parents have been through a lot – want to deliver the best Desire for certainty of water safety – more predictability Courses need to be affordable because classes need to be affordable
	Different Strokes for Different Folks	**Understanding how the child perceives the world (link in how teachers understand ASD from experience)**	Understanding a different perception needs a different learning style Not a disability, a super power
		Respect for individuality	Every child is different (P and T) Respect their unique needs
		Meeting the child where they are	Expect the unexpected – each child and each day is different Adapt who you are all the time – in response to where they are
		Observe and react (linked "wing it")	Work with what you see – observe and react No point in planning – wing it!
		Be aware of your expectations	No expectations – see what they can do and go from there Adjust your expectations – child specific not compared to others Set the bar higher – expect that learning is a possible outcome
		Trial and error – learning as you go	Wing it! – trial and error (every child is different)
	Personal presentation and traits	**It takes someone special →**	It takes a certain type of person to teach special needs children. (B)

			The type of teacher (and group) and relationship will influence learning skills and enjoyment (B) Training in teaching special needs is not as important as the teachers personality – passion for special needs (P)
		Patience	Working with special needs takes patience and understanding (B) – all parents and teachers
		Perseverance – tenacious	Get on with it – perseverance (B)
		Observant and flexible/adaptable	Present and observant – especially for safety (one-on-one) (B)
		Intuition/Instinct	Instinct and intuition of the teacher are important. (B)
	Teaching techniques (Every child is different, but some techniques are helpful for all of them)	**Groups vs one-on-one**	Individual lessons work best – focus on that child One-on-one is a priority (P) Children learn by observing – groups are better
		Physical guidance, demonstrations and verbal instructions	Physical guidance is helpful Demonstration useful teaching tool Straightforward, simple, clear instructions work well. (B)
		(Go slow and break it down)	Take longer to learn than typical children Slow start – no pressure Build relationship and trust
		Duration of lessons	Longer lessons allow time for learning Shorter lessons help concentration and learning
		Use of equipment and toys	Equipment can be difficult to use Textures of pool toys can be challenging Toys can help motivate attention (b)
		Boundaries	Boundaries and firm handling are important
		Repetition and routines	Repetition and routine helped lessons Change in routine caused difficulty for child
		Goals setting and safety	A clear goal for lessons is important Goals of lessons are different from typically developing children Safety is the first priority

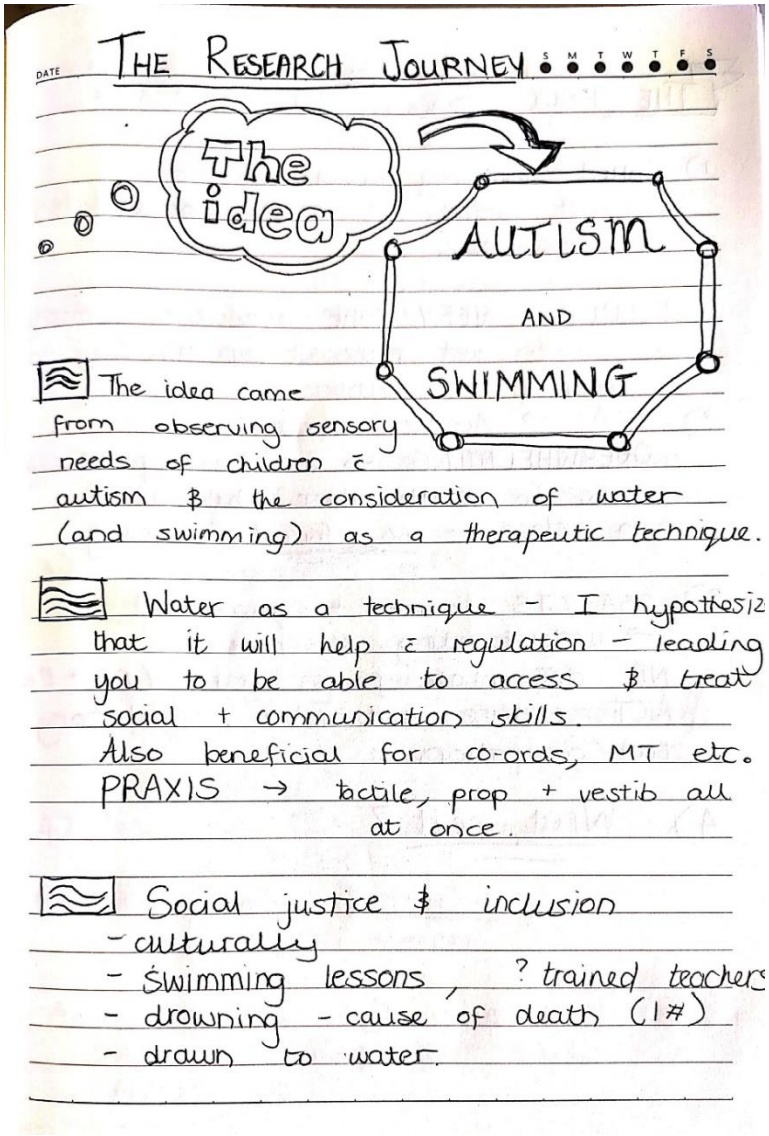
		Role of the environment in attention	Performance changed with different teachers in different environments (P) Noisy, busy environments can be overwhelming (B) Water as a "stim" - Using this to improve learning/ attention
		Other tricks	Distraction while doing something they don't want to Give them a break and come back Use all your tricks
		Other teachers for support - soundboard **Professional support**	Support from other teachers is valuable -Problem solve together Knowing others with knowledge to contact for support would be useful. Support from a HCP was helpful – built confidence and skill
From just keeping your head above water to making a splash and going for gold – parents and children's changing experiences	**Swimming for survival - the initial reason why parents started swimming lessons**	Parent's experiences of child with water → Fear of drowning	Fear of drowning developed through experience of risk taking behaviour/elopement towards/around water (all parents) Role of poor verbal skills in fear Need to be proactive
		Children with ASD: Drawn to water	Children with ASD are drawn to water (T) and P Loves bath time (All parents)
		Drawn to water and risk taking behaviour → safety as a primary goal for parents	Safety as the primary aim for swimming lessons (T) Swimming as a survival skill Water safety to allay fear (P)
	The changing meaning of swimming lessons for parents and children	**Love for water and swimming** **Swimming as a meaningful occupation**	Loves the water and swimming parents happy to be providing child with something they can see they enjoy "safe space", free, no performance anxiety Swimming as a lifelong and valued occupation

		Sense of achievement • **Having something to aim at** • **"I am capable"**	Sense of accomplishment/achievement, receiving medals, pride in participation Importance of having a dream/goal and something to aim for → motivation to participate
		Proud to see progress	Satisfaction and pride at seeing your child happy and engaged Proud to see change/progress Satisfying seeing proud parents (T)
		As a parent – your child's happiness is your main priority	Love and acceptance of who the child is – honour their interests and needs – other people will do the same. Lead by example
		There are still challenging days and difficult emotions • **Seeing your child upset** • **Feeling judged by others**	Some days are tough – perseverance is important → results will come First lesson was challenging and overwhelming Still have good days and bad days Anxiety initially for parent to more satisfaction and security Difficult emotions during bad lessons when younger – feeling judged by others in the pool area when behaviour is poor (speaks to inclusion and awareness) Emotionally draining to see your child upset
		Swimming, family time and holidays	Loves family time in the water – family activity on holiday. Sun City as a favourite holiday destination Holidays to places with a pool – keeps the kids busy, outlet and opportunity to engage with whole family → LOVE IT
		Opportunities for sibling interaction in aquatic environment **Can be difficult to balance their needs**	Balancing siblings needs – overwhelming if they can't both successfully participate Siblings interacting in the water – allows more physical contact Competition between siblings when swimming can lead to meltdowns

			Wanted to swim with brother – motivating factor Siblings swimming skills improved faster
	The multifaceted nature of swimming → means and an end	**Swimming as a leisure activity/for exercise**	Swimming as a form of exercise and physical outlet (B) Swimming can develop into a hobby/leisure activity – lifelong activity
		Swimming as a career/productive occupation	Swimming can become a career – as a teacher/assistant teacher Childhood occupations becoming adult occupations – productivity
		Swimming for sensory regulation – inherently therapeutic	Water as therapeutic Participating in the environment is reward enough Primarily a survival skill – also a sensory regulation strategy → improved participation in class and at home Participating in the environment is reward enough
		Regulation and motivation from swimming led to improvements in other occupations (dressing, washing hair, social participation, school)	Regulation from swimming enables engagement in other occupations improves participation in school. enables social participation better tolerates lying back in the bath and hair washing Learnt independent dressing at school from getting changed for swimming Improvement in other skills attributed to swimming Water as therapeutic Hearing children's behaviour has also improved outside the pool is rewarding Progress in the pool translated to home and school, Attention improved over time
Teamwork makes the dream work	**Parent and swimming teacher experiences**	**Knowing the diagnosis allows for preparation and improved lesson quality**	Disclosure enables preparation Disclosure enables participation and service delivery The more I understand, the better I can do my job

		Parents don't always know the diagnosis	Once they had the diagnosis and knew what they were dealing with → more satisfying experience (P) Not knowing the diagnosis yet made it difficult to understand behaviour (P)
		Disclosure builds relationships between parents and teachers **Working at a school for special needs was different to privately**	Disclosure builds relationships **Parent is an "expert" on the child** **Establishing the parents expectations builds relationships** Educating the parents is equally important as teaching the child (T) Parent and teacher commitment is important Good communication is important (T) Communication with the teachers – sense of ease and trust (P) Swimming teachers and parents need to work together to make lessons successful (P)
		Not knowing can cause conflict, frustration and poor service delivery	Parent acceptance (or lack thereof) stops disclosure Diagnosis shouldn't be a secret – there is no shame Acceptance not possible without disclosure Hard to ask parents/fearful Teachers want to provide the best service but can't
		Parent's perspective – desire for inclusion and awareness – not always the experience	Want a teacher/swim school who understands ASD/has experience (P) Children with ASD should have equal access to opportunities (P) Difficulty and frustration with finding a swim school that could cater for his needs (P) Inclusion with a child with ASD is challenging because people aren't informed. Exhausting for parents (P)

APPENDIX H: REFLECTIVE JOURNAL



DATE

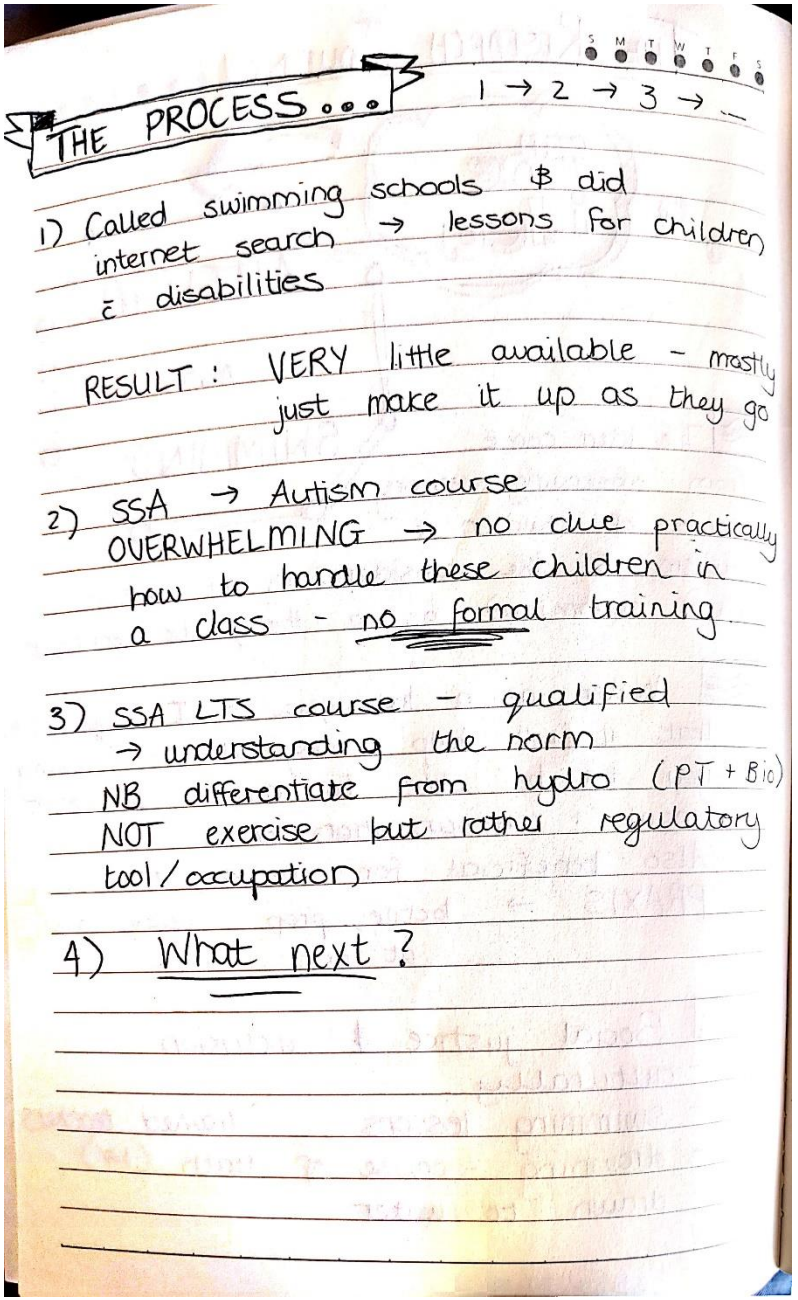
THE RESEARCH JOURNEY

S M T W T F S

The idea came from observing sensory needs of children & autism & the consideration of water (and swimming) as a therapeutic technique.

Water as a technique - I hypothesize that it will help & regulation - leading you to be able to access & treat social + communication skills.
Also beneficial for co-ords, MT etc.
PRAXIS → tactile, prop + vestib all at once.

Social justice & inclusion
- culturally
- swimming lessons, ? trained teachers
- drowning - cause of death (1#)
- drawn to water.



THE PROCESS...

S M T W T F S

1 → 2 → 3 → ...

1) Called swimming schools & did internet search → lessons for children & disabilities

RESULT: VERY little available - mostly just make it up as they go

2) SSA → Autism course
OVERWHELMING → no clue practically how to handle these children in a class - no formal training.

3) SSA LTS course - qualified → understanding the norm
NB differentiate from hydro (PT + Bio)
NOT exercise but rather regulatory tool / occupation

4) What next?

DATE

RESEARCH Idea's *

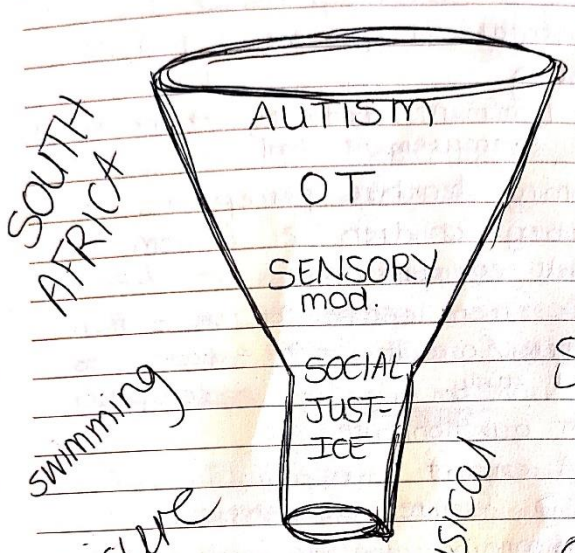
1) Experimental ĩ pre int. ß post int. testing
   ↳ treatment modality → too broad
   ?measurement tool.
2) Swimming teachers perceptions of teaching children ĩ autism
   ? well equipped
   ? Is there scope for us to train them / consult → = access to occupation
   ? Pilot study.
3) Parent questionnaire
   - SA context
   - ASD leisure engagement
   - swimming specific
   - childs experience of water etc.
   - Do parents actually want access to it?
4) Are Any OT's using aquatic Rx for ASD?

Rx idea's: use of teachh
minimal speech

Are children ĩ ASD able to choose leisure activities that meet their sensory needs.

DATE

Literature Review



SOUTH AFRICA
SOCIAL PART-ICIPATION
swimming
leisure
physical
sensory
OCCUPATION
ASD
Praxis
OT
MEANS
END
JOHANNESBURG
?coastal

DATE S M T W T F S

OVERSEAS: swimming programs have been researched & implemented for learners c ASD
- BY OT's
- Positive effects noted.

Articles not available:
1) strategies for teaching children with autism spectrum disorder in a recreational aquatics program. (E Kraft, R LeBlanc, D Culver) - Dec 2018
2) Effectiveness of a multisystem aquatic therapy for children with ASD (Jun 2018 – Journal of autism and developmental disorders)

3) A systematic review of SPI's available for children c ASD.
→ SIT vs SBI
→ SIT - v. effective.

NB look again at sensory interventions for ASD.

4) Clinicians perceptions of the benefits of Aquatic therapy for young children c ASD: a preliminary study

DATE S M T W T F S

Is it / is it not happening?

If yes/no why?

? Culture → depends on socio-ec. & culture - swim (not very african
- limited understanding of ASD in communities
- limited access to leisure (are municipal life guards trained in LTS)

SSA autism course (Friday 16 March 2018) reflections → can I include this info if long before & where? +/- 1 year ago.

Difficulty defining location of population
↳ cape, durban + JHB may gather different data
↳ how do I set this in my title?

DATE

Method ?

S M T W T F S

- Try for in depth interviews
  - swimming teachers
  - parents of kids in swimming lessons

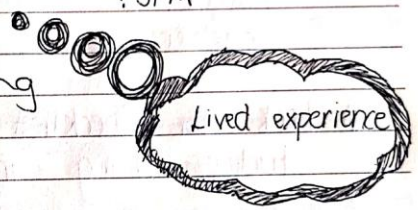
? selection & sampling

? Recruitment
- LP
- CCC
- swimming schools
- SSA.

? Develop interview questions

Qualitative study.

? SPM



Stats through coding
? sampling.

Title: Examining the lived experience of children with ASD engaging in swimming lessons / aquatic environment in Johannesburg.

? Ask parent for video of child in swimming class.

DATE

S M T W T F S

TITLE:
Swimming as an Occupation for Children c ASD ; Parent & Swimming teacher perspectives / perception & experience.

Questions
Is there a role for OT in aquatic therapy for children c ASD ?

Obj.
Parent
Teacher

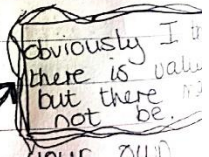
* Look for Checklist for Descriptive Qual study using in-depth interviews.

Data Analysis

Interview → transcription → coding (use softwar

+/- 4 themes out of a study.

Inductive coding.



BRACKET → you will discuss your own prejudice / bias & exam it so it doesn't affe result.

DATE

NB → Validation strategies

1) Triangulation
2) member checking
3) ~~present info~~ external auditor
4) Reflective journalling.

TO DO:

- Email Lyndsey (articles)
- Find out about transcription
- Max QDA.

PROTOCOL PRESENTATION F/B 08/03/1

Write objectives as "explore their experience".
→ through Journalling. + acknowledge

? Bracketing - do you discuss it as validation strat
? Careful in bringing together components in Lit review (ASD, swimming, SI, meaningful occupation - while still being neutral).
? ~~Deductive coding if certain ideas not in questions.~~
? OT's/services offering this

* Very Little known → need to understand experiences of those already using.

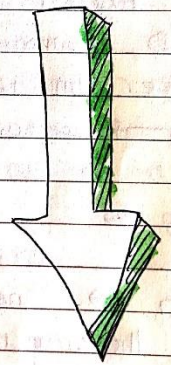
DATE

REFLEXIVITY:

→ "The writer is conscious of the biases, values and experiences that he/she brings to a qualitative research study (Creswell, 2007).

BRACKETING

"The process of data analysis in which the researcher sets aside, as far as humanly possible, all preconceived experiences to understand the experiences of participants in the study" - (Moustakas, 1994).



* Validation method

REFLECTIVE Journa

DATE 08/03/2019

Research presentation & discussion (informal).

Today we briefly reviewed our research proposals with our research supervisors. Among the broad base of topics discussed, one very important component with regards to qualitative research became evident — validation techniques/strategies. Importantly the two topics on the previous page (reflexivity & bracketing) were discussed. In order to ensure I am able to validate my research, I am starting my reflective journal today.

I had already started keeping this journal as a way of tracking my thought process, but will now try to examine my biases, preconceived ideas & experiences to reflect the participants experienc as accurately as possible.

DATE

My background:

I engaged in swimming from a young age & have personally derived a great deal of value from swimming as a leisure activity. Furthermore, I have experience with treating children with autism, especially using a sensory-based approach. This is what ultimately lead to my interest in the field & making the connection (or wanting to understand) between ASD & swimming as a therapeuti strategy. I do however acknowledge that although I may perceive this link/benefit, this may NOT be the perception/experience of those with ASD (their parents, other therapists or those providing the service).

Following my peaked interest in this area, it lead me to do informal investigation into the use of aquatic therapy as a treatment modality (executed by OT's) for children with ASD. I found many studies in the USA

that found positive results. This can further be influencing/biasing my view that it may have value in a South African context. I further looked at services available in SA & found no formal services.

I attended a course run by Swimming South Africa (aimed at swimming teachers) on Autism & Swimming (16 March 2018 - presented by Victoria Lamb - teacher at JSA). She explained the background of ASD well, but the overwhelming consensus from the swimming teachers was that of a lack of practical handling tools leading to anxiety & uncertainty. This may further bias my outlook as I have already had exposure to this population.

I went further to obtain my SSA Learn To Swim Instructor qualification - to better understand the "norm" and environment. It is important to note in terms of equal accessibility that there is NO formal ~~ac~~ training for swimming teachers on how to teach children with disabilities to swim. Teachers who are doing so currently may have had some informal training or are using a trial & error approach. This further exposure to this population/environment may further bias me.

With all these biases considered, I feel that my experiences (which lead to my biases) also ~~make~~/equip me with the right skills to determine the ~~exper~~ answers to my research question. I am interested in knowing not only if there is value in swimming for ASD BUT also if there IS NOT value. I believe that to do this, I first need to examine ~~the~~ the current paradigm and lived experience of parents of children c ASD & their swimming teachers, in the swimming context.

I put aside any preconceived ideas about the benefits/limitations that may be within my rationale for this study.

DATE S M T W T F S

I must be particularly aware of Bias when writing my literature review (to be sure I have included all relevant literature), data collection & interpretation (co-coder & external auditor to validate) and report writing.

DATE S M T W T F S

31/05/2019

Research presentation
1st draft

f/b Prof De Wit
Olindah

Analysis of what is inherent in swimming

Early activity analysis research (OS)

"Value"
↳ Therapeutic value.

inherent characteristics of swimming.

Group analysis of swimming
(by OT's)

Card sort → Read-up

* frame of reference
* Delphi

ASD school where swimming is done.

The value of occupation
↳ inherent.

DATE S M T W T F S

INTERVIEW FEEDBACK

Probes : NB → tell me about your child
↳ must get to who she is
↳ must probe into WHO not only facts

LIFESTYLE
in what ways are your children different

Listen a bit more for
* emotional trigger words.
chaos, freaked out, calm.

Can compare the experiences.

Thoughts + feelings.
What did you think?
What are some of the emotions you felt?

it's different
↳ pick one.

* When was the last time you swam with your child? Tell me about it?

DATE S M T W T F S

Initial expectations
How did that compare to experience

What kind of reactions

Add demographic info sheet
↳ send before

Don't over interpret for person
Describe your 1st session
Becareful of being patronizing.
↳ or rushing
Transcriber → exact transcription
→ then remove identifying information (eg: school etc)
∴ you can speak freely.

Becareful of survey questions
only 1/2.

Hook demographic info in from the beginnin
Need about 1 hour.

DATE

Donna
↳ Mom of ASD kid + Aupair

03/03/20

Set up interview - confirmed had 2 kids ẽ ASD.
@ interview - ASD + ADHD confused
- spoke about other diagnosis
Generally not well understood.

10/03/20

Personality + experience have influence on willingness to try new things

Access to a health care prof. made it easier

Jana - has worked ẽ alot of children ẽ ASD. → ⊕ source → ⊕ insight

Most teachers wanted me to watch their lessons → shows the practicality of the field - talking not as easy.
↗ HCP/parent/teacher
? Research on care giver personality
↳ incl in lit review.

PARENT QUESTIONS:

Question	Probe	MUST GET DOWN TO DEEPER LEVEL OF WHO THEIR CHILD IS
Tell me about your son/daughter	Can start with questions like age, gender etc. to make person more comfortable, then move onto: likes/dislikes, personality and more abstract concepts if necessary	
Why did you start taking them for swimming lessons?	How did you find a swimming school? Does anyone else in your family swim?	LISTEN FOR EMOTIONAL TRIGGER WORDS
What has your experience of swimming lessons been?	What has been positive/negative? How did you find it initially? How do you think your child experiences swimming lessons? Have you noticed any changes in behaviour/social engagement?	DESCRIBE STEP-BY-STEP What does it look like? How has this changed? EXPECTATIONS VS EXPERIENCE

TEACHER QUESTIONS: (Be aware not to sound condescending – temper voice)

Question	Probe	STAY ON TOPIC
Tell me about your career as a swimming teacher?	When did you start? Why did you choose swimming? What has it been like? What do you enjoy/not enjoy about it?	
What do you understand about autism?	How do children with ASD behave? What do they find hard/easy? Where did you gain this understanding?	
What has your experience been of teaching children with ASD to swim?	How did you **feel initially?** How do you **feel now?** Was it **easy/hard and why?** Have you had any **support/special training?** If yes, **what was it and how has it helped you?**	LISTEN FOR **THOUGHTS AND FEELINGS** – PROBE THOSE – What did you think? How did you feel? DESCRIBE A **TYPICAL CLASS** COMPARE TO TYPICAL CHILDREN INITIAL **EXPECTATIONS - COMPARE**

xxx

DATE S M T W T F S

13/05/20

1st video call interview

Went well

✓ connection + call quality

used whatsapp

on own in house

part. on own in room

↗ not limiting.

↙ "new norm"

cont. to use seperate recording device

↳ only audio → ⊕quality.

2nd video call interview

↳ quality of call + accent mode

recording slightly poorer quality

↳ whatsapp

↳ on own, ē headphones on

no disruption

15/05/20 → was set up before other teachers - CoVID affected.

↳ different swimming approach

↳ time → confidence

↳ children of colour

from disadvantaged comm.

ALSO sent videos

✓ call quality via zoom.

2 x dads	
3 x moms	
1 x male +	
5 x female †	

~~Contrast~~ → DD

No new themes ↳ did give broader view

→ DATA COLLECTION →

DATE 18/05/2020 S M T W T F S

First read through of teacher articles while my final 3 articles get transcribed.

Overarching idea's coming out so far:

1) Parent - teacher relationship
   + comm. is key
   − Disclosure matters
2) Autism awareness
   - what it is + what it isn't
3) Chaos, nervousness
   Excitement, love, fulfilment
4) Every child is different

Hobby ↕ Can't plan → wing it

Software
5) Support + training matter
6) Schools = ✓ mediator for services

TECHNIQUES

7) ↑ Physical handling — one-on-one
   ↓ expectations — learn by demo
   repetition — not just "naughty"
   routine
   "not that different to normal kids"

Wait to read parents tomorrow

↳ write down initial understanding

↳ Then combined

Awaiting final transcripts.

APPENDIX G: PERMISSION LETTER FROM SSA

From: Bronwyn Carter <brondudley11@gmail.com>
Sent: Friday, 07 February 2020 2:31 PM
To: Shirley Leech <administrator@easterngautengaquatics.co.za>
Subject: Swimming for children with Autism - Research

Dear Shirley,

I hope you are well and that this year has gotten off to a good start. I'm not sure if you remember me chatting to you about my interest in swimming and autism when I did the LTS course. This was in fact the main reason I did the course.

I am in my second year of my Master's degree in Occupational Therapy at WITS this year, and the topic for my research is "Swimming as an occupation for children with Autism Spectrum Disorder: Parent and Swimming Teacher experiences". I'm hoping to understand what the experience has been so far, and if there is anyway that OT's can help to make this a more positive experience for everyone involved (if it isn't already) in the South African context.

Part of this research involves conducting in-depth interviews with swimming teachers who have taught a child with ASD for at least 6 months and who are LTS trained.

I want to ask if it would be possible for SSA to send out an email on my behalf to all it's registered LTS providers in Gauteng to ask for participation in the study. I would send you the wording for the email and consent forms to be attached - following which if anyone wants to participate, they would communicate with me directly. Please let me know if this would be a possibility?

Look forward to your response.

Kind regards,

Bronwyn Carter (Maiden Surname: Dudley)

072 192 9234

On Sun, 09 Feb 2020, 11:12 AM Shirley Leech, <administrator@easterngautengaquatics.co.za> wrote:

Hi Bronwyn,

Definitely, no problem. I am desperately trying to find someone to talk at my workshop in April on teaching “special needs” any suggestions?

Take care,

Shirley Leech

EGA Administrator

Turn It In Report

Research Report

ORIGINALITY REPORT

11%	8%	6%	5%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

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11	www.ncbi.nlm.nih.gov Internet Source	<1%
12	Maria A. Fragala-Pinkham, Stephen M. Haley, Margaret E. O'Neil. "Group swimming and aquatic exercise programme for children with autism spectrum disorders: A pilot study", Developmental Neurorehabilitation, 2011 Publication	<1%
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121	Liezl Schlebusch, Shakila Dada, Alecia E. Samuels. "Family Quality of Life of South African Families Raising Children with Autism Spectrum Disorder", Journal of Autism and Developmental Disorders, 2017 Publication	<1%
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