AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF MOTHERS' EXPERIENCES RAISING AN AUTISTIC CHILD

A thesis submitted in fulfilment of the requirements for the degree of

MASTER OF SOCIAL SCIENCE IN PSYCHOLOGY (BY THESIS)

of

RHODES UNIVERSITY

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March 2021

Abstract

There has been an increasing research focus on Autism Spectrum Disorder (ASD) and the experiences of those affected by autism. Previous research has demonstrated that mothers experience difficulties in all spheres related to their autistic child. Mothers were focused on exclusively in this study as previous research found that it is mostly mothers who take on the primary caring role for their children. As a result, this research aimed to explore the perceptions and experience of six South African mothers raising their ASD child. This research used a qualitative research approach and an interpretative phenomenological analysis methodology. Two semi-structured interviews were held with each participant, with interviews being audio recorded. After analysis, five themes were found, namely: (1) learning their child has a condition or diagnosis, (2) learning and sharing about ASD, (3) the mothering experience, (4) interventions and cost and (5) supportive resources. Careful anonymisation choices were made in this research to ensure the anonymity of participants as best as possible, due to the recruitment through a gatekeeper organisation and snowball sampling. The main findings of this study were that mothers experienced difficulties and challenges as they navigated the medical world in search of a diagnosis for their child. Mothers also reported following their intuition when it came to their children's care, interventions, and schooling. The passage of time was a significant issue to mothers, as they described several delays and waiting periods. Mothers also described their concerns regarding their children's future and the fact that their child would be dependent on them and would not be able to form autonomous mature relationships with others. They also reported various thoughts on disclosing their child's diagnosis to their children. This research, therefore, added to and expanded upon South African literature on the experiences of mothers raising their ASD child. Concurring with previous research, this project found that mothers experience many challenges in the raising of their ASD child.

Keywords: autism spectrum disorder; experiences; mothering; mothers; interpretative phenomenological analysis

Plagiarism Declaration

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Signed: A Hewson Date: 03/08/2021

Acknowledgements

I would like to extend my gratitude to every participant mother who agreed to take part in this research. Without you, this research would not have been possible. Thank you for being so willing and so open to sharing your experiences with me.

I would like to thank *Autism South Africa* for their role as gatekeeper for this research project, and for sharing my recruitment advert on their email databases as well as providing information about and access to support groups.

To my supervisor, Professor Lindy Wilbraham - this has been quite a journey! Thank you for all your advice, feedback, and many suggestions, turning my multiple rough "final, final" drafts into this actual final project. I cannot thank you enough for all the times you helped me when I was feeling useless as a researcher and writer and helped put me back together after "falling to bits". I will always fondly remember your metaphors about the octopus and eagle – I finally got the octopus into the glass and soared like an eagle above the forest. Of course, thanks must also be extended to Wren and Chi for doggie cuddles during our meetings.

To Bradley and Katherine – my goodness! Two of my biggest supporters. Without your encouragement and listening to my rambling thoughts, ideas, constant worries, and wiping away many tears, I would not have been able to complete this research. Thank you.

I would also like to thank my parents for their constant support and encouragement and listening very patiently to my ideas, and for answering questions about parenting.

Finally, I would like to thank Rhodes University for awarding me a merit award which covered my fees for my first year of Master's, and the Health and Welfare Sector Education and Training Authority (HWSETA) for funding my second year of study with their generous bursary.

Abbreviations

ABA	Applied Behavioural Analysis
ADI-R	Autism Diagnostic Interview-Revised
ADOS-G	Autism Diagnostic Observation Schedule – General
APA	American Psychiatric Association
ASA	Autism South Africa
ASD	Autism Spectrum Disorder
BISCUIT	Baby and Infant Screen for Children with Autism Traits
DSM	Diagnostic and Statistical Manual of Mental Disorders
EC	Eastern Cape
GP	General Practitioner
HIV/Aids	Human Immunodeficiency Virus, Acquired Immunodeficiency Syndrome
IPA	Interpretative Phenomenological Analysis
KZN	KwaZulu-Natal
LMIC	Low- and Middle-Income Countries
LSEN	Learners with Special Education Needs
M-CHAT	Modified Checklist for Autism in Toddlers
ND	Neurodiversity
NDM	Neurodiversity Movement
OT	Occupational Therapy
OTC	Over the Counter
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise Specified
RDO	Regional Development Officer
RRB	Restricted and Repetitive Behaviours
RUESC	Rhodes University Ethical Standards Committee
SLT	Speech and Language Therapy
SSA	Sub-Saharan Africa
SSI	Semi-Structured Interviews
TB	Tuberculosis
ToM	Theory of Mind
UK	United Kingdom
USA	United States of America
US FDA	United States Food and Drug Administration
WC	Western Cape

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Chapter One: Introduction

1.1. Background and rationale

In 2018, I had the opportunity to homeschool tutor a teenager with Asperger's Syndrome. This experience led to my interest in Asperger's Syndrome, which now falls under the umbrella term Autism Spectrum Disorder (ASD). I had little knowledge of what ASD was at that time, except what I had learnt from popular culture. In the months that followed this homeschooling experience, I reflected on it and started becoming more and more interested in autism, generally. When the opportunity arose in February 2019 to begin my Master's in Psychology by dissertation at Rhodes University, I knew I wanted to research autism and mothers. After several discussions with my supervisor, we decided on the current research topic – of exploring mothers' experiences of raising their ASD children.

Shortly after starting my Master's, I attended an Autism Workshop in April 2019 held in Adelaide, Eastern Cape (EC), presented by *Autism South Africa* (ASA). This workshop included an introduction to ASD (which covered the history of ASD, what ASD is, according to the American Psychiatric Associations (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) 5, the causes of ASD, early signs of ASD, as well as facts and myths about ASD), and presented "Golden classroom tips for teachers". As this workshop was requested by educators in the area, it was not surprising that the workshop was well attended by educators from schools in Adelaide as well as surrounding towns. As expected, the majority of educators were women. Of the educators who attended, a handful were also mothers to an ASD child. After introducing myself as a researcher interested in ASD, I got quite an interesting reaction from the other attendees – best described as apprehension.

After the workshop, two mothers cautiously approached me and asked about my research and volunteered to participate. I approached the workshop presenter who is the EC Regional Development Officer (RDO) of ASA and introduced myself and my research project. After a short discussion, I asked the RDO if she and her organisation would be interested in participating as a gatekeeper for my research project, to recruit participants within the EC. The EC RDO explained that she had previously assisted other students with their research and was more than happy to share her contact details with me so that I could email her more information about my research. This began the open discussion between myself, the EC RDO as well as the National Director of ASA, regarding ASA's participation as the gatekeeper for my research project.

After attending this workshop presented by the EC RDO from ASA, my supervisor and I realised that there were particular issues facing mothers of children with autism in the EC. Some of these issues included poor access to resources, difficulty with accessing experts due to experts being located in large urban centres, long distances between facilities, as well as a lack of easily accessible advice and support networks. This, therefore, suggested that there might be particular dynamics of ASD experience in the EC, and ASA was willing to collaborate with me to explore this – as it may have been useful to ASA to develop knowledge, reach, and resources within the EC.

Secondly, after gathering some research literature on the experiences of raising ASD children in South Africa, I found that the research on mothering or parenting an ASD child was centred mostly around universities in the bigger urban centres such as Cape Town [University of Cape Town (Guler, de Vries, Seris, Shabalala & Franz, 2018)], Pietermaritzburg or Durban [University of KwaZulu Natal (Fewster & Gurayah, 2015; Mitchell & Holdt, 2014; Mthombeni & Nwoye, 2018; Reddy, Fewster & Gurayah, 2019; Wetherston et al., 2017)], Johannesburg [University of Witwatersrand (Alli, Abdoola, & Mupawose, 2015; Meiring, Seabi, Amod, Vorster, & Kern, 2016); Pretoria [UNISA (Clasquin-Johnson & Clasquin-Johnson, 2018)] and Port Elizabeth [Nelson Mandela University (Olivier & Ah Hing, 2009)], which conducted research studies focusing on those cities and provinces. These South African studies focused on regional areas to explore the impact of geographic location and provincial resources on experiences of mothering an ASD child.

So, following that, I wanted to use Rhodes University in Makhanda as a base to explore EC mothering experiences. Thirdly, referring to the two points above, and without access to external funding for the research project, it was decided to limit sampling to the EC. This was done because two physical, face-to-face interviews with each participant would require me to travel to meet my participants, twice, and secondly, because there was a limited network for support to refer participants to if they became distressed or needed to talk through issues that came up, during or after interviews.

However, though this research aimed to recruit all the mothers for this research from the EC, this became difficult when the Covid-19 pandemic of 2020 happened. After lockdown level five was implemented, and face-to-face interviews were no longer possible, I had to alter parts of the research, such as changing from interviewing face-to-face to online through Zoom, for Covid-19 compliance, but I also had to recruit more participants during this difficult time as there were not enough participants to meet IPA quality assurance criteria. While I tried to gain more participants through snowball sampling from the three previously interviewed participants recruited through the ASA network, only one further participant was found through snowballing. As a result, I requested ASA to send out my recruitment advert again on their networks, which was inadvertently sent out on the national network, instead of the EC network. However, since there was no further interest from EC mothers after my recruitment advert was sent out a second time, or through snowballing, two respondents from other provinces were included in the sample.

1.2. Contextualising the study

> Having a child with an autistic spectrum disorder is deeply overwhelming. It simply (or actually, in a complicated way) takes you over. Just becoming a parent is a profoundly challenging and transformative experience. But absorbing the blow that your child has a disability can be disorganizing, shattering, and devastating. Grief, loss, and anger, along with the sheer weight of the work, care, support, and mapping out of services, can pin you down for years (Crown, 2009, p. 70).

From the above extract from Crown (2009), it can be seen that the ASD world is a difficult and stressful world to navigate for a parent, with this stress lasting for years. Previous South African literature (Fewster & Gurayah, 2015; Olivier & Ah Hing, 2009; Reddy et al., 2019) has shown that it is difficult to find any aspect of a mother's life that has not been infused with the struggle of this mothering – it is an all-encompassing role. Mothering or raising an ASD child sprawls over into and becomes an all-encompassing experience, which takes over every aspect of life and identity for a mother.

Research focusing on ASD and the experiences of those affected by ASD is increasing as there has been an increase in individuals being diagnosed with ASD, and there is a growing recognition of the importance of understanding the complex impact that ASD has on families (Cridland, Jones, Caputi, & Magee, 2015). Previous South African literature on mothering an autistic child has found that it is an expensive journey (Guler et al., 2018; Mitchell & Holdt, 2014; Reddy et al., 2019), where more access to resources determines how much support one can mobilize (Reddy et al., 2019). It has also been found that navigating the medical or diagnostic world is challenging (Fewster & Gurayah, 2015; Reddy et al., 2019). There is also much difficulty in finding appropriate schooling. Parents reported experiencing stigma due to ASD being an invisible condition i.e., few physical symptoms are apparent except in severe cases (Guler et al., 2018; Olivier & Ah Hing, 2009; Reddy et al., 2019).

Porter (2010) explained that "the diversities of the contexts of mothering – for example, the financial position of the mother; the number of children she has, her health; her education; her support or lack of it; the health of her children; her race; her class; whether she has a partner, what her partner may be like – all influence mothering" (p. 6). This study, therefore, aims to explore the complex impact that ASD has on mothers specifically, in their role as primary caregiver.

This research project chose to focus on 'mothering' experiences, and not 'parenting' experiences. This choice was made as some ASD mothering literature (McAuliffe, Thomas, Vaz, Falkmer, & Cordier, 2019; Nealy, O'Hare, Powers, & Swick, 2012; Nicholas, et al., 2016; Safe, Joosten, & Molineux, 2012) found that mothers do most of the daily care work with their children. At the same time as this daily care work, mothers are also looking after other children, managing their household, as well as their careers, while fathers seemingly play a supportive, financial role. This designation of patriarchally gendered roles within nuclear-patterned families was reproduced within early psychoanalytic attachment theories regarding the idealised roles of mothers and fathers in the raising of their children, following the disruptions of family life during World War 2 (Burman, 2017). Burman (2017) argues that Bowlby's Attachment Theory 're-socialised' mothers back into domesticity to meet children's needs for mothering. Even when research and parenting manuals deliberately refer to the gender-neutral term "parents", in most cases it is still mothers who do the majority of the care work (Sutherland, 2006).

1.3. Research aim and methodology

This study aimed to explore the experiences of mothers raising their child diagnosed with ASD in South Africa. This research sought to explore this experience with an Interpretative Phenomenological Analysis (IPA) methodology. Semi-structured interviews were used as the method of material collection in this study.

Storey (2016) warns about the use of psychological theory in IPA research and explains that many researchers have opted to only invoke theory when discussing the thematic findings of the study, to not violate participants' meanings and sense-making. IPA does not typically try to test a pre-determined hypothesis. Rather, the aim is to explore the area of concern flexibly and in detail (Brocki & Wearden, 2006). The theory, therefore, does not drive the analysis but is used as an explanatory resource after participants have made sense of their experiences (Storey, 2016). The use of a priori theory could result in psychological theories being used to 'test' theories and to judge mothers according to these theories (Storey, 2016). An example of this theory is Attachment Theory by John Bowlby.

Erica Burman (2017) has offered a feminist critique of the implications for women who are mothers, of Bowlby's Attachment Theory, formulated in Post World War 2 Britain. According to this critique, Bowlby's mother ideology has promoted the idealised view that women's place is in the home with their children, and a mother's absence from the home (for example, full-time work) results in children who have personal or behavioural problems later in their lives, as they have not been mothered adequately (Burman, 2017). When taking this feminist, critical view into account, it can be suggested that in many cases, mothers are blamed for their children's problems (Burman, 2017). It was not the goal of the current research to 'test' or to judge experiences according to a psychological theory. This research project moved away from this trend of using external lenses, such as the psychoanalytical attachment theory to evaluate or critically analyse mothers' experiences, and rather wanting to explore mothers' experiences phenomenologically.

1.4. The significance of the study

This study will contribute to the body of knowledge on mothering an autistic child in South Africa by clarifying their experiences, and on what they found difficult or easy. By understanding these experiences, it can be determined how mothers can be assisted and their experiences and difficulties made easier.

While this research is not directly therapeutic to the interviewed mothers, it provides an opportunity for mothers to share their experiences, and if they were feeling isolated and overwhelmed, to put them in touch with support networks. However, this research can be considered beneficial in the sense that it can be of great use and value to wider groups. Having a better understanding of the experiences of South African, and EC caregivers of ASD children, assists ASA in planning and advocating for more resources to support mothers or parents, and by extension, ASD children. This is also of potential benefit in training psychologists, and in State provision of posts, welfare services and grants, particularly in resource-poor provinces like the EC.

1.5. Concept clarification

The following concepts are to be clarified below: ASD, ASD child, high and low functioning autism, and neurotypical.

1.5.1. ASD

ASD is a lifespan (Matson, Rieske, & Tureck, 2011; McKenzie & Dallos, 2017) neurodevelopmental disorder characterised by issues or deficits in social interaction and communication, the presence of restricted and repetitive behaviours (APA, 2013), as well as sensory processing (Autism South Africa (ASA), n.d.; Fiene & Brownlow, 2015).

1.5.2. ASD child - identity-first terminology

For the purpose of this study, I will use identity-first terminology to refer to ASD persons (such as ASD child or autistic child), as opposed to the person-first terminology (such as a person with autism) (Dyck & Russell, 2020; Jaarsma & Welin, 2012; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013; Owren & Stenhammer, 2013). However, this is a debate holding different positions related to disability rights and identities, and thus the choice of terminology varies according to each autistic person and person within the autism community. This debate will be discussed more in chapter two.

1.5.3. High and low functioning autism

At several stages in this research report, the terms high functioning and low functioning autism are used. It should be noted that these are not official autism diagnoses but are rather informal terms used by lay-people in society to indicate the degrees of severity of autism, on an "autism spectrum" continuum. However, since the changes in the DSM-5, the severity of ASD should be recorded by stating the level of impairment according to their tabularized guidelines (APA, 2013). Physicians can specify the severity for social communication and restricted, repetitive behaviours, according to three levels, ranging from "requiring very substantial support" to "requiring substantial support" to "requiring support" (APA, 2013). Those previously considered to have low functioning ASD are now considered to require very substantial or high levels of support, while those with previously known high functioning ASD are considered, in theory anyway, to have "lower" support requirements. However, many in society still use the terms low and high functioning as these are less clinical than ASD level 1 (low support), 2 or 3 (high support), which is perhaps why parents still prefer to use these terms. Since it is these terms, high and low functioning, that mothers participating in this study refer to, this research report will also use these terms.

1.5.4. Neurotypical

The term neurotypical is a term typically used by those in the ASD world to refer to those who do not have ASD or other 'neurologically different' conditions (Runswick-Cole, 2014). In other words, it refers to 'normal' functioning individuals.

1.6. Structure of research project

This research project on the experiences of mothers raising their ASD child in South Africa comprises eight chapters, including the current chapter:

- This first chapter introduces the research topic and the methodology used to investigate mothers' experiences raising their autistic children in South Africa.
- The next three chapters present reviews of the clinical and scholarly literature, in three interrelated themes. Chapter two outlines ASD's characteristics, aetiology, prevalence, diagnostic and screening tools, and treatment options, from the view of the deficit or psychiatric theoretical perspective, before presenting the alternative neurodiversity perspective.
- In chapter three, local research studies on the contextual factors which affect ASD and the experiences thereof in South Africa are reviewed.
- The previous research literature on the experiences of parents raising their ASD child in both South Africa and internationally is reviewed in chapter four.
- Chapter five outlines the research design and methodology used to address this study's research question. This chapter describes how the research participants were selected and recruited, as well as how qualitative, experiential material was collected via interviewing and analysis, which was in line with the chosen methodology. Furthermore, this chapter also discusses the ethical principles that were considered and applied, as well as how trustworthiness was ensured.
- Chapter six reports the findings of the study in the form of presenting themes, with interview extracts to support the themes generated from the analytic process.
- Chapter seven provides a discussion of the findings and links the current study's findings to some of the research literature reviewed in chapters two, three and four.
- Chapter eight provides a summary of the study, the implications of the study findings, the limitations of the current study, and recommendations for future research.

Chapter Two: Literature review - Autism Spectrum Disorder

2.1. Introduction

This chapter presents a review of clinical and psychiatric literature about the characteristics, aetiology, prevalence, diagnostic and screening tools, and treatment options of autism spectrum disorder from the view of the deficit or psychiatric model (a theoretical perspective), which is considered to be the primary and most common view of disorder and disability. After this, an alternative theoretical and political disability perspective is presented – that of "neurodiversity" – which has challenged dominant deficit or psychiatric views.

2.2. What is Autism Spectrum Disorder?

ASD is a neurodevelopmental disorder (APA, 2013). The core domains which are affected by ASD include social interaction, communication, restricted and repetitive behaviours (RRBs) (APA, 2013), and sensory processing (ASA, n.d.; Fiene & Brownlow, 2015). In terms of social interaction and communication deficits, social-emotional reciprocity, which is the engagement with others and sharing of thoughts, is one of the areas that those with ASD struggle with (APA, 2013). In young ASD children, the lack of social-emotional reciprocity is seen, as they show little interest in social interaction, sharing of emotion, or imitating the behaviours of others (APA, 2013). In addition, the language used by these young children is often one-sided used only to "request or label, rather than to comment, share feelings, or converse" (APA, 2013, p.53).

The RRBs, or stereotyped behaviours, include hand-flapping, finger flicking, rocking, spinning, and self-injury such as head-banging and hand biting (Baker, Lane, Angley, & Young, 2008). Anxiety is linked to these RRBs, as the stereotyped behaviours are suggested to function as a strategy to control, manage and regulate their environment (Baker et al., 2008; Wigham, Rodgers, South, McConachie, & Freeston, 2015). This relationship is not well understood, but the RRBs are thought to self soothe to avoid or reduce stimulation, or alternatively to create stimulation (Wigham et al., 2015).

As sensory processing issues are a common early feature of ASD, they can be used in the diagnosis of ASD (Crane, Goddard, & Pring, 2009; Fiene & Brownlow, 2015). All eight of the senses are implicated in ASD: auditory, visual, tactile (Kern et al., 2006; Tomchek & Dunn, 2007), taste, smell (Crane et al., 2009), interoception (Fiene & Brownlow, 2015), proprioception, and vestibular (Baker et al., 2008). Each of the sensory abnormalities experienced by the ASD individual can be hypersensitive (high sensitivity or reactivity) or hyposensitive (low sensitivity or reactivity or sensory seeking) (Crane et al., 2009; Fiene & Brownlow, 2015). Hyper-and hyposensitivity can occur in the same individual and can differ and fluctuate for each sensory modality (Wigham et al., 2015).

Since ASD encompasses several other disorders, such as Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) and Asperger's Syndrome, it exists on a spectrum, due to varying manifestations of the disorder according to severity, developmental level, and chronological age (APA, 2013). The previously mentioned disorders each had their own diagnostic category in the DSM-IV, but were grouped together to form autism spectrum disorders in the 2013 revision of the DSM (APA, 2013).

While the exact aetiology of ASD is unknown (Jones et al., 2018; McKenzie & Dallos, 2017; Newschaffer et al., 2007; Roberts, Lyall, Rich-Edwards, Ascherio, & Weisskopf, 2013), suggested aetiologies include genetic susceptibility and environmental factors (APA, 2013; Franz, Chambers, von Isenburg, & de Vries, 2017; Jaarsma & Welin, 2012; Mthombeni & Nwoye, 2018; Newschaffer et al., 2007) that act either in isolation or together (Fett-Conte, Bossolani-Martins, & Rosan, 2015). These suggested aetiologies can be described as stemming from a Western, psychiatric perspective (Gona et al., 2015), and might not be appropriate in all cultural contexts, such as in South Africa, where some communities, and certain generations, such as the older generation isiZulu-speaking people, believe in supernatural aetiologies (Mthombeni & Nwoye, 2018; van Schalkwyk, Beyer, & de Vries, 2016). Similarly, it is not only ASD that is understood differently in South African cultures. Schizophrenia, for example, has been understood as a cultural calling to become a sangoma or traditional healer, a process known as ukuthwasa (Bakow & Low, 2018; Niehaus et al., 2004). The African traditional cultural views of ASD will be discussed in more detail in chapter three.

The prevalence of ASD is estimated to be 1-2% of the population, both worldwide and in South Africa (Franz et al., 2017; Reddy et al., 2019; van Biljon, Kritzinger, & Geertsema, 2015), with the diagnostic ratio of 4:1 in males versus females (APA, 2013). While studies on the prevalence of ASD have been conducted in several countries across the globe, more specifically in the United States of America (USA), Europe, and Western Pacific, few studies have been published on the prevalence, incidence, and impact of ASD in South Africa (Franz et al., 2017; Malcolm-Smith, Hoogenhout, Ing, Thomas, & de Vries, 2013; Springer, van Toorn, Laughton, & Kidd, 2013; van Biljon et al. 2015; van Schalkwyk et al., 2016). Suggested reasons for the lack of prevalence and epidemiological studies in South Africa will be discussed in chapter three.

Since there are no biological or medical tests for ASD (McKenzie & Dallos, 2017) and there is no single feature that will confirm or rule out ASD (Malcolm-Smith et al., 2013), the diagnosis thereof is often based on behavioural observations, level of impairment in the core domains (Mitchell & Holdt, 2014; Newschaffer et al., 2007; Steiner, Goldsmith, Snow, & Chawarska, 2012), and occasionally on historical information (APA, 2013). Two common diagnostic assessment tools are the *Autism Diagnostic Observation Schedule - General (ADOS-G)*, considered to be the 'gold standard' assessment tool in the global North (Chawarska, Klin, Paul, Macari, & Volkmar, 2009), and the *Autism Diagnostic Interview - Revised (ADI-R)* (Germani et al., 2014). Screening tools such as the *Baby and Infant Screen for Children with Autism Traits (BISCUIT)* and the *Modified Checklist for Autism in Toddlers (M-CHAT)* (Matson et al., 2011; Mitchell & Holdt, 2014) are used as alternatives to the *ADOS-G* and *ADI-R*, which are time-consuming and difficult to administer (Jiang, Matson, Issarraras, & Burns, 2017). There is a focus on the early detection and intervention for ASD (Matson et al., 2011) as it is suggested to result in a better prognosis for the child (Mitchell & Holdt, 2014). Unfortunately, standardised, validated, and accessible tools for screening and diagnosing ASD need to be developed for use in South Africa (Franz et al., 2017; Malcolm-Smith et al., 2013) as there is a lack of appropriate tools in African languages (van Schalkwyk et al., 2016). However, this is a challenging feat due to many language translations, validations, training costs (Franz et al., 2017), and cultural sensitivities that need to be considered. There is also a lack of knowledge about ASD generally (van Schalkwyk et al., 2016), which has resulted in ASD often not being diagnosed or being diagnosed late (Malcolm-Smith et al., 2013).

The early diagnosis and treatment of ASD have been cited as resulting in a better prognosis for the ASD child, as the brain is still creating, strengthening, and pruning neural networks in the early stages of life (Mitchell & Holdt, 2014). Early intervention can also be delayed as some physical symptoms only become apparent when children start engaging in social activities (Mitchell & Holdt, 2014). However, occasionally the diagnosis of ASD is delayed as parents start doubting their concerns about their child as healthcare practitioners allocate parents' concerns to late development (Mitchell & Holdt, 2014). Since there is a strong focus on the early intervention of ASD, there is an equally strong focus on the early detection of ASD (Matson et al., 2011). While parents often noticed autistic symptoms in their children at a young age, they did not seek medical help about these symptoms until a few months have passed (Matson et al., 2011). Even then, the diagnosis is often delayed until preschool age when 'school readiness' is considered (Steiner et al., 2012). This is because when they did seek paediatric help, it was unlikely that these professionals would diagnose ASD, due to overlaps in symptoms across conditions, with the paediatrician then often referring the family to psychiatrists or clinical psychologists (Matson et al., 2011). Other factors impacting the delay in early diagnosis is the lack of adequate screening tools, delayed action by paediatricians after parents voice their concerns, as well as limited availability of specialised diagnostic services for young children (Steiner et al., 2012).

Since ASD is a lifespan condition (Matson et al., 2011; McKenzie & Dallos, 2017), interventions and treatments for ASD aim to optimise functioning by reducing core symptoms and treating behavioural and psychiatric co-morbidities (Louw, Bentley, Sorsdahl, & Adnams, 2013; Newschaffer et al., 2007). The most commonly cited interventions and treatments include Applied Behavioural Analysis (ABA) (ASA, n.d.; Mthombeni & Nwoye, 2018; Wetherston et al., 2017), speech and language therapy (SLT), occupational therapy (OT) (ASA, n.d.; Wetherston et al., 2017), biomedical (meaning medicinal or drugs) therapy, and lifestyle interventions such as dietary changes (Wetherston et al., 2017). While there are no United States Food and Drug Administration (US FDA) approved medications to treat the core symptoms of ASD, the FDA has approved the use of two medications, risperidone, and aripiprazole, for treating the ASD associated behaviours of irritability (aggression, self-injurious behaviour, temper tantrums) (Lamy & Erickson, 2018; Louw et al, 2013). Across the world, the use of other treatments, such over the counter (OTC) "medications" and lifestyle interventions are often cited, even though evidence of their efficacy is poor (Akins, Angkustsiri, & Hansen, 2010; Louw et al., 2013). OTC "medications" are those supplements and medications which are not prescribed by any doctor or psychiatrist, which are also known as self-medications. OTC "medications" include vitamins, minerals (Akins et al., 2010), probiotics and homeopathic remedies (Louw et al., 2013). An example of a lifestyle intervention is change to diet, such as a gluten-free casein-free diet (Akins et al., 2010).

2.3. The deficit or psychiatric model of ASD

The deficit model, or psychiatric model, described above, has dominated autism discourse over the last century (Kapp, 2019; Robertson, 2009; Tomlinson & Newman, 2017). This model influences the public and scholarly view on ASD, largely as a result of Baron-Cohen's Theory of Mind (ToM) (Tomlinson & Newman, 2017). This theory sees ASD as a "biological and cognitive defect that manifests in social, communication and imagination problems" (Tomlinson & Newman, 2017, p. 93). This view of ASD implies that ASD individuals' experiences and lives are tragic, abnormal and that they need treatment (Tomlinson & Newman, 2017). The deficit model therefore can be suggested to see autistic individuals as severely limited by disordered neurology, resulting in major impairments in their interaction with the social and physical world, as well as in their cognition (Kapp et al., 2013; Robertson, 2009; Russell, 2020). Under this deficit model, autistic individuals are presented as broken, ill individuals who need to be "fixed", treated or supported, in order for them to live and function normally (Jaarsma & Welin, 2012; Robertson, 2009). The deficit model largely ignores the cognitive strengths, talents, skills, and ways of being of autistic individuals (Kapp, 2019; Robertson, 2009).

However, a different theoretical and political perspective on intellectual disabilities, which is starting to challenge the deficit model and starting to gain acceptance, is that of the neurodiversity perspective (Robertson, 2009). The neurodiversity perspective focuses on the idea that autism and other neurological conditions are neurological differences and natural variations amongst humans (Dyck & Russell, 2020; Jaarsma & Welin, 2012; Owren & Stenhammer, 2013), which are valuable (Jaarsma & Welin, 2012; Reading, 2018). These conditions are considered to be a different way of existing which is not handicapped or pathological (Dyck & Russell, 2020; Jaarsma & Welin, 2012), but which should be tolerated and respected in the same way as other human differences (Jaarsma & Welin, 2012; Owren & Stenhammer, 2013). Furthermore, the autistic self-advocates within the Neurodiversity Movement (NDM) see their autism as inseparable from their identity (Kapp et al., 2013), challenging the efforts to eradicate, prevent, treat and cure ASD (Baron-Cohen, 2019; Kapp et al., 2013). A further focal point of this movement is about the rights, non-discrimination and other political issues related to autism and neurological conditions (Jaarsma & Welin, 2012). Those who adopt the neurodiversity perspective are more likely to emphasise the strengths, talents, and gifts of ASD people (Robertson, 2009; Tomlinson & Newman, 2017).

2.4. An alternative perspective to ASD – the Neurodiversity Movement

For many autists, struggling with their differences is a lonely experience (Kapp et al., 2013). During the 1990s, NDM awareness arose primarily on the internet, propelled by high-functioning autists (Jaarsma & Welin, 2012) who felt marginalised by organisations run by the parents of autistic people (Kapp et al., 2013). The NDM mobilized through different websites such as *Aspies for Freedom, The Autist, Autcom, Angelfire, Wrongplanet,* and *Neurodiversity.com*, mostly based in the USA and Europe (Dyck & Russell, 2020). This movement, arguably still in its infancy, has historically been led by and comprises autistic and other neurodivergent advocates and activists (den Houting, 2019). However, it is not only autists who are included in this movement. Individuals with other disabilities and conditions have also used the NDM to resist labelling as ‘disabled’ or ‘abnormal’ (Russell, 2020). However, this thesis will focus on ASD and the NDM.

Several authors have explained that the NDM is vocal in its view on the language used to refer to autistic individuals (Dyck & Russell, 2020; Jaarsma & Welin, 2012; Kapp et al., 2013; Owren & Stenhammer, 2013). According to these authors, the NDM, and their autistic self-advocates, prefer the terms “autistic person” or “autist” (described as identity-first), rather than “person with autism” (described as person-first, often used by the research community) (Dyck & Russell, 2020; Jaarsma & Welin, 2012; Kapp et al., 2013; Owren & Stenhammer, 2013). They explain that in the former terminology, autism is inseparable from the person since being autistic affects every single part of the person (Kenny et al., 2016; Owren & Stenhammer, 2013), while in the latter phrasing, it implies that there is a normal person trapped behind the autism and that they are separable from their autism (Dyck & Russell, 2020; Jaarsma & Welin, 2012). In a study conducted in the United Kingdom (UK) regarding preferences for terminology within the autistic community, Kenny et al. (2016) found that most autistic adults, their family members, friends, and parents endorsed the term ‘autistic’, while most professionals endorsed the term ‘person with autism’. However, this choice in terminology is very person-specific, with every autist and person within the autism community having their own preference regarding terminology (Jaarsma & Welin, 2012; Kenny et al., 2016). There is also a wider debate among a wide range of disability scholars and persons regarding the preferred terminology.

The ‘different way of existing’ referred to above refers to ASD individuals’ different ways of socialising, communicating, and sensing, which may not always be a disadvantage for those persons (Jaarsma & Welin, 2012). The NDM promotes subjective well-being and adaptive functioning, such as reliable but not necessarily spoken communication, rather than typical functioning (Kapp et al., 2013). They oppose those interventions which try to eliminate those unusual, harmless behaviours, such as avoiding eye contact, and repetitive body movements (Kapp et al., 2013). ABA is one of the greatest sources of tension between self-advocates and parents, as the self-advocates criticize behavioural interventions as focusing too narrowly and forcefully on normalization (Kapp et al., 2013). Furthermore, self-advocates see ABA as cruel since it exposes ASD children to stimuli that cause distress and subsequently tries to discourage their unwanted behaviours (Dyck & Russell, 2020).

The deficit or psychiatric model and the NDM are at odds with each other regarding the cause and importance of curing autism (Kapp et al., 2013). The DSM-5 classification of ASD is described as a typical psychiatric model classification, where individuals are seen as disabled because of their deficits and difficulties (Jaarsma & Welin, 2012). In this model view, the focus is on fixing, curing, and correcting any deficits and difficulties the individual may have so that they may live in a ‘normal’ society (Jaarsma & Welin, 2012; Kapp et al., 2013). In alignment with this model, some parents of autistic people pursue treatments for their child in the hope of a cure, recovery, or normal appearance, with many of these parents becoming knowledgeable about psychiatric discourses and practice, often acting as co-therapists (Kapp et al., 2013).

By contrast, the NDM adopts a social model of disability, which distinguishes between the individual's actual physical and biological impairments from the disabling attitudes and practices of the society within which we live (Dyck & Russell, 2020; Kapp et al., 2013). Linked to this, one of the most common criticisms of the NDM is that it sees autism as a difference and a cultural identity, but not a disability (den Houting, 2019). This is seen as a weakness of the NDM since, for some autistic people, autism is a clear disability (den Houting, 2019). While den Houting (2019), an autistic autism researcher, agrees that ASD is a disability, this researcher only sees it as a disability because of the failure of the environment and society within which we live, to accommodate their physical, social and emotional needs, and not because of the autism itself (Bailin, 2019; den Houting, 2019; Dyck & Russell, 2020). For example, a wheelchair user is not disabled when they have access to ramps and elevators, as they have access to all the same things as a person who walks (Bailin, 2019; Kenny et al., 2016). Living in a society that is not designed for ASD people contributes to and exacerbates the daily living challenges faced by ASD people (Robertson, 2009). However, this social model of disability cannot ameliorate all impairments, such as chronic pain, by providing a more accommodating environment, for example (den Houting, 2019). However, for most within the NDM, the social model of disability describes the experiences of autistic people well (den Houting, 2019).

The NDM specifically protested against the medicalization of Asperger's Syndrome, which considered autism as being high-functioning or low support autism, since it may stigmatize those individuals who are placed in the same DSM category as those with low-functioning and high support ASD (Jaarsma & Welin, 2012), such as what has occurred in the changed diagnostic criteria for ASD in the DSM-5. However, while the NDM has tried to de-medicalise autism, by describing autism as a normal human variation, which should not be considered a disorder or be considered in medicalised or psychiatric or deficit terms, they also use biologically or neurologically grounded models of understanding of difference – "neuro"-differences and "neuro"-diversity (Russell, 2020).

The autistic culture has been described as a minoritized culture as autists suffer discrimination and exclusion (Jaarsma & Welin, 2012; Owren & Stenhammer, 2013). However, the internet has given autists a way around their social and communicative exclusion, since the internet is free from neurotypical ways of timing, interpreting body language, eye contact, and managing body language (Jaarsma & Welin, 2012). The virtual environment is more autism compatible (Jaarsma & Welin, 2012). However, this is seemingly only applied to those who are considered as high functioning and low support autists (den Houting, 2019; Jaarsma & Welin, 2012). This is one of the critiques of the NDM – that they are mostly made up of less impaired individuals (Asperger's Syndrome and high functioning ASD) who do not represent people with more severe problems (den Houting, 2019;

Russell, 2020) since those who require higher support needs are too disabled to be included in the NDM (den Houting, 2019). den Houting (2019) explains that this criticism however overlooks the variation and fluctuation in the capability that autistic people experience. While an autist may struggle with one skill, they may excel in another, or they may be able to perform the skill one day and not the next (den Houting, 2019). This is corroborated by Robertson (2009) with his explanation that the ASD individual will have varying strengths and weaknesses within each of the core domains. To place high and low functioning autists as dichotomous erases their variations in ability and restricts their access to support for those considered as high-functioning and denies autonomy and agency to those considered low functioning (den Houting, 2019). Since the term low functioning serves to lower expectations and limit their opportunities for success, it would be better to assume competence, thereby giving them the opportunity for achievement (den Houting, 2019).

Jaarsma and Welin (2012) described a paradox within the conception of neurodiversity (ND). If ND is accepted as a special culture, autists may not get the help and care they need as their autism would be regarded as a natural variation (den Houting, 2019; Jaarsma & Welin, 2012). The acceptance of autism will not cure the difficulties they face with relationships, communication, rigid behaviours, or sensory issues (Jaarsma & Welin, 2012). However, if ND is not accepted as a separate culture, high-functioning autists will suffer from the stigma of having a deficit, even if some do not need special care and support (Jaarsma & Welin, 2012). However, den Houting (2019) argued that this is not a correct view of this paradox. ND advocates consider autism to be both a natural variation and a disability – they fight for acceptance and respect of all ASD individuals as well as fight for appropriate support and services to meet the needs of the ASD community (den Houting, 2019).

The political identity among autistic self-advocates is one of pride in identity and opposition to treatment towards a cure (Kapp et al., 2013). Kapp et al. (2013) and Mitchell (2019) suggest that autistic people may view research on the cause and cure of ASD as a lower priority, as it may divert resources away from services needed by autistic individuals. The autistic community is more focused on calls for services to improve the subjective quality of life and wellbeing while respecting and preserving the autistic ways of being, rather than reducing or eliminating autistic traits (den Houting, 2019).

2.5. Conclusion

The purpose of this chapter was to present an overview of ASD and its characteristics, aetiology, prevalence, diagnostic and screening tools, as well as treatment options. This chapter presented this information from the view of the psychiatric or deficit model, which has previously dominated autism discourse. This model presumes dysfunction in need of a cure. However, the neurodiversity perspective is a young movement that is starting to challenge the deficit or psychiatric model. This movement sees autism and other neurological conditions as natural variations amongst people which should be celebrated. In the chapter that follows, research studies focusing on the contextual factors which affect ASD in the unique context of South Africa will be reviewed.

Chapter Three: Literature review - Contextual factors impacting ASD in South Africa

3.1. Introduction

This chapter aims to review the empirical studies done in South Africa focusing on how different contexts impact understandings of and diagnosis and resources for ASD children. While South Africa is considered to be a low and middle-income country (LMIC), it is the most unequal country according to the GINI coefficient (Franz et al., 2018; Makombe et al., 2019; Westaway, 2012). The majority of the country's people live in poverty. More than half of South Africans live on less than R1000 a month per person (Makombe et al., 2019). This impacts parents' ability to pay for out-of-pocket private services (Makombe et al., 2019). The majority of South Africans rely on the public health system for their basic healthcare needs (Franz & de Vries, 2019). South Africa's stark health disparities (Franz & de Vries, 2019; Guler et al., 2018) are evident in the public health sector which provides care for approximately 84% of the population with only 30% of the medical workforce (Guler et al., 2018). From this, it can be inferred that there are several challenging contextual factors related to accessing diagnostic and treatment options in South Africa. The provision of services for ASD individuals is also impacted by the lack of epidemiological studies, problems with accessing schooling, language considerations due to South Africa being a multilingual country, as well as different cultural beliefs regarding the cause of ASD. These contextual factors will all be reviewed in turn.

3.2. Diagnosis and its various issues

In South Africa, there is a very low diagnosis rate of ASD seen in health and educational records, suggesting that ASD is significantly under-identified and that many people are not receiving appropriate services (Chambers, de Vries, Delechanty, & Wetherby, 2018). While children's ASD can be reliably diagnosed through social and communication dysfunctions by 18-24 months in high-income countries (Chambers et al., 2018; Steiner et al., 2012), the same cannot be said for LMIC, such as South Africa, where there is a lack of knowledge about early signs of ASD (van Schalkwyk et al., 2016), lack of quality education about ASD, unclear referral routes, and a failure of the healthcare system to effectively manage their clients (Chambers et al., 2018). In addition, "doctors may not refer cases from disadvantaged communities for assessment, due to lack of available services" (Malcolm-Smith et al., 2013, p. 2). As a result, ASD is often not diagnosed or is diagnosed late in these disadvantaged communities (Malcolm-Smith et al., 2013).

While it is assumed that South African university hospitals provide diagnostic services for those with possible symptoms of ASD, there are only eight of these medical schools (van Schalkwyk et al., 2016). Diagnostic and intervention services at state level are therefore scarce (Malcolm-Smith et al., 2013). The ones that are in place are heavily overburdened (Malcolm-Smith et al., 2013). There are also very few neurodevelopmental paediatricians and specialist child and adolescent psychiatrists in South Africa (van Schalkwyk et al., 2016). This could mean that there are very few individuals who receive an early diagnosis of ASD (van Schalkwyk et al., 2016). In the Western Cape (WC), it is estimated that about ten individuals are assessed and evaluated for ASD every week, while in Johannesburg, ASA was reported to run an assessment clinic once a month for those individuals who could not access medical centres (van Schalkwyk et al., 2016). This then suggests that there is a low diagnosis rate, therefore negatively skewing the prevalence in South Africa.

Health care practitioners have been described as being fearful of making an incorrect diagnosis, due to the stress that accompanies the diagnosis, lacking information about ASD, and being unfamiliar with screening and evaluation tools for ASD (Mitchell & Holdt, 2014; Springer et al., 2013). Corroborating this, in 2013, a Durban based general practitioner (GP) conducted a formal interview study, and described how most physicians have a low awareness of autism, and fear and avoid making the diagnosis (Bateman, 2013). This GP explained that they had little exposure to autism at medical school, except as something to exclude when diagnosing (Bateman, 2013). When this GP and her fellow GPs graduated in 2004, they only had a single one-hour lecture on developmental disorders, and one line about autism in their paediatric textbook (Bateman, 2013). This GP goes on further to explain what this means: “at least those who graduated 8 years ago (2004) the awareness just wasn’t there” (Bateman, 2013, p. 276). This illustrates the potential lack of knowledge among health care practitioners. However, it cannot be expected that GPs be knowledgeable about every disorder and condition, especially not psychiatric symptoms, and diagnoses. Since GPs are often the first port of call for those who experience unwellness, GPs refer individuals to those who are trained on neurodevelopmental issues, for example, since they have this specialist knowledge. In addition, physicians often have limited time with patients, and as a result, focus on the most obvious or troublesome symptoms.

The time spent with each patient is impacted by the doctor to patient ratios – for example, for every one government-employed doctor, 2457 people need treatment in the public sector, i.e., those not covered by medical aid (Medical Brief, 2018). On the other hand, for those who have access to medical aid and private doctors, there were between 429 and 571 people per doctor (Medical Brief, 2018). Should doctors or clinicians have access or want access to the ‘gold standard’ diagnostic tools, they would need to have paid for the tool, which is usually quite costly, have extensive training in the tool, as well as have enough time with each patient to administer the tool properly (Durkin et al., 2015). Furthermore, an added limitation to these tools is the 'per use fees' and the inability to translate or adapt the tools into contextually relevant languages without paying additional fees, making these tools even more inaccessible to most low middle-income settings (Durkin et al., 2015). For those who work in multi-cultural and multi-lingual settings, such as South Africa, adapting, translating, and validating diagnostic tools is essential – however, this is prohibited by the licensing restrictions on the most commonly used tools (Durkin et al., 2015). This makes access even more difficult.

Access to resources, and having a higher socioeconomic status, is also linked to receiving a diagnosis earlier. For parents accessing private healthcare, the diagnosis was less than a year, while for those accessing public healthcare, the diagnosis took years (Reddy et al., 2019). However, accessing private healthcare does not guarantee a quick diagnosis. For example, in the case of Clasquin-Johnson and Clasquin-Johnson (2018), who are on medical aid and accessed private healthcare, their son's diagnosis still took over a year, after waiting months for appointments with specialists. However, a year is a short time in comparison to other studies. While the socioeconomic status and medical aid access of participants were not discussed in the study in KwaZulu-Natal (KZN) by Mitchell and Holdt (2014), the diagnosis of the participants' children ranged from two years to seven years, with an average of just over three years to reach a diagnosis.

In addition, those from lower socioeconomic status may not be able to afford to get a diagnosis (Mitchell & Holdt, 2014), especially for those from rural areas, further impacting the researcher's accessibility to low socioeconomic status participants. To illustrate, a study by Neely and Ponshunmugam (2019) on healthcare access in rural KZN found that those living in rural areas experienced long waits (sometimes several hours or days) at governmental hospitals and clinics – sometimes even having to leave and return the next day or week; having to rely on poor public transportation or to spend large amounts on private transportation by paying neighbours to get to the governmental clinics or hospitals; experiencing clinic sisters and nurses as rude and unwilling to help, and having to return for multiple consultations to clinics and hospitals, often being referred from one to the next, to the next. Therefore, those from a low socioeconomic status background may not be able to afford the multiple trips to and from hospitals and clinics to get a diagnosis for their child. The same would be true for those who already have a diagnosis of ASD. They may not be able to afford the cost of the treatment, in addition to the cost of transportation, among other things.

3.3. Treatments in South Africa

Not all South Africans have access to the services affiliated with ASD interventions and treatments. Parents and caregivers have experienced difficulty in accessing treatment facilities and health professionals specialising in ASD (Wetherston et al., 2017). Challenges include limited healthcare professionals and treatment facilities, long waiting lists, long distances to travel for treatment (Wetherston et al., 2017), as well as the cost involved with appointments and treatments. The few specialist health providers in South Africa cannot address the population needs for early ASD intervention (Franz et al., 2018; Makombe et al., 2019). As seen by the doctor to patient ratios above, access to specialist care is limited (Franz et al., 2018) in the public health sector. Furthermore, while there were many options on the internet, very few of these were available in South Africa (Wetherston et al., 2017). It was also difficult to find treatment in the parent's or child’s mother tongue (Wetherston et al., 2017).

South Africa has limited education resources, healthcare, and support services for families and individuals with ASD (Guler et al., 2018; Malcolm-Smith et al., 2013; Reddy et al., 2019). In a South African study by Guler et al. (2018), caregivers only had access to one 30-minute session per month of either speech or occupational therapy, provided by the South African Department of Health. While there is access to these very limited state or governmental diagnostic and intervention services, these are overburdened (Malcolm-Smith et al., 2013). To combat this lack of feasibility and access, it has been suggested that parents should be involved in treatment delivery, to overcome the financial and human resource barriers (Franz et al., 2018; Guler et al., 2018; Makombe et al., 2019).

However, there are challenges involving parents or caregivers in treatment delivery. Caregivers have described a lack of skills transfer between settings (clinic and home) (Guler et al., 2018). In some cases, these caregivers do not receive education or training to help them engage with their children and support their child’s development (Franz & de Vries, 2019). Caregivers also described limited space, lack of material or resources, and chaotic home environments – especially in those families who had financial constraints or lived-in informal dwellings (Guler et al., 2018). Caregivers, therefore, preferred in-home service delivery, due to its convenience and the fact that it would allow therapists, such as OTs, to understand their living experiences and their child’s behavioural challenges at home (Guler et al., 2018).

Treatments are described by South African parents as very costly, and there is a lack of government support and funding (Wetherston et al., 2017). The most common interventions used in a study by Erasmus et al. (2019) across six autism-specific schools in South Africa included speech and language therapy (SLT) and occupational therapy (OT) (Erasmus, Kritzinger, & van der Linde, 2019a). SLT is not surprising as it addresses the core deficits of ASD (Wetherston et al., 2017). However, parents report using alternative approaches to treatment to treat their child's core symptoms, such as dietary changes or supplements (Erasmus et al., 2019a). A study by Louw et al. (2013) conducted in Cape Town revealed that there was a high use of psychotropic medication use amongst severe ASD children. The prevalence of OTC "medications" use was also high (Louw et al., 2013). While using a combination of treatments is most effective, this becomes expensive and time-consuming (Wetherston et al., 2017).

Since there are very few and heavily overburdened state intervention services, parents or caregivers are often forced to seek out and resort to expensive private intervention services (Erasmus et al., 2019a). Even though some South African families have private medical cover, these medical aid schemes often do not cover the long-term costs of disability interventions as they are too expensive (Erasmus et al., 2019a) or do not regard ASD as a primary medical benefit (Wetherston et al., 2017). Therefore, parents often have to cover the cost of intervention services themselves (Erasmus et al., 2019a). This would be difficult for those with few resources, or who live in poverty. Furthermore, since all children respond to interventions differently, and because it is not possible to predict which intervention will work best, parents often have to try a myriad of expensive treatments (Erasmus et al., 2019a). Erasmus et al. (2019a) found that parents or caregivers spend up to 20% of their monthly income on school fees and therapy services.

While there are governmental grants available, the amounts are very low (Erasmus et al., 2019a) and would not cover all the costs associated with ASD. Since there is a lack of governmental financial support, and sometimes little disposable income due to poverty and/or being a single parent (Guler et al., 2018), some parents might not be able to afford any or all the costs involved in diagnosing, treating, and raising an ASD child. Services, therefore, need to be inclusive with no hidden costs, be subsidized and available to all children, irrespective of their ability to pay for services (Guler et al., 2018). Other suggestions include coming up with creative alternatives for costly therapeutic materials – for example, instead of using a plastic chair, parents can use a small wooden seat for a child (Guler et al., 2018). Raising an ASD child has been described as a financial burden due to the high costs associated with it.

3.4. Access to schools

There is limited provision of special needs services in formal education and insufficient material resources in educational settings, which poses significant threats to receiving the education special needs children need (Malcolm-Smith et al., 2013; van Biljon et al., 2015). In 2013 there were only nine government-funded dedicated schools for ASD (Bateman, 2013; Makombe et al., 2019). Of the nine schools, six are in the WC, two are in Gauteng, and one is in the EC (Franz et al., 2018). There are an estimated 135 000 ASD children not receiving specialised education (Bateman, 2013). The few dedicated schools were overstretched and were inaccessible to the majority of children who needed them (Bateman, 2013), perhaps due to the poor public transport system in South Africa (Erasmus et al., 2019a) or the long waiting lists. Public transport is generally inaccessible to children with special needs which prevents them from accessing these special schools (van Biljon et al., 2015). These public special schools are mostly in urban areas, which is a further disadvantage for children from rural areas (van Biljon et al., 2015). Parents either have to enrol their child into a private school, which is expensive or pay excessively for private transport for their child to get to school (Erasmus et al., 2019a).

Most children, however, have to wait for years to be placed in a special-needs school (Franz & de Vries, 2019). In the WC, for example, the number of ASD children on the waiting list for school placement increased by 276% from 2012 to 2016, as cited by Franz and de Vries (2019). Long waiting lists for schools (Wetherston et al., 2017) affected the age of assessment at the special schools, which decreases the opportunity for timely educational and therapeutic intervention at the schools (van Biljon et al., 2015). Other than challenges related to accessibility to special schools, the language diversity in South Africa limits first language education for all (van Biljon et al., 2015).

3.5. Language

Since South Africa is multilingual, with 11 official languages, as well as many other unofficial languages (Benjamin, Swartz, Chiliza, & Hering, 2016), language can sometimes be a barrier to services (Guler et al., 2018; Makombe et al., 2019). Caregivers prefer that their child be taught in their home language, or the language they choose to speak (Guler et al., 2018). Caregivers also prefer that their child's therapist be matched to them, based on language (Guler et al., 2018). While some caregivers described that they preferred English as the language of instruction for therapeutic service delivery, others preferred their family's native language as they felt that they would not be an active member of their household or community if they could not speak their home language (Guler et al., 2018). However, they agreed that they wanted their children to have one language of instruction across therapeutic and educational settings (Guler et al., 2018).

Generally, however, it is difficult for parents who speak indigenous languages to access medical care and help in their home language, due to English being the most common language in the medical discipline, with most health practitioners not being able to speak any of the indigenous languages of South Africa (Benjamin et al., 2016; Deumert, 2010; Levin, 2006). The language barrier leads to misunderstandings and confusion about diagnoses, medication (Deumert, 2010; Levin, 2006) and follow-up appointments, as well as non-adherence to medical advice (Levin, 2006). Participants in the study by Deumert (2010) explained how they felt that they could not give equal care to all their patients because of the language barriers. These medical staff further explain that since they are unable to communicate in the same language with their patients, that they do not get accurate histories from their patients, which is highly important for diagnosis (Deumert, 2010). This is an important aspect to note since occasionally ASD is diagnosed based on the histories taken from patients (APA, 2013), as well as from the descriptions of behaviours from parents. While the use of translators or interpreters has been suggested, this comes with its own set of difficulties and challenges as discussed by Benjamin et al. (2016) and Deumert (2010).

3.6. Cultural aetiologies struggling against 'western psychiatric or deficit' aetiologies

In some communities in South Africa (Grinker et al., 2012), Kenya (Gona et al., 2015), and Nigeria (Bakare et al., 2009), for example, the focus on ASD from the Western psychiatric or deficit perspective means that in these communities, the cultural aetiologies of conditions are not understood or considered, which then affects the diagnosis and treatment for those individuals and their families (Mthombeni & Nwoye, 2018). Since there is a mismatch between perspectives (Nwoye, 2015), access to interventions is delayed which can lead to a poorer prognosis (Mthombeni & Nwoye, 2018). In South Africa, the cultures and beliefs are diverse and therefore require sensitivity (Guler et al., 2018). Since South African cultures vary in their backgrounds and beliefs, caregivers in a Cape Town-based study felt that service providers needed to be more sensitive and display an understanding of cultural beliefs and practices, and to incorporate this knowledge when working with their children (Guler et al., 2018).

In some South African communities and cultures, the central tenet to understanding illness rests on determining 'who' is responsible for the illness, and 'why' it happened to them (Mthombeni & Nwoye, 2018; Nwoye, 2015). 'Abnormal' presentations of illness are not seen as an ordinary illness, but as a problem that has hidden meanings and messages which need to be interpreted in order to find a solution (Nwoye, 2015). The more uncommon the illness, the more supernatural the cause is thought to be – especially when 'western psychiatric or deficit' approaches have failed in their approaches in diagnosis, treatment, and intervention (Mthombeni & Nwoye, 2018). In an attempt to discover the hidden meaning of an illness, or to determine if a particular ancestor or spirit is the cause of the illness, family members of the sick individual may see a traditional healer (Nwoye, 2015). This is the practice of some communities in South Africa (Nwoye, 2015). The traditional healer will then identify a procedure (Washington, 2010), such as a sacrifice or a verbal recognition and affirmation of the ancestor concerned, for the family to follow, to deal with the situation (Nwoye, 2015).

The most commonly cited supernatural cause of an illness is as a result of punishment or bewitchment from ancestors (Edwards, 2011; Grinker et al., 2012; Guler et al., 2018; Nene, 2014; van Schalkwyk et al., 2016). If ancestral spirits are displeased by an event or the failure of the community to follow custom (Edwards, 2011; Washington, 2010), this displeasure is expressed through the child through an illness (Grinker et al., 2012), since their protection has been withdrawn (Mthombeni & Nwoye, 2018). Another suggested supernatural cause of illness arises from the withdrawal of protection by a supernatural god, spirit, or ancestor (Mthombeni & Nwoye, 2018). Appeasement and cleansing rituals are then followed and completed by the community, to placate the ancestors (Edwards, 2011; Grinker et al., 2012).

Other cited causes are demonic possession (van Schalkwyk et al., 2016) and being cursed (Guler et al., 2018). In a study conducted in Cape Town, a caregiver of a child with ASD described how her mother and community members denied the ASD diagnosis, rather attributing the symptoms to spirits that were trapped in her son's throat that needed to be released through traditional practices of cutting (Guler et al., 2018).

As can be seen above, there are various cultural perspectives of the aetiology of illness in some communities in South Africa, and more generally, in Africa. While this is not an exhaustive list of the cultural aetiologies and communities, it does give a general overview of some of the cultural aetiologies that are important to consider in the South Africa context, when looking at ASD. ASD symptoms are therefore understood as expressing displeasure from the ancestors who display it through the child, in the form of an illness, in order for the community where the child lives to perform the correct ceremonies or customs. It is important to note, however, that not all communities and black Africans would believe in this theory of illness causation.

3.7. Lack of epidemiological studies

The lack of population-based studies, both systematic and peer-reviewed, regarding the incidence, prevalence, and impact of ASD on South Africa (Malcolm-Smith et al., 2013; van Schalkwyk et al., 2016), and Africa, is partly due to the barriers associated with a lack of access to the 'gold standard' screening and diagnostic tools (Durkin et al., 2015; Franz et al., 2017). There is a need for ASD research in Sub-Saharan Africa (SSA) as less is known about the prevalence and treatment methods used than in any other continent (Guler et al., 2018). As a result, most research on ASD comes from the USA or other high-income countries (Guler et al., 2018). Since standardized assessment tools for ASD in South Africa are scarce, studies from the global North have found that ASD is often under-identified in low socioeconomic status communities, such as South Africa (Malcolm-Smith et al., 2013). The lack of research in low and middle-income settings impacts the timely access to services and support (Durkin et al., 2015). It can also be argued that it impacts governmental service provision since there is no confirmed incidence, prevalence, or impact data on ASD in South Africa.

Furthermore, suggested reasons for the lack of epidemiological research in South Africa include the fact that other communicable diseases, such as Tuberculosis (TB) and human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS), have dominated the health priorities, that there is a lack of systematic research programs, and a lack of appropriate screening and diagnostic tools for autism in African languages (van Schalkwyk et al., 2016). It is anticipated that the current Covid-19 pandemic will further impact the priorities of stretched public health services.

Epidemiological surveys in the USA, however, have reported increasing numbers showing children and adults being diagnosed with ASD (Springer et al., 2013). A similar trend was reported in a South African study that showed an increase in the number of children presenting with ASD features at a developmental clinic in Johannesburg over 1996-2005 (Springer et al., 2013). This increase in prevalence has been suggested to be due to the increased awareness of ASD among professionals and parents or to the broadening diagnostic criteria (APA, 2013; Springer et al., 2013). The changes in the DSM criteria have perhaps resulted in confusion regarding the tracking and comparison of ASD cases since the separate autism diagnoses in the DSM-IV now fall under one broad ASD umbrella as from the DSM-5 update in 2013. However, other contributing factors in South Africa including poverty, the high prevalence of HIV/Aids and TB, and a lack of contextual evidence, may mean that the prevalence of ASD may be higher than in developed countries (van Biljon et al., 2015).

3.8. Conclusion

Chapter three focused on reviewing the specific contextual challenges that could affect mothers or caregivers' experiences raising their ASD child in South Africa. These contextual factors included 1) multiple issues associated with diagnostic services and accessing medical professionals, 2) few and overburdened governmental treatment options, resulting in many caregivers having to pay out of their pockets for private services, 3) limited access to special needs schooling, 4) a multi-lingual South Africa which makes it difficult for caregivers to access services in their home language, 5) that cultural understandings of the cause of ASD need be considered by the medical system, and 6) that there is a lack of knowledge regarding the incidence, prevalence and impact of ASD on South Africa, which affects the provision of services. While this section has discussed possible contextual factors, which may affect the experience of raising an ASD child in South Africa, chapter four reviews empirical research studies on the lived experiences of caregivers in South Africa and also considers some international literature regarding parenting experiences.

Chapter Four: Literature review - Experiences of raising an ASD child

4.1. Introduction

This chapter will review research studies that focused on the experiences of raising an ASD child. Most of the literature reviewed in this chapter uses experience as a theoretical lens and operates in a qualitative paradigm. The chapter reviews qualitative empirical literature from across South Africa, as well as some international literature, pointing out differences and similarities between the various contexts on how parents experience raising their ASD child. The chapter also comments on how engagement with these empirical research studies critically shaped my own study that follows.

4.2. Experiences

4.2.1. Alternate explanations and treatments for ASD not always considered

There are multiple and varying "OTC" and lifestyle treatments and complementary approaches that parents utilise in the search for answers regarding their child's autism, both in terms of diagnosis and treatment. It can be seen that some parents use a multitude of approaches and treatments, or have tried specific approaches and treatments, before moving onto other options. What follows are examples of some of the alternate explanations and treatments that parents have considered.

For most studies conducted in the global North and developed countries, and for some conducted in the global South and South Africa, the aetiology of ASD is understood from the Western perspective of a deficit or psychiatric model, since this is the dominant model. However, not all people or communities within the global South, such as in South Africa (Guler et al., 2018; Mthombeni & Nwoye, 2018; Reddy, et al., 2019) and Kenya (Kamau, 2017; Gona et al., 2015), believe in this perspective only. They also believe in supernatural explanations. Some available research suggests that these supernatural beliefs in South Africa seem to be prevalent more amongst the older generation amaZulu people, upholding African traditional cultural views (e.g. Grinker et al., 2012; Mthombeni & Nwoye, 2018).

There has been a shift in the younger population and their beliefs in the supernatural aetiologies (Guler et al., 2018; Mthombeni & Nwoye, 2018; Reddy et al., 2019), presumably because of their engagement with the 'modern' psychiatric model. It is also important to note that often it is not one or the other – the psychiatric model or a supernatural explanation, but a combination of the two that is used by the younger generation, as is evident in the study by Mthombeni and Nwoye (2018).

Participants in a Kenyan study by Gona et al. (2015) also used both psychiatric and cultural supernatural perspectives to understand ASD and the treatment thereof.

A study conducted by Grinker et al. (2012) revealed that parents from rural communities who took their children to traditional healers for treatment felt less concerned about the spiritual cause of their child's difficulties if they received a 'western' diagnosis of ASD as well. Nene (2014) also found that black African parents around Pretoria used both Western and traditional methods of healing. Furthermore, while these parents preferred to use both methods of healing, most of the parents stated that they had never consulted a traditional healer more than once, and some not at all (Nene, 2014). They argued that while they did believe in traditional healers, they were not their first priority when seeking help (Nene, 2014). The author suggested that this was because of the connotations associated with traditional healers – that they are witches, or opportunistic, rather than genuine healers (Nene, 2014). The participants in this study further explained that they were scared of traditional healers but would see them in secret if necessary (Nene, 2014). Like in the study by Mthombeni and Nwoye (2018), the participants in Nene's (2014) study agreed that they would consult both Western and traditional methods of healing if their first preference 'failed' or did not help.

Since this dual and complementary view of psychiatric and supernatural events exists in some communities, some parents noted the importance of doctors and other health care practitioners considering their cultural beliefs when it comes to diagnosis and treatment (Guler et al., 2018). Mthombeni and Nwoye (2018) suggested an integration of the indigenous model and the psychiatric model, to help parents in their diagnostic journey.

Some participants in a single South African study used religion to explain their child's disorder – saying that it was God's wish for parents to have an ASD child, or that their child was a gift from God (Reddy et al., 2019). Myers, Mackintosh, and Goin-Kochel (2009), in an American study, also found that some parents in their study also believed that God had brought a special child to them and that God would help them to raise their child by giving them the strength and knowledge to deal with the ASD. Similar beliefs are held amongst Kenyan parents, that it is God's wish that they have an ASD child, and they used that as an explanation for why treatments were not effective (Gona et al., 2016).

4.2.2. Experiences of medical professionals as mostly negative

Few parents seem to have positive experiences with health care practitioners, such as various doctors and various types of therapists. A common experience for South African parents was that doctors were scared to or unwilling to make a diagnosis of ASD (Clasquin-Johnson & Clasquin-Johnson, 2018; Mitchell & Holdt, 2014). This was also the case in India (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012). Perhaps it was for this reason that some parents consulted many different medical professionals for a diagnosis. One parent in the study by Mitchell and Holdt (2014) elaborated by explaining that their doctor, while unwilling to give a diagnosis, also did not refer their child to psychiatrists to make an official ASD diagnosis. Clasquin-Johnson and Clasquin-Johnson (2018) reported waiting five months for an initial appointment; another six months for their follow-up consultation, only for the paediatric neurologist to give them a verbal diagnosis of autism, with a written diagnosis suggesting speech therapy only. They were only given a written diagnosis after the parents insisted on it for their SARS income tax return (Clasquin-Johnson & Clasquin-Johnson, 2018). It then became clear to the parents that they would have to return every six months for the foreseeable future, with the neurologist not giving them any new information each time (Clasquin-Johnson & Clasquin-Johnson, 2018). Parents in the Mitchell and Holdt (2014) study consulted, on average, over seven practitioners before receiving a diagnosis, and waited, on average, over three years to receive a diagnosis. Similarly, in Reddy et al. (2019), while it took one parent two years and numerous consultations to receive a diagnosis, for another parent in this study, it took three years to diagnose their child. If this is the route to receiving a diagnosis, the majority of the South African population might or would not be able to access the diagnosis due to the costs involved in seeing the multiple medical professionals and the multiple consultations required.

Furthermore, parents in South Africa (Fewster & Gurayah, 2015; Mitchell & Holdt, 2014; Olivier & Ah Hing, 2009; Reddy et al., 2019; Wetherston et al., 2017) and Kenya (Kamau, 2017) reported that they perceived their doctors as having very little knowledge about ASD. Similarly, in a UK study (Lloyd, Osborne, & Reed, 2019), parents also described experiencing medical professionals having little knowledge about ASD, as well as having to engage in a lengthy diagnostic process. In contrast, a study in Australia by Rabba, Dissanayake, and Barbaro (2019) found that parents received an influx of information which was overwhelming. The stress after the diagnosis was mostly linked to the expectations of their child, rather than accessing services, such as was the case in developing countries.

In some cases, in South Africa, diagnosis is delayed, and access to services is reduced, as some parents did not want to attend their community clinics because of the healthcare workers there, who were described as unprofessional (Guler et al., 2018; Neely & Ponshunmugam, 2019) and as having a high turnover (Guler et al., 2018). Parents specifically seemed to mistrust the community health workers who lived in the same community as them, due to perceptions of anonymity and confidentiality breaches, and community-based stigma about mental conditions (Guler et al., 2018). Similarly, in primary health care settings (public health system), parents and their children would have to sit in large communal waiting rooms for many hours, with community members they might be familiar with.

Mothers, in particular, described an instinct or intuition of knowing that there was something wrong with their child (Fewster & Gurayah, 2015; Mitchell & Holdt, 2014). This intuitive sense of knowing can be suggested as having come from experience gained from treatment received regarding their previous children. However, this is not limited to just experienced mothers – a mother in the Mitchell and Holdt (2014) study, who had an only child, intuitively knew that something was wrong with her child, even though others had tried to assure her that her child was fine. Mothers reported their concerns to their GPs who often dismissed the mother's concerns (Desai, Divan, Wertz, & Patel, 2012; Fewster & Gurayah, 2015; Mitchell & Holdt, 2014), especially when they were not able to fully verbalize what they were worried about (Fewster & Gurayah, 2015). Parents were told by doctors that their child would "grow out of it" (Mitchell & Holdt, 2014, p. 55), or that there's "nothing to worry about, boys are just slow" (Fewster & Gurayah, 2015, p. 32). This was also the case in Kenya, with mothers being told their son would grow out of the ASD (Kamau, 2017).

Some parents in India (Desai et al., 2012) and South Africa (Fewster & Gurayah, 2015; Reddy et al., 2019) experienced doctors as harsh, rude, and uncaring. One parent in the Reddy et al. (2019) described how her doctor had asked her "why can't you discipline your child" (p.45), which worsened the mother's stress about her child. Another parent in the Indian study by Divan et al. (2012), was verbally accused by her doctor of 'poor parenting' since she did not recognize the implications of her child's symptoms.

However, not all parents experienced medical professionals in a negative way. Some parents experienced their medical professionals to be protective and supportive factors in their journey (Reddy et al., 2019). One couple in the study by Fewster and Gurayah (2015) experienced their medical professional to be extremely helpful and accommodating towards them in their consultation. Parents in Wetherston et al. (2017) explained that their positive relationships with health care practitioners were as a result of good communication, the willingness of medical professionals to help, and working as a team with the parents.

Therapists, such as occupational or speech and language therapists, were also described negatively by some South African parents. Clasquin-Johnson and Clasquin-Johnson (2018) suggested in their autoethnography that therapists, in particular, take advantage of parents. It is therefore up to parents to ensure that the number of therapy sessions is motivated by the therapist; that support plans and strategies are explained, and that follow-up feedback meetings are conducted with therapists to make sure that that did not happen (Clasquin-Johnson & Clasquin-Johnson, 2018). They went further, explaining that “therapists seldom tell parents that a child has had sufficient therapy” (Clasquin-Johnson & Clasquin-Johnson, 2018, p. 7). Similarly, the following extract from Reddy et al. (2019) also seemed to suggest receiving little support and feedback from their child’s therapist: “one parent consulted a psychologist for two years, receiving no direction about schooling, and [had to] independently approach a Learners with Special Education Needs (LSEN) school, for placement for her child” (p.45). However, not all parents had negative experiences of their child’s therapists, such as in the case of parents in the Wetherston et al. (2017) study, where parents experienced their health care providers as communicative, and helpful.

Once parents received a diagnosis of ASD, in some cases, medical practitioners did not provide any guidance on treatment or advice, going forward (Clasquin-Johnson & Clasquin-Johnson, 2018; Reddy et al., 2019; Wetherston et al., 2017), leaving parents to ‘scramble’ and fend for themselves (Reddy et al., 2019) to find and access treatments for their children. That also seemed to be the case in the UK (Ludlow, Skelly, & Rohleder, 2011), the USA (Nealy et al., 2012), and Canada (Woodgate, Ateah, & Secco, 2008).

4.2.3. Emotional experience of the diagnosis

For many parents in South Africa, receiving their child’s diagnosis was not a positive emotional experience as they described feelings of anxiety, confusion (Martins, Walker, & Fouché, 2013; Olivier & Ah Hing, 2009), being overwhelmed, shock, denial, and grief (Mitchell & Holdt, 2014; Reddy et al., 2019). For some of those parents, their reaction was due to the limited knowledge they had of ASD, with some hearing the term ASD for the first time at their child’s diagnosis (Reddy et al., 2019). For other parents, receiving the diagnosis meant re-evaluating the child they thought they had, the child they expected, and altering the hopes and dreams they had had for their child (Fewster & Gurayah, 2015; Martins et al., 2013; Olivier & Ah Hing, 2009). However, receiving a diagnosis meant that parents could then seek appropriate help and support, and start to understand more about their child and his/her behaviours (Clasquin-Johnson & Clasquin-Johnson, 2018; Martins et al., 2013; Mitchell & Holdt, 2014; Reddy et al., 2019).

In a South African study (Fewster & Gurayah, 2015), parents explained that their difficulty with their child’s diagnosis stemmed from their perceptions of their health practitioners not having the necessary knowledge about ASD, minimising their concerns, or providing a bleak prognosis and explanation about ASD. In another South African study (Reddy et al., 2019), parents explained that their interactions with the medical practitioners defined their experience of ASD, with supportive and empathetic professionals being a protective factor. On the other hand, only one South African study (Clasquin-Johnson & Clasquin-Johnson, 2018) explained an easy acceptance of the diagnosis from the start, which the authors attributed to their educational backgrounds and their previous exposure to ASD children, which they explained made the diagnosis less overwhelming than it could otherwise have been.

Similarly, in India, parents also described feelings of shock, disbelief, and rejection of the ASD label, as they tried to understand ASD, a condition they had not heard of before their child's diagnosis (Divan et al., 2012).

Internationally, parents in developed countries such as Australia, Canada, and the USA had similar emotional responses to the diagnosis. Parents also described feelings of anxiety, depression, frustration (Nealy et al., 2012), sadness (Myers et al., 2009; Rabba et al., 2019; Safe et al., 2012), shock, denial (Rabba et al., 2019) and guilt (Myers et al., 2009; Nealy et al., 2012). In the case of Nealy et al. (2012), some parents described feeling guilty that they could not fix their child. As in South Africa, parents in other international studies (Lloyd et al., 2019; Lutz, Patterson, & Klein, 2012; Myers et al., 2009; Safe et al., 2012) explained their heartache at the loss of the child they had expected and having to alter their expectations for their child. Conversely, parents in the study by Lloyd et al. (2019) felt that the ASD diagnosis gave them an understanding of their child and his/her behaviours, and the ability to be able to research and learn more about ASD.

4.2.4. OTC "medications" and lifestyle interventions

Parents in South Africa (Guler et al., 2018) and the USA (Myers et al., 2009) were willing to try any treatment to help their child reach their full potential and were willing to go into debt and spend all their savings on any type of treatment that would work. Perhaps it can be suggested that parents in these instances might simply want to show that they are trying everything they can to help their child so that they are not judged or stigmatised by society for not trying everything; or for not being a 'responsible' and 'caring' parent.

Even when parents had an ASD diagnosis for their child, their access to interventions or special treatment programmes was difficult, partly due to the lack of these services in South Africa (Meiring et al., 2016; Reddy et al., 2019; Wetherston et al., 2017). In addition, accessing these interventions or special treatment programs is costly, with medical aids not covering all the costs involved

(Wetherston et al., 2017), resulting in parents paying out of their own pocket. Other reasons for difficult access include long waiting lists for services – as was discussed previously.

Since some parents did not want to or could not afford to medicate their child, and some parents disagreed with the principles of certain types of therapies [specifically, ABA (Clasquin-Johnson & Clasquin-Johnson, 2018)] or otherwise, could not afford or access therapy, parents may find alternative treatments for their child. While these alternative treatments may not be scientifically proven to be effective, some parents have reported positive results from using these kinds of alternative treatments (Wetherston et al., 2017). An example of such an alternative treatment might be a change of diet in the household, considered to be a lifestyle intervention, or the use of OTC "medication" such as supplements.

Internationally, few parents reported the use of OTC "medications" or alternative treatments, with the exception of a few parents in one Canadian study (Fletcher, Markoulakis, & Bryden, 2012) and one American study (Nealy et al., 2012). However, even then, these parents still depended more on traditional medical treatments. Perhaps the difference between South Africa and internationally is because OTC "medications" and alternative treatments may be more cost-effective for families. For example, Clasquin-Johnson and Clasquin-Johnson (2018) described some costs involved regarding therapy – they received a therapy account of over R13 000 for a single month when their medical aid funds were exhausted; and they experienced high costs for ABA therapy: 40 hours a week, at a medical aid rate of R440 per hour, added up to R17 600 per week for ABA treatment. Additionally, while they did not mention the costs of their other therapies, at 32 sessions a month of speech therapy and occupational therapy, we can assume this added up to quite a sum.

On the other hand, OTC interventions, available at most pharmacies, supermarkets, or health shops are easily accessible for parents who do not have the funds to pay for other treatments. However, it cannot be assumed that parents in South Africa would only use these OTC "medications" because they are cheaper (although an important consideration considering the socioeconomic status of many South Africans) – perhaps other medical therapies had not been effective for their child, or they did not have access to other therapies. However, alternative treatments such as lifestyle interventions such as a diet change mean that management of such falls to caregivers to implement, regulate, and maintain these interventions. As suggested previously, parents are willing to try alternative treatments if it means helping their child.

OTC "medications" included vitamins, minerals, dietary supplements, probiotics, and homeopathic remedies (Louw et al., 2013). Mostly, it was parents who initiated these OTC preparations, but occasionally it was GPs, psychiatrists, paediatricians, homeopaths, nutritionists, and pharmacists who recommended them (Louw et al., 2013). These OTC “medications” can become costly (Louw et al., 2013), especially when parents are using more than one OTC “medication” as well as traditional medicalised therapies. While income does not necessarily predict OTC “medication” use, ethnicity might do so – with white South Africans and Asians being more likely to use OTC preparations than black African or coloured groups (Louw et al., 2013). The authors suggested that this might reflect differences in cultural beliefs around OTC “medications” (Louw et al., 2013). However, the authors did not ask about the use of traditional medicines and suggested that such treatments may not have been considered by the participants to be OTC preparations, and may therefore have been under-reported (Louw et al., 2013).

Parents in Kenya and South Africa reported making lifestyle changes by changing their children’s diets as they found that removing all sugary foods (Gona et al., 2016; Kamau, 2017; Louw et al., 2013), and those containing gluten and casein (Kamau, 2017; Louw et al., 2013; Reddy et al., 2019; Wetherston et al., 2017) and reported that it resulted in positive changes in their children’s behaviour. (Gona et al., 2016). Researchers in Canada (Fletcher et al., 2012) and the USA (Nealy et al., 2012) stated that parents also reported changing their children’s diets.

Other parents in Kenya (Gona et al., 2015; Gona et al., 2016) believed in the healing power of prayers, or what is known as spiritual or prophetic healing. Similarly, in India (Divan et al., 2012), some parents attended healing retreats, engaged in prayer, did “ceremonies to remove bad spirits, consuming blessed foods and holy water, making offerings, tying holy threads, and fasting” (p.197). However, some parents felt as if they were being taken advantage of by these religious practitioners (Divan et al., 2012).

Some parents in South Africa (Mthombeni & Nwoye, 2018) and Kenya (Gona et al., 2015; Kamau, 2017) turned to traditional healers to try to find a cure or treatment for their child’s ASD. However, while some parents in the study by Mthombeni and Nwoye (2018) did not see any positive changes from the traditional medicine, they still persevered in continuing treatment in case it was successful in curing their ASD child. In the case of Kenya, Kamau (2017) suggested that the use of spiritual healers and traditional healers were as a result of the lack of research and knowledge about the treatment options for ASD. In India, some parents turned to Ayurveda, a traditional system of medicine, for help in treating their child/children (Desai et al., 2012), and experienced positive results (Divan et al., 2012).

4.2.5. Schooling as a problem

Some parents in the KZN-based study by Reddy et al. (2019) described schooling as helpful in positive ways. This was associated with several factors: 1) schools that had specialised units for autism, where children were taught Makaton, a type of sign language, to facilitate their communication, 2) where children thrived due to the knowledge of the educators, 3) where parents felt supported as they did not receive phone calls about their children's bad behaviour, and 4) were confident in their children's educators' abilities to manage bad behavioural situations. In contrast, reports within this study itself, and what was commonly reported across other studies in South Africa (Clasquin-Johnson & Clasquin-Johnson, 2018), Canada (Woodgate et al., 2008), and the USA (Myers et al., 2009) showed that parents had problems with the schooling system.

In South Africa, there are a limited number of dedicated schools for ASD, and those that are available, are not easily accessible, in terms of distance and resources (Reddy et al., 2019). There are also year-long or longer waiting periods for public LSEN schools (Clasquin-Johnson & Clasquin-Johnson, 2018). Parents perceived educators at LSEN schools as having inadequate skills and knowledge of ASD and of how to teach their ASD children, and as a result, not being able to harness their child's full potential, and not being able to manage their children's bad behaviours (Clasquin-Johnson & Clasquin-Johnson, 2018; Reddy et al., 2019). Also, LSEN schools did not have sufficient resources to manage ASD specifically (Reddy et al., 2019). For example, Clasquin-Johnson and Clasquin-Johnson (2018) were told by the educational psychologist at a public LSEN school they were considering for their child, that their child would never matriculate, which led them to eliminate the public-school route and seek-out other alternatives. Similarly, as in South Africa, the difficulty with schools in India was partly because of the perceived lack of understanding by teachers of their children's ASD (Divan et al., 2012).

Another schooling option is also available – private schools which parents also experienced negatively (Clasquin-Johnson & Clasquin-Johnson, 2018). Clasquin-Johnson and Clasquin-Johnson (2018) explained that some private schools insisted that facilitators should attend school with their ASD children for the teacher's convenience, and not for their child's. Some parents resorted to private schools in South Africa to ensure smaller class sizes and more individual attention from teachers (NGO Pulse, 2017).

Similarly, in the USA (Myers et al., 2009), in the UK (Lloyd et al., 2019), and in Australia (Safe et al., 2012), schools were described as not meeting parents' and children's needs, and as providing little support. Special needs schools were also difficult to access (Lloyd et al., 2019; Safe et al., 2012). In the Myers et al. (2009) study, the parents also distinguished between public and private schooling, with public schooling not having a positive view, especially regarding the educators being unable to manage their child's bad behaviours. A mother in the Safe et al. (2012) study described how she wrote off the educational system since the schools did not meet her and her child's needs, and instead, she resorted to homeschooling her child.

The views of parents who homeschooled their ASD children were not prevalent in the literature. It could be suggested that since there is a shortage of special needs schools in South Africa (Bateman, 2013; Makombe et al., 2019; Reddy et al., 2019), that perhaps many parents of ASD children, homeschool their children. The drawback is that other parents and their children are isolated by homeschooling – they do not come into contact with other parents, and therefore their children would not have friends, in order for the ASD parents to meet their parents. Also, the children would not have access to friends; and accessing other parents for research could therefore be difficult.

Clasquin-Johnson and Clasquin-Johnson (2018), in their autoethnography, also described how their child has moved schools five times – an average of once a year, and how these have all been different types of schools: a mainstream preschool, a specialised school for autism, two special schools, and a mainstream primary school, which was not able to cater for their needs. They explain their multiple moves in the following extract: "parents often know when a particular school has done what they can and when it is time to move on" (Clasquin-Johnson & Clasquin-Johnson, 2018, p. 5). However, deciding to move schools also implies that there are viable alternative options (Clasquin-Johnson & Clasquin-Johnson, 2018). In the end, these parents gave up on the idea of a 'special school' and enrolled their son at a private school that catered to children with special needs and neurotypical children, where their child learned the official curriculum with a lot of extra support (Clasquin-Johnson & Clasquin-Johnson, 2018). If this is the experience of parents who have access to resources and who can move schools' multiple times until they find one that suits their needs and expectations and who can move into residential areas close to their child's school, then what are the experiences of those parents whose children attend mainstream public schools, and who cannot afford other alternatives. Perhaps then, these children do not attend school at all.

Another finding in the South African context was the idea that the older a child is, the less parents are worried about their academic ability, but are more worried about life skills and being able to look after themselves (Meiring et al., 2016; Reddy et al., 2019). LSEN schools and other similar institutions have been under scrutiny for not presenting their official curriculum, and rather teaching manual skills such as gardening, shelving groceries, and washing cars (Clasquin-Johnson & Clasquin-

Johnson, 2018). These authors argue that this is preparing children for lifelong financial dependence (Clasquin-Johnson & Clasquin-Johnson, 2018). However, Meiring et al. (2016) argued that teaching them life skills would allow the ASD individual to transition out of the household successfully. This idea of practical life skills was particularly important for parents when thinking about the future when they were no longer around to care for their child (Meiring et al., 2016). By having practical life skills, these ASD individuals would earn an income to cover some of their costs.

4.2.6. Worry about the future

While some international parents reported that they were concerned about the future: specifically, who would care for their child once they were no longer around (Ludlow et al., 2011; Nealy et al., 2012; Nicholas et al., 2016; Rabba et al., 2019), only one of these studies (Lutz et al., 2012) elaborated on their plans for their children. In an American study (Lutz et al., 2012), while one mother had thought about her child's future by considering an adult program or facility, another mother, whose son would live with her, had organized that her son folded pizza boxes twice a week so that he could acquire some skills so that in the future, he could get paid for his work. Meiring et al. (2016) and Mitchell and Holdt (2014) were the only two South African studies found to discuss these worries about the future.

The South African study by Meiring et al. (2016) focused specifically on the transition of young adults out of schooling and the household. Parents were aware of their own mortality and tried to teach their child to be as independent as possible (through life skills) or tried to place their child into a care facility (Meiring et al., 2016). It seemed as though most parents did not have a plan for their child post-school, with some parents wanting to keep their child in school for as long as possible (Meiring et al., 2016).

While parents in this study (Meiring et al., 2016) described their feelings of worry and concern regarding their child moving out of the house and into a residential placement, they also viewed this transition as beneficial for the child. There are several benefits for parents when their children move into these facilities, such as decreased constant caregiving, no more limiting of activities and an increase in social interactions. However, these parents seemed to have resistance against a move into a facility. This resistance was in relation to the available support for their ASD child (as most services are for special needs individuals and not specifically for ASD), fears that their child would be taken advantage of and that they could not communicate discomfort or abuse (Meiring et al., 2016). Accessing these facilities, however, assumes that parents have the resources to do so.

In the study by Mitchell and Holdt (2014), parents reported their worries about their child's future, and the care and support they would need throughout their lives, and how to best provide for this future. Many of the parents had financial provisions in place for their child should anything happen to them (Mitchell & Holdt, 2014). One parent in the study also seemed to worry about whether her child would be able to cope in society and whether he would get employment (Mitchell & Holdt, 2014). However, it is unclear and unresearched as to what would happen to those children whose parents do not have the resources to provide for their children's future needs, such as those parents from lower socioeconomic status brackets – and what would happen to those ASD children when they became adults.

Parents also reported that there was very little external support or facilities for ASD adults in South Africa, with this responsibility falling to parents (Meiring et al., 2016). Perhaps those who are available are expensive and are located in large urban centres, making it inaccessible for many in South Africa. According to ASA's website (ASA, 2020), there are four facilities for support in the Eastern Cape: two are located in Port Elizabeth, and two are in East London. These are two fairly large urban centres, which are inaccessible to many in the EC, because of their distance from them. A search on Google for adult facilities that care for autists, among others, reveals several centres available in larger urban cities, such as Johannesburg, Pretoria, and Cape Town. Again, these would be inaccessible to most in South Africa, because of distance and cost, as well as perhaps not suiting parents' or children's needs.

4.2.7. ASD as an invisible disability

Since ASD is considered to be an invisible disability or condition (i.e., there are no visible symptoms except in more severe or high support cases) (Lloyd et al., 2019; Reddy et al., 2019; Woodgate et al., 2008), parents experienced severe social stigma for their 'naughty', 'bratty' children, and were perceived to be ineffective at parenting, by both family members and strangers, in South Africa (Guler et al., 2018; Olivier & Ah Hing, 2009; Reddy et al., 2019), Kenya (Gona et al., 2016) and internationally (Ludlow et al., 2011; Myers et al., 2009; Nicholas et al., 2016; Safe et al., 2012). Some parents described how their family members offered to discipline the bad behaviours out of their child since they viewed the child's parents as ineffective at doing so (Olivier & Ah Hing, 2009; Reddy et al., 2019). Many parents (South African and overseas) attributed these views to a lack of awareness of the nature of ASD (Mitchell & Holdt, 2014; Safe et al., 2012; Woodgate et al., 2008) and the 'normal' appearance of their children (Lloyd et al., 2019; Mitchell & Holdt, 2014; Reddy et al., 2019). Canadian mothers in Nicholas et al. (2016) have resorted to dressing their children in t-shirts or hats expressing statements like “I’m not bad. I have ASD. Please be patient” (p.928) when going out into public spaces in order to combat negative ideas about poor parenting.

Findings regarding this idea of invisible disability were raised by parents in two separate international studies. In the study by Lutz et al. (2012), parents described how others perceived the diagnosis of ASD to be an excuse for their child’s behaviour, while in another study (Nicholas et al., 2016), parents were accused of abusing their child due to the self-harm scars and sores inflicted by their child on themselves. Another mother felt that she received less sympathy for her ASD child than other parents of other disabilities such as Down’s Syndrome receive, due to the invisible nature of ASD – “you don’t get the warm fuzzies from [ASD]” (Nicholas et al., 2016, p. 927). Similarly, a mother in the Woodgate et al. (2008) study felt as if less value was placed on the lives of ASD children.

This invisible nature of ASD can perhaps explain why family members and other friends seem to deny the diagnosis of ASD (Ludlow et al., 2011; Rabba et al., 2019) and think that the child will ‘grow out of it’ or ‘snap out of it’ (Myers et al., 2009). Fathers have been specifically mentioned in that they deny the diagnosis, and that they still hope that their children will grow out of the disorder (Ludlow et al., 2011). Perhaps this is because fathers spend less time with their children, as they are usually more focused on bringing in an income, and therefore do not experience their behaviours as often as mothers do (who usually care for their children all the time).

Furthermore, parents experience stigma from their communities - parents are blamed for their child’s behaviour or their children are labelled as naughty, resulting in caregivers isolating themselves, being secretive about their child, and feeling ashamed (Guler et al., 2018). These stigmas and a sense of isolation result in parents avoiding public health facilities and diagnoses.

4.2.8. Contact with other parents with ASD children

There are contradictory views in the international literature regarding support groups and socialising with other parents who have ASD children. While some parents saw support groups as helpful (Ludlow et al., 2011), others did not (Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010). Likewise, some parents experienced contact with other parents with ASD children as extremely helpful and as a large source of support (Lloyd et al., 2019; Ludlow et al., 2011), while other parents did not want contact with other parents of ASD children, as then their whole life then became about ASD (Fletcher et al., 2012; Lutz et al., 2012; Myers et al., 2009; Nealy et al., 2012; Safe et al., 2012).

Since relationships with parents who have neurotypical children are difficult for parents with ASD children because of a lack of understanding and patience (Lloyd et al., 2019; Safe et al., 2012), other parents of ASD children provided a source of support, understanding, advice for dealing with difficulties, and ideas and strategies for coping (Ludlow et al., 2011; Safe et al., 2012). This support from other parents with ASD children made parents feel as if their child was not ‘as disabled’ or ‘as bad’ as other children who have more severe ASD (Ludlow et al., 2011).

Parents also described feeling fortunate about some of the behaviours that their child engaged in (Safe et al., 2012), such as being affectionate since other parents did not have this relationship with their ASD child (Ludlow et al., 2011). However, for parents whose children were not affectionate, for example, it was difficult for them to hear about these behaviours since they wished their child could be doing those things (Kuhaneck et al., 2010). Occasionally, mothers described support from other mothers with ASD children as more work since they would be around another ASD child, who might be more severely autistic with behaviours that were more difficult to handle (Safe et al., 2012). Similarly, support groups were also described by some mothers as ineffective in meeting their needs since the children were so different from each other, and there was a lack of emotional connection (Kuhaneck et al., 2010).

In South Africa, some parents wished that they had access to a support group, to share ideas with parents who had similar challenges (Olivier & Ah Hing, 2009; Reddy et al., 2019). Similarly, in the study by Lloyd et al. (2019), parents uploaded videos of their experiences to YouTube as a way to reach out to other parents with ASD children, since they did not have access to support groups or other parents with ASD children to share their experiences with.

4.2.9. How parents coped through support

Parents across the world and in South Africa described and experienced how important support from their spouses or families was in the raising of their child (Fletcher et al., 2012; Guler et al., 2018; Kuhaneck et al., 2010; Reddy et al., 2019). Sharing the load and experiences with and getting emotional support from spouses was identified as a coping mechanism by mothers in an American study by Kuhaneck et al. (2010). They described spousal help as allowing mothers to have respite time or ‘me time’ (Kuhaneck et al., 2010).

Perhaps so many of the previous literature research participants are those who are married because they have the respite time to participate in such research. They have help from their spouses and extended family members in order to engage in ‘me time’. An unmarried single mother in the study by Kuhaneck et al. (2010) reported that since she did not use babysitters as she was not comfortable with it and did not have a spouse to share the workload, she never had any downtime for herself. In the Reddy et al. (2019) study, it was reported by one parent who did not have spousal or extended support that they considered sending their child to boarding school to deal with the constant care and difficult reality they faced every day. The views and experiences of these mothers could be significantly different to mothers who have spouses, but perhaps they simply do not have the time to participate in research.

Furthermore, some of the coping mechanisms used by some South African parents in the study by Reddy et al. (2019) included distracting their child through television, using calming techniques on their child, sticking to routine, and allowing the child to engage in their comforting peculiarities or restricted and repetitive behaviours. In the American study by Kuhaneck et al. (2010), mothers reported the following coping mechanisms – thus making time for themselves to exercise or go shopping; planning and sticking to routines, and increasing their knowledge of ASD.

4.3. Empirical observational findings

4.3.1. Implicit reference to Neurodiversity by parents

The neurodiversity perspective, while not mentioned explicitly, is followed by some parents. This concept can be seen through the statements that parents made about seeing their child for who they are and appreciating small achievements and rethinking how they defined success. This could point to the relative ‘newness’ or ‘recentness’ of the movement amidst international and national awareness around disability rights, and to the numerous disability studies’ degree programmes in universities, leading to social justice led activism. There seem to be more references to this concept of neurodiversity in international literature. Parents in Canada (Woodgate et al., 2008) described how they accepted that their ASD children would not meet neurotypical developmental outcomes at the same time as their neurotypical peers. Instead, parents treated their ASD child’s milestones as normal and celebrated each one as it was achieved. Another Canadian study (Nicholas et al., 2016) also reported making changes to their expectations of their children and celebrating achievements that would otherwise have been inconsequential, such as initiating play with another child. Similarly, American parents reported learning to appreciate the small achievements (Kuhaneck et al., 2010; Lutz et al., 2012; Myers et al., 2009) and that they appreciated their children’s special differences, as their children were different, complex, interesting, and funny (Myers et al., 2009). In the Kuhaneck et al. (2010) study, parents discussed specifically that they saw their child as “Steve” or “Mandy” instead of autistic. They explained that referring to a child as autistic, brings certain expectations or connotations to mind, such as being unaffectionate and uncommunicative, which while for some children is true, is not the case for all ASD children (Kuhaneck et al., 2010).

While few South African parents mentioned ideas related to this movement, the two that did referred to ideas about treating their child as normal and not treating them differently to their other children, as far as they could (Olivier & Ah Hing, 2009), while the second referred to finding joy in small achievements and rethinking success and accomplishments, as she just wanted her child to one day be able to stop wearing nappies and to say their name (Reddy et al., 2019). Another way in which parents redefined success was by replacing academic expectations with independence in daily life skills (Reddy et al., 2019).

4.3.2. Types of sample recruitment in empirical studies

As a result of the type of sample recruitment used by researchers in South Africa, a certain type of participant was focused on, being first, those who had young ASD children, and secondly, those who were from middle to high socioeconomic classes.

The majority of the South African and international studies reviewed in this chapter concentrated on the experiences of parents who have young children with ASD, and who are struggling with getting diagnoses and finding appropriate schools and support. This can be suggested to be the case in South Africa because researchers seemed to recruit specifically from LSEN schools (Alli et al., 2015; Mitchell & Holdt, 2014; Mthombeni & Nwoye, 2018; Reddy et al., 2019; Wetherston et al., 2017) or therapy centres (Fewster & Gurayah, 2015; Martins et al., 2013; Wetherston et al., 2017) where young children – and their parents - are easily accessible.

Only one South African study (Meiring et al., 2016) focused specifically only on ASD adolescents aged 16-18 years. Furthermore, some of the research both in South Africa (Guler et al., 2018) and internationally (Fletcher et al., 2012; Rabba et al., 2019; Safe et al., 2012) had specific inclusion criteria limiting participants to mothers who had young ASD children. This meant that the views of those who have older children with ASD are not present in the literature. It is equally as important to study older children or young adults, as the problems experienced in childhood may continue to be experienced into adulthood.

Secondly, the views of low socioeconomic status parents are not captured in the literature as fully as the views of middle to higher socioeconomic status participants. This limited access to lower socioeconomic status participants and their experiences is in part due to the type of recruitment used by researchers, focusing on the LSEN schools (Alli et al., 2015; Meiring et al., 2016; Mitchell & Holdt, 2014; Mthombeni & Nwoye, 2018; Reddy et al., 2019; Wetherston et al., 2017) and private facilities (Fewster & Gurayah, 2015; Martins et al., 2013; Wetherston et al., 2017) where access to parents is easier than access to those in the rural areas, where arguably, the poorer individuals reside.

It can therefore be inferred that these recruited participants were from middle to higher socioeconomic status since they could access these resources. Thirdly, as researchers often conduct their research in English since it is the language of instruction at most universities (Nyika, 2015), access to individuals to participate in research is therefore influenced by language, with participants in rural areas, arguably the poor, speaking their own home language which could be one of many dialects of the official languages of South Africa.

4.3.3. Mothers as participants due to parental roles

A further observation made regarding previous empirical studies was that mothers participated mostly as research participants, even when participation was open to both mothers and fathers. Much of the South African (Alli et al., 2015; Fewster & Gurayah, 2015; Guler et al., 2018; Mitchell & Holdt, 2014; Mthombeni & Nwoye, 2018; Wetherston et al., 2017) and international (Lloyd et al., 2019; Ludlow et al., 2011; Myers et al., 2009; Rabba et al., 2019; Woodgate et al., 2008) literature on the experience of parenting an ASD child reported on mothers' experiences.

A suggested reason for this occurrence is the roles that parents take on when caring for their child (Kuhaneck et al., 2010; Nealy et al., 2012) – it is mostly mothers who are the primary caregivers of their children. Fathers are described as taking on the role of disciplinarian in relation to the children (Martins et al., 2013; Reddy et al., 2019), while mothers take on all the other roles (Martins et al., 2013; McAuliffe et al., 2019; Nicholas et al., 2016; Safe et al., 2012).

Furthermore, as is typically expected by the traditional ideologies and beliefs that exist within a society that mothers and women should care for children, some mothers in South African studies reported giving up their careers to care for their child at home; largely because of the time and input needed for their child's therapeutic interventions (Mitchell & Holdt, 2014; Reddy et al., 2019). However, while some mothers were employed full-time (Clasquin-Johnson & Clasquin-Johnson, 2018; Reddy et al., 2019), other mothers reported working part-time, in order to contribute to household income (Mitchell & Holdt, 2014; Reddy et al., 2019).

Similar findings were reported internationally. Parents across developed countries reported financial difficulty as a result of only having one household income (Myers et al., 2009; Nicholas et al., 2016). As in South Africa, mothers internationally reported being employed full-time (Fletcher et al., 2012;

Nicholas et al., 2016; Rabba et al., 2019), part-time, or unemployed, but caring for their child at home (Kuhaneck et al., 2010; Nealy et al., 2012; Nicholas et al., 2016; Safe et al., 2012).

Suggested reasons for the variation in the employment status of mothers specifically, is that some families may have access to more resources and are therefore able to stay at home to care for their child, or conversely, they do not have enough resources to afford another carer or facilitator for their child, and so mothers opt to stay at home to care for their child. Furthermore, perhaps the severity of their child's ASD has an impact; meaning that those with lower caring needs are able to attend schools or daycare establishments, thus allowing mothers to work, while those with higher caring needs are sometimes unable to attend schools or daycares, resulting in mothers staying at home to care for their child.

It could also be that some parents homeschool their children (because of the schooling issues and access or waiting lists, or not accommodating their child) and therefore remain at home to school and care for their child. However, these are merely suggestions as none of the studies reported specific reasons for mothers remaining at home and being unemployed, other than caring for their child.

All of the above themes impacted on and influenced sampling in this current study. This study recruited mothers through ASA, via email and snowball sampling, which resulted in a certain type of mother responding – those with higher functioning ASD children. This will be discussed in the following chapter.

4.4. Conclusion

The purpose of this literature review was to explore the available research literature on the experience's caregivers reported about raising their ASD child. The review found that parents from across the world experienced many difficulties and challenges in the raising of their ASD children, but this conclusion summarises findings from only South Africa and other African countries. There were challenges regarding the mismatch between Western psychiatric perspectives and African traditional cultural explanations of ASD. Parents felt that their medical professionals were unwilling to diagnose ASD, had little knowledge about ASD, felt that their concerns were dismissed by medical practitioners, or felt that they were being taken advantage of. Most parents described a very emotional diagnostic experience. Most feelings were negative in nature, such as shock, grief, and denial, at hearing their child's diagnosis. Many parents in South Africa used traditional medical therapies and, if they could afford it, OTC "medications" and lifestyle interventions for their children. Schooling was described as a major challenge for parents. Parents expressed concern about the financial independence and care of their child’s future. Many parents struggled with the stigma and judgment they experienced from family and strangers as a result of their child’s invisible condition but were supported by their spouses and partners financially, and who facilitated their wives’/spouses’ time-outs. The type of recruitment used by researchers resulted in a specific type of mother and ASD child being recruited. This chapter has therefore reviewed the experiences that other South African parents have of raising their ASD children.

Chapter Five: Interpretive Phenomenological Analysis - Methodology

5.1. Introduction

The previous chapter reviewed the empirical research literature, focusing on the experiences that South African and international mothers had raising their ASD child and outlined the difficulties and challenges they experienced. This research was originally focused on the experiences of mothers raising their ASD children in the Eastern Cape from a research base at Rhodes University in Makhanda since most of the above South African research focused on other large urban centres. However, due to the unforeseen circumstances of the Covid-19 pandemic in 2020, as well as recruiting issues, this research recruited four mothers from the EC, one mother from Gauteng, and one mother from KZN, after the recruitment advertisement was posted nationally.

This chapter discusses the steps followed during this research regarding the approach and paradigm followed; how participants were recruited, how the material was collected, how the material was analysed, as well as the ethical considerations. This chapter will also detail the changes made during the course of the research study as a result of Covid-19 compliance. Finally, this research also discusses the ways in which research projects' quality can be determined through trustworthiness.

5.2. Research aim

The aim of this research was to explore the perceptions and experiences mothers had of raising their ASD children in South Africa.

5.3. Research approach and paradigm

This research was based on an interpretivist paradigm. Interpretivists see 'facts' as social constructions of people who understand the world through their individual interpretations of it, shaped by local contexts of meaning and experience, and not as 'facts' waiting to be discovered (Makombe, 2017). Researchers gain access to people's common sense understanding of a phenomenon and attempt to interpret their actions and the social world from their point of view (Bryman, 2012). This paradigm allows researchers to understand and view the world through the perceptions and experiences of the research participants (Thanh & Thanh, 2015).

Since the paradigm determines the approach (Makombe, 2017), a qualitative research approach was used in this research. Qualitative research methods understand truth as being relative and that knowledge is constructed by people in particular contexts (Bless, Higson-Smith, & Sithole, 2013).

Therefore, people understand the world (as their context) through their personal assumptions, biases, and prejudices (Bless et al., 2013). Generally, this qualitative research method uses smaller samples to gain a better understanding of the investigated phenomenon (Bless et al., 2013). It is focused on examining how participants think and feel about a specific topic (Bless et al., 2013), and understanding phenomena in their situated contexts (Bless et al., 2013; Pietkiewicz & Smith, 2014; Thanh & Thanh, 2015). Qualitative researchers are concerned with meaning, and the quality of meaning, rather than causal relationships (Pietkiewicz & Smith, 2014). Qualitative methodologies are less concerned with generalizability and are more concerned with a deeper understanding of the research topic in its unique context (Tuli, 2010).

Qualitative approaches, therefore, allow for rich, experiential material that is needed for interpretivists to understand contexts (Thanh & Thanh, 2015). The ontological and epistemological assumptions of the interpretivist paradigm are therefore that reality is subjective, that it differs from person to person, that it is constructed by each individual (ontology), and that meaning is constructed by the individual's interactions with their particular lifeworld (epistemology) (Scotland, 2012). The methodology of the interpretive paradigm is therefore aimed at understanding phenomena from the individual's perspective; the interactions amongst people as well as the contexts within which people live (Scotland, 2012). The methodology of an interpretivist qualitative approach can therefore be phenomenological, case studies, hermeneutics, or ethnography, while the methods can include interviews, focus groups, open-ended questionnaires, or any archival or textual methods which generate experiential material that can be analysed (Scotland, 2012).

A suitable methodology that fits into this interpretivist qualitative research paradigm is Interpretive Phenomenological Analysis (IPA). IPA incorporates ontological, epistemological, and methodological aspects in its design, conduct and analysis. It is an interpretive version of an original, descriptive, or naïve Phenomenology approach (Willig, 2013), which sees reality as subjectively experienced. It uses semi-structured interviews to gather suitable qualitative, experiential material, which is then analysed inductively, into shared themes. These aspects are covered below.

5.4. Interpretative Phenomenological Analysis

The main goal of IPA is to explore individuals' lived experiences in detail, and to show how these individuals make sense of these experiences in a particular context (Brocki & Wearden, 2006; Pietkiewicz & Smith, 2014; Smith, 2004, 2011). IPA's main currency is the meanings that particular experiences have for participants (Smith & Osborn, 2003). It also aims to produce an in-depth examination of a specific phenomenon, and not the generation of a generalizable theory (Pietkiewicz

& Smith, 2014). Since this research study wanted to explore the lived experiences mothers had of raising their ASD child in South Africa, IPA was considered to be a suitable methodology.

According to Willig (2013), while IPA "wishes to capture the quality and texture of individual experience" (p.260), it acknowledges that direct access to participants' life-worlds is impossible. While it aims to explore the participants' experiences from their perspective, it also recognises that this must implicate the researcher's own world views as well as the interaction between researcher and participant (Willig, 2013). As a result of this interaction, the analysis produced is always an interpretation of the participants' experiences (Willig, 2013).

IPA draws on the fundamental principles of Phenomenology, Hermeneutics, and ideography (Smith, 2011). It is phenomenological in the sense that it is concerned with the subjective accounts and experiences of the participant, not with objective accounts (Brocki & Wearden, 2006; Smith, 2011; Smith & Eatough, 2016; Smith & Osborn, 2003). In other words, it is concerned with examining experience in its own context, without it being influenced by prior psychological theory or a researcher's personal beliefs (Smith, 2017).

IPA is interpretative and Hermeneutic as it recognises that the researcher is central to analysis and research (Brocki & Wearden, 2006; Smith, 2004, 2017). While the researcher tries to access the participants' experiences as far as is possible, IPA acknowledges that since the researcher has an active role (Smith & Osborn, 2003) that this access is dependent on and complicated by the researcher's own personal conceptions, and that these are required in order to make sense of the participants experiences through the process of interpretation (Brocki & Wearden, 2006; Smith & Eatough, 2016; Smith & Osborn, 2003). As a result, there is a two-stage interpretation, or double hermeneutic process (Smith, 2011; Smith & Eatough, 2016). This double hermeneutic process illustrates the dual role of the researcher. On the one hand, the researcher, like the participant, is drawing on shared mental or cognitive processes of meaning-making, but on the other hand, the researcher is different as they engage in second-order sense-making of the participants' experience (Smith & Eatough, 2016).

IPA is strongly idiographic since it is committed to analysing each individual case in their unique contexts in a research study sample (Pietkiewicz & Smith, 2014; Smith, 2011; Smith & Eatough, 2016). Only when the researcher has examined each case, is there an attempt to conduct a cross-case analysis (Smith, 2004) as the themes are interrogated for convergences and divergences (Smith, 2004, 2017). It is only then that any general statements can be produced (Pietkiewicz & Smith, 2014). IPA researchers concentrate on depth, rather than breadth (Pietkiewicz & Smith, 2014; Smith & Osborn, 2003). This is the idiographic aspect of IPA (Smith & Osborn, 2003). IPA aims to produce an in-depth examination of a specific phenomenon and is not aimed at generating a theory to be generalised (Pietkiewicz & Smith, 2014). However, IPA is not opposed to making more general claims (Smith & Osborn, 2003). Comparing multiple cases and experiences of a specific phenomenon allows for the generation of insights into possible universal patterns (Pietkiewicz & Smith, 2014).

IPA is also inductive in its approach, which allows for unanticipated themes or topic to emerge during analysis (Smith, 2004). It does not try to verify or negate specific theories or hypotheses, based on existing literature but is rather focused on broad research questions which allow for expansive material to be collected (Smith, 2004). IPA identifies the participant as a "cognitive, linguistic, affective and physical being and assumes a chain of connection between people's talk and their thinking and emotional state" (Smith & Osborn, 2003, p. 54). It also recognises that this is a complicated connection in that people sometimes struggle to express what they are thinking and feeling. They may not want to disclose some details, and the researcher has to interpret their mental and emotional states from what they say (Smith & Eatough, 2016; Smith & Osborn, 2003).

5.5. Sampling

Since IPA is idiographic, it focuses on conducting studies on small sample sizes (Smith, Flowers, & Larkin, 2009), although guidelines on sample sizes vary. Smith et al. (2009) recommend between three and six participants as the sample size for a student project using IPA. In a book chapter, Smith and Osborn (2003) suggested a sample size of between five and six as a reasonable sample size for a student project, while in another paper, Smith (2004) suggested a sample size of between five and 10. This sample size allows for a detailed analysis of each case, as well as having the ability to conduct analyses of similarities and differences across cases (Smith et al., 2009; Smith & Osborn, 2003). Other authors have also published their thoughts regarding sample sizes for phenomenological qualitative studies: Creswell (2014) describes a sample size of between three and 10, Alase (2017) describes a sample size of between two and 25, while Morse (2000) describes a sample size of between six and 10. Pietkiewicz and Smith (2014), Smith and Eatough (2016), as well as Smith et al. (2009), explained that there is no right or wrong sample size for an IPA study, as the sample size depends on several factors: 1) the commitment to the analysis and reporting of each case, 2) the richness of the individual cases, and 3), the constraints that the researcher is working under. These three factors will now be discussed.

1) Commitment to the analysis and reporting of each case

Smith et al. (2009) commented that a researcher should focus on quality, instead of quantity, since IPA's primary concern is to give a detailed account of individuals' experiences, perceptions, and understandings (Smith et al., 2009) in their particular contexts, rather than make more general claims (Smith & Osborn, 2003). Therefore, while some researchers have opted for larger sample sizes in their research so as to avoid criticism from examiners who may be more comfortable with quantitative research and its larger samples (Smith & Eatough, 2016; Smith et al., 2009; Wagstaff et al., 2014); what often occurs, in this case, is that the researcher is then overwhelmed by the material and produces a superficial qualitative analysis, while still not having an adequate sample size to satisfy quantitative criteria (Smith & Eatough, 2016). The sample size should therefore provide enough cases for the development of meaningful similarities and differences between participants, but what should not happen is that the researcher is overwhelmed by the amount of material (Smith et al., 2009). Smith et al. (2009) elaborated, saying that "it is more problematic to try to meet IPA's commitments with a sample size which is 'too large', than with one that is 'too small" (p. 51). Therefore, this research project is committed to focusing on the quality of the interview material, instead of on a large volume of material, in order to commit to an in-depth analysis of each case.

2) Richness of individual cases

Smith et al. (2009) explained that the number of interviews, rather than the number of participants, is also an important factor to consider when it comes to sampling size. Multiple interviews with each participant allowed the "IPA analyst to develop a more detailed and multifaceted account of that phenomenon" (Smith et al., 2009, p. 52). This meant that I was able to delve deeper into certain topics that emerged from the first interview in the second interview, adding to and improving the richness of the experiences. The reasoning behind using a double interview in this current study is discussed below in section 5.7.

3) Constraints that the researcher is working under

While there are phenomenological principles for good quality research, there were circumstances beyond the researcher's control when it came to recruiting participants for this research. There was some 'slowness' or reticence when recruiting participants for this study, even after two rounds of recruitment and snowball sampling. This could be due to several reasons. Firstly, mothers, and women in general, may have little free time due to the unpaid housework they engage in (Ascher, 2020; Tolmay & Morna, 2020; Wayland & GroundUp, 2019).

Domestic chores, such as looking after children, cleaning the house, doing laundry, caring for the elderly, and cooking have been considered as the duty of the woman of the house (Awung & Dorasamy, 2015; Guy & Arthur, 2020). Married women are therefore described as working 'double shifts' – meaning their paid job as well as their unpaid household job (Awung & Dorasamy, 2015). Dealing with the demands of both these jobs and balancing them has been described as a struggle for women, resulting in stress and frustration for many (Awung & Dorasamy, 2015), and little free time.

Secondly, the Covid-19 pandemic of 2020 resulted in further difficulties, stressors, and pressures for families generally (Coyne et al., 2020). Parents had to consider the effects of travelling to and from work (if they were performing an essential service) potentially contaminating their homes and exposing their families to the virus, meeting their own employment requirements, ensuring that elderly family members are cared for and safe, dealing with homeschooling their children or completing homework packs (Coyne et al., 2020), while also having to deal with the opening and closing of schools (Jordaan, 2020).

This all resulted in one or both of the parents staying at home to care for their child and having to do without the extra support provided by domestic workers (Tolmay & Morna, 2020). However, regarding those professionals who are allowed to and are able to work from home, it should be noted that they also have to care for their children in the same space, when the schools are closed. A mother explained that while she was still employed and working from home during the lockdown, her husband was furloughed – but instead of her children interrupting her husband who was watching Netflix, they would interrupt her work phone calls (Ascher, 2020).

Parents with children with special needs may have been placed under further stress regarding the schooling and education of their children since many of these children have specialized education programs, educators, and therapists (Pedro, Mthimunye, & Bust, 2020). Parents therefore may not have had the knowledge, emotional resilience, or training required in order for them to educate and help their child during this pandemic while their children are at home (Pedro et al., 2020). Furthermore, because of the restrictions of movement and access to public spaces, routines (such as attending school, and playing outdoors) were disturbed, which for some special needs children resulted in frustration, and anxiety; resulting in aggression and depression (McKenzie et al., 2020).

Thirdly, Jowett (2020) questioned the ethical implications of interviewing a participant during a global pandemic which might have affected the participants' state of mind and cautioned that the researcher should consider the participants' health and wellbeing (Jowett, 2020). The researcher should therefore not add any additional unnecessary stress to the participant during this crisis (Jowett, 2020). It should be emphasized here that it was up to the participant to contact me, to take part; it was the participant's choice to participate, knowing how they were feeling and coping during this time.

Lastly, in addition to the little free time that mothers may have as a result of their household care work and stress experienced as a result of the Covid-19 pandemic, there may be other reasons why mothers did not want to participate in this research. Firstly, the mothers may have been wary or fearful of sharing their experiences with a stranger (Mfutso-Bengo, Masiye, Molyneux, Ndebele, & Chilungo, 2008). Secondly, they did not see any benefits in participating in the research for themselves or their communities, or thirdly, they had previously had bad experiences with research (Mfutso-Bengo et al., 2008).

It also could have been too much effort for them to participate, or the information wanted by the researcher was too sensitive for the individual to disclose (NSF Consulting, 2015). A further reason could have been difficulty in accessing reliable, stable internet or lacking the knowledge in navigating and using these online platforms, where the online interviews were meant to take place (Dodds & Hess, 2020; Jowett, 2020). All this has meant that mothers and their families could have felt under pressure during this time, which meant less leisure time as well as less routine (Coyne et al., 2020). If it were not for the pressures just mentioned, mothers might have had more time to be interviewed about their experiences raising their child with autism.

Therefore, based on the above discussion and considerations which were kept in mind about the stressors which mothers experience, this research project aimed to draw upon a sample that was able to generate enough material for an in-depth exploration of mothers’ experiences raising their children with ASD, while being aware of the issues of having too much material to discuss. Therefore, this research project had a goal sample size of between four and six mothers prior to recruitment, which was suitable as it allowed me as the researcher to have a manageable set of interview material to analyse. That allowed for a thorough and in-depth analysis of each participant’s experience (Noon, 2018), by examining the similarities and differences between participants (Pietkiewicz & Smith, 2014), and providing an opportunity to comment in detail, ideographically and in context-specific ways, on participants’ perceptions, experiences and understandings of the topic (Smith & Osborn, 2003).

5.6. Recruitment

Based on the guidelines discussed by Smith and his colleagues (Pietkiewicz & Smith, 2014; Smith & Eatough, 2016; Smith & Osborn, 2003), the participants for this study were recruited via nonprobability purposive and snowball sampling. Since qualitative studies, such as phenomenological studies are also concerned with the type of people included in the sample (Coyle, 2014), participants are selected purposively based on their access to the particular phenomena under study (Smith et al., 2009), and are typically a fairly homogenous sample (Pietkiewicz & Smith, 2014; Smith & Eatough, 2016; Smith & Osborn, 2003).

The research question should be meaningful to these participants (Smith et al., 2009). These participants, therefore 'represent' a specific perspective, rather than that of the whole population (Smith et al., 2009). Therefore, there were specific inclusion criteria for mothers in this study. The mothers or primary caregivers had to have a child or children previously diagnosed with ASD; they (mothers) had to be adults over the age of 18, be fluent in English, and be caring for their child at home, i.e., not in a residential facility. Irrespective of whether the autistic child was in formal schooling or not, the mother or primary caregiver should be caring for (or have cared for) their child at home.

There was no limitation placed on the severity or degree of ASD experienced by the child. There was also no restriction regarding the age of their child, as this study sought to explore the experiences of mothers as a whole, not a specific group of mothers with children under a certain age. Furthermore, since this research used face-to-face in-depth interviews in 2019, the participating mothers had to live within the EC province, in order for me to travel to the participant. However, during the Covid-19 lockdowns in 2020, after the recruitment advert was inadvertently sent out on a nationwide network by the *Autism South Africa* (ASA) gatekeeper, and no further interest from EC mothers was shown, mothers could be recruited from all provinces across South Africa. Through purposively sampling for participants, I was able to find a group of participants for whom the research question had importance and significance (cf. Pietkiewicz & Smith, 2014; Smith & Eatough, 2016; Smith & Osborn, 2003). I identified an individual from ASA who put me into contact with the National Director of ASA, who was willing to participate as a gatekeeper (Appendix A for gatekeeper access request; Appendix B for ASA approval). In 2019 and 2020, I requested that the gatekeeper forward an 'invitation to participate' (Appendix C for 2019; Appendix D for 2020) to their network of caregivers, allowing for participants to voluntarily contact me. The 'invitation to participate' (Appendix C for 2019; Appendix D for 2020) detailed the purpose, expectations, and ethical considerations of the research. Interested participants volunteered by responding directly to me by phone, text, or email.

Since only three mothers responded to the 'invitation to participate' (Appendix C for 2019) sent to ASA's network of EC caregivers in 2019, snowball sampling was also used in 2020 to recruit participants. Snowball sampling is when previously sampled or interviewed participants suggest or refer other participants who have the relevant experiences or characteristics necessary for the research (Bryman, 2012; Smith et al., 2009). I, therefore, asked the previously interviewed participants (asked in 2020) if they knew of any other mothers of ASD children who would be interested in participating, allowing the previously interviewed participants to speak to these potential mothers first to check whether they were willing to participate. I forwarded Appendix D for 2020 (the invitation to participate) to the previously interviewed mothers to forward to any new potential mothers. This meant that each of the potential new mothers could contact me by phone, text, or email themselves to discuss participation, should they be interested.

However, since only one mother responded from the snowball sampling, I requested that the gatekeeper recirculate the ‘invitation to participate’ (Appendix D for 2020) to their networks once more in 2020 (after ethical changes were approved, i.e., from face-to-face to online interviews). The gatekeeper sent the invitation to their South African database, inadvertently, resulting in an overwhelming response from mothers across South Africa. While the researcher hoped for more EC-based mothers to respond, none did. As a result, my research supervisor and I decided to allow participation from mothers from other provinces. Two of the first mothers to respond were selected, in order to reach the sample size of six mothers. The research project was, therefore, able to fulfill its maximum sample size of six mothers. Six mothers residing within South Africa participated in this research study. All information was correct at the time of the interview. Four of the mothers were based in the EC, one mother was located within Gauteng, while the sixth was located within KZN. All the mothers had more than one child, with an average of two children each. See table one for participant details.

Table one: Participant details

Total number of participant mothers		n = 6
Race or ethnicity		
	Black African	n = 2
	White	n = 4
Mothers’ marital status		
	Married	n = 5
	Single or divorced, with a non-residential father	n = 1
Mothers’ employment status		
	Full-time	n = 6
	Part-time	n = 0
Gender of ASD child		
	Female	n = 1

	Male	n = 5
Age of ASD child		
	0 – 12 years	n = 2
	13 – 21 years	n = 4
Degree of ASD		
	High functioning or low support	n = 6
	Low functioning or high support	n = 0

The advantage of including mothers from other provinces was that their identities could be protected. Within the EC sample, it became difficult to protect mothers' identities from each other due to the snowball sampling (friends nominating and inviting friends to participate), as well as the recruitment through the EC network of ASA (small, so mothers know each other from workshops or support groups). This resulted in mothers having to be completely anonymized and their identificatory details neutralized in the analysis that followed, to protect the anonymity of the mothers, their ASD children, and any schools, teachers, doctors, or therapists who were mentioned. This is discussed further in the section on ethics below. Even though mothers were from different provinces, there was no clear discernible difference in their experiences. Furthermore, by including mothers from various provinces, this let the participant mothers see that their experiences were similar to those of a larger group of struggle and difficulties. This was achieved as this study used snowball sampling, which meant that participants were known to each other to some extent. In addition, this thesis was also shared with ASA and the participant mothers as feedback.

5.7. Collection of interview material

As IPA studies require a flexible material collection technique (Smith & Osborn, 2003), the semi-structured interview (SSI) was suggested as being the most appropriate material collection tool (Pietkiewicz & Smith, 2014; Smith & Eatough, 2016; Smith & Osborn, 2003). The advantage of using this type of interview is that I could follow up on interesting and important issues that came up during the interview, i.e., a dialogue in real-time (cf. Pietkiewicz & Smith, 2014; Smith & Eatough, 2016; Smith & Osborn, 2003). The pre-constructed schedule served as a guide during the interview, rather than dictating the interview (Smith & Eatough, 2016). Constructing the interview beforehand therefore allowed for questions to be sensitively phrased and for problems or other topics that arose to be considered (Smith & Eatough, 2016; Smith & Osborn, 2003). The interview questions were constructed and developed by myself and my research supervisor from the literature reviewed, about the experiences of parents.

I was able to probe interesting topics that arose and follow the participants' interests and concerns related to the topic at hand (cf. Smith & Eatough, 2016; Smith & Osborn, 2003). Since IPA wants to explore a specific topic or area of experience, these types of interviews allow for the establishment of an empathic relationship with the participant and facilitating the participant in giving their account of their experience, in structuring and describing the experience they had (Smith & Eatough, 2016; Smith & Osborn, 2003). This type of interview also allowed for a change in the sequencing of questions as topics arose and it then allowed for rephrasing of questions (Smith & Eatough, 2016; Smith & Osborn, 2003). The participant is therefore an active agent in shaping the interview progression (Smith & Eatough, 2016).

Researchers using SSI should encourage their participants to speak freely about the topic without too much prompting, as this allows the researcher to get as close as possible to the thoughts of the participant (Smith & Osborn, 2003). Prompts can however be used to help guide the participant or to help them to talk about the topic (Smith & Osborn, 2003). SSI's typically last for an hour or more and are better done in quiet areas (Pietkiewicz & Smith, 2014; Smith & Eatough, 2016; Smith & Osborn, 2003). Participants are most at ease in familiar environments, as this helps them to feel more relaxed, as mentioned above (Smith & Eatough, 2016; Smith & Osborn, 2003).

In this research project, the three mothers recruited in 2019 participated in face-to-face interviews, while the other three mothers recruited in 2020 participated in virtual online interviews. Under Covid-19 lockdown in 2020 under level five, four, and three; South Africans had to social distance and were encouraged not to have physical contact with others outside their households. Jowett (2020) explained that video-calling apps such as Zoom are suitable methods that could virtually replicate the face-to-face interview. Therefore, I used Zoom to interview several participants.

The online interview still allowed the participant and me as the interviewer to see and hear each other in real-time interaction. The interview could also occur at the participant's convenience (Archibald, Ambagtsheer, Casey, & Lawless, 2019; Dodds & Hess, 2020; Hanna & Mwale, 2017).

However, one of the potential problems with online interviewing was the internet connection. Poor internet connections could have impacted the rapport between researcher and participant, potentially impacting how much the participant shares about their experiences (Hanna & Mwale, 2017). Further, 'glitchy' internet connections could have resulted in a lack of flow between myself and the participant, resulting in a disjointed flow of communication (Archibald et al., 2019; Dodds & Hess, 2020; Hanna & Mwale, 2017). To overcome this, I explained that should the internet connection during the interviews not be stable enough, the online interview would be rescheduled to a time and date that suited the participant.

For all participants, a mutual, informal checking-in was done during the first contact with them, to make sure that the purpose of the study, the expectations, and mutual understandings of the inclusion criteria were understood; before a meeting was set up for the interview to take place.

For the participants recruited in 2019, once the mutual informal check-in was done, I asked them for dates, times, and locations that suited them for the informed consent negotiation and interview to take place. The reason for the first meeting and the interview happening on the same occasion was that the participants were resident in different towns of the EC – not necessarily in Makhanda. Thus, I travelled to a place that was convenient for the participant. Allowing the participants to choose the venue, allowed them to choose a space where they were comfortable, and where the interview might be conducted without undue interruptions or fears of being overheard (Smith & Osborn, 2003). This perhaps helped them in honestly sharing their experiences. As recommended by Smith and Osborn (2003), these locations included participants' homes and other neutral venues outside their normal routines, such as coffee shops. Several days before the first face-to-face interview, I sent the interview questions (Appendix G) to each mother via email. Before this face-to-face interview commenced with each participant from 2019, I went over the informed consent form (Appendix E), verbally with the participant, before we both signed the written form together.

For the participants recruited in 2020, once the mutual informal check-in was done, I asked them for dates and times that suited them for their interviews to take place. For these participants, the informed consent form (Appendix E), as well as Appendix F (the addendum to the informed consent) for those residing outside the EC, was emailed prior to the interview, for their perusal. Appendix F (an addendum to the informed consent) gave details for the Regional Development Officers (RDOs) details for each province in order for mothers to contact these RDOs should they need extra support. That was recommended by ASA. Several days before their online interviews, I sent each mother a copy of the interview questions (Appendix G). Approximately 30 minutes prior to each Zoom interview with the participant mothers, I emailed Zoom details to the participants, which contained a link to the Zoom session, a username, and a password. Once the interview started, the participant and I read over the informed consent as well as the addendum before signing. The participant then scanned a copy of their signed consent form to me, where I signed and scanned the fully signed form back to the participants. Full disclosure about the nature of the study and expectations was offered, here and throughout the research process. Furthermore, participants were invited to ask questions at any stage of the research process if they were unsure or confused about any part of the research or their participation.

It must be emphasized that the participants were informed that they could withdraw from the research at any stage, without a reason, as stated in the informed consent form (Appendix E). Once I went over the form, verbally and in written form, both the participant and I signed it. The interviews began following the SSI schedule as set out in Appendix G. An appointment for the second interview was negotiated at the close of the first interview, and verbal consent for this to proceed was attained. This demonstrates a continual process of checking-in and negotiating informed consent as the research unfolded.

The first interviews with the mothers lasted for approximately an hour and a half, while the second interview, conducted approximately a week to two weeks after the initial interview, was a shorter, follow-up interview, lasting approximately an hour. Vincent (2012) discussed several benefits of multiple interviews: 1) questions can be tailored for each participant, to gain further insight and clarification from initial interview material; 2) a better rapport is established as the participant can make informed decisions about the researcher's motivations and interests in the topic; and 3) covering initial interview material in the follow-up allows participants to see that they have been listened to (thus enhancing rapport), while also allowing them to validate and edit the researcher's interpretations and comments. Furthermore, I could enquire about how the participant was feeling after the initial interview and ask if they needed further support.

Following each interview with each participant, I sent them an email thanking them for their participation as well as reiterating that they could ask questions at any stage should they wish to.

It was necessary to audio-record interviews and to transcribe these interviews for the actual analysis of IPA (Smith & Eatough, 2016; Smith & Osborn, 2003). For the mothers interviewed in 2019, an audio-recording device was utilised, while in 2020, the online platforms of Zoom allowed for the recording of the meeting, with the option to download the audio and video files. Permission to record the interview for transcription purposes is detailed within the informed consent form (Appendix C). Audio recording allowed me to concentrate on what the participant was saying rather than trying to write everything down. Writing everything down during the interview could also have interfered with how smoothly the interview ran and with establishing rapport with the participant (Smith & Osborn, 2003). For IPA, the level of transcription needs to be at a semantic level; in other words, all false starts, pauses, laughs, and other features need to be included (Smith & Osborn, 2003). Transcription was time-consuming but necessary (Smith & Eatough, 2016; Smith & Osborn, 2003). Wide enough margins were left on each side of the transcript to allow for researcher commentary (Smith & Osborn, 2003).

5.8. Analysis of material

I carefully followed the guidelines, to the letter, provided by Smith and colleagues when it came to analysing the interview material (Pietkiewicz & Smith, 2014; Smith & Eatough, 2016; Smith et al., 2009; Smith & Osborn, 2003). These guidelines comprised four stages.

5.8.1. Stage One: reading and rereading

I read and reread the transcribed interview transcripts several times, in order to stay grounded within the experiences of the participants. I also listened to the audio recordings again to re-immerse myself in the material, to recall the atmosphere of the interview, and the setting in which it was conducted. This relistening and rereading was important as it allowed for understanding the context of meanings and for the possibility of new insights each time (Pietkiewicz & Smith, 2014; Smith & Osborn, 2003). I used the right-hand margin to note anything that seemed significant, that was of interest to me, as well as any observations or reflections I made. This initial analysis was the most detailed and time-consuming since it examined the semantic content and language on an exploratory level (Smith et al., 2009). The first stage could be described as a free textual analysis since there were no rules about what could be commented on (Smith et al., 2009). Furthermore, some parts of the interview transcripts were richer than others and therefore warranted more commentary (Smith & Osborn, 2003; Smith et al., 2009). As I moved through the transcript, I picked up on the differences, similarities, amplifications, and contradictions within the transcript (cf. Smith & Osborn, 2003).

These initial notes, which contained descriptive comments, had a clear phenomenological focus, as they stayed close to the participants' explicit meaning (Smith et al., 2009). These comments described those things which were important to the participants and the meaning the participants ascribed to those experiences (Smith et al., 2009). The interpretative aspect came in when I was trying to understand how and why the participants had concerns, by looking at their language use, their context and lived world experiences, and identifying abstract concepts to make sense of the patterns of meaning in their accounts. Therefore, it can be seen that there were three different processes with different focuses for exploring the transcripts: 1) descriptive and 2) linguistic exploratory commentary, and 3) conceptual commentary (Smith et al., 2009). This conceptual interpretative commentary moved away from the explicit claims of the participants, shifting my focus towards the participants' overarching understandings of the topic at hand.

5.8.2. Stage Two: emerging themes

Next, I used the left-hand margin to transform the initial notes from stage one into more specific phrases or themes which aimed to capture the essential quality of what I found. This then moved to a slightly higher level of abstraction and involved psychological terminology (Smith & Osborn, 2003). The link between what the participant actually said and my initial responses were apparent. I was working more with my notes in the right-hand margin than with the actual transcript. At this stage, the entirety of the transcript was treated as material still, and no attempt was made to omit or select specific passages (Smith & Osborn, 2003). There was also no requirement to generate themes out of every passage (Smith & Osborn, 2003).

Once this was complete, I noted the emerging themes on a piece of paper, and connections were sought between them. Initially, the themes were chronologically ordered but as the connections were made, this fell away and a more analytical or theoretical ordering was used (Smith & Osborn, 2003; Smith et al., 2009). Some of the themes clustered together and some emerged as superordinate concepts (Smith & Osborn, 2003). I then checked these clustered themes against the transcript to ensure the connections worked for the primary source material – the actual words of the participant. This was an iterative process, involving close interaction between myself and the text (cf. Smith & Osborn, 2003). I drew on my interpretative resources to make sense of what the participant had said, but at the same time, checked my own sense-making against what the participant had actually said. Next, I created a table of themes, which was ordered coherently. Clusters of themes were identified during the above process which captured the participants' concerns about the topic (Smith & Osborn, 2003). These clusters were given names and represented superordinate themes (Smith & Osborn, 2003). One part of the hermeneutic circle was employed here – parts from the whole transcript were fragmented here and used, with these parts becoming a whole again at the end of the analysis in the write-up (Smith et al., 2009).

5.8.3. Stage Three: refining and condensing themes for a final table

Once stage two was complete for the first case or participant, Smith and Osborn (2003) and Smith et al. (2009) suggested that for studies that have more than one participant, such as this current study, the IPA researcher should look in detail at one transcript before moving onto the examination of the second, and so on – in other words, working case by case. This was the process I followed in this study. This also followed the idiographic approach to analysis, starting with one case and their experiences, and slowly moving towards general categories and claims (Smith & Osborn, 2003). That however meant less consensus across the cases.

Once each interview transcript had been analysed through the process described above, I looked across the multiple cases and themes from stage two in order to refine and condense the themes and to discern connections between them, before grouping them together according to conceptual similarities and providing each cluster with a descriptive label. Once this process was complete, I created a table showcasing the differences and similarities between cases, usually using extracts from each participant. I then decided which themes to focus on – I prioritized the material and reduced the number of themes, which was challenging. Themes were not only selected on prevalence, but also on the richness of the accompanying passages that highlighted the theme, and how the theme illuminated other aspects of the participant's account (Smith & Osborn, 2003). Once this process was complete, a final table representing the themes and superordinate themes was created by me. These tables (for each participant and their superordinate themes) were not included as an appendix to this research report, due to protecting the participants' anonymity – this anonymity is further discussed in the ethics section below. The tables will be made available to examiners separately.

5.8.4. Stage Four: write up of narrative

At the end of stage three, I had a table of superordinate themes and subordinate themes. This table was the outcome of an iterative process where I moved between the analytic stages ensuring that what the participant had said was preserved. Using the table, I started the formal process of writing up a narrative. This writing and rewriting took the analysis deeper as I focused on making explicit the interpretative commentary on key things that the participant had said. The aim was to provide a close contextual reading of the participants' account moving between description and different levels of interpretation; at all times differentiating between account and interpretation (Smith & Eatough, 2016). I wrote up each theme individually – each described and exemplified with extracts from the interviews, followed by analytic comments from me. Verbatim quotes illustrated the phenomenological aspect of IPA, as these quotes capture the lived experiences of the participants (Smith et al., 2009). The interpretative aspect of IPA was my analytical commentary (cf. Smith et al., 2009). The use of extracts also enabled the reader to assess the relevance and appropriateness of the interpretations and retained the voice of the participant's personal experience in a particular context and gave a chance to present the emic perspective (Pietkiewicz & Smith, 2014).

This narrative account is followed by a discussion section which related identified themes to existing literature (Smith et al., 2009), as well as a reflection on the research and comments about the implications and limitations of the study, and ideas for future development (Pietkiewicz & Smith, 2014), which is included in the conclusion chapter. The end analysis is an account of how I think the participant is thinking – this is the double hermeneutic at play. Therefore, the truth claims of IPA are always tentative and the analysis is subjective (Smith et al., 2009). However, the reader is able to check this subjectivity (Smith et al., 2009) through the verbatim extracts.

5.9. Material management and storage

The audio files from the audio-recording device used in 2019 were moved across onto a password-protected computer after the initial interview, for transcription to take place. In the case of the Zoom recordings in 2020, once the audio was downloaded, they were also kept on a password-protected computer. Zoom offers the advantage of secure recordings without the use of third-party software, encryption of meetings as well as user-specific authentication (username and password) (Archibald et al., 2019). Only myself as the researcher and the research supervisor had access to the recordings. Once the transcription of the audio, and the analysis thereof, was complete, all the audio recordings were deleted. The transcriptions will however be kept secure for five years on a password-protected computer by the research supervisor. Within the informed consent form (Appendix E), the participant was notified that only their interview transcriptions could be used in future presentations, studies, published journal articles, and textbook chapters by myself or the research supervisor. In addition, the research project could be utilised by ASA since they are acting as gatekeepers and a copy of the final project will be provided to them. The interview transcriptions will not be made available to ASA.

5.10. Ethical considerations

This research received ethical clearance from the Rhodes University Ethical Standards Committee (RUESC) on 14 August 2019, with tracking number 2019-0692-774 (Appendix H). On 14 August 2019, the ethical clearance document from RUESC as well as Appendix C for 2019 (invitation to participate) was sent to the ASA gatekeeper to distribute amongst their caregiver networks in the Eastern Cape. The ethical clearance for this study was extended for 2020. In addition, due to the Covid-19 pandemic and the resulting lockdown across South Africa, changes had to be made to recruitment strategies, as well as to the collection of material (both have been detailed above). These changes were approved by RUESC on 10 June 2020 (Appendix I), and the updated invitation to participate (Appendix D for 2020) was sent to ASA on 27 July 2020. In addition to the ethical considerations of voluntary participation, informed consent and discontinuance discussed above, this research also considered the following: anonymity and confidentiality, non-maleficence, beneficence, justice, and appropriate referral.

5.10.1. Anonymity and confidentiality

In terms of anonymity, in an ideal world, participants should not be traceable or identifiable from the material presented about them (Saunders, Kitzinger, & Kitzinger, 2015). I found it difficult to protect the identities of the participants just by changing their names, children's names, schools' names, and locations (amongst others), as there were still details after the first stage of anonymization that was identificatory. As a result, my research supervisor and I followed some of the anonymizing techniques used by Saunders et al. (2015) in their study on families' experiences of having a relative with consciousness disorders, such as vegetative or minimally conscious states, in a particular *National Health Service* hospital in the UK. The authors were concerned that interviewed participants might have recognized each other and their relatives from details given in the final report, since the ward-sample was small and copies of the report would be distributed to nursing staff, participating relatives, and some patients or former patients themselves. Saunders et al. (2015) also described a particular problem in their study with the snowball sampling they used to recruit participants. Internal confidentiality might have been breached, since multiple members of the same family were interviewed, with some not wanting their other family members to identify what they had said about each other, or about patients. Some patients were spoken about, and due to their mental state were not able to give consent or be interviewed. As a result, Saunders et al. (2015) explained the challenges that arose while anonymizing their participants 1) names, 2) places, 3) religious or cultural backgrounds, 4) occupations, 5) family relationships, and 6) other potentially identifying information, and how they worked around those challenges.

As a result of the possibilities of identification of mothers, and their ASD children (some under 16 years of age and classed as "vulnerable" with a potentially stigmatizing diagnosis), this research deviated from qualitative research norms, by not using pseudonyms or any other way to track which extract was related to another. This current research study also used snowball sampling through friends and social networks related to ASA, and direct recruitment through ASA as an organisation. This research report will also be shared with both ASA and the participants. Therefore, the risks of identification in this research context were very high.

The pseudonyms originally selected revealed the race of mothers, which was also potentially identificatory. Thus, following ethical arguments about anonymization of sensitive material by Saunders et al. (2015), the use of pseudonyms in this study allowed a reader to track a "pattern" or "confluence" of biographical details in a thread of distinctive quotes or extracts (e.g. always named "Jenny") that were very identificatory of (1) mothers who may be friends or acquaintances through ASA, (2) children diagnosed in very particular circumstances, (3) families and where they lived, and

(4) medical professionals, hospitals or schools which might be embarrassed or offended by one side of the story being presented. As a result of this possible identification, my research supervisor and I decided to avoid using pseudonyms in this research report completely and to rather use neutral terms to protect participants' identities and identificatory information. This was carefully done; following some suggestions by Saunders et al. (2015), which in some ways is contra IPA, since Smith et al. (2009) advocated for the labelling of each extract with the participant's pseudonym for the reader to track and follow the story of each individual throughout the analysis.

Therefore, for confidentiality and anonymity, the mothers, and their children's identificatory details were not referred to by any pseudonyms. Within extracts, identificatory details have been removed and replaced with square brackets "[ ]", indicating where changes or clarifications were made. The extracts are numbered chronologically, and there should not be a way to track individual mothers within quoted extracts. Here is a fictitious example:

> *Extract 0:*
> She [the paediatrician] told him [my husband] that ~~he~~ [child], our ~~son~~ [child] had autism

The anonymization of participants was difficult for me as it felt as if all the individuality of the participants was being erased. However, I recognized the importance of maintaining the anonymity of the participants and their stories. Occasionally, anonymizing participants identificatory details meant 'neutralizing' the details which were very interesting and added diversity. The irony here is that the very details which make the topic more diverse, are the details that need to be masked and anonymized to protect identities. In other instances, details and experiences that mothers shared had to be omitted from the research, as mothers found these experiences difficult to share with me and did not want others to know their thinking and understanding of their experiences of raising their child. The anonymization and exclusion of details such as these, while resulting in the protection of the mother, also reproduces the shame they feel at sharing and having these details known by others. Recommendations for future researchers faced with similar anonymization issues are to build the respondent validation or member checking step into their research process. This second informed consent step would allow participants to (1) review their interview transcripts and to delete what they felt uncomfortable with, and (2) review the analysis or thematic findings chapter once anonymization was complete, to check that they were okay with the final representation of themselves. This was not done in the current research project due to time constraints and the Covid-19 lockdown that intervened and disrupted the process. As a result, my research supervisor and I took every possible precaution to maintain participants' anonymity.

Since the transcriptions of the interviews are available for myself and my research supervisor to use in future presentations, studies, published journal articles, and textbook chapters, within the transcriptions, and naming of the files, the participant chose the pseudonyms that were used to ensure anonymity and confidentiality within the transcriptions. In future writing, the ethical considerations considered in this current research project regarding protecting anonymity should also be considered. Furthermore, as stated above, the individual theme tables for each participant are not included as an appendix to this research report, to ensure the anonymity of the mothers in the report. If the individual theme tables were included, the participants and other readers would have been able to refer to the appendices and undo the careful anonymization-work in this research report.

5.10.2. Beneficence

Beneficence is the idea that research should potentially contribute to the wellbeing of others (Bless et al., 2013). The expected benefit of this research was to explore mothers', or primary caregivers', experiences, and perceptions of raising their autistic children, and to give this feedback to the participants, to the gatekeeper ASA, and through publication and presentation to other psychologists and parents. The aim of this research was not directly therapeutic to the interviewed mothers or primary caregivers, but provided an opportunity to share their experiences, and if they felt isolated and overwhelmed, to put them in touch with local networks of support. However, this research can be considered beneficial in the sense that it can be of great use, more generally, to wider groups. With a better understanding of the experiences of EC mothers and caregivers of autistic children more generally, this assists ASA in planning and advocating for more resources to support parents, and by extension, autistic children. This is also of potential benefit in training psychologists and in State or governmental provision of posts, welfare services, and grants, particularly in resource-poor provinces like the EC.

5.10.3. Non-maleficence

By conforming to non-maleficence, the research aimed not to harm any participants through their participation (Bless et al., 2013). One of the ways used to minimize this risk or harm was to provide the participants with a copy of the interview schedule (Appendix G) before their interviews. This meant that the participants were prepared for what was asked and could select what they wanted to say or share. Furthermore, since the interview schedule was an SSI, that allowed participants to speak openly about their experiences without me dictating what questions came next. If I saw visible distress from the participant, during the face-to-face interviews as well as the online interviews, I moved away from asking questions that elicited the distress. The participants were also able to refuse to answer any distressing questions, could ask for responses to be withdrawn or reworded, or withdraw from the study at any time. A second follow-up interview allowed time to reflect on these aspects, to receive feedback and reassurance, and to request further support if this was needed.

5.10.4. Support groups

During any research project, the wellbeing of the participant may be inadvertently compromised as a result of their participation (Bless et al., 2013). I anticipated these risks and made provisions to protect participants in my study. Previous literature suggested that mothers of special needs children may experience stigmatization (Guler et al., 2018; Olivier & Ah Hing, 2009), rejection (Ludlow et al., 2011), guilt (Nealy et al., 2012), and depression (Fletcher et al., 2012; Ludlow et al., 2011; Myers et al., 2009; Reddy et al., 2019) (among others), and as such, they would be considered a vulnerable population. That may be triggered by talking about their experiences with their children, particularly if discussing difficulties. For this reason, within the informed consent form (Appendix E), details were provided about several support groups provided by the gatekeeper from ASA. One of these was a WhatsApp support group, which could be accessed from anywhere and at any time. The participants could approach these support groups at any stage of the research, including weeks and months afterward. To the researcher's knowledge, no participants followed up on this; but there was no objective way to find out about this as the support groups are an ongoing ASA resource. This is important to note as a copy of the research report was given to those participants who requested a copy, a few months after they completed the interviews.

5.10.5. Feedback

Regarding feedback to the participants, within the informed consent form (Appendix E), it was stated that the participants could request feedback regarding their interview transcription and interpretation thereof and that they could request a copy of the final research project. The reason for participants requesting the final report, and not just receiving it automatically at the end, is that if the participant mothers are already overwhelmed and anxiety is triggered by the interviews, they might be further impacted by the final report. It should be the mother's decision whether to receive the final report or not. That put the decision on whether to give feedback to the participant into the hands of the participant; depending on their response and the resilience they showed after the interview. If they found the interviews overwhelming or likely to trigger anxiety, they might not want to read the report. This is a way for the participants to manage the impacts for themselves and for me to behave ethically towards the participants.

5.11. Evaluation and validation

Trustworthiness was used to determine the quality of this qualitative study since the traditionally positivist concepts of reliability and validity are often inappropriate to use in qualitative research (Rodham, Fox, & Doran, 2015; Yardley, 2000). Smith et al. (2009) discussed Yardley's (2000) four criteria as being sophisticated and taking a pluralistic stance, as the criteria are broad, offering various ways to establishing quality, and the criteria can be applied to any theoretical orientation used in a qualitative study. The four principles of trustworthiness are 1) sensitivity to context, 2) commitment and rigour, 3) transparency and coherence, and 4) impact and importance (Yardley, 2000). These principles were understood via the definitions provided by Yardley (2000) and Smith et al. (2009).

I displayed sensitivity to context through exploring previous literature about mothers' and parents' experiences of raising their children, and therefore had some background knowledge of the types of difficulties these parents have. This was important because I did not have any personal experience of mothering my own children. This assisted me to be sensitive and empathetic towards participants during interviews and putting the participant at ease that no judgement would be shown concerning their experiences or the manner in which they raised their children. Sensitivity to context was further demonstrated during analysis through the use of numerous verbatim extracts from participants in support of the argument; thus, giving the participants a voice in the report and allowing the reader to check my interpretations. Since I listened to the participants' interviews several times prior to analysis, sensitivity to context was shown.

Commitment to collecting in-depth interview material was demonstrated by allowing the participant to select a venue they felt comfortable in, in the case of the face-to-face interviews in 2019. Furthermore, a commitment was shown through using an audio recorder as well as the online recording function on Zoom, to listen intently to what the participant was saying, instead of trying to write everything down. Rigour was shown through the careful sampling criteria, in order to ensure a relatively homogenous sample.

Transparency has been demonstrated during this methodology chapter, by detailing the sampling and recruitment of participants, how the interviews were conducted, and the steps followed during analysis. Furthermore, a short discussion about my assumptions, intentions, and actions that may affect the research – known as reflexivity – is another manner in which to demonstrate transparency (Yardley, 2000). Reflexivity will be discussed shortly.

Coherence was shown through the careful drafting and re-drafting of the final research product in order to ensure a coherent, logical argument that had dealt with any ambiguities or contradictions. Coherence can also be seen through the careful commitment to the phenomenological and hermeneutic aspects of IPA, in the thematic findings chapter.

The importance of conducting this research was discussed in the introduction chapter. Kacprzak (2017) argued that the impact and importance of the research occurred when participants were interested and willing to participate in it. This topic was important enough for mothers to be willing to share their experiences with the researcher.

While the above criteria are used to determine the quality of a research paper, Smith et al. (2009) suggested that the independent audit is the best way to determine the research paper's validity. As mentioned above, the use of raw interview material allows the reader to check the analysis conducted by me. Furthermore, I had filed and stored all the literature used in the research project in order for an outsider to follow the 'chain of evidence' from start to end of the research project. Some quality controls for thematic research requires an independent audit to establish 'reliability' or consistency between thematic criteria and decision (Yardley, 2000). For this interpretivist IPA study, the research supervisor offered an outside eye and a sounding board by reading drafts of the research project chapters, as well as checking my initial notes, coding, and themes on one interview transcript.

5.12. Reflexivity

According to Yardley (2000) explained above, reflexivity is a way in which researchers can further establish transparency. It is important to explain the positionality and assumptions of the researcher since these may influence and play a role in how the researcher interprets and understands phenomena. I am a 25-year-old white, English-speaking woman. I am not a mother. I grew up in a rural citrus farming community in Addo. I never had much exposure to individuals with conditions or disabilities. I mentioned one of my first experiences with differently-abled individuals, in the introductory chapter. I struggled with that experience as I did not understand ASD very well and made many incorrect assumptions about 'laziness' or 'brattiness', for example, since there was no visible disability. I was subjected to the usual stereotypes and popular understandings that are circulated in media. From that experience, my interest in ASD grew, thus prompting this research. Through the course of learning about ASD and doing much research on it, my views changed considerably prior to my research interviews, and I realized my previous assumptions were incorrect.

As a researcher, I had only had one other interview experience during my Psychology Honours year. I was quite nervous to do the interviews and to meet the mothers in person or via Zoom. Most of my previous communication with the participants was via email or phone call. However, my nerves subsided quickly as I started talking to the mothers at the interviews – and realized that they, like me, were also nervous to talk. Before conducting the interviews, I was concerned that the mothers would not be willing to share their experiences with me – that they would only give short and to-the-point answers. However, that was not the case at all. I was received by the participants warmly and embracingly. The participants were excited to share their stories and their experiences of raising their child, with me. They seemed to regard the interview as an opportunity to speak, engage and share their lived experiences with an individual, outside of their usual social networks. Most of the mothers thanked me for the opportunity to share their experiences, and for having someone to listen to their experiences fully, without interrupting.

At some stages, I felt like an intruder in their lives, like a parachute researcher, going in and out, getting what I needed, and not leaving anything behind for them in return. This feeling was further exacerbated during the second follow-up interviews with them when I felt as though I knew mothers and their stories, and they knew very little about me. It seemed an unfair exchange of information.

During interviews, there were times I struggled since I had not had the experience of mothering and dealing with the difficulties my participants had to deal with, nor did I share any religious beliefs with my participants. That was where the interview schedule assisted me to some extent, as I could stick to the questions more or less, without satisfying my own curiosity. During the interviews and throughout the analysis, I started empathizing with the participants and the difficulties that they had experienced. Perhaps it is possible that this might have led to more exploration of certain experiences than others. Nonetheless, I tried to be aware of that and tried to focus not only on mothers' difficulties but also on the positives they experienced and described.

When mothers were sharing experiences and stories with me, occasionally I was concerned about the potential risk of power abuse within the study, stemming from my position as the interviewer, and about mothers being concerned about sharing as much information as possible, even if it made them uncomfortable. The mothers seemed very concerned with the type of information they shared with me – with some seemingly going beyond their comfort zones to share experiences with me. To try and minimize this, I continually discussed consent with the participants and explained that they could share only what they felt comfortable with (cf. Wagstaff et al., 2014) and that they could contact me at any stage to remove any information they no longer wanted to share. For this reason, it was important to my research supervisor and me to maintain the participants' anonymity and confidentiality as they shared sensitive material and experiences with me.

5.13. Conclusion

Chapter five discussed the research methodology used to explore the experiences of mothers raising an ASD child. This research study utilised a qualitative research approach, with an IPA methodology. It also provided discussions around the sampling and recruitment of participants, the collection of material through SSI schedules, how this material was managed and stored, and the steps followed during the analysis of the findings. The chapter also discussed the challenges which were faced and the changes which were made as a result of Covid-19. Furthermore, the ethical considerations, as well as the trustworthiness of this qualitative research, were considered. The chapter which follows covers the thematic findings of the study after following the methodology in this chapter.

Chapter Six: Thematic findings

6.1. Introduction

After I followed the four stages of IPA analysis detailed in chapter five, five superordinate themes were identified (table two). Each of these five themes will be discussed in turn.

Table two: Superordinate and subordinate themes

Superordinate themes:	Subordinate themes:
1. Learning their child has a condition or diagnosis	• Noticing possible problems or issues • Multiple consultations with medical professionals • Mothers' reactions to the diagnosis • Re-evaluating their child
2. Learning and sharing about ASD	• Access to information • Mothers' understanding of the cause of their child's ASD • Family understandings of the cause of ASD • Sharing knowledge of ASD with others • Sharing ASD diagnosis with their child • Mothers' understanding of their new ASD child
3. The mothering experience	• An all-encompassing role • Behaviours that mothers struggled with • Worried but hopeful for their child's future • Positive mothering experiences
4. Interventions and cost	• Schooling • Types of interventions • Importance of interventions • Intervention as costly – in both time & money
5. Supportive resources	• Sharing experiences with family and friends • Religion • Support groups • Self-care and facing reality • Avoidance of unsupportive environments

6.2. Superordinate Theme One: Learning their child has a condition or diagnosis

This superordinate theme is focused on the six participant mothers' experiences of the diagnostic journey for their children. It covers the initial concerns or difficulties that mothers had with their children that led them to seek help from medical professionals. For all mothers, this meant seeking help from multiple medical professionals before finally reaching a confirmed diagnosis of autism. This consultation of multiple medical professionals was, in certain of the cases, as a result of these mothers' uncertainty about the accuracy of the diagnosis or were as a result of medical professionals' unwillingness to diagnose ASD. Most mothers then described a process of trying to reconcile their layman understanding of autism, with what autism actually is, and what it meant for their child.

6.2.1. Subordinate theme: Noticing possible problems or issues

All six mothers had noticed behavioural issues or changes in their children. The most common behavioural issues reported by mothers were speech and language delays, possible hearing problems, and tantrums or stubbornness. Five mothers noticed these issues in their children between the ages of two and three years old, while the sixth mother noticed her child's difficulties from about six weeks old. Two of the six mothers described knowing that something was 'wrong' with their child, and attributed this to a mother's intuition and their prior mothering knowledge:

> *Extract 1:*
> one could always just tell that something is wrong with this child

> *Extract 2:*
> I think if [child] was our first child, we might not have noticed

This mothering intuition is a result of mothers being their children's primary caregiver and spending the most time with their child. This intuition can also be said to be based on and influenced by mothers comparing their children with their and other people's children, or with reference to childcare manuals that new mothers use and read like bibles. As a result of this knowledge, mothers developed an intuition or gut feeling that something was amiss with their child when they did not reach typical developmental milestones. For two mothers, the knowledge of these behavioural issues did not prevent the feeling of shock when their children's preschool teachers expressed their concerns regarding the behaviours of their children. The shock was a result of the perception that a trained professional had noticed these problems. Neither mother could ignore their child's issues any longer, for example:

> *Extract 3:*
> she [teacher] wasn't just a nursery school teacher, I mean her actual occupation was an OT, so I knew that she knew what she was talking about

For both mothers, hearing that their child's teacher had concerns regarding their behaviour, meant that they could no longer ascribe their child's problems to 'slow development' but that there was something more to it. This also spoke to the perception that a trained professional's knowledge is more important and accurate than a mother's intuition – mothers would rather take a professional's 'objective', i.e., outsider or expert, view than rely solely on their own subjective intuitions, experiences, and observations.

Both these mothers had different emotional responses to others noticing problems:

> *Extract 4:*
> you think, have you not been doing enough? Uhm, we, we thought that we were helping [child] by doing extra things at home, but obviously, it's not helping.
>
> *Extract 5:*
> it was a bit of a relief probably that actually to have [schoolteacher] tell me that she wonders if there isn't more to this.

However, three other mothers felt that their concerns were ignored when raising their concerns regarding these behavioural issues. For two mothers, family or medical professionals ascribed their child's behaviour to slow development. The outcome of this was that these mothers felt that, even after multiple appointments with their children's paediatricians, they were not being listened to:

> *Extract 6:*
> when I physically wanted to harm the child, because I couldn't cope any longer, and I couldn't help [child], I couldn't help myself any longer, that we went back to the paediatrician again, and I said to him [paediatrician], now you sit here, and you listen to me. I will tell you what is wrong with my child.
>
> *Extract 7:*
> everybody was just looking at that [child's cuteness] and not hearing what I was saying.

From the above extracts, it can be seen that both mothers were frustrated with the doctors they had consulted with. The mothers had an intuitive sense that something was wrong with their child, yet this intuition was, on multiple occasions, dismissed by medical doctors. The dismissal of her concerns resulted in one of these mothers experiencing severe mental, emotional, and physical distress, which is indicated by her reference to nearly "landing up in a mental institution". She was suffering from sleep deprivation caused by the pure frustration of not knowing what was wrong with her child.

6.2.2. Subordinate theme: Multiple consultations with medical professionals

All but one mother had to consult with more than one type of medical professional before receiving a final diagnosis of autism for their child. The types of medical professionals that these mothers consulted with ranged from paediatricians, educational and clinical psychologists, general practitioners (GPs), occupational therapists (OTs), speech and language therapists (SLTs), and paediatric neurologists. The reasons why they consulted with multiple medical professionals varied. Two mothers felt as if their children were misdiagnosed, and sought a different opinion:

> *Extract 8:*
> I thought, no, this isn't, you know, this isn't the case. You know, one doesn't want to look at things like that as a parent sometimes.

> *Extract 9:*
> we thought ag man, this is a misdiagnosis, and the other thing was that the doctor was not a very pleasant person. He [paediatrician] was just dismissive.

In extract eight above, this mother rejected the first diagnosis of ADD or ADHD her child received, as she was wanting to see the best in her child. After this first diagnosis, her child was also diagnosed with oppositional defiant disorder, as well as ASD. These diagnoses were all rejected, however, as this mother felt intuitively that these were incorrect diagnoses for her child at the time. This includes the first time her child was diagnosed with ASD, which was about five years prior to her child's official diagnosis. The mother in extract nine felt that the diagnosis was incorrect as she had taken her child for their hearing to be tested and ended up with another diagnosis completely, which was received from a dismissive paediatrician. For two other mothers, who consulted multiple professionals after being given referrals by their doctors, it seemed that their medical professionals were unwilling to confirm the diagnosis of ASD:

> *Extract 10:*
> She [educational psychologist] can't tell you that [child] has autism. She needs everyone else's diagnoses, so that was something you not prepared for. You are hoping to get a definite diagnosis.

> *Extract 11:*
> He [paediatrician] said to us, I won't put a stamp on this diagnosis. You need to go to the [hospital] in [city in another province] and there they will give you the final diagnosis.

Another mother explained that, while her child's original paediatrician had not believed her concerns, or taken them seriously, she consulted another paediatrician who noticed her concerns immediately, giving her a sense of relief:

> *Extract 12:*
> he [paediatrician] looked at [child's] reaction and said uh, uh, this is not the reaction I am looking for. Do you, have you realized something? And I said I am glad you realized it too because everybody hasn't believed me when I say I've realized something is wrong.

It can be seen that these mothers consulted with, and were referred from medical professional to medical professional, in the search for a diagnosis, receiving little to no certainty and reassurance from these medical professionals regarding a clear diagnosis, prognosis, or treatment options. The mother in extracts 13 and 14 felt as if the doctor she consulted did not know her child well enough to diagnose them with ASD. The mother seemed to struggle to reconcile her concern with the professionalism and recognition that surrounds doctors:

> *Extract 13:*
> it felt like such an informal session that we had with him [paediatric neurologist] but he is such a professional person as well, so one, the one side you feel like oh it's such an informal process he doesn't know [child] very well, but he is a recognized uhm professional. We didn't get a piece of paper to tell us that this is the diagnosis, so and we, all, we received all of it verbally

As she did not receive a physical piece of paper that confirmed her child's diagnosis, this mother felt that the diagnosis was not accurate because of the lack of proof. After receiving the autism diagnosis from the paediatric neurologist, this mother consulted with another medical professional several months later. She explained that this occupational therapist suggested that her child did not have ASD:

> *Extract 14:*
> that sort of gave me hope again, like [child] doesn't have autism, it might just be a sensory processing difficulty, but uhm, and [child] didn't even have a disorder, [child] had a difficulty

From this, it can be seen that this professional's choice of words in describing her child's difficulties gave this mother hope that her child did not have ASD. To the mother, the word 'difficulty' did not have as bad a connotation as 'disorder'.

Furthermore, two mothers questioned the accuracy of their children's diagnoses since neither mother could reconcile their child's behaviours and abilities with their expectations or understanding of their child's diagnosis:

> *Extract 15:*
> this is one thing that how shall I say made me think then there's nothing wrong, you know? You know, like you label these things as sort of wrong or something like that, because [child] has these abilities. You know, [child] is able to deduce things, [child] was talking to me about emotions when [child] was five. I say how the heck is this an autistic child. I didn't know there was a spectrum.
>
> *Extract 16:*
> our conversation was around [child] is able to do 1,2,3 and 4, [child] is able to 1,2,3, and 4, potty training and everything, fast, so why? We were still in denial, and then she [GP specialist in ASD] showed us why, how [child] was doing things, the arranging things, and all those things.

While two mothers did not doubt their child's diagnosis, it was their children's therapists (OT and psychologist) who doubted the accuracy of the diagnosis:

> *Extract 17:*
> she [OT] said to me she feels like we should get a second opinion, she didn't actually feel that this was the correct diagnosis, but uhm, ya we just took it in and decided we are going with it.
>
> *Extract 18:*
> even after the neurologist came back and said, yeah this is autism, she [psychologist] just didn't like it. I don't know, she's very close to [child], and I, I don't think she wanted to see anything sort of wrong.

The mother in extract 17, however, explained that she knew her child better than the OT who only saw her child for an hour every two weeks and that she, as the mother, could see that this ASD diagnosis was the correct diagnosis. This questioning of the diagnosis by mothers and professionals can be linked to denying the diagnosis in some way, as explained by the mother above in extract 18. By doubting and questioning the diagnosis, mothers are given hope that there is nothing wrong with their child; that their child is normal, and that a mistake has been made.

6.2.3. Subordinate theme: Mothers' reactions to the diagnosis

Mothers' reactions to their children's diagnoses were related to what knowledge they had of ASD prior to their child's diagnosis. Two mothers were not surprised at the diagnosis since they had already started suspecting ASD. The first of these two mothers acquired her knowledge from the paperwork during the diagnostic session with the clinical psychologist, prior research she had undertaken of ASD, and prior knowledge of ASD from her friend's child who had already been diagnosed. The other mother gained her knowledge through her research of ASD:

> *Extract 19:*
> I knew uhm something was, was going on … it really wasn't a big shock by the time that we got the actual diagnosis.

> *Extract 20:*
> when he [paediatric neurologist] said this child is autistic or had explained to us all of the other stuff, it just fell into place. We said ahh now we understand.

For the mother in extract 20, the diagnosis falling into place was also made easier by the fact that her child had suggested the diagnosis of ASD. Furthermore, after researching ASD herself and learning about the various co-morbidities that could accompany ASD, the multiple misdiagnoses her child received made more sense to her, and this lead to her feeling that this second ASD diagnosis was correct. On the other hand, four mothers experienced confusion at the diagnosis, since they had little to no knowledge of ASD, for example:

> *Extract 21:*
> I asked her, what is autism…and you know, when she [medical professional] said autism, I thought … maybe it has something to do with the audibility of the ears. I didn't know that it's a world on its own.

> *Extract 22:*
> you have no cooking clue what it means. What does it actually mean?

> *Extract 23:*
> you trying to even understand what autism is, and you've got all these uhm stereotypes in your mind, that you're to understand, and so ya, it was trying to come to terms with what it was, but trying to measure it and now knowing, not sure how to measure it.

These responses from the mothers indicate that, despite receiving a diagnosis from their medical professionals, what actually was wrong with their child was not adequately explained to them. It was just a label they knew nothing about. This lack of understanding could point to a lack of knowledge of ASD in general, in the public view. It is not a condition typically understood and known about unless one is directly affected. Furthermore, like the mother in extract 23 alluded to, the knowledge that many people have about ASD comes from popular films or series. The understanding of ASD from these films or series (such as being socially awkward, being sensitive to touch or noise, or being gifted in certain aspects) does not generally match up with mothers' experiences of their child's behaviours. For one mother, however, receiving the diagnosis was a positive experience as she described everything falling into place for her child and their family. Both this mother and another mother described the diagnosis as giving them a place to start gaining as much knowledge as possible to help their children:

> *Extract 24:*
> it does help because it's like putting something on a wall. Okay, I can start here. It's not like where do I start, what on earth do I do with this [child]?

> *Extract 25:*
> it helps too, to cope better knowing that there is a diagnosis and that you know that this is what it is, this is how you need to deal with it.

Two mothers, however, described a two-year period of adjustment to their children's diagnoses, before being able to start working through their child's diagnosis, for example:

> *Extract 26:*
> I was completely bewildered, what do I actually do with this child. You know, I've never dealt with an autistic child, how do I deal with this [child], and it's one thing reading it, hey, and it's another thing putting into practice.

> *Extract 27:*
> it's like getting a diagnosis that you've got cancer. Oh my god, what do I do now? It's not anything that I know about.

> *Extract 28:*
> although you work with it, and you work with, you know what it is. But to actually emotionally let it settle and mellow out and not become such a shock to the system, it took me roughly about two years of nightmares. Dream. Actual dreams. Waking up in the morning and having that 'I had a dream' and it's like oh shit, it's not a dream, it's real.

The mothers in extracts 27 and 28 both use metaphors to describe their reactions to their children's diagnosis. Their reactions can be described as reactions of shock and catastrophic thinking in imagining the worst-case scenarios for their children. This two-year adjustment period could be thought of as a denial phase, where one mother wished for the cancer to go into remission and the other wished for the nightmare to stop. For the mother in extract 28, her dreams acted as a silent hope that her child would be different the next day.

6.2.4. Subordinate theme: Re-evaluating their child

For four of the six mothers, receiving the autism diagnosis meant re-evaluating their children, and who they thought their child was before they could start learning how to help their child:

> *Extract 29:*
> when the diagnosis comes through and you hear that it's autism or anything like that, and it's never curable, and your child would never be the same as any of the others, you have to re-evaluate your own perceptions of your child, and your own hopes and dreams for the child.
>
> *Extract 30:*
> it was like a mourning process … child is uh, [child] died, the person you knew, the hopes and the dreams and everything have now died. It's not going to be like you thought it would be. This is a completely different person that you are getting to know now.
>
> *Extract 31:*
> the pain of having this expectation, my, my [other child] was, I was not comparing them, but I was …
>
> *Extract 32:*
> it's like you have to learn to relate to an alien something, you know what I mean? Because it's so not neurotypical.

Three mothers described a mourning process – losing the child they thought they had for this unknown, new, foreign child, an 'alien' child as the mother in extract 32 termed it. Mothers had to learn to relate to an entirely new person, a person who now had this diagnosis and label, but also relating to the connotations that came with the diagnosis. One of these mothers described a stage post-diagnosis where she wished she could make her child normal again, presumably in an attempt to hold on to the child she had thought she had, her expected child:

> *Extract 33:*
> after we got that diagnosis, I would have given anything. I would have sold my house, my car, my kids, I would have sold anything that I could to find a magic miracle cure.

Furthermore, as another attempt to hold onto their expected child, two mothers described a kind of "ignoring" of the diagnosis, hoping that it would disappear if they did not acknowledge it:

> *Extract 34:*
> me saying autism, it was like I was embracing it, and saying you are going to be a part of us. I wanted it to go away. I wanted it to go away, so I couldn't embrace it.
>
> *Extract 35:*
> I never denied that [child] was autistic or different. It was simply a fact of I don't want to. Leave me, leave me. I don't want to know about it. I don't want to know. I just, but it wasn't denial. I knew [child] was different. It was just not now, please not now.

6.3. Superordinate Theme Two: Learning and sharing about ASD

This superordinate theme discusses how, after receiving their children's diagnosis, mothers made sense of the diagnosis. After mothers learned about ASD, they had a better understanding of what ASD was, what it meant for their child, as well as the possible causes of their child's condition. Further, while most mothers were willing and happy to share information about ASD with others, mothers had different thoughts on sharing the diagnosis with their child.

6.3.1. Subordinate theme: Access to information

As discussed in the theme above, most mothers seemed to have little or no knowledge of ASD, prior to the diagnosis of their child. Mothers learned about ASD through workshops, researching and reading, through courses, and through their own experiences of raising their child. It seemed as if the time period in which the children were diagnosed made a difference in accessing information about ASD. For four mothers, information, and workshops about ASD was easily accessible, while for another mother, information about her child's diagnosis was not as simple, because internet research or connecting with other parents was difficult:

> *Extract 36:*
> there's no internet because it's years ago, [many] years ago. We didn't have internet; we didn't have Google. I didn't even have a cell phone to look things up with, so you have to phone people.

> *Extract 37:*
> we found it scary as a family because no one else knew anything about this.

This mother described phoning and gathering information from mothers and others knowledgeable about ASD from across South Africa. She explained how some people's explanations of ASD or answers to questions she had, did not make sense, which resulted in more phone calls to others to clarify matters. However, in the end, this mother was able to gather the information she needed about her child's diagnosis as she needed it over time.

After understanding more about ASD and looking back on their own experiences, three mothers described how they experienced the length of time it took for their children to be diagnosed. One mother described her frustration at the length of time it took for medical professionals to diagnose her child; time that was valuable which they had lost while trying to reach the diagnosis:

> *Extract 38:*
> they say it's not possible to give a diagnosis early for autism. Which I find is not true at all because you can diagnose as soon as two years … I think they could have, they didn't want to, and they didn't listen to me as a mom.

From the above extract, it can be seen how medical professionals ignored this mother's intuition that something was wrong. This then resulted in a delayed diagnosis and delayed or shortened intervention time. On the other hand, another mother believed that the diagnosis happened at the right time. If it had happened earlier, they might not have received the correct diagnosis, and her child might have been diagnosed incorrectly with delayed milestones. For another mother, the length it took for her child's medical professionals to reach the ASD diagnosis, helped her and her family with accepting and processing the diagnosis. These thoughts and experiences refer to the idea of 'readiness' for a diagnosis – some mothers are desperate and want or need a diagnosis to understand and help themselves and their children. Conversely, others are not ready to accept a diagnosis yet, so the time taken to diagnose helps them with acceptance.

After accessing information and learning about ASD, two mothers described regrets they had about the way they had parented their child. Both felt as if they could have been better parents and raised their children differently than they did. These regrets point to overarching societal expectations of what it means to be a good mother. For example, reading parenting books that explain the best way to raise a child, and the types of things a parent should and should not be doing. This knowledge resulted in one mother feeling like she was not a good mother:

> *Extract 39:*
> I still think oh my God, I can't believe I did this to this child. You know, I don't think I'm the world's greatest mother either. But you know, I now understand, I'm doing my best. Even at that time, I was doing my best. Even though it wasn't good enough.

However, this mother explains that she was doing the best she could at the time, considering her circumstances. This mother had to deal with her child's diagnosis amongst a myriad of other issues, such as looking after other children, dealing with her own health and self-care, dealing with grief and loss, dealing with employment expectations, and running a household, to mention a few.

Caring for her special needs child was just one of the responsibilities this mother had. She was doing her best with the information and resources she had available to her. Each medical professional she had consulted had different advice and a different diagnosis. In the end, this mother resorted to reliance on her intuition on what to do with her child – even though regretting this years later – at the time it was how she coped and dealt with her child.

6.3.2. Subordinate theme: Mothers' understanding of the cause of their child's ASD

Post-diagnosis, it is understandable that mothers would want to understand what caused their child's ASD. All the mothers described and hypothesized about more than one possible cause for their child's condition during interviews, with most explaining that they did not know for certain what the cause was, but that there were several ideas they ascribed the condition to or thought the condition was caused by. These possible causes were a result of the research that mothers had done, as well as their own thoughts and beliefs about what made sense to them. Mothers' understandings and thoughts on the aetiology of their child's ASD shifted over time, or they held multiple understandings, struggling to decide between them what they should do. The most commonly discussed possible causes included self-blame, divine power, genetics, and the environment. Three mothers discussed how for a short time after their child's diagnosis, they blamed themselves for their child's ASD because of issues they had experienced during their pregnancy. Examples of this self-blame included having an x-ray during pregnancy, having an epidural during labour, and having a blood clot during pregnancy. However, all three mothers dismissed this initial self-blame and had different understandings of what had caused their child's ASD. The mother in extract 40, however, described how she did not blame herself for her child's ASD in any way:

> *Extract 40:*
> if my [other child] isn't autistic, why would [child] be then? So, it wasn't something we did, and we understood that.

This mother explained that she knew she did nothing wrong during the pregnancy and had raised another child who did not have the condition, so there was nothing she had done as a parent that could have caused her child's ASD. The mother in extract 41, on the other hand, also considering her other child, seemed baffled that both her children struggled with the same things – learning, speech, and sensory difficulties – but only one of her children developed ASD:

> *Extract 41:*
> you think, why did [other child] also have problems, and [other child's] not autistic, but [child's] got autism and you're always trying to uhm figure out where it started, why it started, why does [child] have it, why doesn't [other child] have it?

The second cause discussed by mothers was that their child was given to them by a divine power. Half of the mothers considered that God was involved in their child having ASD, for example:

> *Extract 42:*
> I know [child] is a gift. In fact, there are instances where I say, this child is greatly placed with me because [with my current job] I am able to support [my child].

> *Extract 43:*
> between my two children, I had many, many health issues … and uhm to me, you know, just being pregnant again was such a gift, and carrying that baby full term was another gift, and then uhm having such a special child, and I feel to say … is really a special child and not a special needs child, [child] really is unique and [child] is so special to me.

While these mothers articulate positive understandings of their child's ASD as divine intervention, there was also a counter-position expressed, about why God had not protected her child from ASD:

> *Extract 44:*
> we believe He [God] can protect us, so why didn't He protect [child], uhm, and what went wrong, what didn't we do?

This extract speaks to an idea of punishment – that they as a family had failed to do something right. This mother, however, further explained that she believed that her child's autism was a plan by the divine to get their family to return to faith.

Two mothers described how they did not believe in any traditional or cultural beliefs regarding their child's ASD:

> *Extract 45:*
> with the ancestors' things, I do not believe that they were out to punish me. I don't see any reason why my grandparents, my great grandparents, and my parents would punish me

> *Extract 46:*
> maybe wrong to say that they, they, they believe that they're that the traditional rituals can cure their children. Maybe that was the only chance they thought they had, whereas, for me, I knew I had other options

Like the mother in extract 46 explained, both mothers had other options to consider and had access to more or other knowledge sources, other than traditional explanations. The third potential cause discussed by mothers was genetics and the environment. Four mothers looked at the possibility of their children's disorder being genetically inherited.

However, one of the four mothers was very careful to explain that her child's ASD was a part of her child's own individual genetic difference, and not a genetic anomaly within the family, thus avoiding any potential blame. However, three mothers made a direct link between their children's diagnosis and themselves, indicating a genetic transference component:

> *Extract 47:*
> if you have an autistic child, go, and have a look. There's depression somewhere, there's bipolar somewhere, there's this kind of thing, ADD or whatever down the line. Now [child's] dad I believe was decidedly [clinical diagnosis], okay. And I, I've been suffering from depression for as long as I know. Okay, and my current psychiatrist said that I'm on the [clinical diagnosis]

> *Extract 48:*
> I even say some of the, of the things that [child] does, of the traits that [child] has, [child] has taken them from me

> *Extract 49:*
> I still do believe my husband has it. I have it. I don't want to lie. To a certain extent. We do have autism and then it manifests more in our children or our progeny.

This linking of their child's behaviours to their own could allow mothers to feel more connected to their child and would allow them to understand their child better when thinking of and understanding the ASD behaviours as being similar to their own traits and behaviours. However, while the above mothers saw this genetic transference in a positive way, the mother in extract 50 viewed ASD as a possible genetic mutation:

> *Extract 50:*
> I thought maybe this is genetics working its way and trying to show us that even when we are people of certain levels should not marry together, they shouldn't ya, they shouldn't have, have, uh, what do you call, the genetic material of movement together.

Following this explanation or understanding by this mother, applying it to herself means that her husband and herself caused her child's ASD as they were too genetically similar with similar intellectual characteristics, thus perhaps blaming themselves for causing their child's ASD. However, this mother did not explain what this thinking meant for herself and her child.

The fourth cause discussed by several mothers was related to the environment, but not in isolation – rather as an interplay between genetics and the environment:

> *Extract 51:*
> I think it's that, maybe a bit of genetics, but definitely the environmental. You know, what's happening around you like I told you, I think [child] would have been a difficult child anyway. But when [life-altering event in household happened]; it just threw [child] over the edge.

> *Extract 52:*
> did [child] already have the condition, genetically predisposed to it, but then was, and then the environmental factors bring it up?

> *Extract 53:*
> because [child] was on one after another antibiotic, that [child] system was compromised in some way and that was the trigger for the autism to start.

By referring to a 'trigger' for the ASD to start, it is implied therefore that this mother's child was also predisposed to ASD, and that it started because of the trigger; implying that if there never was a trigger, her child's compromised immune system, maybe her child would never have developed ASD. This mother describes relying on her 'gut' feeling, referring again to a mother's intuition that this is what might have caused her child's ASD to start or develop. Not being able to pinpoint an exact cause for ASD resulted in the mother in extract 54 being unwilling to have another child after having given birth to her autistic child, as she was worried that her next child might also have ASD, and she would not want to repeat this difficult mothering experience:

> *Extract 54:*
> I'm not going to have any child after [child] because I was just wondering what if you know, and

> I wouldn't want to go through that again, ever, ever, and I wouldn't want to wish it upon my worst enemy

As can be seen above, mothers had varying and multiple theories for what caused their child's ASD. Since there is no confirmed cause for ASD, mothers seemed to search and try their best to understand the cause according to what made sense for them, as to why their child would have developed ASD.

Over time, these accounts and understandings varied as new information, and more research and reading were done by the mothers, their families, and medical professionals. Divergent views are speculating about whether ASD was 'given' versus what had been 'done or happened' to children and families; to cause ASD in families.

6.3.3. Subordinate theme: Family understandings of the cause of ASD

Three mothers discussed how there were different understandings amongst their extended family members of their child's ASD. This difference in understanding resulted in conflict about childcare and child development within families, households, and the extended family. This could be why mothers emphasized their focus on following their intuitions and gut feelings – as there could always be someone else in the family who thinks the mother could have done something differently or wrongly, to cause her child having ASD. These mothers explained that the extended family members denied the ASD diagnosis completely. The following extracts show the diverse understanding of the cause of ASD that extended kin families have:

> *Extract 55:*
> there are people that are in the family, they believe that family in ancestors, and they believe that [child] has a calling. There are family members in the family that are traditional doctors. So, they believe that this is part of [child's] journey.

> *Extract 56:*
> my aunts didn't understand. They thought that I was not disciplining [child]. Because [child] was always running around. My grandfather even said he wants to have a special switch made for [child] because [child] doesn't listen.

> *Extract 57:*
> in the back of my dad's head is you know like people make mistakes and that they have the wrong diagnosis all the time and that they did it with me, so I think it's gonna just take him a bit longer to get used to the idea.

> *Extract 58:*
> we [family members] would have seen it, you know, [child's] eyes would be skewed, [child's] head would be shaped somehow, you know, things like that. This one looks perfectly normal …when I told them that ah, ah this is too much, and now they understood that no child under normal circumstances in their good behaviour or whatever other could play with their poo or even touch it or whatever the case may be, that's when they saw ah, ah somethings wrong.

The mothers in extracts 55 and 56 demonstrated that even within their extended family there are multiple understandings of ASD. There is not just one understanding or perception that exists within families. However, even though extended family members had these ideas regarding mothers' children, which sometimes led to conflict within the family, two mothers explained that they no longer tried to convince their family members otherwise:

> *Extract 59:*
> this is my journey, my sister, my boyfriend, the paternal family members, it's their journey. They will understand this thing in their own way.
>
> *Extract 60:*
> I tried to persuade him [mother's dad] otherwise, and then I gave up, so I am now just trying to go with it.

These mothers explained that it was their family members' own journeys to understand ASD and that they would not spend their time trying to convince them, since people had their own beliefs and often had made sense of their situation already by themselves. It was not worthwhile expending energy to continue trying to convince them.

6.3.4. Subordinate theme: Sharing knowledge of ASD with others

After working and struggling through their child's diagnosis, mothers educated themselves as much as they could about their child's condition. After educating themselves and gaining an understanding of the condition their child had as a result of raising their children, mothers sought to share their understanding with others.

Five mothers described how they would like to increase knowledge about ASD in the public sphere, by willingly sharing information about ASD with others – should they be asked or given the opportunity to speak to others.

Since most mothers had had little to no knowledge of ASD prior to their child's diagnosis, they were eager to share information about ASD with others to create a general awareness of ASD and their experience. This could also be linked to wanting to make their child's transition into the public social sphere more effortless and to decrease the stigma surrounding ASD. They realized that the more people got to know about ASD, the more embracing and accepting society would, could, or might be towards it:

> *Extract 61:*
> so, what I do when a person is asking questions when in, I'm in a [retail shop] or what, I take the time to educate them. I use that time to educate and say [child] has autism; this is what it is.

> *Extract 62:*
> that's why when I finally understood what it actually is, I took it upon myself to say every person that I meet, I'll make sure that every colleague that I have, they know what autism is, and they understand because maybe someone somehow or maybe anybody can have an autistic child without knowing it.

6.3.5. Subordinate theme: Sharing ASD diagnosis with their child

While most mothers seemed eager about sharing their knowledge about ASD with others, some mothers struggled with sharing this information and knowledge with their child. The six mothers had different views on their child being aware of their diagnosis or sharing the diagnosis with them. Three of the six mother's children knew about their diagnosis, in some form or the other, for example:

> *Extract 63:*
> [child] knows, I have autism … I have autism and I'm living with it. I'm autistic, [child] will tell you that.

> *Extract 64:*
> [child] doesn't know the actual word for it like it's Asperger's or it's autism, but [child] does know that [child] has to take medication to help [child] focus better and to be able to get through a day.

These mothers explained that they shared their child's diagnosis with them in order for their child to understand themselves and their behaviours better. Extract 65 shows a mother contemplating what the right time and what the correct way is to tell her child about their condition:

> *Extract 65:*
> [child] doesn't know yet, and I, I have always wanted to Google it, to find out how to do it because I haven't come across, I haven't found someone, I don't think the time is right yet, it feels like it's coming, it's going to be soon. It's like that talk you've got to have with your children, the bees, and the, the birds and the bees. So uhm, I, I haven't had the time but I'm also like, it's going to happen at the right time, when it's supposed to happen.

Extract 65 refers to telling a child about their diagnosis as a rite of passage. This mother explains that this will influence how her child sees themselves in relation to their condition, and the way in which she explains it will shape how they see their condition. The manner in which her child is informed of their condition could determine if her child takes the news well or not. This mother described how she was worried that she would do it wrong, and, therefore, wanted to get more comfortable by acquiring knowledge and an understanding of ASD before telling her child about their diagnosis.

On the other hand, extracts 66 and 67 displayed decisions not to share the ASD diagnosis with their children:

> *Extract 66:*
> why do that to a child? You just mess with their brain.

Extract 67:
it's a name on a piece of paper with a doctor's signature on it. But it's not who [child] is. [child] is [child]. So why should [child] be autistic [child]. [child's] just [child]. So, [child] doesn't have to know [child] has autism unless it impacts or challenges [child] in daily life.

The mothers in extracts 66 and 67 decided against telling their children about their diagnosis – a diagnosis which they might then use to define and see themselves by. They see their child as normal and want their child to see themselves that way too, and not as autistic.

6.3.6. Subordinate theme: Mothers' understanding of their new ASD child

After learning about and understanding what ASD actually is and what it means for their child, mothers redefined their understandings of the word 'normal'. Four mothers emphasized that their children were their own kind of normal, a different kind of normal, but still normal:

Extract 68:
it's all about you are different my [child]. You are different and I hammer it in [child's] head. You are different, and you are not doing to what [friend] does, you're not going to do what [friend] does, what [friend] does, you're different.

Extract 69:
it is not something that is wrong with your child. It's just a different way of being.

Extract 70:
[child] is actually scarily normal. It's just the perception that because [child's] autistic, [child] should be different. And ya, [child] is different, but different, we are all different.

Extract 71:
I take autism for [child] as a challenge, and believe you me, [child] does a lot of normalcy. A lot of it. The challenges are small, they're small – interaction with other people, being able to form a normal conversation with another person, just striving to be understood. Isn't that what we are all striving for?

In extract 71 above, it can be seen how this mother compares her child's difficulties with social interaction to difficulties that any other person would have. In this way, the mother normalizes her child's difficulties with social interaction, much like the other mothers see their children's behaviours as a different kind of normal.

Three mothers understood ASD as another facet of their child's personality, after learning about ASD:

Extract 72:
[child] has autism versus that that is [child's] sole identity.

Extract 73:
[child] cannot be defined by one trait that is not even disabling [child].

> *Extract 74:*
> to me that's changing [child's] personality you know, is to take the autism away, you would change who [child] is, and I wouldn't want that.

While the mother in extract 74 describes not wanting to remove her child's ASD, the mother in extract 75 described a phase of wanting to 'fix' her child:

> *Extract 75:*
> it's hard to know where it's [child's personality] and where it's the autism. I still don't completely understand the idea of wanting to fix [child], uhm. It's a very hard one to explain because uhm, I think at this stage what I would love to have changed if I were to be able to ask for any miracle it would be for [child's] attention to come right.

Nevertheless, the initial thoughts of the mother in extract 75 changed when her understanding of an abundant life changed:

> *Extract 76:*
> we still believe that God wants you to have an abundant life, but I think our idea of abundant life was very different to what is it now.

6.4. Superordinate Theme Three: The mothering experience

This superordinate theme covers the all-encompassing role that mothers play in the raising of their ASD children, the difficulties that mothers have with some of their child's behaviours, their concerns and hopes regarding their child's future, as well as the positive impacts that their child's diagnosis had on them. Mothers described their all-encompassing role as focusing almost exclusively on their ASD child, to the detriment of their own health, and their relationship with their other children. The all-encompassing mothering role seemed to fall to mothers mostly, with fathers seeming to take an inactive role.

This can be linked to societal thoughts on traditional gender roles regarding childcare. Some mothers also explained that their caring role helped them in finding their passion in terms of their career, while for another mother, it resulted in changes to their career. All six mothers in this research were their children's primary caregivers as well as held full-time positions of employment. Most of the mothers in the current study reported sharing some childcare responsibilities with domestic workers after their children had returned from school.

6.4.1. Subordinate theme: An all-encompassing mothering role

Two mothers mentioned the all-encompassing role of mothering an autistic child, illustrated by the following extract:

> *Extract 77:*
> It takes your emotional being, it takes your mental being, it takes your intellectual being, to actually understand this particular human being standing in front of you, and what [child] wants or what [child] doesn't want or what is going on in their mind. You do the thinking, you do the talking, you do the walking, you do everything for that particular person, so much that you even forget about yourself for a moment.

It can be thought of as this mother, and the other mothers, living double lives – one for herself, and one for her child; where her child's life takes precedence over her own. A mother explained that there was a shift in worries and responsibilities post-diagnosis – a shift from mother to child. To illustrate: focus now fell on concentrating on their child's health, wellbeing, and their futures, and no longer fell on their own emotional and physical needs. Mothers described this mothering role as taking up a large part of their lives, resulting in little time for themselves, their own health, and their own wellbeing, amongst other responsibilities such as their career, other children, and partners, as well as other household responsibilities.

While most mothers had residential husbands to share the childcare responsibility with, amongst other responsibilities, mothers still did most of the childcare:

> *Extract 78:*
> he's [husband] not going to go do research about it but he, he's uhm very open to what I tell him you know, and he relies on me to kind of get the information and relay that information to him … I have kind of taken, taken charge in a sense you know of what needs to get done.
>
> *Extract 79:*
> it's just my husband and myself who have to deal with this, and mainly me, because I can't frustrate him too much too you know.
>
> *Extract 80:*
> I have to recommend [to husband] why don't you do this, why don't you do that. Uhm, I want you to do [child's] homework uhm every day please because I taught [child]. I want you to take [child] on the farm now and let [child] spend time with you. I want [child] to lie next to you in the morning. I want [child] to uhm, I want you to do Bible with [child] every night

From the extracts above, it can be seen how their child's primary care was left to mothers, with fathers taking a 'backseat' role. This could be due to traditional ideologies and beliefs regarding gender roles that are present within society – that women or mothers do the childcare and housework in their primary caregiver role, while men or fathers provide for the family, financially. Mothers seem to take on the role of caring for their children, feeding them, entertaining them, bathing them, doing homework, and managing their play behaviours, which can be considered to be normal caring behaviours for children. However, these 'normal' childcare activities are done in conjunction with the requirements of special needs care, such as special education, various forms of therapy, and management of their behaviours. This caring role is therefore not 'just childcare' but includes additional aspects of caring for a special needs child.

Since most of the mothers interviewed assumed that mothers take on the primary caring role with their children, extract 81 explores a mother's reasoning for this gendered division of care work, and she questions what her husband understands about ASD:

> *Extract 81:*
> I tend to be a bit more patient and wait and hear what [child] has got to say and I actually understand [child] better than [husband] does, but also [husband] sees through [child's manipulative behaviours] sometimes what I don't see.

This difference in understanding could be due to the difference in time that this mother, as primary caregiver, and her husband spend with their child. As the mother spends more time with her child, it could be suggested that she might have more understanding and patience with her child's behaviours than her husband. However, she also questions how much of her child's manipulation she actually notices, indirectly questioning her own ability as a mother. While mothers took on the majority of their child's care, mothers also emphasized the importance of having or choosing the right caregiver or nanny to help mothers care for their child in the home:

> *Extract 82:*
> As a parent of a child with a disability or with autism in this case, yoh, you have to have a person that loves the child, doesn't matter whether the person cannot clean or whatever, or the problems, but need to love the child and understand the child … there are times when I feel yoh, I don't want to be around [child] sometimes, I want to go away, and imagine, if I want to go away how much more about this one that is going to be left with my [child], you know, so it has to be that kind of a person who is patient, very patient

> *Extract 83:*
> I do have to try and get her [the nanny] to realize that she mustn't do everything for [child] you know, I, I, I'm also trying to help her see that uhm she mustn't take over the role of whatever, she must let [child] do things for [themselves]. Because she's so loving in that sense that she wants to help, and she wants to be available, so she does tend to just do things for [child]

> *Extract 84:*
> the nanny that [child] was with is also, she's also, we trusted her, but she's also not a very good communicator. She's not a very playful nanny, she cared for them, but she wasn't the ideal nanny to have raise a child who's two years' old

These mothers refer to an 'ideal' nanny, a mother substitute for when they themselves are not home, and who should have certain characteristics. From this, it is seen that there is a hierarchy of care that occurs in the home – mothers are primary caregivers but are assisted by other motherly figures to help them in their caring role. When mothers are not available to care for their child (if they are at work or are attending to other children, or other household responsibilities, for example), a mother substitute stands in for the mothers in the form of caregivers or nannies. This all-encompassing mothering role extended to the time mothers spent with their other children. Mothers were so fully involved in their ASD child's life that their other children seemed to have suffered for a brief time as a result:

> *Extract 85:*
> it's easy if your whole life goes around this one child, which is difficult for the other children. You know? Because poor [other child]. [other child] feels like [other child's] the good child and all the attention goes to the other one.
>
> *Extract 86:*
> I was so busy with [child], everything sort of revolved around [child] as well, that I didn't forget about [other child] but disconnected from [other child].
>
> *Extract 87:*
> I think [other child's] had to deal with, [other child] had to become more independent at an earlier age so that I could be more available to my younger child, you know, so I feel in a sense you know the siblings uhm suffer a lot as well, is that [other child] really had to knuckle down and just had to get on with life you know and had to do things [themselves] so that I could be there for [their sibling].

These three mothers describe how their ASD child took all their attention, resulting in their other children feeling neglected. Their other children had to learn to care for themselves during those times and to find a way to cope. However, all three mothers explained that once they had realized what was happening and how their other children were feeling and how they were affected, they started to spend more time with their other children. Two mothers whose other children were several years older than their child with ASD did not describe their concerns regarding the time difference spent between their various children.

Since mothers were and are so focused on their ASD child, it is understandable that their careers were also affected. Two mothers described how their child's diagnosis affected their finances:

> *Extract 88:*
> I stopped working when [child] was diagnosed. I said my husband can't cope with this, working and going to therapy once a week, and still with the kids and fetching and carting them from school, so I had to give up my job at that stage. Maybe it was a bit of a fight between my husband and myself because I felt I needed to be here, he [my husband] felt I needed the income.
>
> *Extract 89:*
> If [child's] expenses are 6000 per month, I pay three, and [child's father] pays three. And that was also the case with the [other child]. So now I have to always do something to supplement the salary because the uhm as a [career], you don't you don't earn much as [career]… so I have to always do something to supplement the money, so I am a [job], I am a [job], I have started this [job], in [rural town], what is the other thing, I do [job].

However, for the mothers in extracts 90 and 91, their child's diagnosis meant finding their passion, by aligning their new interests and skills, learned from their experiences with their ASD child, and being able to help others:

> *Extract 90:*
> [child's] diagnosis was also I think a huge, it played a huge role in my decision to become an [educator]

> *Extract 91:*
> I had a bad supporting experience the first time around which is possibly why I do my job today because this is what I want to do; help other people cope with what we did not cope with when my [child] was diagnosed

Extract 92 explores a mother downscaling her professional career to facilitate a better work/life balance, and spend more time with her child and family:

> *Extract 92:*
> I asked if I could move down to [job-downscaling as an educator], and I know being demoted isn't what you want in your career but I just I uhm I felt like it was the right thing to do and I don't have the [prep work] and stuff, and so I have been a different parent this year. I feel so at peace because I feel like I have placed my kids first.

6.4.2. Subordinate theme: Behaviours that mothers struggled with

As part of their caring role, most mothers described dealing with some difficult, hurtful, and frustrating situations and behaviours. Four mothers described some frustration and hurt at their children's communication:

> *Extract 93:*
> we often have to who, what, when, and how, to help [child] explain to us what [child] is talking about, and that causes a lot of frustration in communication.

> *Extract 94:*
> [child] would just wail for no reason and I would want to understand [child] what's the problem and [child] would not be able to tell me.

> *Extract 95:*
> [child] is unable to sugar coat things, [child] will tell you [mom] you are looking clumsy today, [child's] just like that. The comments just come sharp, [child] doesn't care, [child] doesn't know how to put it nicely.

> *Extract 96:*
> [child will] say things so matter of factly, sometimes I'm like how can you say that? That's so insensitive you know.

Other than communication issues, two mothers described difficulties with their children's crying and screaming, for example:

> *Extract 97:*
> [child] would just cry for no reason at times, when [child] has anxiety.
>
> *Extract 98:*
> [Child] was impossible from my perspective then. You know, we didn't know what to do with [child]. [Child] was having what I later understood to be meltdowns that were seemingly, seemingly unjustified, you know, I saw them as tantrums. I didn't know about meltdowns and stuff like that.
>
> *Extract 99:*
> I used to say to [child] for goodness' sake, stop it. I didn't know then. I said stop it. I can't stand you screaming like this, I'm going to leave because it was triggering me something terrible you know. Yeah. Poor child. I guess sometimes, let me tell you, very honestly, I used to sometimes get into the car with my younger [child] and just disappear for an hour because I couldn't cope with it you know… I only realized later that [child] actually needed me in those times more than what [child] needed me at any other times, you know, [child] needed me to be there. So, I'd brace myself and sit with [child], and sometimes I was okay. But other times I would lose it deluxe within an hour because it rattled me so much.

From the above extracts, it can be seen that mothers described their children's problems with emotional regulation. The mother in extracts 98 and 99 described how her understanding of her child's "meltdowns" changed once she learned about her child's diagnosis, and as she came to learn of the problems typically associated with ASD children and their emotional regulation. The mothers mentioned very extreme situations and behaviours that drew public attention, and which put children at risk, and these were traumatic for mothers to deal with. These examples included a child running away following an argument; and allegations of child abuse after neighbours heard a child shouting and screaming. These problems could be linked to ASD children having trouble with emotional regulation and managing conflict.

A further difficulty half of the mothers described struggling with was their children harming others:

> *Extract 100:*
> then they came running in a little while later, [other child] was hysterical. No, [child] tried to drown [other child].
>
> *Extract 101:*
> the one day [other child] could be tickling [child] and [child] will laugh but the next day [child] will get so upset and [child] will actually bite or slap or you know do something completely out of the normal that we never suspected or expected to happen.
>
> *Extract 102:*
> at school [child] would harm other learners, then it would be so, so serious to an extent that I couldn't just let it be. I would have to go and visit the parent in person and … explain to the parent that you know [child] is different and the parent would understand, but I will take it upon me to go personally. Because somethings it will be something very visible, [child] would bite, and then it would be something very visible.

Two mothers described how their own sleeping habits, but also those of their families were disrupted as a result of their child's issues with sleeping:

> *Extract 103:*
> [child] was going nana at one stage, I mean [child] was keeping us awake at night. [child] was keeping [other child] awake at night, poor [other child] couldn't function, [other child's] marks dropped, and I don't know what. We soundproofed [child's] room, and it still didn't help

> *Extract 104:*
> [child] used to go to sleep at minimum two o'clock in the morning and wake up before five in the morning. So, one of us, mainly me had to be awake with [child]

In extract 104, it can be seen how this mother took on the role of caregiving for her child's night-time. This can be linked to the traditional roles assigned to mothers and women – mothers sacrificing their sleep, for example, so that their husbands or partners may sleep and be fresh for work the next day.

Other difficulties that mothers struggled with and mentioned included that their child did not share their toys with friends, violent behaviours such as kicking holes in doors, displaying suicidal tendencies, anger management, lack of independence, repetitive behaviours, and greeting everyone in public.

6.4.3. Subordinate theme: Worried, but hopeful, for their child's future

Since mothers' care for their children themselves, they know what their child's specific difficulties are, which resulted in concern and worry about their child's future. However, some of their children's behaviours also gave them hope. All six mothers described their worrying, but also expressed some sort of hope regarding their child's future. These concerns regarding their children's future were focused on Western developmental outcomes for maturity and autonomy, forming a relationship and having a family, and having a productive job.

Four mothers described a worry regarding the relationships that their children would form with future partners, and were concerned if their children would be able to build and sustain these relationships:

> *Extract 105:*
> the one concern that I used to have was if [child] would find a partner and would [child] be able to adapt, to like being so close to someone you know that sort of thing …

> *Extract 106:*
> I have [other child] that has this diagnosis, I have a [child] that may not live a normal life, and I'm this person who may not even have grandchildren … and as far as I know [child] may not even have a [partner].

> *Extract 107:*
> what we want is to get [child] out of this sheltering and expose [child] to disappointment so that … we can be correcting how [child] handles disappointment you see, to see that I can have a [partner], the [partner] can dump me and I don't have to kill myself or run away.

> *Extract 108:*
> maybe I will never have grandchildren from [child], you know, that sort of thing. [child] will never get married, [child] will never have a [partner], not that I'm saying it won't ever happen …

In terms of their children's future career prospects, most mothers thought that their child would be fine in the working world, as long as they were involved in their special interests and skills:

> *Extract 109:*
> When the time is right, the penny will drop. And [child] will do what [child] will do, I have complete faith in [child], you know. I have more faith in God because sometimes I'll look at this and think oh my God, I don't know what you are going to do with your life if you are playing games all the time. Then I say, okay, fine, let me sit back now.
>
> *Extract 110:*
> the future is a lot brighter because of technology and [child] is obsessed about becoming a cartoonist.
>
> *Extract 111:*
> it could be if you can be, [child] can be allowed to be [themselves], to a certain extent, and [child] learn the way [child] wants to learn, the way [child] is able to learn, and we capitalize on [child's] strengths, [child] can be a big thing. [child] can do, [child] can be an inventor of something.
>
> *Extract 112:*
> [child] left school [x] years ago now, if it weren't for the fact that [child] is skilled and that [child] can do something for [themselves], [child] would be sitting at home being hugely frustrated because [child] does not have anything. [child] would be bored. [child] would not be productive.

However, a mother in extract 113 was wary of her child's ability to handle conflict and work under pressure:

> *Extract 113:*
> there are times when I see autism as a disorder, simply because I see [child] as somebody whose gonna have to go into a sheltered, uhm, working environment you know, a sheltered working environment as in I don't think [child] can be able to handle of the pressures that we go through as normal people.

Two mothers mentioned specific concerns that they had about the future care of their child:

> *Extract 114:*
> the hopes and dreams are different, because obviously, I wanted [child] to have a completely different life, but [child] not going to have it, so the reality is [child] will be with us and I will look after [child], or [child] will look after me eventually, I don't know. [Child] will be with us until we can't one day look after [child] anymore.
>
> *Extract 115:*
> maybe even if [child] can be independent, maybe [child] will need to rent out the backroom but be on the premises where we can be able to help where we need to you know.

The mother in extract 116 was further concerned about her child's independence, and the impact this would have on her:

> *Extract 116:*
> a child is not a punishment where you, where a child hangs on you for the rest of your life. You want to one day you want to say I have done my bit; I have transferred values and I have raised [child] up, and it's [their] time to go and, and venture out there.

These worries and hopes regarding their children's futures can be said to be based on mothers' expectations of a normal developmental outcome for their child, and also for themselves. If either of these things (relationships and employment) fails, their child will be dependent on their mother for the rest of their life. The responsibilities of mothering then appear to be daunting and without respite.

6.4.4. Subordinate theme: Positive mothering experiences

While most mothers spoke of the difficulties they had with their children, some mothers spoke of the personal growth they had experienced as a result of their ASD child:

> *Extract 117:*
> it's been a tremendous thing. It showed me who I am, what my sort of problems and abilities are, and that kind of thing. I've grown tremendously. I won't swap that child for anybody.

> *Extract 118:*
> I'm grateful for what I have learned through the autism because I'm, as a [educator], definitely, I have more compassion and I've learned a lot and I feel like I'm more equipped to help other parents because and not as someone that's gonna give the solution but uhm to help to be a resource like the therapist or the doctor, playing some small role that uhm made the journey, that makes the journey easier.

Mothers also described their deep love and appreciation for their children, exactly as they are:

> *Extract 119:*
> as [child] was growing older and I learned to manage [them] and learned to love [them] for who [child] is, and that's another thing. You've got to start loving the child you've got, not loving the idea. So, once I started changing inside myself, I was like ag no man what are people talking about, I don't want to cure my child. I want [child] just like [child] is now … I'm so happy with who [child] is now

> *Extract 120:*
> having such a special child and I feel to say really a special child and not a special needs child, [child] really is unique and [child] is special to me. That was such a blessing, [child] is very, very close to my heart.

> *Extract 121:*
> It doesn't matter how, how uhm unbearable, the world can be to you. Your child can actually be your everything. And, and it matters. It matters the most, to see your child through more than what anybody else can say. And whatever anybody says to you, it can never amount to the love

The mother in extract 122 described a mind-shift she experienced when dealing with her child, and their difficulties:

> *Extract 122:*
> This statement isn't that your child is giving you trouble. Your child is having trouble. You know what I mean? That's a major mind switch you know that kind of also just dropped when I read it.

This shift in view resulted in the different way in which this mother approached her child and their difficulties. Her increased understanding of ASD allowed her to make this shift in the understanding of giving trouble versus having trouble.

6.5. Superordinate Theme Four: Interventions and cost

This superordinate theme discusses the various interventions that mothers tried with their high functioning autistic children. This theme includes schooling as an intervention. Their children attended either mainstream schooling, special needs schooling, or online schooling, depending on what was best suited for their child. These various schooling options and the resultant experiences will be discussed here. Mothers used and tried multiple treatments or interventions for their children – psychiatric medication, therapy, "OTC", and lifestyle interventions. This could be because mothers are willing to try anything to help their children. Naturally, all these interventions come at a cost – both monetary and timewise. Some mothers stated that they had medical aid cover for their expenses, while others had to pay out of their pockets. However, in the end, the mothers agreed that the expenses were worth it as it was for their child's benefit and for their child's health and wellbeing.

6.5.1. Subordinate theme: Schooling

Mothers had different experiences of finding appropriate schooling for their children. When it came to special needs schooling, three mothers explained their reservations against this type of schooling. These mothers instead saw mainstream schooling as the best option for their child. While three mothers were concerned about the possible regression effects of a special needs school for their child, the fourth mother in extract 126 experienced this regression:

> *Extract 123:*
> In a mainstream environment, [child] is copying typical behaviour, normal behaviour. However, there [in a special needs school] [child] will come back with grunts and everything.
>
> *Extract 124:*
> [child] definitely does copy others, you know, so ya, I, I could rather see [child] being in a mainstream school where [child] would rather copy uhm children without disabilities whereas ya, and, and, and being pushed academically.
>
> *Extract 125:*
> I also just felt like socially, I would want [child] to be exposed to more social uh a more normal social environment, so that [child] would be pushed to [child's] limits

> *Extract 126:*
> Now [child's] language was not developing very well, just not progressing. And [child] had gone back, you know, they were still some children who still were not potty trained in the school, and [child] was trying to emulate everything that they're doing. So, we ended up taking it upon ourselves now to look for another school now that will serve [child's] needs

All of the mothers' children have high-functioning autism, and the mothers in extracts 123, 124, and 125 were eager for their children to 'pass for normal' within mainstream schooling systems. This can be thought of as mothers needing or expecting their child to 'fit in' with societal and developmental norms. It can be seen as an attempt to make the diagnosis more acceptable for them and others – that their child can go to a normal school, and that they can be seen as a normal family – like others in their communities. The mother in extract 127 referred to this idea of the negative connotations of a special needs school extending to herself as the mother:

> *Extract 127:*
> thinking of a special school you also have this connotation and it's dreadful, it's one of those dreaded things that her child has to go to a special school

Everyone would then know that her child is not 'normal' and requires extra help from trained professionals within these special schools. She therefore felt as if she were on the outskirts of society and was pitied by others. However, once her child attended a normal mainstream school, these worries dissipated as this community judgement was no longer a possibility. A mother attributed her positive experience of her child's education to the fact that she is a teacher at her child's mainstream school and could communicate very easily with the school and her child's teachers. The mother in extract 128 also had a positive experience of her child's mainstream school as a result of the experience the school and its teachers had with other special needs children prior to her child attending the normal school:

> *Extract 128:*
> we are really blessed to have them you know, they are all amazing teachers, and they, they really listen you know to, to the parents' input as well, which I think is really important especially with special needs children.

However, for four out of the six mothers, finding the best school for their children was not simple or straightforward. These mothers' children attended multiple schools – private, public, and special needs schooling. Two of the four mothers resorted to home-, or online-schooling for their children as neither mainstream nor special needs schooling worked for their children or themselves. The children of these mothers attended a range of between two and eight schools, which ranged between mainstream, special needs, private and online schooling, before the right fit was found. There were multiple reasons why certain schools were not suitable for these mothers and their children:

> *Extract 129:*
> they were teaching our kids Makaton, and I was against it because my child is verbal. If you take [child] to Makaton, you are actually depriving [child] of the chance to improve [their] speech, which is what I would like, and they said no, no, no, no, if you don't want it, it means [child] doesn't belong here.

> *Extract 130:*
> we took [child] out of school, both of them actually, took them out of any kind of school. I had them in a public school, in a private school, and all sorts of things and they now doing online learning both of them. I was cautioned against that, but my gut feeling was this is the way to go. So, unfortunately, one of the problems is this, because of [child's] sensory processing issues, [child] finds it really difficult to listen to the voices.

> *Extract 131:*
> I have observed that [child's] not getting what, [child's] not getting the education [child] is supposed to be getting in a mainstream school because teachers are not, are not trained to work with children, with children with autism, therefore, I need to get a school that is going to be able to educate [child] the way, you know the concept that that, you, they should learn the way they want to learn, that they want to learn, so I was thinking that I should take [child] for homeschooling

In addition to the above, one of the main struggles that mothers had with schooling was the lack of understanding and knowledge at the school regarding their children's autism:

> *Extract 132:*
> they don't understand what autism is, so the moment you say autism, they go all 'uhh we don't deal with those kids, we not trained', and I mean it's the end of the story.

> *Extract 133:*
> when you try to raise it with other people, the first thing they would say was 'ha, you are saying your child can talk?', and I would say yes, [child] can talk, and 'you can have a conversation with your child?', yes, I can have a conversation with my child. And they would say 'now what are you doing here', you know. It was devastating to get that, and you would get that from the teachers, you would get that from the parents.

> *Extract 134:*
> I was feeling sorry for the lady for the attack [child was physically restrained by teacher and child started physically attacking the teacher when they saw their mother], but I was also angry at the way that she handled [child] because uh in most cases, schools would say no, we have two, three children with autism here and we work very well with them but now you find that they do not know the basics.

From the above extracts, it can be seen that the mothers' children were 'othered' as 'different', in both mainstream schooling and special needs schooling. As a result of the lack of knowledge and understanding regarding ASD in multiple schools visited by the mother in extract 135, she explained how she had to tell a white lie in order to get her child into a pre-primary school:

> *Extract 135:*
> we said [child] is not a behavioural problem, not much, we embellished a little bit, okay, but we needed to get [child] into a school. So, as parents, we proposed the better side of [child], ha-ha, little lie, little lie, but we got [child] in there. They did a test with [child], and [teacher] screened

> [child], and then [child] went there for 2 and a half years. [child] was 7 when [child] went, eventually went to [special education needs] school. And then from [special education needs] school, [child] was in there for 8 years

Telling this white lie illustrates how desperate this mother was to find a school that would accommodate her child. Previous schools she had consulted with either had long waiting lists, or her child did not fit into the school, or they would not accept her child as they did not know much about ASD. Telling this white lie allowed this mother's child to get accepted into this school, which allowed for her child's subsequent acceptance and completion of high schooling, and the creation of a successful business.

For their child's current and future education, mothers have tried and are considering different options and strategies to ensure that their children are successful in their schooling:

> *Extract 136:*
> you know what I'm doing? I'm paying [child] for each unit [child] does. That's what I started to do in the hope that that would motivate [child] … and then [child] was still not performing. Okay, so I understood how we have a problem here. [child] really has a problem; [child's] not just making up because [child's] lazy

> *Extract 137:*
> we are now thinking of homeschooling our children when it comes to high school age uhm because both of our children are quite shy and they are introverts; very much in the sense that they will definitely not cope in the hostel environment and we do not have a school close by that we will be able to send our children to daily you know like for daily schooling so homeschooling is the, definitely the way that we will be going but I am worried about the social aspect of it.

> *Extract 138:*
> the reason why I chose this homeschooling that I chose, was because it's not an isolated environment where the tutor will come in and just tutor the learner and go home. No, it's a small environment. There are about 15 children from different grades but what is important is that each child is given the individual attention

The mothers above had moved or were going to be moving their child into a homeschooling environment as they believed this was the best option for their child.

6.5.2. Subordinate theme: Types of interventions

The following subordinate theme covers the types of interventions that mothers used for their children. All mothers tried multiple interventions in an attempt to find what worked for their child. The use of multiple modalities speaks to the idea that mothers are willing to try anything to help their child, illustrated by the following extract:

> *Extract 139:*
> wasted money like you can't believe it because somebody would suggest there is this thing and you have to go and do it because it's like the best thing in the world and then you pack up your

> kid and you pay the money and you go and you do these tests that's horrific for the child and nightmare for you as a parent to go through and in the end its completely useless but if you didn't go and try it, maybe it was something that would have worked, just maybe, there was a chance, so you get up to scary things as a parent because you want the best for your child

This extract explained why mothers used numerous interventions for their child – just in case the suggested intervention was the one that 'cures' or 'fixes' their child. This could also speak to those societal expectations of what it means to be a 'good mother' – being willing to try anything to help their child. The most common interventions that were discussed and used by mothers' children were Ritalin, various forms of therapy, "OTC" interventions, and lifestyle interventions. With regard to Ritalin, there were two groups of mothers – those for Ritalin and those against Ritalin. Two mothers explained that their children took Ritalin to improve their concentration and focus at school. The mothers in extracts 140 and 141 showed the positive effects of medication use as well as the reservations they had about this use:

> *Extract 140:*
> It helps [child] to see better in a sense, it helps [child] to, to cope better so why would you take that away from someone, if you could give them that aid to help them, and that really, that really helped me to, to be okay with putting [child] on medication

> *Extract 141:*
> I was on [medication] for many, many years from the time that I was about seven to I think I was about 15 when they eventually said I shouldn't have been on it, and that caused quite a bit of damage to my health, you know, uhm, so for me it was a big thing to overcome; to actually put [child] on medication and see that it was beneficial and was not doing any harm to [child].

Two mothers refused Ritalin for their children. Both mothers referred to the possible negative side effects of Ritalin:

> *Extract 142:*
> I refused Ritalin because I had seen young children that are on Ritalin becoming the opposite of what is expected. Because others become very like, very numb, I didn't want that to happen, ya so I refused

> *Extract 143:*
> wherever this poor child went is put [child] on Ritalin, put [child] on Ritalin. I said there's no ways. I'm not turning my child into a robot

The mother in extract 142 rather sought out alternative means for her child to work off their excess energy. This was in the form of a trampoline. The second mother, in extract 143, felt justified in her refusal of Ritalin when a counsellor at her child's school told her that her child was suffering from absent seizures and that Ritalin would have been the worst thing to put her child on to. However, after she refused Ritalin, this mother admitted to 'giving in' and putting her child onto another medication, Strattera, which did not work:

> *Extract 144:*
> I don’t even think [child] was on it for two weeks, because I just saw very negative effects, hallucinating, [child] was walking around like a numb ghost, and so on, and barely eating, so I don’t know, it’s not worth doing this.

The mother in extract 145 described how it was her child’s medical professionals who were against Ritalin:

> *Extract 145:*
> the people who were against Ritalin were the, [child’s] neurologist and [child’s] occupational therapist. They’re the ones who said, no let’s try alternative ways because [child] can respond. [child] listens to us, and [child] responds very well. when you tell [child] something, [child] responds very well. let’s try that instead of using Ritalin. [child] can function fully without any medication, not myself saying I don’t want it.

In terms of therapy, all six children had attended some form of therapeutic intervention. At the time of the interviews, none of the mothers' children were attending therapy. Most of the mothers reported that their children had attended both occupational therapy (OT), and speech and language therapy (SLT). Other therapies were also suggested and tried by mothers and their children; these included behavioural therapy and physical therapy.

The mothers tried several “OTC” interventions such as supplements, homeopathy, Epsom salts, and rash and wound creams for their children. They also tried several lifestyle interventions such as changing the child’s diet and tried behavioural and emotional changes in dealing with their children’s emotional regulation problems. Lastly, several mothers also tried physical therapies such as pressure massages. The mother in extract 146 explained how she educated herself on mentalization-based parenting approaches, to help manage her child’s behaviours and to help them cope with their feelings:

> *Extract 146:*
> what really worked was sitting down, talking it through, as I think I’ve told you, holding [child], making [child] feel contained, and loved and whatever because most of the time the poor [child] grew up thinking [child] was unloved and how can you blame [child] thinking that when [child’s] mother was freaked out all the time, smacking [child], shouting and whatever.

From the above subordinate theme, it can be seen that mothers are willing to do and try anything if it means helping their child.

6.5.3. Subordinate theme: Importance of interventions

Three mothers emphasized the importance of early intervention, for example:

> *Extract 147:*
> we feel as a family the intervention time that we had with [child] was two years shortened because

> we could've started two years before already if we could just get a diagnosis then because the intervention at that age would have meant a bigger and better outcome for [child] later
>
> *Extract 148:*
> the right things happened at the right time for [child], so I think it could have been much worse, definitely, the early intervention made our life much easier.

For all mothers, accessing this early intervention meant that their child would have been better off in the future.

The mothers in the extracts below explained that it was only because of the hard work with their child, such as doing therapy with their child, that their child improved:

> *Extract 149:*
> I'm not scared of working with my child. It's my child I want the best for [them], so ya I don't take no for an answer easily, even from [child]. [child] will also have to work, and that's how we get a success, that's how we work towards a bit of progress is because you just don't give up. Why must you give up? It's your child, [child] matters.
>
> *Extract 150:*
> it's only because of our efforts that [child] is able to do certain things the way other people do them and be acceptable.
>
> *Extract 151:*
> if you really want your children to learn, you actually take what they say and you do it with your child, and it works like wonders. It's just that, I always wonder whether other people were doing it.
>
> *Extract 152:*
> if you not going to get the ball rolling and do what they've recommended, it also is useless.

6.5.4. Subordinate theme: Interventions as costly – money and time

Mothers in this study described several costs when it came to their child's intervention, including both monetary costs and time costs. All the mothers described making multiple trips to medical professionals for both diagnosis and treatment. While the mothers did not mention the specific costs involved, it stands to reason that these multiple trips must have been costly, considering the cost of fuel, accommodation, meals, the purchase of items if recommended by medical professionals, as well as the cost of the actual appointment, if not covered by medical aid. Beside the cost of the trips, these visits to medical professionals may also have resulted in mothers having to take leave from work, cancelling time with and commitments of their other children, make alternative care-arrangements for the other children, or cancel their own private commitments.

The mothers in extract 153 and 154 described seeking out state medical resources and professionals for both diagnosis and treatment, due to the cost involved:

> *Extract 153:*
> financially, we couldn't afford all these tests and things and so we did it through the state in [city in a different province]

> *Extract 154:*
> it was hard because financially you don't have that support system like you would overseas where you can just go to people, you had to go find the people and you also had to then pay, so we went through the state again to [a town 100 kilometres away] [for therapy]

Like the mother in extract 154, the mother in 155 also struggled with medical professionals who were a distance away:

> *Extract 155:*
> it's a very difficult thing for us to come by at this stage is to actually have people to help because they are so far away. It's not just the money, it's actually finding the time to be able to go there and uhm is it really worth your while going, and then you can only do it maybe once every two months and is it really then, is it really helpful then to do it so little?

As a result of this lack of access and little free time, this mother downloads therapy exercises off the internet and does therapy exercises with her child in their home.

When it came to the cost of interventions, some of the mothers described having some sort of access to a medical aid that helped them with payment of these services. While some mothers had positive experiences, others did not. The mother in extract 156 described some trouble with medical aid not covering specific tests that her child had needed when they were trying to determine what was wrong:

> *Extract 156:*
> medical aid doesn't cover all of these things, so it was a hectic amount of money.

However, paying for initial doctors' visits was sometimes at the mothers' own expense because of a lack of medical aid, illustrated by extract 157:

> *Extract 157:*
> by the end of the day, we didn't even have access to medical aid or whatever so whatever you do, you always borrowing money, to get my child there, it was quite stressful.

While the mother in extract 158 described how she was fortunate enough to be on a good medical aid because of her employment, but that this changed when she changed careers:

> *Extract 158:*
> we did change our medical aid recently as well because I worked for the [a government institution] when I was, I was, you know, so I was on [medical aid], and now when I changed now to a [private sector job] obviously, I lost that so we, we are still on medical aid, it's just not, it's not as good as [medical aid] was, so they don't cover as much.

This mother goes on to further say that this has not been an issue as her child has not been attending therapy due to time and distance constraints.

Two mothers also described expenses related to their child's schooling. For one mother, the new schooling she was considering for her child cost far more than her child's current school. A mother in extract 159 described the high cost associated with her child's private remedial school, which included therapy:

> *Extract 159:*
> it's a very small school and it's very expensive. That's where now the challenge is that I feel the Department of Education is actually not looking after us because for [child] to be in that school I actually pay every month R11 500 for [child] to be in that school, every month

Other specific costs that the mothers mentioned included paying children to complete modules for online learning, the large sums of money spent physically phoning people due to a lack of easily accessible information about ASD, having to buy very specific items of clothing and paying for a stand-in or back-up carers should the usual carer not be available.

However, even though there are varying and multiple costs that might not be necessary for a neurotypical child, some mothers agreed that the cost was well worth it if it meant a better outcome for their child:

> *Extract 160:*
> it was a lot of money but so worthwhile.
>
> *Extract 161:*
> as long as my [child] is okay and that if I die, [child] can be able to live without me.
>
> *Extract 162:*
> it does [add up]. But [child's] worth it. Absolutely worth it. And it's worth having peace in our home, through greater understanding.

6.6. Superordinate Theme Five: Supportive resources

Mothers drew on multiple supportive resources during their journey of raising their ASD child. These included sharing their experiences, engaging in self-care, facing reality, and avoiding unsupportive environments like the church and public spaces.

6.6.1. Subordinate theme: Sharing experiences with family and friends

The mothers drew on their spouses, sisters, extended family, friends, or their work colleagues for support. The specific coping mechanism associated with these supportive individuals was their willingness to listen to mothers and their problems, to share ideas and thoughts, to give advice and provide encouragement, and importantly, emotional comfort, for example:

> *Extract 163:*
> it's been hard, I can't really talk to, to my husband always, but we do talk but I know it actually makes him angrier, but definitely, I can talk to my husband and talk to my family, talk to grannies … and talking to fellow colleagues about it. They, because they know exactly what I uhm and they have got such sympathy.

> *Extract 164:*
> I have good friends who listen to me and cried with me when I was feeling desperate about failing as a mother, you know, all that kind of thing.

It can be seen how different individuals serve different supportive roles for mothers. Mothers sought support, advice, comfort, and sympathy from those who knew their children and might have experienced what they have experienced. Mothers described a kind of 'emotional release' to be able to share their concerns and receive advice and help from others. While for some mothers their husbands provided them with a 'reality check' in their household, for others it was occasionally difficult to discuss their difficulties with their husbands as they got angry. Mothers who had sisters described them most positively as providing the greatest support, in the form of sending encouraging messages and attending workshops with mothers. While a mother found her friends provided her great support and comfort, another mother described how she had to sacrifice her relationships with certain friends because of their attitudes and reactions towards her child. Another mother explained that only another parent of an ASD child would understand what it was like to raise an ASD child. This is why this mother and others chose to give up those friends who did not have ASD children since they did not understand what it was like to raise an ASD child. However, the mother in extract 165 only agreed to a certain extent that another parent with an ASD child would understand:

> *Extract 165:*
> it's like speaking to any other parent that doesn't have a child with autism basically because they don't understand your specific child.

The difficulty in having friendships with other parents with autistic children is that these children are so different from each other – something that one mother struggles with, another mother wishes her child could do. This makes asking for advice from other mothers difficult and potentially frustrating as they do not have that specific knowledge or experience of the specific child. Furthermore, what works for one autistic child and mother does not work for another, since each child is so different, and symptoms and behaviours vary in presentation, degree, and context. This makes asking for advice and support from other parents quite an alienating experience. A further supportive resource for four mothers was therapists of different kinds. Two mothers drew on their own personal psychotherapists, while two other mothers drew on their children's therapists (OTs or SLTs) for supportive resources and advice regarding difficulties they were having with their children:

> *Extract 166:*
> I could tell them [OT and SLT] where I am battling with [child] and they could adapt their therapy to that.
>
> *Extract 167:*
> The beauty about having a therapist of being in therapy, it creates self-awareness. I can feel when my energies are depleted.

Sharing experiences with a therapist allowed mothers to release any pent-up frustrations and difficulties with their child and allowed someone external to the situation to provide a fresh perspective and advice. These therapists also built up good experiential knowledge of and a relationship with the autistic child over time.

6.6.2. Subordinate theme: Religion

Another supportive resource for mothers was drawing on their religion in the form of prayer and faith. Praying allowed mothers to share their frustrations, ask for advice and ask for the strength and understanding from God to help their child:

> *Extract 168:*
> my religion would be believing in God that He can make a way for me to understand this particular child that He has given me.
>
> *Extract 169:*
> every challenge that comes, I go to God who can bring you to it, then He can bring you through it. So just hang tight, better is coming. We are working through this problem because He is in control. He is in charge.
>
> *Extract 170:*
> I honestly can say that the Lord has either spoken to me and I have calmed down about it, and not spoken audibly but like given me advice. Something will pop into my head and I will try that.
>
> *Extract 171:*
> our desires for [child's] future is you know we don't want [child] to be stuck with this situation and we want to help [child] as much as we can so we believe that God can help uhm in amazing ways, so we were always praying, and we know that our family has always been praying and I feel like that's also why the right things happened at the right time.

Two mothers, on the other hand, disagreed with this idea of wanting to change or fix their child, for example:

> *Extract 172:*
> it was on a religious group, but to me, it was the wrong thing to pray for, is for me, I would rather pray that I would be a better mother, that I would be uhm be able to cope with it. That I would be able to help [child] deal with it and certain situations
>
> *Extract 173:*
> the reason why I stopped, I stopped because 1) the support. 2) some churches and their beliefs of autism having been prayed away, it can be prayed away, and thirdly, it's personal, it has to do

> with the fact that I decide you know what I need to have in my own personal relationship with God

6.6.3. Subordinate theme: Support groups

Another supportive resource that some mothers drew on or tried to draw on was support groups. Mothers had both positive and negative experiences of support groups, with some mothers finding alternatives online. Other mothers explained that they wished they could access physical support groups, but that none were available in their rural towns. The mother in extract 174 felt that both her problems and support seeking were rejected by the support groups she attended, which resulted in some alienation:

> *Extract 174:*
> they were not serving what I had gone through and you would be, even the therapist who was running the support groups would shut you down to say no, no, no, you don't have a problem. Let's hear the others. I do have a problem too but it's not as severe as you have, but I still need to be listened to.

This feeling of rejection felt by the mother in extract 174 could also be a result of the variability and specificity of each mother's experience, which made it difficult to receive and give support when listening to diverse experiences the other members might not be able to relate to. Two mothers described positive experiences with online Facebook-based support groups, where, after reading and sharing with others, they realized that they were not alone in what they were experiencing and feeling about their child. One of these mothers felt as if she had been given hope for her child's future based on the stories she had been reading that were posted by other mothers:

> *Extract 175:*
> it was so nice to see on Facebook that there are already grown-up, uhm, autistic people you know like living normal lives and having families.

These online support groups are immediately available for mothers when or should they need extra support from others. It was a quick and easy way to get reassurance or advice from other parents, instead of waiting for a weekly, bimonthly, or monthly support group, should they have access to support groups. Furthermore, the use of online support groups provided some anonymity for the mothers, where they could access help from a safe, comfortable environment, like their homes. The mother in extract 176, however, experienced support groups from a different angle than the other mothers in this study – that of hosting support groups. However, this mother explained that while in the beginning the support groups were well attended, in the end, they were a chore for her as she would organize the support meetings and organize speakers and no parents would arrive. For this reason, physical support groups came to an end. However, this mother explained the support group then moved online to WhatsApp:

> *Extract 176:*
> we built up the same support group that we had on a physical level in a group situation in a classroom. Now we have built it so that it is an ongoing fluid thing on WhatsApp. Anyone who has a problem anywhere can post on the WhatsApp group and someone will answer them so it's an ongoing support system

As explained above in the case of the Facebook support groups, this WhatsApp support group provides instant available support and help should anyone ask for help on the group. There is no delay in receiving advice. It allows parents to receive peace of mind or advice the moment they need it, responsive to a particular question they post.

6.6.4. Subordinate theme: Self-care and facing reality

A further coping mechanism used by mothers was self-care and facing reality. Half of the mothers emphasized the importance of self-care and taking time to care for themselves, as they usually concentrated on the health and wellbeing of their children instead of their own. For three mothers, self-care included weekend getaways without their children to rest, relax and recharge. Two mothers used exercise as a way to decrease their stress and frustration levels. Three mothers also learned to request and take time-outs from their children when necessary, to deal with their own emotions. Another coping strategy for three mothers was facing life's realities head-on, day by day, and dealing with problems as they came up:

> *Extract 177:*
> I'm looking at this child that I have, and I'm thinking, oh my goodness. How am I going to cope with this child? And, and this, but every day, [child's] alive … This is my person and I brought this, you know, I'm only saying that, oh my goodness, and I'm sure God is not happy with me, I always say, you are my person. I made you, and I am going to take care of you.
>
> *Extract 178:*
> you know that thick skin that I spoke about? Hmm, that's exactly where that comes from. I've still got a soft heart because I love my child, I love [child], but you have to grow that thick skin eventually and say enough is enough. I can't deal with this anymore.
>
> *Extract 179:*
> My big feet that are small. Big feet, I will go in there and show them how it's done instead of don't tell me you can't, ha-ha don't tell me. Because I can do it, so then you can do it. And I'm nothing special. I'm just Mom. I can deal with this child, then I can teach you how to do it.

From extracts 180 and 181, it can be seen that acknowledging the severity of ASD was a way for mothers to face their realities and cope with their experiences, which could then provide them with some comfort, for example:

Extract 180:
it's not as colourful as I think you know as other people who have had it tougher but ya, shoo, our experience is quite normal in a way.

Extract 181:
when I look at those situations and that we don't need to send [child] to a school, then I realize how much easier we have it.

The thought that their child could have been more severe resulted in some degree of thankfulness which helped them to cope and deal with those things they struggled with, knowing that they could have had it worse.

6.6.5. Subordinate theme: Avoidance of unsupportive environments

Three mothers perceived the Christian church congregation to be unsupportive and judgemental towards their children and their behaviours, resulting in their coping mechanism of avoiding the church environment:

Extract 182:
I used to take both kids to church with me until I had to leave the church service because of little [child] screamer, and then I just decided you know what, God is portable. He [God] goes with me wherever I go, and I can still be a Christian, but I don't have to sit with my face and my bum in church.

Extract 183:
they would give me that look that you are not looking after your child, so it made me feel very bad ... Since then, I don't go to church. I, my reasons then was the fact that uh church people are not supportive in the, are not, are not supportive and ignorant about different uh conditions that people have

Extract 184:
I wouldn't want [child] disturbing others and we are in the Afrikaans NG Kerk, so you know, it is, it's a very kind of stiff mode in there. So, uhm, you, you, you have more of the older people, not many young people go, so uhm, ya. It was definitely a case of I did not want [child] to disturb them, but you also wonder what they think of you.

While two mothers did not return to the church and worship with their congregations, the mother in extract 184 explained that after her child went onto Ritalin, and had more normal behaviours that were controlled by the Ritalin, they as a family felt comfortable enough to return to the church, without worrying about judgment or disturbing others.

While the three mothers in extracts 182, 183, and 184 struggled with the church environment, the mother in extract 185 explained that she avoided public gatherings as she was not ready to deal with the questions that were asked:

Extract 185:
you'll find yourself trying to avoid such gatherings … but deep down, you know that I'm just not

> ready to explain myself again. I don't. I don't want them to actually see this. I don't want them to actually judge me or my child, or I don't want them to think I have a retarded child, or somehow, you know when people don't understand what is going on the first thing, they think 'ah [child's] mad', 'ah [child's] retarded', and [child's] not, you see. so somehow, I limited myself from doing that until I understood exactly what is going on.

This mother referred to the general misconceptions that people have about those with special needs – that they are retarded or mad. That pointed to the ignorance that society has about conditions, the stigma that surrounds conditions as well as the shame that mothers feel.

It is this ignorance that results in mothers isolating themselves from others. However, while the avoidance of public interactions such as the ones described above manages judgement and embarrassment; it also increases the stigma of children experiencing neuro-diverse symptoms.

6.7. Conclusion

This chapter reported on the thematic findings of this study with the aim of addressing the research question of the study, which was to explore the experiences of mothers raising their ASD child in South Africa. The findings of this IPA study produced five superordinate themes. These included 1) learning that their child had a condition or diagnosis, 2) learning and sharing about ASD, 3) the mothering experience, 4) interventions and cost, and 5) supportive resources. The chapter which follows, chapter seven, is a discussion of these findings.

Chapter Seven: Discussion

7.1. Introduction

The preceding chapter, chapter six, presented the five themes found by me after completing an analysis of the interview material, following Interpretive Phenomenological Analysis (IPA) guidelines. The goal of this research study was to explore the experiences and perceptions that mothers had of raising their children diagnosed with ASD in the South African context. This research utilised an IPA methodology to explore six mothers' lived experiences of raising their child and how they made sense of these experiences. This study highlighted several challenging experiences that mothers in the current study faced while raising their ASD children in South Africa. This current chapter aims to explore, interpret, and describe the findings of this research in light of the previous empirical literature discussed in chapters three and four, as well as to explain any new findings that emerged as a result of this current study.

7.2. Discussion on cross-cutting issues and themes

As explained in the methodology chapter, IPA researchers try to examine the experiences of individuals in their own contexts, without these experiences being influenced by prior psychological theory or the researcher's personal beliefs (Smith, 2017). The main currency for IPA, therefore, is the meanings that participants ascribe to their experiences (Smith & Osborn, 2003).

This study – along with Guler et al. (2018) – found that social contexts shaped mothers' experiences with their children. As a result, this study's findings will be discussed in relation to mostly South African, or LMIC qualitative research studies which included mostly high-functioning ASD children as samples, as these are the most similar to the current study's context and will therefore assist in the determining of recommendations for further research and relevant interventions or practices. Furthermore, research from across South African provinces will be utilised.

While I initially expected to see differences amongst the experiences of mothers from different provinces, the thematic findings chapter showed that the experiences of mothers across provinces were similar. This is because mothers were from similar socioeconomic status backgrounds, which 'allowed' for a particular kind of experience, conditions, and resolutions to issues; as they were able to access similar resources afforded to them. What follows will look at those cross-cutting issues that came up across the themes, as well as a discussion about some of the themes presented in the previous chapter.

7.2.1. Cross-cutting issues

Six cross-cutting issues will be discussed in this section, including 1) the type of mother recruited, 2) mothering roles, mothering blame and a mother's intuition, 3) access to resources, 4) poverty of knowledge of NDM, 5) the passage of time and 6) cultural practices.

7.2.1.1. Type of mother recruited

Research can be said to "construct" mothers' stress and experiences in particular ways. For example, this current research project was centred on the experiences of mothers raising autistic children with higher functioning autism, as this was the type of mother who volunteered to participate. The severity or degree of ASD on a spectrum, the child's age, as well as a mother's socioeconomic status and the supportive network of care arrangements and public or private professional services around her, would make a difference to the mothering experience – in the same way as these factors would affect mothering a neurotypical child.

However, it was not as simple as having access to resources or not. While middle-income contexts do have more money and better resources to receive professional advice or support in the private sector and access better schooling than those from lower-income contexts, middle-income households are also often "nuclear patterned", which sets mothers up as their children's primary caregivers, supported by domestic workers, largely, as nannies or back-up caregivers when mothers work – with husbands there to provide financial support (Bray, Gooskens, Kahn, Moses, & Seekings, 2010). This experience is different in lower socioeconomic status or working-class communities and families where households are more likely to be extended – where there are many adult caregivers who can support mothers in caring for their child, and nearby relatives and neighbours are willing to chip in with caregiving support (Bray et al., 2010). This means that while mothers go to work, their child can be cared for by an extended family member, such as a grandmother – this context can be said to be richer in care-resources, but not necessarily monetary-resources. However, in this context, there are fewer free resources for special education, consultations with private doctors and therapists, and special diets, for example.

This research project recruited volunteer participant mothers through ASA, which resulted in a particular kind of mother volunteering to participate – those mothers whose children fall under the higher functioning ASD or less severe ASD, who were cared for at home. It is understandable that the snowballed participants would then have a similar background or experience to the mothers recruited through ASA since mothers and parents would have friends or acquaintances who have a similar experience to them since it is more relatable. It is difficult to know exactly why mothers responded to the recruitment through ASA. Two reasons might be considered. Firstly, responding to their isolation, mothers may have wanted to talk with someone who was interested and supportive, about their mothering experience. Secondly, these mothers may have wanted to raise more awareness for their children since they were not seen as severe as they could be and are at times misunderstood in the public sphere as their children's condition is largely invisible. This invisibility is linked to the few physical manifestations of ASD (Matuska & Gallagher, 2020), except in severe cases. Furthermore, since mothers were recruited through ASA, via an email database, this meant that mothers had to have both email and internet access, as well as being a part of the organisations' communication and social media networks. This may have affected the type of mother recruited, for example, those who had reliable, stable internet access.

Similarly, it can be seen in Reddy et al. (2019) how the recruitment they conducted also resulted in a specific type of parent responding. The authors recruited through LSEN schooling, which resulted in the middle to high socioeconomic status parents participating in the study since it is those parents who can afford this level of schooling. That also meant that these parents could afford to get a diagnosis for their child, as well as search for treatments and supportive interventions.

7.2.1.2. Mothering roles, mothering blame, and a mother's intuition

Kruger (2006) explains that "it is often because of societal expectations that motherhood is such a stressful experience for women" (p. 183). This study also found this to be the case. Traditional ideologies and beliefs regarding mothering often promoted and perpetuated the view that mothers are responsible for raising happy, well-adjusted, promising (Kruger, 2006), 'normal', healthy (Burman, 2017), and communicative children. Having a disabled child or a child with a developmental disorder or condition, therefore, breaks the model of the 'perfect mother', as the family did not produce a 'normal' child (McDougall, Swartz, & van der Merwe, 2006).

These traditional prescriptions of how to be the best mother to have a healthy, happy child resulted in an ideal, a stereotype, where every woman and mother believes that they have to be able to give her all to her child for their growth and happiness (Kruger, 2006). A good mother was and is seen as always available, devoted, and attentive to her child; always attending to and attuning to her childs' needs (Burman, 2017). This ideal mother can therefore be described as self-sacrificing (Kruger, 2006). These stereotypes of how to be a good mother, therefore, became the "constructs against which mothers and society measure the adequacy of 'mothering'" (Kruger, 2006, p. 187).

This self-sacrificing mother can be seen in the way that mothers in the current study described that they have an all-encompassing role that they had to fulfill in the raising of their ASD children, which was also found by three other South African studies (Fewster & Gurayah, 2015; Olivier & Ah Hing, 2009; Reddy et al., 2019). The traditional patriarchal ideologies and beliefs have affected the roles that mothers and fathers take on when it comes to raising their children. Fathers typically have or take little responsibility in everyday childcare, as it is seen as a mother's duty, with fathers' roles typically being relegated to providing financial support and emotional support for mothers (Burman, 2017), or sometimes "entertaining" children by playing with them when the father comes home from work (Richter, 2006). Richter (2006) explained that it was mostly mothers who took on the 'responsibility' dimension of caring for children – mothers planned, anticipated, enacted, monitored, and followed up on their children's needs. This was seen in the current study where mothers explained that it fell mostly to them to care for their child and to do research about autism. However, nearly all the mothers reported receiving a lot of support from their husbands.

Some mothers in this current study described the regrets they had about their behaviours and actions towards their child. It can be said that these mothers internalized these traditional ideologies and beliefs, and were 'beating themselves up' that they could not have been better mothers for their special needs children, had circumstances and resources been different.

For a mother in the current study, comparing her actions and behaviours towards her child while studying published mothering manuals about ASD children, led the mother to question her ability as a mother, and made her feel as if she were not a good enough mother for her child, suggesting that there is a concept of a 'perfect, ideal' mother. This can be linked to earlier thoughts on what it means to be a good mother; and the resulting blame and shame that stems from these ideas of what it means to be a 'good, perfect' mother.

Guler et al. (2018) described parents' desire to have better parenting skills, to be better able to handle the difficulties that come with raising an ASD child. Guler et al. (2018) suggested that parent-training approaches may be acceptable in order to fill the knowledge gap that parents feel they have. However, these training approaches could also be prescriptive for 'good mothering' or 'good parenting' practices; once again creating an ideal which had to be worked on very hard to achieve, and further causing anxiety when this could not be sustained in their particular household arrangements (Wilbraham, 2009).

This out of reach 'perfect mothering' ideal could be why most mothers emphasized following their intuitions or 'gut feelings' when it came to their children, based on their personal experience and observations in close relationships and proximity with their own children, which was emphasized by most mothers throughout the thematic findings chapter. Mothers followed their intuition that something was amiss with their children which led to their search for answers, which was also found by Fewster and Gurayah (2015) and Mitchell and Holdt (2014). They also reported following their intuition when choices regarding schooling and interventions had to be made, and when or how to tell their children about their diagnoses, for example.

Since mothers could not reach this mothering ideal, mothers trusted their intuitions for what the best course of action was for their child – Winnicott (1988 as cited by Jacobs, 1995) explained that "there are very subtle things that the mother knows intuitively and without any intellectual appreciation of what is happening, and which she can only arrive at by being left alone and being given full responsibility" (p.50). Despite the social pressure and expectations and responsibilities, Winnicott in the above quote explained that mothers have their own personal meaning and response that they work out through being attuned to their child. While mothers and families chose interventions and schooling options that best suit their child, these choices further added to mothers' all-encompassing role as they then had to become at-home-teachers (in the case of the move to homeschooling), and had to regulate, manage, and sustain special changes in diet, for example. They also had to become therapists for their children at one stage or another – be it, following homework exercises received from therapists, or becoming lay-psychologists or counsellors for their children, in the sense of providing emotional support for their children. This was also found to be the case in Reddy et al. (2019) where a mother became an ABA instructor to help herself and others. Mothers in Australia also described how they tried to make up for shortages in services for their children by becoming lay therapists for their children, as they were the ones who had to work through the therapy techniques with their children (Safe et al., 2012).

This intuition that mothers have regarding their children is a result of their role as being their child's primary caregiver in a close attachment relationship, spending the most time with their children, and perhaps comparing their children's milestones and behaviours to other children or to childcare manuals that new mothers often treat as bibles. From these experiences and knowledge, mothers have a 'gut feeling' or intuition that there is 'something wrong' with their child. This is usually related to problematic behaviours or interactions with their child or that their child is not meeting developmental milestones, such as turn-taking interactions, making eye contact, responding to mother's voice and words, amongst others, described in mothering books. This intuition can be described as a close attunement to their child and measuring their child's development according to norms that are published and popularised. This mothering intuition is because of their close attunement with their children as their primary caregivers. This is what Mary Ainsworth called maternal sensitivity – which is understood as a mother's ability to "perceive and to interpret the signals of her child, and [to] promptly and appropriately respond to them" (Neuhauser, 2018, p. 127). This can also be thought of as learned responsiveness to children's needs and behaviours and a kind of mentalization, which is hypothesizing or imagining about what is going on in the mental states of another or a child (Frosh, 2012) because mothers have traditionally carried out most of the childcare responsibilities.

Within the thematic findings chapter, there was constant, pervasive worry from mothers about their mothering behaviours and always trying to determine what was the best course of action for their child, with most mothers referring to their intuition again, in determining what was best for their child. The willingness to try another treatment, intervention or another school could be linked to wanting to prove to others and perhaps themselves that they are being a good mother by trying everything they can for their child.

Also, in all mothers' cases in the current study, it fell to mothers to make behavioural observations and to take note of and raise these concerns with their medical professionals. This points to the idea that mothers have to be super knowledgeable regarding 'normal' development. Blame would then fall on mothers if they took too long to notice their children's changes or issues (Burman, 2017). Following Burman's (2017) argument, then, this also could imply that the late diagnosis of ASD is a reflection of mothers and their ability to parent and care for their child, which could lead to blaming mothers for their child's ASD – despite the clear findings in this study and the literature reviewed that late diagnosis was clearly health professionals' fault.

Mothers in the current study trusted their intuitions and considered multiple causes for their child's condition, not settling on one cause, but rather considering multiple causes simultaneously. For mothers generally, it is frightening and stressful to manage this uncertainty about the cause of their child's condition within the societal expectations that mothers are responsible for their children's developmental outcomes. Mothers are also judged on the fact that their child is adjudged 'not normal' or not neurotypical. Mothers in general are set up as responsible for their children's developmental outcomes (Burman, 2017) in two ways. Firstly, during pregnancy, mothers should not drink, not smoke, take the appropriate vitamins and supplements, and not engage in certain behaviours (Jawad, Patel, Brima, & Stephenson, 2019), and secondly, through attachment theorists and their thoughts on mothers' roles on raising a healthy, happy child who is communicative and secure (Burman, 2017). With regard to the first point above, some of the mothers in the current study blamed themselves for their child's diagnosis, due to issues they had experienced during pregnancy or choices they made during labour. However, as mothers researched and learned about ASD, they moved on from this self-blame and hypothesized about multiple other potential causes. Many mothers understood the cause to be an interplay between the environment and genetics.

7.2.1.3. Access to resources

After receiving their child's diagnosis, mothers' worries and stressors increase as they think about their child's schooling, their future careers, their independence, and future care, as well as about possible therapeutic interventions. This is an important consideration in the South African context; a context where professional and support resources for mental health and developmental disorders are limited and almost entirely privatized, i.e., not routinely available in the overburdened public sector, and as a result, are expensive, and therefore unaffordable for many (Erasmus et al., 2019a; Guler et al., 2018; Wetherston et al., 2017). As a result of the limited resources available to mothers in terms of special needs care, support, and facilities (Mazibuko, Shilubane, & Manganye, 2020; Mitchell & Holdt, 2014), mothers in this study reported that they had to cover and stand-in for the shortcomings of state services and NGO support in the care of their children. This also resulted in mothers feeling a sense of isolation and desperation as they struggled with their child's symptoms and behaviours.

While parents in Guler et al. (2018) described difficulty in skills transfer between therapy, clinic and home, mothers in the current study did not describe difficulty with the skills transfer. The difference here is that parents in Guler et al. (2018) who described this difficulty struggled financially or resided in informal settlements, while the mothers in the current study were middle class. Most mothers were involved in their children's therapy and practiced their child's exercises, as a result of their access to resources (monetary, language, therapy, hospitals, clinics). Therefore, access to resources plays a large part in the ability of mothers to engage in such skills transfer.

When it came to interventions, other South African studies (Clasquin-Johnson & Clasquin-Johnson, 2018; Guler et al., 2018; Mazibuko et al., 2020; Mitchell & Holdt, 2014; Mthombeni & Nwoye, 2018; Olivier & Ah Hing, 2009; Wetherston et al., 2017) described the financial burden of raising an ASD child in South Africa. Mothers in the current study also described the high cost of caring for their child, which included the cost of therapy, the cost of schooling, and the cost of driving to and from doctor and therapy appointments (sometimes hundreds of kilometres away in the EC province). Other costs included spending time at work or having multiple jobs, to cover their child's expenses; or conversely, losing a second household income, to care for their child at home. In the end, however, families' costs were varied and multiple and often resulted in very little disposable income for families, which Guler et al. (2018) also reported. The cost of the intervention was burdensome for some families, and intervention costs should be an important factor to consider, where many families in South Africa have limited financial resources (Guler et al., 2018).

Most of the mothers in the current study referred to access to medical aid, which aided them in paying for their children's multiple medical appointments for diagnosis, check-ups as well as various forms of therapy. As reported in other South African literature (Clasquin-Johnson & Clasquin-Johnson, 2018; Olivier & Ah Hing, 2009; Wetherston et al., 2017), mothers in the current study also reported having to pay out of their own pocket for certain expenses that their medical aid did not cover. While those mothers would fall under the fortunate few who are able to access and afford medical aid in South Africa, there are restrictions within medical aid schemes, which exclude certain medical professionals and treatments, or impose stringent category limitations on benefits for the whole family; which results in mothers having to pay for these services, or pay the shortfall between medical aid and private practitioner rates, all of which drained their medical aid schemes saving pockets. Continued attendance of therapy was not reported by any mothers in the current study. Mothers explained that it was either difficult to access therapy due to the distance to travel to access therapists, or that they had received help for the specific problem their child was struggling with. It is suggested that prolonged therapy is not affordable for most families. However, specific medical aid coverage was not explored in the current study.

7.2.1.4. Poverty of knowledge on NDM

While only half of the mothers had known or heard about the neurodiversity movement, the other mothers still followed the central tenets of the NDM. Most mothers in the current study saw their child as normal with a different way of being, with ASD simply being another part of their personality. This is one of the central ideas of the NDM (Dyck & Russell, 2020; Jaarsma & Welin, 2012). As the NDM is arguably still in its infancy (den Houting, 2019), it is understandable that only half of the mothers knew the name of the movement – those who knew were either part of a larger autism organisation (which had knowledge about disability rights and had the resources and facilities to support this), or their children had been diagnosed in the last five years, and perhaps there was more knowledge about the NDM at this time, compared to mothers whose children were diagnosed earlier.

When mothers learned about their child's diagnosis, some mothers described difficulty in understanding how their stereotypical knowledge of autism (such as from Rain Man) would relate specifically to their child, since they presumably had partial, inaccurate, or only theoretical knowledge of ASD. Mothers typically explained that they had known "nothing" or "little" about ASD prior to their child's diagnosis and this view might be explored a bit further. Often popular culture and media portrays autism as “less superior or less capable than neurotypical individuals because of their disability, or impressive and inspiring for overcoming their disability” (Audley, 2020, p. 3). As a result of this either-or view, it is suggested that mothers or those affected by ASD are left wondering and confused about where they fitted in when their child seemed so different from other children. Therefore, due to the stereotyping of autism (either as high functioning or savant, or very severe) in popular culture, and the variability and co-morbidity of presentations and diagnoses, knowledge of ASD has to be contingent and applicable to their particular child. Therefore, mothers explaining that they knew “nothing” about ASD possibly signifies that it was difficult for mothers to find “relevant” or “useful” information that was consensual and agreed upon by all interested stakeholders or parties. This further emphasizes the importance of public awareness of neurodiversity and autism – so that mothers and others have an understanding beyond stereotypical portrayals of ASD, for example, or as ‘crazy’, ‘mad’, ‘gifted’, ‘dangerous’ or at risk of abuse or exploitation by others.

7.2.1.5. Passage of time

The passage of time was discussed by most mothers in the current study. Most mothers in the current study described the time they had to wait between doctors’ appointments, as they moved from one physician to the next, in order to determine their child’s diagnosis. Some mothers viewed this negatively as they were eager for a diagnosis so that they could find out what was wrong, so they could start helping or treating their child. On average, mothers in the current study waited between two and three years for their child to be officially diagnosed from when they first reported problems to their medical professionals. In the South African study by Mitchell and Holdt (2014), parents also described waiting an average of three years before their child was officially diagnosed from the time they started seeking help, being referred to and from multiple medical practitioners. In the study by Reddy et al. (2019), parents described waiting anywhere from six months to three years to receive a diagnosis, with the difference being allotted to access to medical aid by the authors (shorter time due to medical aid access). This speedier diagnosis because of access to medical aid was not found in the current study. From the above, it can be seen then that mothers had to wait for years until they finally knew what was ‘wrong’ with their child. This waiting is difficult as mothers had to deal with their children’s more difficult behaviours, while not knowing how to help their children.

In addition to the time spent waiting for a diagnosis, mothers in the current study then described a time after the diagnosis wherein they had to process their child’s diagnosis, and what this meant for themselves and their children. Some mothers described a two-year adjustment or ‘mourning period’ they experienced after their child’s diagnosis. During this time mothers seemed to process and work through their child's diagnosis while trying to work out what the next step was, which took time. Mitchell and Holdt (2014) explained that the mothers in their study reported experiencing different emotions over time – they had to work through feelings of denial, depression, and anger before they could accept their child's diagnosis. This was similar in the current study, where some mothers experienced confusion and shock at their child's diagnosis before moving on to mourning for the child they had thought they had. The passage of time allowed mothers to work through their emotions.

After receiving their child's diagnosis and working through their adjustment periods, mothers made sense of the diagnosis by learning about it over time. The information mothers gathered was layered, gathered, and built over time. This could have been frustrating for mothers – typically, when receiving a diagnosis, individuals wanted to know everything immediately. Two mothers in the current study described how they had learned about ASD through ASA workshops and talks, while others learned through Internet resources – either through researching ASD or through online courses.

Time also provided a way for a mother in the current study to think backward, retrospectively, or reflexively about her mothering and what she would do differently now if she could start over, which she described as regrets. It could be suggested that the interviews the mothers participated in during this research project, allowed mothers to think back on their experiences; particularly since the research interviews took place some years after an initial ASD diagnosis for their child. In the study by Mitchell and Holdt (2014), mothers were asked to reflect on their experiences, and they concluded that they could have done things differently or helped their child sooner if they had known more about the condition. In this way, the passage of time allowed mothers to consider their experiences and reflect on them.

7.2.1.6. Cultural practices

Previous literature suggested that some black South Africans believe in a traditional cultural aetiology for their illnesses and turn to traditional healers for help (Guler et al., 2018; Mthombeni & Nwoye, 2018; Reddy et al., 2019). Against medical or psychiatric models that draw on scientific methods of clinical research producing empirical evidence, African traditional cultural aetiologies draw in ancestral shades and metaphysical ontology. However, in the current study, neither of the two black participant mothers believed in this theory of illness causation for their children. As suggested by mothers, this was because they had other alternative options to consider as well. In the modern and educated world in South Africa, and amidst a shared public and private health system based on a biomedical model of disease, there is often hybridity between different sets of cultural practices, and often mothers have to wrestle with these contradictory worldviews, where they might not follow traditional cultural practices or values, but their own mothers and extended kin do (Mthombeni & Nwoye, 2018).

Mthombeni and Nwoye (2018) suggested that perhaps this is due to inter-generational differences in belief systems, suggesting that the younger generation does not necessarily ascribe to this traditional cultural theory of illness causation; but are nonetheless knowledgeable about its premises. This could be because the younger generation have access to education and other knowledge systems and have engaged more with the psychiatric model. Both black mothers in this study have a tertiary university education and perhaps could not reconcile their understanding of Western medicine and understanding, with traditional understanding. Corroborating this, a mother in the South African study by Reddy et al. (2019) described being against certain cultural practices as she could not reconcile her nursing knowledge with beliefs that her child was a sangoma and that ASD behavioural symptoms represented a 'calling' by ancestral spirits for training as a sangoma. Perhaps mothers did not see or consider traditional healers for the reasons explained by Nene (2014) that parents sometimes did not see traditional healers as a result of the negative connotation often associated with traditional healers as being witches or opportunists, rather than genuine healers.

Some other South African parents explained that they sometimes only participate in traditional ceremonies to appease older family members (Mthombeni & Nwoye, 2018). A mother in the current study explained ignoring her extended kin's thoughts on traditional causes and ceremonies that need to be done as she did not have the energy to focus on their beliefs and had more things to do with her child. Other South African literature also found that extended kin typically assume ineffective parenting and poor disciplining of bad behaviours (Guler et al., 2018; Olivier & Ah Hing, 2009; Reddy et al., 2019). This difference in understanding could lead to tensions within families.

However, while parents in Mthombeni and Nwoye (2018) saw ASD as a punishment or withdrawal of protection from a spirit, god, or ancestor, some mothers in this study understood their child to be a gift from God. This strongly Christianized understanding of the cause of their child's ASD could have strengthened mothers' religious faith in making sense of and coping with the experience of raising their child, positively. This added a meaning-system, and often, a supportive network of churchgoers who shared values and rallied around in difficult times or crises. This was also reported by another South African study (Reddy et al., 2019).

However, cultural practices do not only refer to African participants or people. There are many different "OTC" and lifestyle approaches, which are considered to be cultural practices, that people engage in. Often, people switch between and combine these cultural practises with psychiatric models and biomedical evidence-based interventions (like OT). Some of these cultural practices may include taking "OTC" supplements, or following dietary recommendations, while switching between and combining these with prescribed medications and therapy (such as speech or occupational) (Louw et al., 2013; Reddy et al., 2019).

7.2.2. Theme discussion

In the section that follows, there will be discussions on five themes, namely: 1) future problems related to the context of experiences, 2) diagnostic experiences, 3) schooling problems, 4) support groups, and 5) disclosing the diagnosis to their child. These five themes were specifically asked about in the interviews and emerged as clear themes in the thematic findings chapter.

7.2.2.1. Future problems related to contexts of experience

Due to communication and relationship, and 'mentalization based' emotional insights or regulation issues in their autistic children, mothers were concerned that firstly, their child would not be able to form mature or autonomous relationships with life partners, and secondly, that their children would be dependent on them for the rest of their lives. In this way, mothers expected that 'normal' developmental trajectories for their children are interrupted and defeated. Furthermore, the concern about dependence on mothers could also be related to their children's difficulties in communication and relationships – a sense that their children would be unlikely to find or settle with a partner; to work together to form an independent household or supportive partnership.

When it came to their children's futures, in South Africa, due to limited resources for work and career options, as well as assisted living arrangements for differently-abled people, this could mean continued dependence on parents. Several mothers were concerned about this continued dependence but had some hope that their child could reach some measure of financial independence due to their higher functioning ASD child or children. However, the responsibility or duty often falls on mothers or parents to find something for their child to do, as there is little to no governmental support when other welfare issues and health services were prioritized over ASD (Meiring et al., 2016). Parents in Meiring et al. (2016) also described struggling between a feeling of fear and uncertainty and alternatively, hope and optimism about their children's futures. Parents in Mitchell and Holdt (2014) also described this concern about the future, with most of the parents putting financial provisions into place for their child's ongoing care.

In the current study, while mothers with younger children were concerned about their ASD children excelling academically for a successful future, mothers with older children seemed to focus more on their child’s interests and on building on these for their futures. Similarly, Meiring et al. (2016) found that parents with older ASD children were concerned about their child’s daily living skills rather than on subject knowledge; making the transition from focusing on academic achievement to functional skills. As mothers and children got older, mothers arguably became more aware of their own mortality, and as a result, their focus shifted to their child/children being able to earn an income to support themselves.

7.2.2.2. Diagnostic experiences

When it came to diagnostic experiences, most mothers described quite a difficult journey with medical professionals. Mothers in the current study turned to their health care professionals for answers when they noticed something was wrong with their child. However, it was not as straightforward as receiving a definitive answer, as mothers were referred to multiple and varying medical practitioners. Mothers experienced medical professionals of different types (GPs, neurologists, paediatricians, psychologists) as being unwilling to diagnose their child, who often referred mothers to other doctors further up the specialist hierarchy to receive a diagnosis. Parents from other South African studies (Clasquin-Johnson & Clasquin-Johnson, 2018; Fewster & Gurayah, 2015; Mitchell & Holdt, 2014) also reported this perception of unwillingness to diagnose. While reluctance to diagnose is one aspect to consider, there are other aspects that need to be considered. Medical professionals could have referred mothers to other medical professionals as they could either have had the knowledge, skills, and tools to diagnose ASD systematically, or they could have had more clinical experience in the diagnosis of autism spectrum disorders.

There are four factors that will be considered which could have impacted mothers’ experiences of the diagnostic process. Firstly, most mothers in this current study initially sought help from bio-medical doctors, such as paediatricians and general practitioners, rather than clinical psychologists or psychiatrists for symptoms or behaviours which would fall under possible neuro-developmental problems. This could be because they sought help from their trusted primary care physicians, and perhaps did not link their child’s symptoms or behaviours to a developmental (psychological) issue. This could have caused the delays that mothers experienced, and the feeling of unwillingness to diagnose coming from GPs.

Secondly, it is further suggested that there is an assumption by mothers, and others, that all doctors – albeit general practitioners or paediatricians – should be knowledgeable about all conditions that affect children. However, this was not the case. There is also a hierarchy of medical professionals, and individuals seeking help are usually referred up the hierarchy, to those with higher degrees of specialization, training, and clinical expertise (Pearson, 1999). This could be another reason why mothers in the current study thought their primary doctors were unwilling to diagnose their children when they were referred to other medical professionals.

A third factor to consider is that perhaps medical professionals did not receive enough information from mothers to suggest an accurate diagnosis. For example, parents in another South African study (Fewster & Gurayah, 2015) reported difficulty in verbalizing what they were concerned about regarding their children's behaviours. However, this then implied that mothers have to be knowledgeable in 'normal' or typical development and should have used medicalized language to report their concerns. In addition, most types of medical doctors are heavily overburdened in terms of caseloads – especially so in the public health sector – and might work, on average, within a 10 to 15-minute consultation model with patients. As a result, mothers and other patients who seek help would have limited time with the physician, and conversely, the physician would have limited time to run tests, do lengthy assessments, take full histories of symptoms and behaviours, prescribe treatments, or make referrals. If mothers are unable to voice their concerns appropriately, medical professionals also struggle to determine if there is something amiss with mothers' children. Therefore, the difficulty in explaining what exactly they think is wrong with their child impacts their medical professionals' ability to diagnose or refer mothers to other more specialized medical professionals.

Fourthly, another factor to consider is the invisible nature of ASD, where there are few physical symptoms of ASD that can be measured (Matuska & Gallagher, 2020), although in extreme cases, this may vary, such as repetitive movements, lack of eye contact, or attentional deficits. For example, mothers in a Canadian study by Nicholas et al. (2016) explained how they felt that other conditions and disorders such as cancer, Cerebral Palsy, and Down's Syndrome received more clinical attention, compassion, and empathy, than ASD did, due to the relative invisibility of its symptoms.

As a result of these few physical measurable symptoms, many cases on the spectrum are difficult to diagnose early because many of children's behaviours are within "normal" ranges, especially when pathology is less extreme, or less debilitating. In addition, there is an overlap of symptoms and behaviours between several conditions affecting children, such as global developmental delay, or attention deficit hyperactivity disorder (APA, 2013), which can make it difficult for medical professionals to know which condition it is – which could also result in multiple referrals. This overlap and co-morbidity in symptoms between conditions could also result in misdiagnosis – which could be another reason why mothers were referred to other medical professionals, who perhaps had more clinical experience to diagnose complex cases. Mitchell and Holdt (2014) also reported that parents and professionals struggled to distinguish ASD from other developmental conditions. As a result, professionals were cautious in their diagnoses to avoid causing any additional stress to families (Mitchell & Holdt, 2014).

7.2.2.3. Schooling problems

Schooling is another facet with which mothers in the current study struggled. This can be seen by the multiple schools and different types of schools that mothers' ASD children attended. One of the biggest problems with schooling described by mothers in the current study was the perceived lack of knowledge about ASD in schooling, and how to deal with their children in the classroom. Previous South African literature (Clasquin-Johnson & Clasquin-Johnson, 2018; Mitchell & Holdt, 2014; Reddy et al., 2019) also found that parents struggled with finding appropriate schooling, which was supportive, had knowledge about and experience of ASD, and met their child's and their own needs.

However, an important consideration in the South African context is that teachers within government schools have to work with the resources available to them. One of the problems is that financial support was not provided to provincial departments to help them take the first steps towards creating an accommodating inclusive environment (Donohue & Bornman, 2014; Erasmus, Kritzinger, & van der Linde, 2019b). In addition to funding problems, mainstream government schools are also suffering from a lack of teachers who have the capacity and knowledge to teach a diverse classroom, without increasing their workload considerably (Donohue & Bornman, 2014; Erasmus et al., 2019b). Teachers are further expected to tailor the curriculum for each learner's needs and pace of needs (Donohue & Bornman, 2014). While the option for training programs is available, teachers explain that these training programs are insufficient in teaching them how to accommodate and teach LSEN (Donohue & Bornman, 2014). In addition, the large class sizes of mainstream government schooling, on average 35 per class, according to the Department of Basic Education in 2018 (as cited by BusinessTech, 2018), makes giving individual attention to learners difficult (Marais, 2016).

This large class size also results in difficulties for teachers in managing behavioural problems (Marais, 2016), often resulting in punitive measures. Furthermore, teachers are expected to cope with multiple dimensions of diversity in their classrooms, such as race, culture, socioeconomic status, gender fluidity, household or family background, health status, and learning disabilities, among others. All these factors are difficult for teachers to manage. The reality in South Africa is that the government education system is not equipped with the resources and facilities needed for the realization of inclusive mainstream education (Pillay & Di Terlizzi, 2009).

While many government LSEN are subsidized, which provides for services such as learner support, therapeutic interventions, and general support (Pillay & Di Terlizzi, 2009), access to these government LSEN schools is difficult as there are so few of these schools (Franz et al., 2018; Makombe et al., 2019; van Schalkwyk et al., 2016), which have year-long waiting lists (Clasquin-Johnson & Clasquin-Johnson, 2018; Dreyer, 2017). As a result, LSEN are 'accommodated' in government mainstream schooling classrooms where they are often marginalized (Dreyer, 2017). It then falls to mainstream teachers, who have little training in special needs education and are given little support, to give support to these learners (Dreyer, 2017). Unfortunately, the school fees at governmental mainstream 'normal' schools are unable to provide for the facilities and resources required by LSEN, which results in parents and learners with special education needs being referred to specialized learning facilities and environments to meet their child's needs (Pillay & Di Terlizzi, 2009). Private mainstream schooling, on the other hand, would presumably be able to provide the facilities and resources required by LSEN, due to their high school fees (Erasmus et al., 2019b).

As a result of the difficulties in government schooling, both mainstream and LSEN, parents in South Africa have had to find and send their children to other schooling, such as private schooling or homeschooling in order to educate their child, since they were placed on waiting lists for placement for years at government schooling (Mithimunye, Roman, & Pedro, 2018). This can be linked back to the few specialized governmental schools, which results in parents having to make alternate education arrangements. However, the move to private or homeschooling comes with its own issues – such as the high cost associated with private schools (Erasmus et al., 2019b), or the teacher role now shifting to mothers in the case of homeschooling – where mothers or other family members have to ensure that their children follow their curriculums and provide support (Steytler, 2019). Linking this to the current study, a mother described the high monthly cost associated with her child's private remedial school. Another mother in the current study described struggling with her child and getting them to complete schooling modules, which formed part of their online homeschooling. This mother explained how she resorted to paying her child per module they completed in the hope that this would motivate them. Therefore, it can be seen that each type of schooling would come with its own challenges, as suggested by some of the examples.

There were contrasting views of Makaton (a type of sign language) held by a mother in the current study and a mother in the study by Reddy et al. (2019). While the mother in the current study did not want her child to be taught Makaton, another South African mother in Reddy et al.'s (2019) found this sign language to facilitate her child's communication, and not take away from it. Perhaps for the mother in the current study, her opposition to Makaton was because of wanting her child to fit into a normal communication or social world, using language; instead of signing, which could be marginalizing.

7.2.2.4. Support groups

There seems to be very little information about available support groups in South Africa, and on how such groups might work. There seemed to be very few support groups in South Africa, with parents expressing their desire for support groups (Mitchell & Holdt, 2014; Olivier & Ah Hing, 2009; Reddy et al., 2019). Some mothers in the current study also expressed this desire for support groups. On Autism Resources South Africa's website, a blog was posted explaining that they would be collecting information about active support groups available for ASD children and their parents, within South Africa but did not list any possibilities (de Goede, 2019). However, this access could be made easier if it were directly involved with an organisation. Perhaps they do not make the information about support groups available publicly to protect parents, families, and their children from hostile comments, for example, but it does make it difficult to access and find these should parents or mothers need them.

According to Clark (2019), South Africa does not have the support networks to meet the basic needs of families with special needs, nor can it provide support groups. Support groups could be few and far between because of the lack of trained, knowledgeable, experienced individuals to run the groups. As explained by a mother in this current study, poor attendance of physical support groups makes it unviable for the group leader to continue having weekly or monthly sessions. In addition, the nature, scope, and work of a support group is the meeting of the same people over a longer period, who learn to trust the space and each other, to share experiences face to face together – and to learn by hearing about practical experiences shared by others (Mayo Clinic, 2020).

A support group does not typically provide instant information and help, nor is it a focused workshop directed at skills. It is talk-based, meaning that commitment and consistency are required, otherwise typically it does not work. Furthermore, since ASD is so variable and diverse in its symptoms, it could be tedious for parents or mothers to have to sit for hours or weeks listening to other people's experiences that may not relate at all to the issues they are urgently experiencing since those who attend the support group might not have an opportunity to speak at every support group meeting.

This is what was experienced by one of the mothers in the current study. She explained that while she was able to access a support group through her child's special needs school, they did not accommodate her experience, making her feel rejected from the group.

Furthermore, for those mothers from more remote or rural areas, accessing physical support groups is challenging since there may not be a support group in that area, resulting in mothers having to travel far distances to join a support group, which is impractical, when most support groups run during the week. However, Facebook support groups have seemed to fill this gap in support (Clark, 2019).

There was only one positive aspect that mothers in the current study mentioned about support groups and this was the accessibility of online support groups by accessing Facebook or WhatsApp. Online support groups have been described as feasible in South Africa due to the growing number of internet users, which is estimated to be over 50% of the population (Guler et al., 2018).

7.2.2.5. Disclosing diagnosis to the child

Mothers in the current study had different thoughts on disclosing their child's diagnosis to them. There is no 'one size fits all' approach when disclosing the autism diagnosis (Sandler & Rosenthal, 2015), nor is there an exact correct age of time to disclose (Wheeler, 2020). Some literature, such as Sandler and Rosenthal (2015) and Wheeler (2020) has explained that a child's age, developmental level, personality, abilities, and social awareness are important factors to consider when deciding whether or not to disclose the diagnosis. While a mother in the current study was not going to share her child's diagnosis with them at all, three other mothers had already disclosed their children's status, and another mother was deciding how and when to disclose it to her child. Of the mothers who had disclosed their status to their child, while it is unclear whether they researched the way in which to disclose, they followed suggestions made by international autism organisations and authors, since there were no South African guidelines for ASD disclosure. These disclosure methods included using metaphors to help their child understand simply, as well as utilising role models through books to help them understand (Sandler & Rosenthal, 2015). Sandler and Rosenthal (2015) also suggested highlighting children's strengths and weaknesses to them as well as respecting their processing style after disclosing to them. A further suggestion made by Wheeler (2020) is to involve a professional to start the disclosure process instead of a family member so that only the role of support and comfort is left to the family.

One of the mother's decisions not to disclose the diagnosis to her child can be linked to the neurodiversity movement, in the way that she sees her child already as a normal variation amongst humans, and that her child does not need a label or the stigma associated with a label. One of her concerns was the negative emotional impact this diagnostic label would have on her child, which has also been found in the literature on disclosure of HIV status to children (e.g. Mahloko & Madiba, 2012).

While I did not find any South African literature about the effects of disclosure of ASD diagnosis to their children, some international studies found that while some that children who knew about their diagnosis felt singled out, abnormal (Eckerd, 2019), depressed that they were confronted with differences they did not know they had (Mogensen & Mason, 2015), and angry at now having a label that had its own set of negative connotations (Huws & Jones, 2008), others felt liberated as they could then understand themselves better, realizing that knowing their ASD status brought them more clarity about their symptoms and behaviour. (Huws & Jones, 2008; Mogensen & Mason, 2015). A study conducted in the United Kingdom by Crane, Jones, Prosser, Taghrizi, and Pellicano (2019) found that most parents opted to disclose their child's diagnosis to their children as it was their child's right to know. It helped them to understand themselves better and helped them not to feel so alone as they could now be part of a wider autistic community.

There is some South African literature on the disclosure experiences of parents sharing their children's HIV status with them. I acknowledge that HIV is quite different from ASD – however, the aim here is to focus on the disclosure management process with children. One of the difficulties that caregivers discussed was knowing when it was the right time and the appropriate age to speak to their child about their HIV status (Heeren, Jemmott III, Sidloyi, Ngwane, & Tyler, 2012). In many cases, caregivers disclosed their child's HIV status to their children once they had started asking questions about their medication or special precautions to avoid injury or other risks (Heeren et al., 2012; Mahloko & Madiba, 2012). In some cases, caregivers explained that they disclosed their child's status to them so that they would adhere to treatment (Mahloko & Madiba, 2012). Caregivers who had not disclosed their child's status to them made this choice because of fears about their children sharing their diagnosis with others, and the possible repercussions from their children disclosing their status publicly (Heeren et al., 2012; Mahloko & Madiba, 2012), as well as concerns about the negative emotional impact the disclosure, could have on their child (Mahloko & Madiba, 2012). On the other hand, some children expressed that they had wished they had been told at a younger age, around five years old instead of in their early teens (Heeren et al., 2012). When it came to disclosing, however, caregivers agreed that they needed help and support from a support group who could advise them and provide accurate information about HIV and how to treat it, combat stigma, and learn about healthy eating and other lifestyle choices (Heeren et al., 2012).

7.3. Conclusion

The aim of this chapter was to explore, discuss and interpret the thematic findings from chapter six of this research report. This chapter discussed several cross-cutting issues and themes which arose from chapter six, the thematic findings chapter. These cross-cutting issues included 1) the type of mother recruited, 2) mothering roles, mother blame and mothers' intuition, 3) access to resources, 4) poverty of knowledge on the NDM, 5) the passage of time, and 6) cultural practices. The theme section included discussions on six themes, namely, 1) future problems related to the context of experiences, 2) diagnostic experiences, 3) schooling problems, 4) support groups, and 5) disclosing diagnoses to children. This chapter showed how contexts within South Africa influenced mothers' experiences of raising their children. The chapter which follows is the concluding chapter of this research project and will provide a summary of this research project, as well as the limitations of the current study, and provide recommendations for the future.

Chapter Eight: Conclusions, limitations, and recommendations

8.1. Introduction

This research project explored the experiences that mothers had raising their autistic child in South Africa. This chapter provides a summary of the main findings of previous literature as well as the current research project. This chapter will also highlight the implications of the findings, the limitations of this current research, as well as recommendations for further research.

8.2. Summary of the study

Cridland et al. (2015) argued that there is a growing recognition of the importance of understanding the impact that ASD has on families. In addition, Porter (2010) explained that the context within which mothering occurs influences mothering and the experience thereof. For example, in South Africa, the needs of the majority of those with ASD are not met, due to poor governmental schooling services and poor professional diagnostic and treatment services in the public health sector for ASD children (Franz et al., 2018; Makombe et al., 2019). In addition, the high cost associated with private health care services for lengthy diagnostic and treatment options are uncomfortably coupled to the high rates of poverty, which affects caregivers' ability to pay out of their own pocket for services (Makombe et al., 2019). As the public health system is heavily overburdened, expensive private health services are often sought (Erasmus et al., 2019a). These factors and others would all affect the mothering experience.

As mothers typically fulfill the caregiving role for their children (Burman, 2017), this research focused exclusively on their experiences of mothering, as opposed to the more gender-neutral term, parenting. This research, therefore, aimed to explore the experiences of six mothers raising their autistic children in South Africa. It was the aim of this research to explore these experiences, in their own right and phenomenologically – and not to use a priori theory, as warned by Storey (2016), to 'test' to judge mothers according to psychological theory. Dominant medical, psychiatric, or deficit theoretical definitions of ASD were considered against neurodiversity challenges to provide some starting points and background, for mothering experience. This research had aimed to focus on EC mothers' experiences since much of the South African literature on experiences of raising an ASD child had been centred mostly around universities in the bigger urban centres. However, this research included two mothers from other provinces when there was no further interest from EC mothers through the gatekeeper's networks or through snowball sampling. As a result of this type of recruitment used, specific decisions were made to ensure the anonymity of each participant mother, following guidelines by Saunders et al. (2015). As a result, mothers, children, and third parties were not referred to by pseudonym, but rather neutral terms were used in "extracts", which prevented tracking identificatory markers. While this was somewhat unusual within IPA's value on contextualized meanings made of experience (Smith et al., 2009), this decision was deemed necessary to protect mothers' identities, their ASD children's identities, as well as identities of third parties, because the final research report would probably be distributed through the ASA website, network, and the study's participants.

Based on the qualitative IPA analysis, five themes were identified by me. These included 1) mothers learning that their child had a condition or receiving a diagnosis, 2) learning and sharing information about ASD, 3) sharing their mothering experience, 4) varying and multiple interventions and costs, and 5) the supportive resources that mothers drew on. Based on these findings, it can be concluded that mothers with ASD children experience many difficulties in their journey into the ASD lifeworld. The findings and discussion chapters indicated that contextual factors play a large role in determining this experience. Context and contextualized resources were also found to be an important consideration in a previous South African study by Guler et al. (2018), and variously assisted and hampered the early diagnosis, treatment intervention, and support of ASD in different communities.

Many of the participant mothers' experiences were scattered with references to traditional ideologies and beliefs about what it meant to be a 'good mother', resulting in experiences of self-blame. These traditional ideologies and beliefs have long determined the roles and responsibilities of mothers and fathers and are deeply entrenched within society. Due to these traditional ideologies and beliefs, mothers have typically been seen and act as their children's primary caregivers. As a result of this role, they developed an intuitive sense of what felt "right" and "wrong" when it came to their children and their development, due to their close attunement with their children. Mothers, more generally, can be said to have internalized this view that if something is 'wrong' with their child, they are to blame. This was found in the current study where mothers wished they could have been better mothers for their children and described regrets about their actions towards their child – the result of that failure being that their child would not have developed ASD.

As there is no confirmed aetiology (McKenzie & Dallos, 2017; Newschaffer et al., 2007), mothers in the current study hypothesized about many causes which made sense in their individual contexts. Initially, this thinking led to self-blame, that somehow mothers were responsible for their child's condition, which could be due to the traditional thinking that mothers are held responsible for their child's health. Mothers described an all-encompassing role that they had to fulfil – mother, wife, career woman, home caretaker. This all-encompassing role became too heavy or difficult when mothers did not have support from those around them. This included the limited resources available to mothers, regarding special needs care. It fell to mothers to cater to their children's needs, especially when much of the care available was privatized and expensive. This results in mothers having to cover the shortcomings of support and become homeschool teachers, conduct therapy exercises at home, as well as managing their children's special diets. Mothers in the current study described the high cost associated with their child – from the initial doctor's appointments to determining what was 'wrong', to the cost of schooling and interventions, and the multiple trips made between service providers. However, while mothers did cite some relief at having medical aid to help assist in paying for costs, medical aids did not cover all costs for their children, due to their restrictions, resulting in mothers paying out of pocket.

Most of the participant mothers struggled when it came to considering their children's futures. As suggested previously, this is in part due to the poor or limited resources for career options for differently-abled individuals, which could result in life-long dependence on parents. This life-long dependence could be further emphasized by the fact that ASD is a lifespan disorder (Matson et al., 2011; McKenzie & Dallos, 2017), and that there is no cure for ASD (Louw et al., 2013). The impact of this is that their children will never be 'normal' like others, who start their own families and homes. Since there is no cure for ASD, mothers tried multiple varying interventions from medical to OTC to lifestyle interventions, to help their children.

There was much difficulty reported by mothers about their experience with medical professionals in South Africa. These difficulties specifically related to the views that these mothers had about the medical professionals' lack of knowledge and willingness to diagnose. However, several other variables need to be considered, such as experience, professional expertise or training, the invisible nature of ASD, as well as an overburdened public health system. The invisible nature of ASD is emphasized since there is no single feature or behaviour checklist that can confirm or rule out ASD (Malcolm-Smith et al., 2013), nor are there biological or medical tests (McKenzie & Dallos, 2017). Symptoms and behaviours vary in severity and contingently in various domains and contexts. It can be seen how their medical professionals referred mothers to other medical professionals who had more clinical experience in diagnosing ASD, due to the very difficulties stated above.

8.3. Implications and significance of the findings

The findings of this study have shown that there are many difficulties that mothers experience in the raising of their autistic children in South Africa. By exploring these difficulties, it can be determined how mothers can be assisted in the future. This research may also assist ASA in planning and advocating for more resources to support mothers and parents, more generally, and by extension, their ASD children. The research findings may also be of help to participant mothers, as it shows that they are not alone in their journeys and that others in South Africa experience similar difficulties.

What this study found which was not expected is how mothers are still affected and influenced by traditional ideologies and beliefs on what it means to be a ‘good mother’. These patriarchal traditional ideologies impacted mothers’ beliefs about their ability to care for and raise their child, with many mothers emphasizing following their intuition. While it may have been naïve of me not to consider this feminist and social psychological perspective on patriarchy, I did not expect it to come through during interviews about how mothers experienced raising their children. Previous South African literature on ASD did not discuss these traditional views as a contextual societal factor that affects experiences of mothering.

Another unexpected finding was the difference in opinion mothers voiced regarding disclosing the ASD diagnosis to their children. I did not find and was unaware of any South African literature on the disclosure of ASD to children. The participant mothers had opposing opinions regarding disclosing, and different experiences on how they disclosed to their child. However, the differences between the mothers’ thoughts on disclosure showed that there is no right or wrong way to disclose ADS to a child. Thirdly, this study also revealed that the passage of time is an important factor to consider – mothers waited several years before receiving a diagnosis for their child, before working through their feelings about the diagnosis for a few more years, followed by the time it takes to learn about ASD. The ASD journey requires time for things to be worked out.

8.4. Limitations

A limitation of the current study is that the study sample was not representative of all mothers raising their ASD child in South Africa, given that the recruitment occurred through ASA, as well as snowballing. As explained previously, a certain type of mother responded via ASA networks and snowballing, i.e., mothers of high functioning ASD children and those from middle socioeconomic brackets, which is not representative of all the mothers in South Africa who are mothering their ASD children, where degrees of severity of symptoms and developmental age of the child would impact on the mothering experience. This study did not specifically limit inclusion to this type of mother (or by association, the ASD child) – these are the mothers who volunteered and agreed to participate.

While one criticism of IPA centres around the role that language plays when participants relay or "construct" their experience to researchers (Willig, 2013), this research had an inclusion criterion that all mothers had to be fluent in English. This meant that mothers were able to verbalize and use language to relay their experiences to me, the researcher.

8.5. Recommendations for ASA

The following recommendations to ASA are derived from the thematic findings chapter and discussion chapter of the current study:

- While ASA does campaign about neurodiversity on their Facebook page, there is a limited audience here, with not everyone who is affected by ASD following this online page. Therefore, a recommendation would be to offer more awareness about ASD and neurodiversity more generally, such as through medical professional practices, hospitals, or schooling. The neurodiversity movement takes a social justice stance in disability rights advocacy.
- There is a need for more parent education and awareness-raising programs regarding ASD symptoms and referral routes to follow. However, this should not be done with a one-size-fits-all model but should include a range of scenarios and symptoms and interactive referral-paths. This would include scaffolding the medical or specialist and auxiliary support hierarchies, explaining what different kinds of medical, psychological, and psychiatric professionals do in different domains of clinical experience and expertise so that parents do not have to struggle on their own to navigate this system and to find suitable services and support applicable to their particular child. This could be rolled out in schools (all types – private, government, LSEN), hospitals, and clinics, and it should include referral and access to alternative or complementary modalities to resist the hyper-medicalization (as a psychiatric DSM-disorder) of ASD.
- Offering online support groups could be a viable alternative to face-to-face support groups that physically meet. While mothers did explain that they joined support groups online, it was not clear whether these were South African or international support groups; or how they worked (e.g., closed, or open membership, contracting confidentiality or excluding members who broke rules of engagement). While ASA was using a WhatsApp support group for the EC, this support group is not easily accessible. Therefore, more information and awareness about Facebook or WhatsApp support groups are needed (which are tailored to specific kinds of ASD diagnosis), more generally, especially if parents are not actively a part of ASA.
- ASA could perhaps host workshops or talks on disclosure experiences, or alternatively, provide advice for mothers wanting to disclose to their children. This advice should include both that it is

fine to disclose, and that it is also fine not to disclose to their child; as well as suggesting ways in which to do this disclosure, should they wish to disclose.

8.6. Recommendations for future research

Based on the findings of this study, future research could focus on:

- How mothers understand their intuition and gut feelings they have when it comes to their children's issues, schooling, and interventions.
- Since there was no South African research found on the disclosure of their ASD diagnosis to children, future research could explore how, when, and why parents and mothers did or did not disclose their child's diagnosis to them.
- Future researchers could also examine and explore medical professionals' views about the diagnostic process and reveal their knowledge about and clinical experience with ASD.
- Since this study captured the experiences of those middle to high socioeconomic status families, a future study could explore the experiences of those from lower socioeconomic brackets.

8.7. Reflection on IPA

The use of IPA was appropriate for the current study, as the research aimed to focus on the experiences of mothers raising their ASD child. IPA also provided the potential for new and interesting insights to emerge (Brocki & Wearden, 2006), since it did not try to examine experiences according to psychological theories (Smith, 2017). Howard, Katsos, and Gibson (2019) argued that IPA is a suitable methodology for autism research since it may "illuminate autistic experience in a way that other qualitative approaches do not" (p.1874) since IPA does not aim to be generalizable. Furthermore, Smith (2004) explained that IPA is appropriate for researchers who wish to explore participants' personal and lived experiences in looking at how they make sense and make meaning from those experiences. This is what this current research project aimed to do.

This research study was my first exposure to conducting IPA research. I was unsure of the 'correct' procedures to follow, even though I had much literature written by Johnathan Smith and his colleagues. At times, I struggled with the vagueness of the guidelines – especially the thematic findings and discussion chapter. While Smith and colleagues (Pietkiewicz & Smith, 2014; Smith & Eatough, 2016; Smith et al., 2009; Smith & Osborn, 2003) explained that their guidelines were not meant to be prescriptive, I felt that I needed a bit more guidance than his guidelines provided. Fortunately, my supervisor was able to assist me and steer me in the right direction on how to conduct IPA research and provided much feedback and advice.

Like Wagstaff et al.'s (2014) critical reflections of problems with using an IPA approach, I also struggled and grappled with the shift from the individual to the shared, struggling to abandon the focus on the individual which I had considered to be a requirement of IPA. I felt as if the idiographic aspect of IPA was being left behind – the focus on the individual and their unique experiences was 'herded' into specific categories, in the search for common themes. This was also found to be the experience of a researcher within Wagstaff et al. (2014). However, I was able to move past this struggle once the participants were anonymized through the use of neutral terms and extracts numbered chronologically. Once this anonymization was complete, I was able to identify patterns and shared experiences more easily. Once the anonymization was complete, I was able to write about the common themes in an abstract way (and not identifying individual mothers) to protect mothers' and ASD children's identities while also conveying the complexity of their experiences and contexts.

8.8. Closing remarks and conclusion

The aim of this study was to explore the experiences of mothers raising their ASD children in South Africa. An IPA methodology was used in order to explore this mothering experience. This study found this mothering experience to be challenging in the South African context of poor access to resources, difficulty in accessing medical professionals willing to diagnose, long distances between facilities and medical professionals, poor governmental support, and the traditional ideologies and beliefs that surround being a 'good mother'.

These challenging contextual factors impacted mothers' experiences of the diagnostic process, determining appropriate interventions, the support they received, as well as their actual caregiving and mothering experience. Understanding and learning about ASD was also challenging for mothers, as they worked through multiple understandings of ASD and what it meant for their child. This mothering role that the participants fulfilled resulted in every aspect of their life being affected. To illustrate the all-encompassing nature of mothering and to emphasize the importance of research on mothering experiences, this research project will close with the following extract from one of the participant mothers:

> *Extract 186:*
> You need to be ready and understand that when I go into this route [mothering or parenting], I'm going with it with all my mind, with all my soul, with all my life.

Reference List

Akins, R., Angkustsiri, K., & Hansen, R. (2010). Complementary and Alternative Medicine in Autism: An Evidence-Based Approach to Negotiating Safe and Efficacious Interventions with Families. *Neurotherapeutics: The Journal of the American Society for Experimental NeuroTherapeutics, 7*(3), 307-319.

Alase, A. (2017). The Interpretative Phenomenological Analysis (IPA): A Guide to a Good Qualitative Research Approach. *International Journal of Education & Literacy Studies, 5*(2), 9-19.

Alli, A., Abdoola, A., & Mupawose, A. (2015). Parents' journey into the world of autism. *South African Journal of Child Health, 9*(3), 81-84.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). Arlington: American Psychiatric Publishing.

Archibald, M., Ambagtsheer, R., Casey, M., & Lawless, M. (2019). Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants. *International Journal of Qualitative Methods, 18*(1), 1-8.

Ascher, D. (2020). Coronavirus: 'Mums do most childcare and chores in lockdown'. *BBC News.* Retrieved July 28, 2020, from: https://www.bbc.com/news/business-52808930

Audley, S. E. (2020). *Autistic Representation in Television: A preliminary survey investigation* (Unpublished honours' thesis). Portland State University, Oregon.

Autism Society (USA). (2020). Asperger's Syndrome. *Autism Society.* Retrieved March 24, 2020, from https://www.autism-society.org/what-is/aspergers-syndrome/

Autism South Africa. (2020). Service Providers: Eastern Cape. *Autism South Africa.* Retrieved March 24, 2020, from: http://aut2know.co.za/eastern-cape/

Autism South Africa. (n.d.). Practical Guide to Autism Spectrum Disorder. *Autism South Africa.* Retrieved February 13, 2020, from http://aut2know.co.za/autism-library/autism-south-africa-booklets/

Awung, M., & Dorasamy, N. (2015). The impact of domestic chores on the career progression of women in higher education: the case of the Durban University of Technology. *Environmental Economics, 6*(4), 94-102.

Bailin, A. (2019). Clearing up some misconceptions about neurodiversity. *Scientific American.* Retrieved February 14, 2020 from https://blogs.scientificamerican.com/observations/clearing-up-some-misconceptions-about-neurodiversity/

Bakare, M., Ogomoh, A., Ebigbo, P., Eaton, J., Okonkwo, K., Onwukwe, J., & Onyeama, G. (2009). Etiological explanation, treatability and preventability of childhood autism: a survey of Nigerian healthcare workers' opinion. *Annals of General Psychiatry, 8*(1), 6-13.

Baker, A. E., Lane, A., Angley, M. T., & Young, R. L. (2008). The Relationship Between Sensory Processing Patterns and Behavioural Responsiveness in Autistic Disorder: A Pilot Study. *Journal of Autism and Developmental Disorders, 38*, 867-875.

Bakow, B. R., & Low, K. (2018). A South African Experience: Cultural Determinants of Ukuthwasa. *Journal of Cross-Cultural Psychology, 49*(3), 436-452.

Baron-Cohen, S. (2019). The concept of Neurodiversity is dividing the Autism community. *Scientific American.* Retrieved February 14, 2020, from https://blogs.scientificamerican.com/observations/the-concept-of-neurodiversity-is-dividing-the-autism-community/

Bateman, C. (2013). Autism - mitigating a global epidemic. *South African Medical Journal, 103*(5), 276-277.

Benjamin, E., Swartz, L., Chiliza, B., & Hering, L. (2016). Language barriers in health: lessons from the experiences of trained interpreters working in public health sector hospitals in the Western Cape. *South African Health Review, 1*, 73-81.

Bless, C., Higson-Smith, C., & Sithole, S. (2013). *Fundamentals of Social Research Methods* (5th ed.). Cape Town: Juta & Company Ltd.

Bray, R., Gooskens, I., Kahn, L., Moses, S., & Seekings, J. (2010). *Growing up in the new South Africa: Childhood and adolescence in post-apartheid Cape Town.* Cape Town: HSRC Press.

Brocki, J., & Wearden, A. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health, 21*(1), 87-108.

Bryman, A. (2012). *Social Research Methods* (4th ed.). New York: Oxford University Press.

Burman, E. (2017). *Bonds of love or losing attachment* (3rd ed.). New York: Routledge.

BusinessTech. (2018). Class sizes in public vs private schools in South Africa. *BussinessTech.* Retrieved February 10, 2021, from https://businesstech.co.za/news/government/259185/class-sizes-in-public-vs-private-schools-in-south-africa/

Chambers, N. J., de Vries, P. J., Delechanty, A. D., & Wetherby, A. M. (2018). Feasibility of Utilizing Autism Navigator® for Primary Care in South Africa. *Autism Research, 11*, 1511-1521.

Chawarska, K., Klin, A., Paul, R., Macari, S., & Volkmar, F. (2009). A prospective study of toddlers with ASD: short-term diagnostic and cognitive outcomes. *Journal of Child Psychology and Psychiatry, 50*(10), 1235-1245.

Clark, J. (2019). Asperger support group near me. *The Star Academy.* Retrieved January 19, 2021, from https://thestaracademy.co.za/asperger-support-group-near-me-2/

Clasquin-Johnson, M. G., & Clasquin-Johnson, M. (2018). 'How deep are your pockets?' Autoethnographic reflections on the cost of raising a child with autism. *African Journal of Disability, 7*(0), 1-8.

Coyle, D. (2014). Phenomenology. In A. McIntosh-Scott, T. Mason, E. Mason-Whitehead, & D. Coyle (Eds.), *Key Concepts in Nursing and Healthcare Research* (pp. 116-124). London: SAGE Publications Ltd.

Coyne, L. W., Gould, E. R., Grimaldi, M., Wilson, K. G., Baffuto, G., & Biglan, A. (2020). First Things First: Parent Psychological Flexibility and Self-Compassion During COVID-19. *Behaviour Analysis in Practice, 1*, 1-7.

Crane, L., Goddard, L., & Pring, L. (2009). Sensory processing in adults with autism spectrum disorder. *Autism, 13*(3), 215-228.

Crane, L., Jones, L., Prosser, R., Taghrizi, M., & Pellicano, E. (2019). Parents' views and experiences of talking about autism with their children. *Autism, 23*(8), 1969-1981.

Creswell, J. W. (2014). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (4th ed.). London: SAGE Publications Ltd.

Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2015). Qualitative research with families living with autism spectrum disorder: Recommendations for conducting semistructured interviews. *Journal of Intellectual & Developmental Disability, 40*(1), 78-91.

Crown, N. J. (2009). Parenting a Child with Disabilities: Personal Reflections. *Journal of Infant, Child, and Adolescent Psychotherapy, 8*(1), 70-82.

de Goede, J. (2019). Autism Support Groups. *Autism Resources South Africa.* Retrieved January 19, 2021, from https://www.autismresources.co.za/blogs/getting-started/autism-support-groups-in-south-africa

den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism, 23*(2), 271-273.

Desai, M., Divan, G., Wertz, F., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural Psychiatry, 49*(3-4), 613-637.

Deumert, A. (2010). 'It would be nice if they could give us more language' - Serving South Africa's multilingual patient base. *Social Science & Medicine, 71*(1), 53-61.

Divan, G., Vajaratkar, V., Desai, M., Strik-Lievers, L., & Patel, V. (2012). Challenges, Coping Strategies, and Unmet Need of Families with a Child with Autism Spectrum Disorder in Goa, India. *Autism Research, 5*, 190-200.

Dodds, S., & Hess, A. C. (2020). Adapting research methodology during COVID-19: lessons for transformative service research. *Journal of Service Management, 32*(2), 203-217.

Donohue, D., & Bornman, J. (2014). The challenges of realising inclusive education in South Africa. *South African Journal of Education, 34*(2), 1-14.

Dreyer, L. M. (2017). Constraints to quality education and support for all: A Western Cape case. *South African Journal of Education, 37*(1), 1-11.

Durkin, M., Elsabbagh, M., Barbaro, J., Gladstone, M., Happe, F., Hoekstra, R., . . . Shih, A. (2015). Autism Screening and Diagnosis in Low Resource Settings: Challenges and Opportunities to Enhance Research and Services Worldwide. *Autism Research, 8*, 473-476.

Dyck, E., & Russell, G. (2020). Challenging Psychiatric Classification: Healthy Autistic Diversity the Neurodiversity Movement. In S. Taylor, & A. Brumby (Eds.), *Healthy Minds in the Twentieth Century: In and Beyond the Asylum* (pp. 167-187). Cham, Switzerland: Palgrave MacMillan.

Eckerd, M. (2019). Disclosure of ASD Diagnosis to Children and Adolescents. *Journal of Health Service Psychology, 45*(1), 17-22.

Edwards, S. D. (2011). A Psychology of Indigenous Healing in Southern Africa. *Journal of Psychology in Africa, 21*(3), 335-347.

Erasmus, S., Kritzinger, A., & van der Linde, J. (2019a). Families raising children attending autism-specific government-funded schools in South Africa. *Journal of Family Studies*, 1-16.

Erasmus, S., Kritzinger, A., & van der Linde, J. (2019b). Profiles of public and private autism-specific schools in Gauteng. *South African Journal of Childhood Education, 9*(1), 1-9.

Fett-Conte, A. C., Bossolani-Martins, A. L., & Rosan, D. B. (2015). Etiology of Autism the Complexity of Risk Factors in Autism Spectrum Disorders. In M. Fitzgerald (Ed.), *Autism Spectrum Disorders - Recent Advances* (pp. 313-333). Rijeka, Croatia: IntechOpen.

Fewster, D., & Gurayah, T. (2015). First port of call: facing the parents of autism spectrum disorder. *South African Family Practice, 57*(1), 31-34.

Fiene, L., & Brownlow, C. (2015). Investigating Interoception and Body Awareness in Adults With and Without Autism Spectrum Disorder. *Autism Research, 8*, 709-716.

Fletcher, P., Markoulakis, R., & Bryden, P. (2012). The costs of caring for a child with an autism spectrum disorder. *Issues in Comprehensive Pediatric Nursing, 35*, 45-69.

Franz, L., & de Vries, P. (2019). *H*ow to offer support for young autistic children in South Africa. *Spectrumnews.org.* Retrieved February 14, 2020, from https://www.spectrumnews.org/opinion/viewpoint/offer-support-young-autistic-children-south-africa/

Franz, L., Adewumi, K., Chambers, N., Viljoen, M., Baumgartner, J. N., & de Vries, P. (2018). Providing early detection and early intervention for autism spectrum disorder in South Africa: stakeholder perspectives from the Western Cape province. *Journal of Child & Adolescent Mental Health, 30*(3), 149-165.

Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. (2017). Autism Spectrum Disorder in Sub-Saharan Africa: A Comprehensive Scoping Review. *Autism Research, 10*(5), 723-749.

Frosh, S. (2012). *A brief introduction to psychoanalytic theory.* New York: Palgrave Macmillan.

Germani, T., Zwaigenbaum, L., Bryson, S., Brian, J., Smith, I., Roberts, W., . . . Vaillancourt, T. (2014). Brief Report: Assessment of Early Sensory Processing in Infants at High-Risk of Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 44*, 3264-3270.

Gona, J., Newton, C., Rimba, K., Mapenzi, R., Kihara, M., van de Vijver, F., & Abubakar, A. (2015). Parents' and Professionals' Perceptions on Causes and Treatment Options for Autism Spectrum Disorders (ASD) in a Multicultural Context on the Kenyan Coast. *PLoS ONE, 10*(8), 1-13.

Gona, J., Newton, C., Rimba, K., Mapenzi, R., Kihara, M., Vijver, F., & Abubakar, A. (2016). Challenges and coping strategies of parents of children with autism on the Kenyan coast. *Rural Remote Health, 16*(2), 3517-3531.

Grinker, R., Chambers, N., Njongwe, N., Lagman, A., Guthrie, W., Stronach, S., . . . Wetherby, A. (2012). "Communities" in Community Engagement: Lessons learned from autism research in South Korea and South Africa. *Autism Research, 5*, 201-210.

Guler, J., de Vries, P. J., Seris, N., Shabalala, N., & Franz, L. (2018). The importance of context in early autism intervention: A qualitative South African Study. *Autism, 22*(8), 1005-1017.

Guy, B., & Arthur, B. (2020). Academic motherhood during COVID-19: Navigating our dual roles as educators and mothers. *Gender, Work, and Organisation, 27*(5), 887-899. doi:10.1111/gwao.12493

Hanna, P., & Mwale, S. (2017). 'I'm not with you, yet I am...': Virtual Face-to-Face Interviews. In V. Braun, V. Clarke, & D. Gray (Eds.), *Collecting Qualitative Data: A Practical Guide to Textual, Media and Virtual Technology* (pp. 256-274). Cambridge: Cambridge University Press.

Heeren, G. A., Jemmott III, J. B., Sidloyi, L., Ngwane, Z., & Tyler, J. C. (2012). Disclosure of HIV diagnosis to HIV-infected children in South Africa: Focus groups for intervention development. *Vulnerable Children and Youth Studies, 7*(1), 47-54.

Howard, K., Katsos, N., & Gibson, J. (2019). Using interpretative phenomenological analysis in autism research. *Autism, 23*(7), 1871-1876.

Huws, J. C., & Jones, R. S. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual and Developmental Disability, 33*(2), 99-107.

Jaarsma, P., & Welin, S. (2012). Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement. *Health Care Analysis, 20*(1), 20-30.

Jacobs, M. (1995). Major Contributions to Theory. In W. Dryden (Ed.), *Key Figures in Counselling & Psychotherapy: DW Winnicott* (pp. 27-63). London: SAGE Publications.

Jawad, A., Patel, D., Brima, N., & Stephenson, J. (2019). Alcohol, smoking, folic acid and multivitamin use among women attending maternity care in London: A cross-sectional study. *Sexual & Reproductive Healthcare, 22*, 1-8.

Jiang, X., Matson, J., Issarraras, A., & Burns, C. (2017). Stability of Autism Symptoms in Young Children. *Journal of Developmental and Physical Disabilities, 29*, 955-967.

Jones, C. R., Simonoff, E., Baird, G., Pickles, A., Marsden, A. j., Tregay, J., . . . Charman, T. (2018). The Association Between Theory of Mind, Executive Function, and the Symptoms of Autism Spectrum Disorder. *Autism Research, 11*, 95-109.

Jordaan, N. (2020). School closures 'regrettable and unjustifiable': SA Human Rights Commission. *HeraldLIVE*. Retrieved July 28, 2020, from https://www.heraldlive.co. za/news/2020-07-24-school-closures-regrettable-and-unjustifiable-sa-human-rights-commission/

Jowett, A. (2020). Carrying out qualitative research under lockdown – Practical and ethical considerations. *London School of Economics and Political Science Impact Blog* Retrieved May 06, 2020, from https://blogs.lse.ac.uk/impactofsocialsciences/ 2020/04/20/carrying-out-qualitative-research-under-lockdown-practical-and-ethical-considerations/

Kacprzak, K. (2017). From bad through good to excellent interpretative phenomenological analysis (IPA) studies - presenting set of criteria to evaluate papers and to provide high-quality future research. *Journal of Education, Culture and Society, 8*(2), 53-68.

Kamau, L. (2017). Autism Spectrum Disorders (ASD) in Kenya: Barriers Encountered in Diagnosis, Treatment and Management. *Journal of Research in Pharmaceutical Science, 3*(7), 01-11.

Kapp, S. (2019). How social deficit models exacerbate the medical model: autism as case in point. *Autism Policy & Practice, 2*(1), 3-28.

Kapp, S., Gillespie-Lynch, K., Sherman, L., & Hutman, T. (2013). Deficit, Difference, or Both? Autism and Neurodiversity. *Developmental Psychology, 49*(1), 59-71.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442-462.

Kern, J. K., Trivedi, M. H., Garver, C. R., Grannemann, B. D., Andrews, A. A., Savla, J. S., . . . Schroeder, J. L. (2006). The pattern of sensory processing abnormalities in autism. *Autism, 10*(5), 480-494.

Kruger, L.-M. (2006). Motherhood. In T. Shefer, F. Boonzaier, & P. Kiguwa (Eds.), *The Gender of Psychology* (pp. 182-197). Cape Town: UCT Press.

Kuhaneck, H., Burroughs, T., Wright, J., Lemanczyk, T., & Darragh, A. (2010). A Qualitative Study of Coping in Mothers of children with an Autism Spectrum Disorder. *Physical & Occupational Therapy in Pediatrics, 30*(4), 340-350.

Lamy, M., & Erickson, C. A. (2018). Pharmacological management of behavioural disturbances in children and adolescents with autism spectrum disorder. *Current Problems in Pediatric and Adolescent Health Care, 48*(10), 250-264.

Levin, M. (2006). Language as a barrier to care for Xhosa-speaking patients at a South African paediatric teaching hospital. *South African Medical Journal, 96*(10), 1076-1079.

Lloyd, S., Osborne, L., & Reed, P. (2019). Personal experiences disclosed by parents of children with Autism Spectrum Disorder: A YouTube analysis. *Research in Autism Spectrum Disorder, 64*, 13-22.

Louw, K.-A., Bentley, J., Sorsdahl, K., & Adnams, C. M. (2013). Prevalence and patterns of medication use in children and adolescents with autism spectrum disorders in the Western Cape, South Africa. *Journal of Child and Adolescent Mental Health, 25*(1), 69-79.

Ludlow, A., Skelly, C., & Rohleder, P. (2011). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology, 17*(5), 702-711.

Lutz, H., Patterson, B., & Klein, J. (2012). Coping with Autism: A Journey Toward Adaptation. *Journal of Pediatric Nursing, 27*, 206-213.

Mahloko, J. M., & Madiba, S. (2012). Disclosing HIV diagnosis to children in Odi district, South Africa: Reasons for disclosure and non-disclosure. *African Journal of Primary Health Care & Family Medicine, 4*(1), 1-7.

Makombe, C., Shabalala, N., Viljoen, M., Seris, N., de Vries, P., & Franz, L. (2019). Sustainable implementation of early intervention for autism spectrum disorder through caregiver coachings: South African perspectives on barriers and facilitators. *Pediatric Medicine, 2*(39), 1-13.

Makombe, G. (2017). An exposé of the relationship between paradigm, method and design in research. *The Qualitative Report, 22*(12), 3363-3382.

Malcolm-Smith, S., Hoogenhout, M., Ing, N., Thomas, K. G., & de Vries, P. (2013). Autism spectrum disorders - Global challenges and local opportunities. *Journal of Child and Adolescent Mental Health, 25*(1), 1-5.

Marais, P. (2016). "We can't believe what we see": Overcrowded classrooms through the eyes of student teachers. *South African Journal of Education, 36*(2), 1-10.

Martins, C., Walker, S., & Fouché, P. (2013). Fathering a Child with Autism Spectrum Disorder: An Interpretative Phenomenological Analysis. *Indo-Pacific Journal of Phenomenology, 13*(1), 1-19.

Matson, J. L., Rieske, R. D., & Tureck, K. (2011). Additional considerations for the early detection and diagnosis of autism: Review of available instruments. *Research in Autism Spectrum Disorders, 5*, 1319-1326.

Matuska, G., & Gallagher, A. (2020). The needs of people with intellectual disabilities and autism during the pandemic: Making the invisible visible. *Nursing Ethics, 27*(7), 1487-1489.

Mayo Clinic. (2020). Support groups: Make connections, get help. *Mayo Clinic*. Retrieved February 10, 2021, from https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/support-groups/art-20044655

Mazibuko, N., Shilubane, H. N., & Manganye, S. B. (2020). Caring for children diagnosed with autism spectrum disorder: caregivers' experiences. *Africa Journal of Nursery and Midwifery, 22*(2), 1-14.

McAuliffe, T., Thomas, Y., Vaz, S., Falkmer, T., & Cordier, R. (2019). The experiences of mothers of children with autism spectrum disorder: Managing family routines and mothers' health and wellbeing. *Australian Occupational Therapy Journal, 66*, 68-76.

McDougall, K., Swartz, L., & van der Merwe, A. (2006). *Zip Zip My Brain Harts.* Cape Town: HSRC Press.

McKenzie, J., Vergunst, R., Samuels, C., & Henkeman, T. (2020). The education of children with disabilities risks falling by the wayside. *University of Cape Town News*. Retrieved July 28, 2020, from https://www.news.uct.ac.za/article/-2020-05-28-the-education-of-children-with-disabilities-risks-falling-by-the-wayside

McKenzie, R., & Dallos, R. (2017). Autism and attachment difficulties: Overlap of symptoms, implications and innovative solutions. *Clinical Child Psychology and Psychiatry, 22*(4), 632-648.

Medical Brief. (2018). Africa Check puts together numbers on doctor-patient ratios. *Medical Brief: Africa's Medical Media Digest* Retrieved February 18, 2020, from https://www.medicalbrief.co.za/archives/africa-check-puts-together-numbers-doctor-patient-ratios/

Meiring, M., Seabi, J., Amod, Z., Vorster, A., & Kern, A. (2016). Transition for Adolescents with Autism Spectrum Disorder: South African Parent and Professional Perspectives. *Frontiers in Psychiatry, 7*(93), 1-6.

Mfutso-Bengo, J., Masiye, F., Molyneux, M., Ndebele, P., & Chilungo, A. (2008). Why do people refuse to take part in biomedical research studies? Evidence from a resource-poor area. *Malawi Medical Journal, 20*(2), 57-63.

Mitchell, C., & Holdt, N. (2014). The search for a timely diagnosis: Parents' experiences of their child being diagnosed with an Autistic Spectrum Disorder. *Journal of Child and Adolescent Mental Health, 26*(1), 49-62.

Mitchell, J. (2019). The danger of 'neurodiversity'. *The Spectator* Retrieved April 06, 2020, from https://www.spectator.co.uk/article/the-danger-of-neurodiversity-

Mithimunye, B. S., Roman, N. V., & Pedro, A. S. (2018). Factors which enhance or hinder meeting the educational needs of autistic children in Western Cape province, South Africa: A parents' perspective. *International Journal of Special Education, 33*(2), 279-294.

Mogensen, L., & Mason, J. (2015). The meaning of a label for teenagers negotiating identity: experiences with autism spectrum disorder. *Sociology of Health & Illness, 37*(2), 255-269.

Morse, J. (2000). Determining Sample Size. *Qualitative Health Research, 10*(1), 3-5.

Mthombeni, Z. C., & Nwoye, A. (2018). Black South African caregivers' understanding and responses to their children with autism spectrum disorder symptoms: a qualitative study. *South African Journal of Psychology, 48*(1), 99-111.

Myers, B., Mackintosh, V., & Goin-Kochel, R. (2009). "My greatest joy and my greatest heartache:" Parents' own words on how having a child on the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders, 3*, 670-684.

Nealy, C., O'Hare, L., Powers, J., & Swick, D. (2012). The Impact of Autism Spectrum Disorders on the Family: A Qualitative Study of Mother's Perspectives. *Journal of Family Social Work, 15*, 187-201.

Neely, A., & Ponshunmugam, A. (2019). A qualitative approach to examining health care access in rural South Africa. *Social Science & Medicine, 230*, 214-221.

Nene, J. O. (2014). The concept of traditional healing and its role in African modern society. *International Journal of Social Science and Human Behavior Study, 1*(1), 1-15.

Neuhauser, A. (2018). Predictors of maternal sensitivity in at-risk families. *Early Child Development and Care, 188*(2), 126-142.

Newschaffer, C. J., Croen, L. A., Daniels, J., Giarella, E., Grether, J. K., Levy, S. E., . . . Windham, G. C. (2007). The Epidemiology of Autism Spectrum Disorders. *Annual Review of Public Health, 28*, 235-258.

NGO Pulse. (2017). Pros and Cons: Public vs Private Schools. *NGO Pulse*. Retrieved February 23, 2021, from http://www.ngopulse.org/article/2017/01/19/pros-and-cons-public-vs-private-schools

Nicholas, D., Zwaigenbaum, L., Ing, S., MacCulloch, R., Roberts, W., McKeever, P., & McMorris, C. (2016). "Live It to Understand It": The Experiences of Mothers of Children With Autism Spectrum Disorder. *Qualitative Health Research, 26*(7), 921-934.

Niehaus, D., Oosthuizen, P., Lochner, C., Emsley, R., Jordaan, E., Mbanga, N., . . . Stein, D. (2004). A Culture-Bound Syndrome 'Amafufunyana' and a Culture-Specific Event 'Ukuthwasa': Differentiated by a Family History of Schizophrenia and other Psychiatric Disorders. *Psychopathology, 37*, 59-63.

Noon, E. J. (2018). Interpretive Phenomenological Analysis: An Appropriate Methodology for Educational Research? *Journal of Perspective in Applied Academic Practice, 6*(1), 75-83.

NSF Consulting. (2015). Unwillingness to answer. 4 reasons why people refuse to respond. *NSF Consulting.* Retrieved July 28, 2020, from http://nsfconsulting.com.au/4-reasons-for-survey-refusals/

Nwoye, A. (2015). African psychology and the Africentric paradigm to clinical diagnosis and treatment. *South African Journal of Psychology, 45*(3), 305-317.

Nyika, A. (2015). Mother tongue as the medium of instruction at developing country universities in a global context. *South African Journal of Science, 111*(1-2), 1-5.

Olivier, M. A., & Ah Hing, A. D. (2009). Autistic spectrum disorder (ASD): Parental challenges and strategies. *Vulnerable Children and Youth Studies, 4*(1), 58-66.

Ortega, F. (2009). The Cerebral Subject and the Challenge of Neurodiversity. *BioSocieties, 4*, 425-445.

Owren, T., & Stenhammer, T. (2013). Neurodiversity: accepting autistic difference. *Learning Disability Practice, 16*(4), 32-37.

Pearson, S. D. (1999). Principles of Generalist-Specialist Relationships. *Journal of General Internal Medicine, 14*(1), S13-S20.

Pedro, A., Mthimunye, B., & Bust, E. (2020). How lockdown could affect South Africa's children with special needs. *University of Western Cape News* Retrieved July 28, 2020, from https://www.uwc.ac.za/News/Pages/How-lockdown-could-affect-South-Africa%E2%80%99s-children-with-special-needs.aspx

Pietkiewicz, I., & Smith, J. (2014). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Psychological Journal, 20*(1), 7-14.

Pillay, J., & Di Terlizzi, M. (2009). A case study of a learner's transition from mainstream schooling to a school for learners with special education needs (LSEN): lessons for mainstream education. *South African Journal of Education, 29*, 491-509.

Porter, M. (2010). Focus on Mothering: Introduction. *Hecate, 36*(1/2), 5-16.

Rabba, A. S., Dissanayake, C., & Barbaro, J. (2019). Parents' experiences of an early autism diagnosis: Insights into their needs. *Research in Autism Spectrum Disorders, 66*, 101415.

Reading, A. (2018). Neurodiversity and Communication Ethics: How Images of Autism Trouble Communication Ethics in the Globital Age. *Cultural Studies Review, 24*(2), 113-129.

Reddy, G., Fewster, D. L., & Gurayah, T. (2019). PARENTS' VOICES: experiences and coping as a parent of a child with autism spectrum disorder. *South African Journal of Occupational Therapy, 49*(1), 43-50.

Richter, L. (2006). The importance of fathering for children. In L. Richter, & R. Morrell (Eds.), *Baba: Men and fatherhood in South Africa* (pp. 53-64). Cape Town: HSRC Press.

Roberts, A., Lyall, K., Rich-Edwards, J., Ascherio, A., & Weisskopf, M. (2013). Association of Maternal Exposure to Childhood Abuse With Elevated Risk for Autism in Offspring. *JAMA Psychiatry, 70*(5), 508-515.

Robertson, S. M. (2009). Neurodiversity, Quality of Life, and Autistic Adults: Shifting Research and Professional Focuses onto Real-Life Challenges. *Disability Studies Quarterly, 30*(1), 1-20.

Rodham, K., Fox, F., & Doran, N. (2015). Exploring analytical trustworthiness and the process of reaching consensus in interpretative phenomenological analysis: lost in transcription. *International Journal of Social Research Methodology, 18*(1), 59-71.

Runswick-Cole, K. (2014). 'Us' and 'them': the limits and possibilities of a 'politics of neurodiversity' in neoliberal times. *Disability & Society, 29*(7), 1117-1129.

Russell, G. (2020). Critiques of the Neurodiversity Movement. In S. Kapp (Ed.), *Autistic Community and the Neurodiversity Movement* (pp. 287-303). Singapore: Palgrave MacMillan.

Safe, A., Joosten, A., & Molineux, M. (2012). The experiences of mothers of children with autism: Managing multiple roles. *Journal of Intellectual & Developmental Disability, 37*(4), 294-302.

Sandler, S., & Rosenthal, M. (2015). Should parents tell their children they have Asperger's? *Autism Spectrum News.* Retrieved January 22, 2021, from https://autismspectrum news.org/should-parents-tell-their-children-they-have-aspergers/

Saunders, B., Kitzinger, J., & Kitzinger, C. (2015). Anonymising interview data: challenges and compromise in practice. *Qualitative Research, 15*(5), 616-632.

Scotland, J. (2012). Exploring the Philosophical Underpinnings of Research: Relating Ontology and Epistemology to the Methodology and Methods of the Scientific, Interpretive, and Critical Research Paradigms. *English Language Teaching, 5*(9), 9-16.

Smith, J. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*(1), 39-54.

Smith, J. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*(1), 9-27.

Smith, J. (2017). Interpretative phenomenological analysis: Getting at lived experience. *The Journal of Positive Psychology, 12*(3), 303-304.

Smith, J., & Eatough, V. (2016). Interpretative Phenomenological Analysis. In E. Lyons, & A. Coyle (Eds.), *Analysing Qualitative Data in Psychology* (2nd ed., pp. 50-67). London: Sage Publications Ltd.

Smith, J., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. Smith (Ed.), *Qualitative psychology: A practical guide to methods* (pp. 53-80). London: Sage Publications.

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research.* London: Sage Publications Ltd.

Springer, P., van Toorn, R., Laughton, B., & Kidd, M. (2013). Characteristics of children with pervasive developmental disorders attending a developmental clinic in the Western Cape Province, South Africa. *South African Journal of Child Health, 7*(3), 95-99.

Steiner, A. M., Goldsmith, T. R., Snow, A. V., & Chawarska, K. (2012). Practitioner's Guide to Assessment of Autism Spectrum Disorders in Infants and Toddlers. *Journal of Autism and Developmental Disorders, 42*, 1183-1196.

Steytler, J. R. (2019). *Homeschooling in South Africa: A multiple case study* (Unpublished masters thesis). University of KwaZulu-Natal, Durban.

Storey, L. (2016). Doing Interpretative Phenomenological Analysis. In E. Lyons, & A. Coyle (Eds.), *Analysing Qualitative Data in Psychology* (2nd ed., pp. 68-83). London: SAGE Publications Ltd.

Sutherland, J. (2006). 'Parenting' or 'mothering'? The case of modern childcare magazines. *Discourse & Society, 17*(4), 503-527.

Thanh, N. C., & Thanh, T. T. (2015). The Interconnection Between Interpretivist Paradigm and Qualitative Methods in Education. *American Journal of Educational Science, 1*(2), 24-27.

Tolmay, S., & Morna, C. L. (2020). Safeguarding women's rights during the Covid-19 shutdown. *Mail & Guardian*. Retrieved July 28, 2020, from https://mg.co.za/article/ 2020-03-24-safeguarding-womens-rights-during-the-covid-19-shutdown/

Tomchek, S. D., & Dunn, W. (2007). Sensory processing in children with and without autism: A comparative study using the Short Sensory Profile. *American Journal of Occupational Therapy, 61*, 190-200.

Tomlinson, E., & Newman, S. (2017). Valuing Writers from a Neurodiversity Perspective: Integrating New Research on Autism Spectrum Disorder into Composition Pedagogy. *Composition Studies, 45*(2), 91-112.

Tuli, F. (2010). The Basis of Distinction Between Qualitative and Quantitative Research in Social Science: Reflection on Ontological, Epistemological and Methodological Perspectives. *Ethiopian Journal of Education and Science, 6*(1), 97-108.

van Biljon, S., Kritzinger, A., & Geertsema, S. (2015). A retrospective case report on demographic changes of learners at a school for children with Autism Spectrum Disorder in the Gauteng Province. *South African Journal of Childhood Education, 5*(1), 42-61.

van Schalkwyk, G., Beyer, C., & de Vries, P. (2016). South Africa and Autism. In F. Volkmar (Ed.), *Encyclopedia of Autism Spectrum Disorders* (pp. 1-7). New York: Springer.

Vincent, K. A. (2012). The advantages of repeat interviews in a study with pregnant schoolgirls and schoolgirl mothers: piecing together the jigsaw. *International Journal of Research & Method in Education, 36*(4), 1-14.

Wagstaff, C., Jeong, H., Nolan, M., Wilson, T., Tweedlie, J., Phillips, E., . . . Holland, F. G. (2014). The accordion and the deep bowl of spaghetti: Eight researchers' experiences of using IPA as a methodology. *The Qualitative Report, 19*(24), 1-15.

Washington, K. (2010). Zulu Traditional Healing, Afrikan Worldview and the Practice of Ubuntu: Deep Thought for Afrikan/Black Psychology. *The Journal of Pan African Studies, 3*(8), 24-39.

Wayland, D., & GroundUp. (2019). South African men must do more housework, says Oxfam. *Times Live.* Retrieved July 28, 2020, from https://www.timeslive.co.za/news/south-africa/2019-09-03-south-african-men-must-do-more-housework-says-oxfam/

Westaway, A. (2012). Rural poverty in the Eastern Cape Province: Legacy of apartheid or consequence of contemporary segregationism? *Development Southern Africa, 29*(1), 115-125.

Wetherston, V., Gangat, S., Shange, N., Wheeler, K., Karrim, S. S., & Pahl, J. (2017). The views and knowledge of parents of children with autism spectrum disorder on a range of treatments. *South African Journal of Child Health, 11*(3), 117-121.

Wheeler, M. (2020). Getting started: introducing your child to his or her diagnosis of autism. *Indiana Institute on Disability and Community* Retrieved January 22, 2021, from https://www.iidc.indiana.edu/irca/learn-about-autism/getting-started-introducing-your -child-to-his-or-her-diagnosis-of-autism.html

Wigham, S., Rodgers, J., South, M., McConachie, H., & Freeston, M. (2015). The Interplay Between Sensory Processing Abnormalities, Intolerance of Uncertainty, Anxiety and Restricted and Repetitive Behaviours in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 45*(4), 943-952.

Wilbraham, L. (2009). Manufacturing willingness: parents and young people talking about sex in an HIV&AIDS epidemic. *South African Journal of Psychology, 39*(1), 59-74.

Willig, C. (2013). *Introducing qualitative research in Psychology* (3rd ed.). New York: Open University Press.

Woodgate, R., Ateah, C., & Secco, L. (2008). Living in a World of Our Own: The Experience of Parents Who Have a Child With Autism. *Qualitative Health Research, 18*(8), 1075-1083.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*(2), 215-228.

Appendix A – Gatekeeper Access Request

Dear Autism South Africa

My name is Aimee Hewson. I am a Master's by Thesis student at Rhodes University, under the supervision of Professor Lindy Wilbraham in the Psychology Department.

This serves as a formal request for your organisation to act as a gatekeeper for access to participants. The research topic is exploring the perceptions and experiences mothers have of mothering and raising their children who have been previously diagnosed with an autism spectrum disorder. We are wanting to hear about experiences, perceptions, coping mechanisms stories, difficulties and anything else they would like to share around their relationships and experiences with their children with autism.

There would be two interview stages – the first interview lasting about an hour and a half discussing these experiences, perceptions, coping mechanisms stories, difficulties and anything else mothers would like to share, while the second interview, conducted approximately a week after the initial interview, will be a shorter follow-up session, providing feedback, answering any questions, or following up on interview material from the initial interview. The interviews will be conducted at the participant's venue of choice.

We would like to use your organisation as a gatekeeper to recruit mothers of autistic children as participants. We would like you to send out the researcher's 'invitation to participate' letter to your network of caregivers, to allow any interested mothers' to voluntarily contact myself as the researcher. This research has a sample size of between four and six mothers.

Furthermore, as discussed informally, we would also like to get your permission for the participant mothers to access your suggested support groups, based in Queenstown, Port Elizabeth, and WhatsApp, should the mothers feel they need extra support.

This research has received ethical clearance from the Rhodes University Ethical Standards Committee, with tracking number 2019-0692-774, pending your approval as being a gatekeeper.

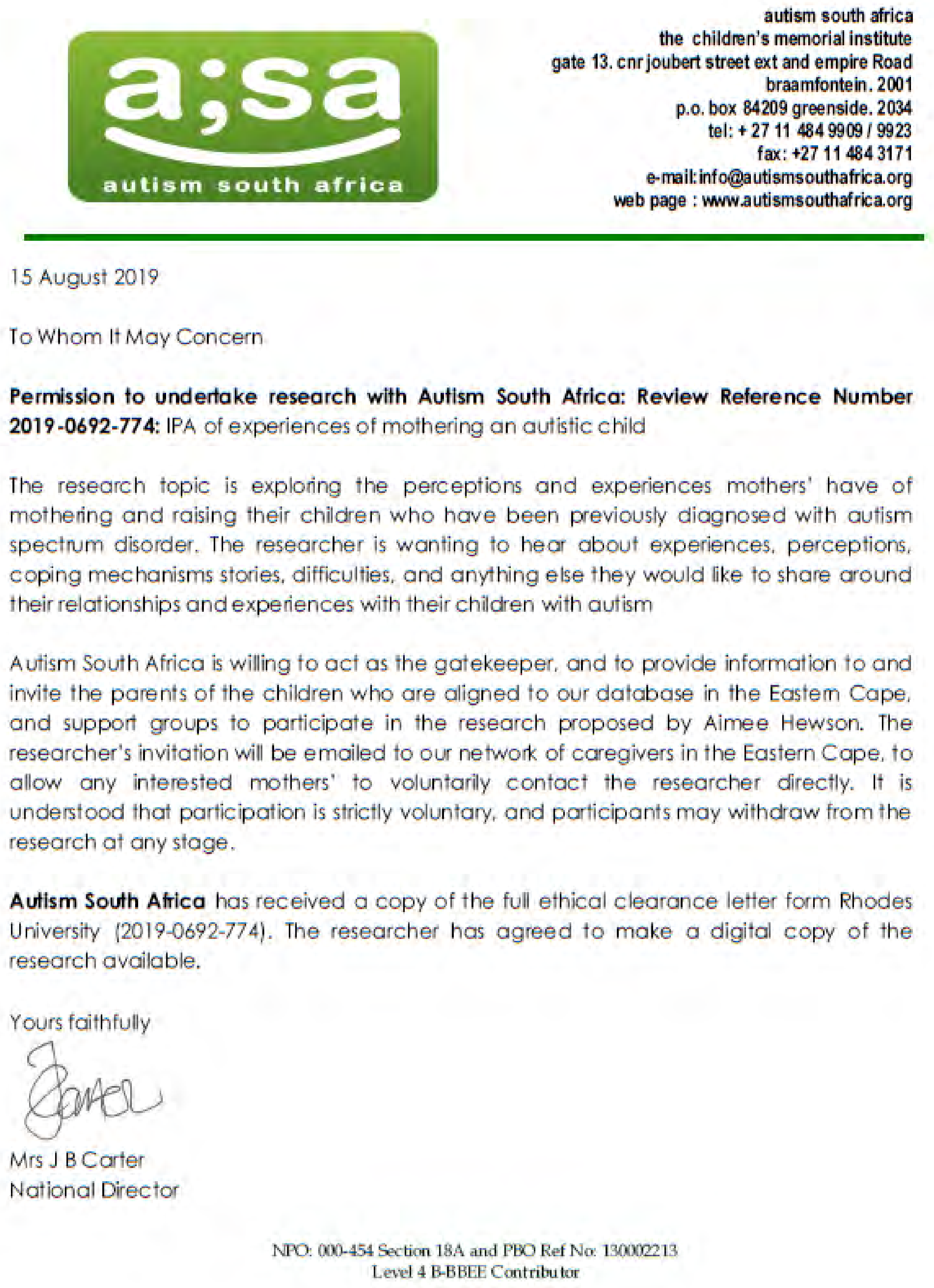
In addition, a copy of the final research project will be provided to you.

Should you have any other questions, please feel free to contact me via email (......) or via cell phone (…).

I look forward to hearing from you.

Kind regards,
Aimee Hewson

Appendix B – ASA Approval



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15 August 2019

To Whom It May Concern

Permission to undertake research with Autism South Africa: Review Reference Number 2019-0692-774: IPA of experiences of mothering an autistic child

The research topic is exploring the perceptions and experiences mothers' have of mothering and raising their children who have been previously diagnosed with autism spectrum disorder. The researcher is wanting to hear about experiences, perceptions, coping mechanisms stories, difficulties, and anything else they would like to share around their relationships and experiences with their children with autism

Autism South Africa is willing to act as the gatekeeper, and to provide information to and invite the parents of the children who are aligned to our database in the Eastern Cape, and support groups to participate in the research proposed by Aimee Hewson. The researcher's invitation will be emailed to our network of caregivers in the Eastern Cape, to allow any interested mothers' to voluntarily contact the researcher directly. It is understood that participation is strictly voluntary, and participants may withdraw from the research at any stage.

Autism South Africa has received a copy of the full ethical clearance letter form Rhodes University (2019-0692-774). The researcher has agreed to make a digital copy of the research available.

Yours faithfully

Mrs J B Carter
National Director

NPO: 000-454 Section 18A and PBO Ref No: 130002213
Level 4 B-BBEE Contributor

Appendix C – Invitation to participate in 2019

Rhodes University
Department of Psychology

Dear Potential Participant

I am a Master's student from the Department of Psychology at Rhodes University. I am under the supervision of Professor Lindy Wilbraham, of the Rhodes Psychology Department.

I would like to interview you to explore your experiences and perceptions of mothering and raising your child who has previously been diagnosed with an autism spectrum disorder. This is not a clinical interview, but rather a discussion about your experiences, perceptions, coping mechanisms, stories, and difficulties you have encountered in the raising of your child. There are no expected right or wrong answers – the aim is to explore your lived experiences.

I have received ethical approval from the Rhodes University Ethical Standards Committee, with tracking number 2019-0692-774 to conduct this research.

Should you agree to participate, I will conduct two interviews with you using a semi-structured interview schedule that should last approximately one and a half hours for the initial interview, followed by a second shorter follow-up interview. The interviews will take place at your venue of choice. Issues protecting your anonymity and confidentiality regarding the interview material will be addressed before starting the interview. You are free to withdraw at any stage of the process. There will be no adverse consequences should you decide to withdraw. Furthermore, you can ask questions at any stage of the research process.

Both your interviews will be recorded and transcribed. I will be transcribing the interviews, thus maintaining your anonymity and confidentiality. In addition to your anonymity, your child's information will also be kept anonymous. This transcribed material will be kept secure on a password-protected computer, while the recordings will be deleted.

During the second interview, you can receive feedback on the general themes I found in the first interview. At this stage, you can verify the meaning and edit your responses, should you wish to change anything.

You can receive a digital copy of the research project once it is completed, should you request it.

Should you be interested in participating, or have any further questions, please contact me on:

(email address) or (email address) / (cell phone number).

Thank you for considering participating in this study.

Aimee Hewson

Appendix D – Invitation to participate in 2020

Rhodes University
Department of Psychology

Dear Potential Participant

I am a Master's student from the Department of Psychology at Rhodes University. I am under the supervision of Professor Lindy Wilbraham, of the Rhodes Psychology Department.

I would like to interview you to explore your experiences and perceptions of mothering and raising your child who has previously been diagnosed with an autism spectrum disorder. This is not a clinical interview, but rather a discussion about your experiences, perceptions, coping mechanisms, stories, and difficulties you have encountered in the raising of your child. There are no expected right or wrong answers – the aim is to explore your lived experiences.

I have received ethical approval from the Rhodes University Ethical Standards Committee, with tracking number 2019-0692-774 to conduct this research.

Should you agree to participate, I will conduct two interviews with you using a semi-structured interview schedule that should last approximately one and a half hours for the initial interview, followed by a second shorter follow-up interview. The interviews will take place via Skype or Zoom due to the current COVID-19 pandemic. Issues protecting your anonymity and confidentiality regarding the interview material will be addressed before starting the interview. You are free to withdraw at any stage of the process. There will be no adverse consequences should you decide to withdraw. Furthermore, you can ask questions at any stage of the research process.

Both your interviews will be recorded and transcribed. I will be transcribing the interviews, thus maintaining your anonymity and confidentiality. In addition to your anonymity, your child's information will also be kept anonymous. This transcribed material will be kept secure on a password-protected computer, while the recordings will be deleted.

During the second interview, you can receive feedback on the general themes I found in the first interview. At this stage, you can verify the meaning and edit your responses, should you wish to change anything.

You can receive a digital copy of the research project once it is completed, should you request it.

Should you be interested in participating, or have any further questions, please contact me on:

(email address) or (email address) / (cell phone number).

Thank you for considering participating in this study.

Aimee Hewson

Appendix E – Informed consent

RHODES UNIVERSITY

DEPARTMENT OF PSYCHOLOGY

AGREEMENT BETWEEN STUDENT RESEARCHER AND RESEARCH PARTICIPANT

I ____________________________ agree to participate in the research project of Aimee Hewson on *mothers' experiences of raising their autistic child*.

I understand that:

1. The researcher is a student conducting the research as part of the requirements for a Master's degree at Rhodes University. The researcher may be contacted at … (cell phone number) or ... (email address) or … (email address). This research is under the supervision of Professor Lindy Wilbraham in the Psychology Department at Rhodes University, who may be contacted on … (office number) or ... (email address).

2. The research project has been approved by the Rhodes University Ethical Standards Committee, with tracking number 2019-0692-774. The contact details of the Ethics Coordinator, xxx, Ethics Coordinator, are … (office number) or … (email address) should I have any ethical issues I would like to report.

3. The researcher is interested in my perceptions and experiences I have raising my autistic child, who has been previously diagnosed. I understand that this is not a clinical or therapeutic study, but rather a study focusing on my lived experiences, coping mechanisms and difficulties I have encountered. I understand that this is not a clinical or assessment-based study and that there are no right or wrong answers.

4. My participation will involve two semi-structured interviews conducted by the researcher. The initial interview will last approximately one and a half hours discussing my experiences and perceptions, followed by a second shorter follow-up interview, conducted approximately a week after the initial interview, which will provide feedback, answer any questions, or following up on interview material from the initial interview.

5. Both interviews will be recorded for transcription purposes, and the audio recording (which will be password protected) will only be accessible to the researcher and the researcher's supervisor, during the transcription, to maintain my own, and my child's, anonymity, and confidentiality. The audio recordings will be deleted once they have been transcribed. I understand that only the transcriptions of my interviews, which will be anonymized, may be used in future presentations or studies by the researcher, supervisor, or Autism South Africa.

6. I can request feedback regarding the interviews, transcriptions, and interpretation thereof, and I may edit or delete any of the transcribed notes if what is said does not convey what I meant.

7. I can request a copy of the final research project.

8. I may be asked to answer questions of a personal nature, but I can choose not to answer any questions about aspects of my life which I am not willing to disclose.

9. I am invited to voice any concerns I have about my participation in the study, or consequences I may experience as a result of my participation, and to have these addressed to my satisfaction.

10. Should I feel I need extra support after the interviews, I can contact xxxx, a Speech Therapist running a support group at the Frontier Hospital in Queenstown (cell phone number); a support group in Port Elizabeth (still waiting for details); or I can ask the researcher to be added to the WhatsApp based support group currently run by the gatekeeper from Autism South Africa in the Eastern Cape. I can contact these support groups immediately or at any time in the future after the interview process. I can also contact these support groups should I feel the need to, once I have received the final copy of the research project.

11. I am free to withdraw from the study at any time, without a reason. There will be no adverse consequences following my withdrawal.

12. The report on the project may contain information about my personal experiences, attitudes, and behaviours, but that the report will be designed in such a way that it will not be possible that neither I nor my child will be identified by the general reader.

Signed on (Date): ______________________

Participant: ___________________________ Researcher: ____________________________

Appendix F – Addendum to informed consent

a;sa
autism south africa
Accepting | Empowering | Including | Supporting

For support in your area, please contact:

EASTERN CAPE
Antoinette Bruce-Alexander
072 678 2452
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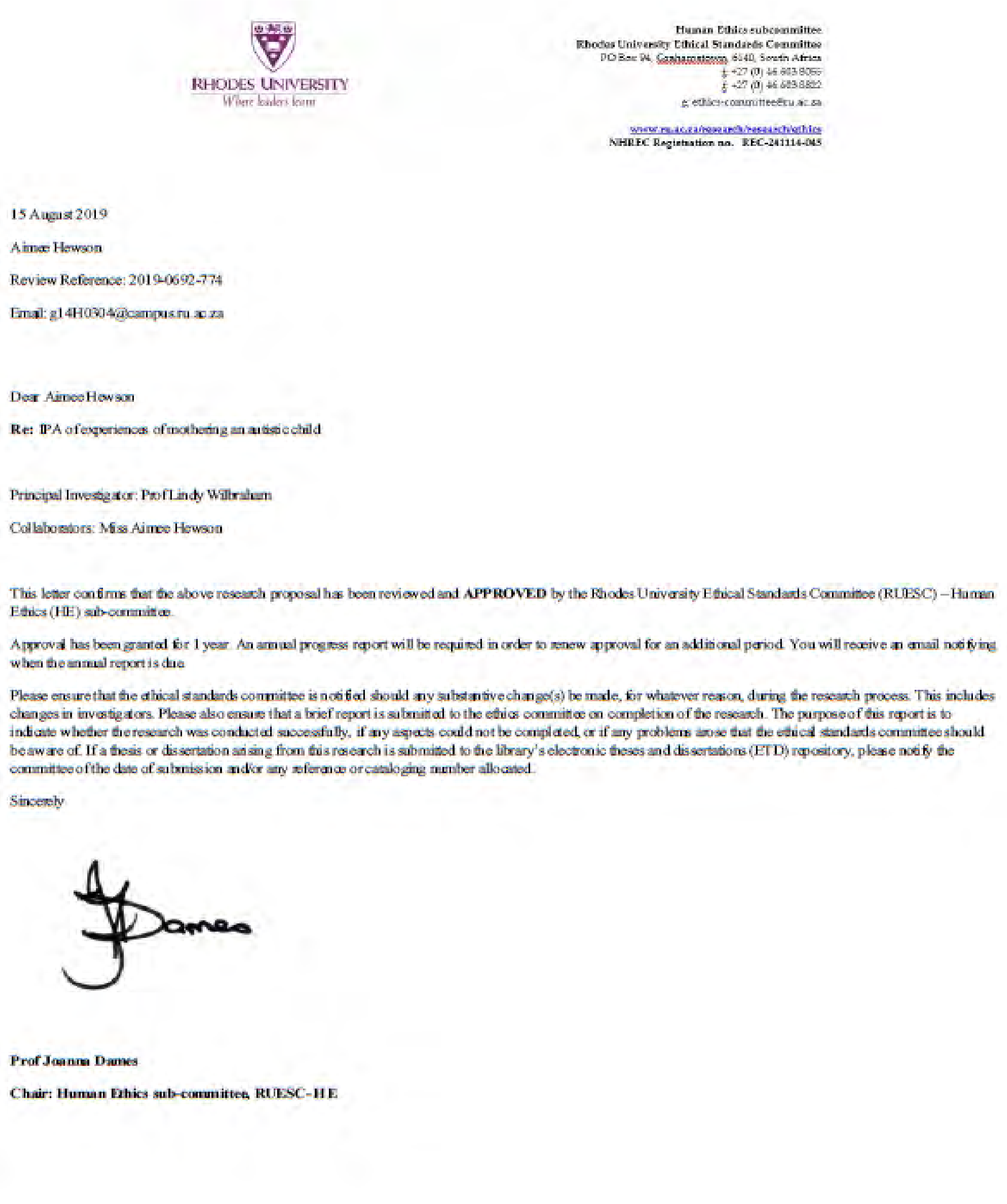
WWW.AUT2KNOW.CO.ZA | INFO@AUTISMSOUTHAFRICA.ORG | 011 484 9909

Appendix G – Semi-structured interview schedule

1. Could you give me a brief history of your ASD journey?
    a. For example, how did you / what led you to discover your child has ASD?
        i. What were the symptoms you identified / characteristics that led you to seek a diagnosis?
2. Could you describe what you understand by ASD?
    a. How has this changed from before to after diagnosis?
3. How do you feel about the ASD diagnosis?
4. On a day-to-day basis, what are some of the things you do for your child?
    a. How does this make you feel?
    b. Is there a daily set routine you follow?
        i. What happens if this routine is interrupted?
5. What are some of your coping mechanisms?
6. Do you think you experience more stress than other parents?
7. Would you be willing to share some stories about your child?
    a. Interesting things they have done or said?
    b. What is rewarding about having an autistic child?
    c. A difficult situation you found yourself in.
8. Do you currently use any treatment methods for your child?
    a. Medication or applied behaviour analysis?

Appendix H – Ethics Approval 2019



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Human Ethics subcommittee
Rhodes University Ethical Standards Committee
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www.ru.ac.za/research/research/ethics
NHREC Registration no. REC-241114-045

15 August 2019

Aimee Hewson

Review Reference: 2019-0692-774

Email: g14H0304@campus.ru.ac.za

Dear Aimee Hewson

Re: IPA of experiences of mothering an autistic child

Principal Investigator: Prof Lindy Wilbraham

Collaborators: Miss Aimee Hewson

This letter confirms that the above research proposal has been reviewed and **APPROVED** by the Rhodes University Ethical Standards Committee (RUESC) – Human Ethics (HE) sub-committee.

Approval has been granted for 1 year. An annual progress report will be required in order to renew approval for an additional period. You will receive an email notifying when the annual report is due.

Please ensure that the ethical standards committee is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators. Please also ensure that a brief report is submitted to the ethics committee on completion of the research. The purpose of this report is to indicate whether the research was conducted successfully, if any aspects could not be completed, or if any problems arose that the ethical standards committee should be aware of. If a thesis or dissertation arising from this research is submitted to the library's electronic theses and dissertations (ETD) repository, please notify the committee of the date of submission and/or any reference or cataloging number allocated.

Sincerely

JDames

Prof Joanna Dames

Chair: Human Ethics sub-committee, RUESC- HE

Appendix I – Ethics Approval 2020

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10 June 2020

Aimee Hewson

Review Reference: 2019-0692-774

Email: g14H0304@campus.ru.ac.za

Dear Prof Wilbraham

Re: IPA of experiences of mothering an autistic child

Principal Investigator: Prof Lindy Wilbraham

Collaborators: Miss Aimee Hewson

This letter confirms that the above research proposal has been reviewed and the amendments have been APPROVED by the Rhodes University Ethical Standards Committee (RUESC) – Human Ethics (HE). The approval was given to Covid19-compliant replacement methods, in this instance, snowballing sampling, a switch to online interviewing and revisions to IC documents.

Approval has been granted for 1 year. An annual progress report will be required in order to renew approval for an additional period. You will receive an email notifying when the annual report is due.

Please ensure that the ethical standards committee is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators. Please also ensure that a brief report is submitted to the ethics committee on completion of the research. The purpose of this report is to indicate whether the research was conducted successfully, if any aspects could not be completed, or if any problems arose that the ethical standards committee should be aware of. If a thesis or dissertation arising from this research is submitted to the library's electronic theses and dissertations (ETD) repository, please notify the committee of the date of submission and/or any reference or cataloging number allocated.

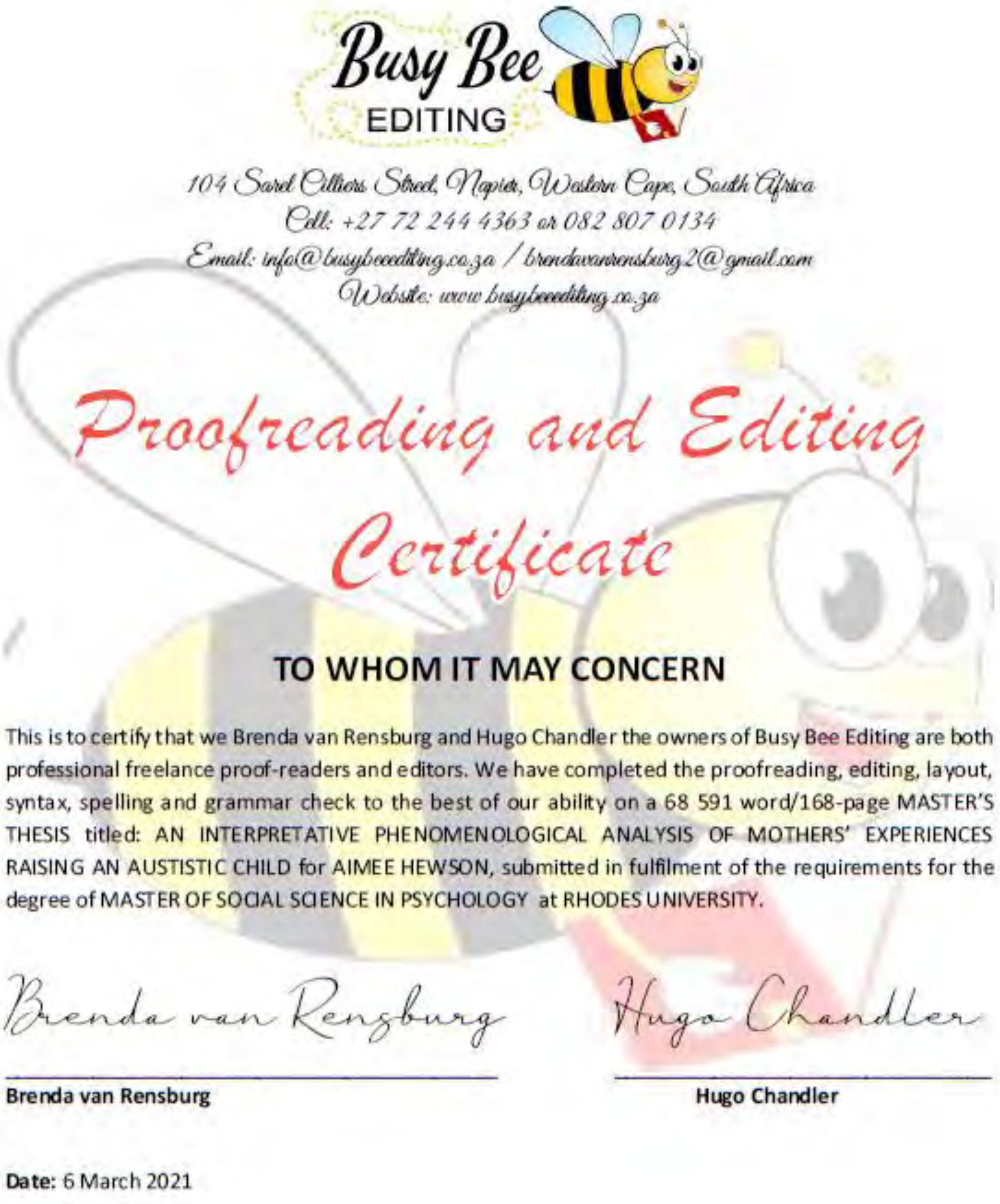
Sincerely,

Arthur Webb

Prof Arthur Webb
Chair: Human Ethics sub-committee, RUESC- HE

Note: The ethics committee cannot grant retrospective ethics clearance.

Appendix J – Proofreading Certificate



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Proofreading and Editing Certificate

TO WHOM IT MAY CONCERN

This is to certify that we Brenda van Rensburg and Hugo Chandler the owners of Busy Bee Editing are both professional freelance proof-readers and editors. We have completed the proofreading, editing, layout, syntax, spelling and grammar check to the best of our ability on a 68 591 word/168-page MASTER'S THESIS titled: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF MOTHERS' EXPERIENCES RAISING AN AUSTISTIC CHILD for AIMEE HEWSON, submitted in fulfilment of the requirements for the degree of MASTER OF SOCIAL SCIENCE IN PSYCHOLOGY at RHODES UNIVERSITY.

Brenda van Rensburg Hugo Chandler

Brenda van Rensburg **Hugo Chandler**

Date: 6 March 2021