Parenting a child with autism spectrum disorder (ASD) in the context of COVID-19 in South Africa: A qualitative study

by

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DECLARATION

By submitting this thesis, I declare that I understand what constitutes plagiarism, that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third-party rights, and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Autism spectrum disorder (ASD) is defined as a neurodevelopmental disorder characterised by restricted and repetitive behaviours, activities, and interests, as well as deficits in social communication. Even in ideal circumstances, parenting a child with ASD can be stressful and impact on emotional well-being due to these characteristics. The 2019 coronavirus pandemic (Covid-19) created a high degree of disturbance to the lives of parents raising a child with ASD. In order to help children with ASD deal with these challenges (unpredictable and complex changes), parents provided specialised support, encouragement, and access to activities that enabled them to master key developmental tasks. It was crucial to investigate the challenges faced by parents raising a child with ASD in South Africa during the pandemic as there was a paucity of literature on the matter. In this qualitative study, I aimed to explore parents' experiences of parenting a child with ASD in South Africa in the context of Covid-19 in order to determine challenges they faced and how they coped with these.

To answer my research question and address my objective, I conducted semi-structured interviews with a total of 23 parent participants (raising children with ASD between the ages of 6 and 12), all of whom provided written informed consent for this. The participants were assured of their anonymity. The interviews took place telephonically or online via Zoom meetings and were audio-recorded using a Dictaphone. I transcribed the interviews verbatim, subsequently analysing the data engendered thematically, using ATLAS.ti version 9. By using thematic analysis, I identified four themes and 12 subthemes that provided insight into the parents' experiences.

The four main themes were as follows: Pandemic challenges- restrictions, routines and remote working, parenting and interpersonal relationships in conditions of confinement, help-seeking and sources of support, finding ways to cope amidst a crisis. The main finding was that parenting a child with ASD during lockdown was complicated and challenging. Indeed, parents reported that their children faced many challenges when it came to adhering to disease containment measures such as the lockdown itself and mask-wearing, social distancing, and hand sanitising. These measures required explanation from parents to children. In terms of interpersonal relationships at home, parent-child ones were affected in a negative or positive manner, given that the family spent more time together. Parents faced challenges balancing their work or house duties against the needs of their children, especially those who were on the frontline of the pandemic such as healthcare workers. Even though

some parents enjoyed support during the pandemic, all parents highlighted the need for additional help. While some used adaptive coping strategies, others took to maladaptive ones such as substance abuse, isolation, and overeating, which impacted them and their child negatively. These findings provide initial evidence that parents of children with ASD in South Africa need additional support in order to effectively manage the Covid-19 pandemic. Future research could include the experiences of raising adolescents with ASD in the context of Covid-19 in South Africa. Moreover, future research might focus on assessing the emotional well-being and stress of parents of children with ASD – and under different levels of restriction.

OPSOMMING

Outisme-spektrumsindroom (OSS) word gedefinieer as ‘n neuro-ontwikkelingsindroom wat gekenmerk word deur herhalende gedrag, -aktiwiteite, en -belangstellings asook gebrekkige sosiale kommunikasie. Selfs onder ideale omstandighede is die ouerskap van ‘n kind met OSS stresvol en het dit ‘n impak op welstand weens die genoemde eienskappe daarvan. Die koronaviruspandemie van 2019, Covid-19, het ‘n hoë mate van versteuring meegebring aan die lewens van ouers wat ‘n kind met OSS grootmaak. Om hierdie kinders te help om hierdie uitdagings tegemoet te kom, veral met betrekking tot onvoorspelbare en komplekse uitdagings, het ouers gespesialiseerde ondersteuning, bemoediging, en toegang gebied, ook met betrekking tot aktiwiteite wat hulle in staat gestel het om sleutelontwikkelingstake te bemeester. Dit was van kardinale belang om die uitdagings wat hierdie ouers in die gesig gestaar het, te ondersoek, aangesien daar min literatuur was wat hierop gefokus het. In hierdie kwalitatiewe studie het ek gepoog om ouers se ervarings rondom die grootmaak van ‘n kind met OSS in Suid Afrika binne die konteks van Covid-19 te ondersoek om sodoende die uitdagings wat hulle in die gesig gestaar het en hoe hulle dit hanteer het, te ondersoek.

Met die oog daarop om my navorsingsvraag te beantwoord en my doelwit te bereik, het ek semi-gestruktureerde onderhoude gevoer met 23 deelnemers wat besig was om kinders met OSS tussen die ouderdomme van ses en 12 groot te maak, waarvan elkeen geskrewe toestemming hiervoor verleen het. Die deelnemers is verseker daarvan dat hulle anoniem sou bly. Die onderhoude is telefonies of aanlyn gevoer deur middel van Zoomvergaderings en is opgeneem deur van ‘n Diktafoon gebruik te maak. Ek het die onderhoude verbatim herskryf, waarna ek die data wat so gegenereer is tematies geanaliseer deur gebruik te maak van ATLAS.ti weergawe 9. Deur middel van tematiese analise het ek vier temas en 12 subtemas geïdentifiseer wat insig gebied het rondom ouers se ervaringe.

Die vier hooftemas is soos volg: pandemie-inperkings, roetines en afstandswerk, ouerskap en interpersoonlike verhoudings onder ingeperkte omstandighede, die soeke na hulp en bronne van ondersteuning, en maniere waarop hanteer kan word te midde van ‘n krisis. Die hoofbevinding was dat die grootmaak van ‘n kind met OSS gedurende die grendelstaat ingewikkeld was en aansienlike uitdagings gebied het. In der waarheid het ouers gerapporteer dat hulle kinders heelwat uitdagings in die gesig gestaar het rondom die nakoming van die siektebeperkende maatreëls soos die grendelstaat self en die dra van maskers, die handhawing van sosiale afstand, en die sanitering van hande. Hierdie maatreëls het heelwat verduideliking

geverg van die ouers aan die kinders. Met betrekkking tot interpersoonlike verhoudings tuis is ouerkind verhoudings negatief of positief geaffekteer, aangesien die gesin meer tyd saam spandeer het. Ouers het dit as ‘n uitdaging ervaar om hulle werks- en huistake te balanseer met die behoeftes van hulle kinders, veral daardie ouers wat in die voorste linie van die pandemie gedien het, byvoorbeeld gesondheidswerkers. Al sou sommige ouers ondersteuning geniet tydens die pandemie, het al die ouers die behoefte aan ekstra hulp beklemtoon. Terwyl sommige ouers aanpasbare coping-strategieë aangewend het, het ander ook nie-aanpasbare strategieë aangewend, byvoorbeeld die misbruik van middele, isolasie, en die neiging om te veel te eet. Dit het hulle en hulle kind negatief beïnvloed. Hierdie bevindinge bied ‘n aanvanklike bewys daarvan dat ouers van kinders met OSS in Suid-Afrika bykomende ondersteuning benodig om ‘n Covid-19 pandemie of soortgelyke situasie behoorlik te bestuur. In die toekoms behoort navorsing die ervaringe rondom die grootmaak van adolessente met OSS in ‘n soortgelyke konteks te bestudeer. Bowendien mag toekomstige navorsing fokus op die assessering van die emosionele gesonheid en stres van ouers met kinders wat aan OSS lei, veral ten opsigte van verskillende vlakke van inperking.

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Firstly, I would like to thank my older brother who is now in heaven. Without his peace, strength, and courage, I would not have been where I am today. Secondly, I would like to thank my supervisor, Bronwyne Coetzee, for her guidance and support from the beginning of this journey. She provided criticism where it was due and encouragement when it was needed. She motivated me to look beyond what was in front of me and really immerse myself in my work and my contribution to the broader field of knowledge. Thank you for your understanding and grace. Thirdly, I would like to thank my parents. Without them it would not have been possible for me to complete a master’s degree. I thank them for always believing in me and for encouraging me to never give up. I would like to thank the Facebook group administrators who allowed me to recruit participants through their community, and the participants themselves. I thank them for sharing their experiences with me and taking time out of their schedules to participate in the project. What they shared was insightful and will contribute greatly to this field of study. Lastly, I would like to thank my siblings for offering their support.

ABBREVIATIONS

ADHD	Attention-deficit/ hyperactivity disorder
ASD	Autism spectrum disorders
DESC	Department ethics screening committee
DSM V	Diagnostic and Statistical Manual of Mental Disorders (Fifth edition)
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision
CDC	Centre of Disease Control
Covid-19	Coronavirus
GI	Gastrointestinal
ICD-10	International Classification of Diseases and Related Health Problems (10th revision).
MKO	More knowledgeable other
OT	Occupational therapy/ therapist
PET	Parent education and training
WHO	World Health Organization
REC	Research Ethics Committee
REC: SBE	Research Ethics Committee: Social Behavioural and Education Research
SSRI	Selective serotonin reuptake inhibitors
ZPD	Zone of proximal development

GLOSSARY OF TERMS

Disability	A physical or psychological impairment that makes it difficult to perform certain activities and/ or interact with the world around the person with the disability.
Impairment	A decline in the functioning of the physical body or psychological functioning.
Lockdown	A state of isolation or restricted access instituted as a security measure.
Mainstream	A school that includes learners with barriers to learning in a classroom with children who do not have those barriers.
Meltdown	A long-lasting, emotional breakdown in a child with ASD, usually when over-stimulated or when experiencing a build-up of anxiety or other factors, resulting in a large-scale tantrum.
Neurodiverse	Individuals of atypical developmental, intellectual, and cognitive abilities.
Neurotypical	Individuals of typical developmental, intellectual, and cognitive abilities.
Pandemic	A disease *outbreak* that spreads across countries or continents.
Parenting	The activity of bringing up a child as a parent.
Routine	A customary or regular course or procedure.
Tantrums	Unpleasant and disruptive behaviours or emotional outbursts.

CHAPTER 1

ASD is neurodevelopmental in nature (Gillberg, 2010). The American Psychological Association (APA) described ASD as a disorder that encompasses deficits in social communication along with repetitive, restricted patterns of behaviour, interests, or activities according to (APA, 2013). It can reliably be diagnosed as early as age two; however, most children are diagnosed after the age of four (Mash & Wolfe, 2019). The diagnosis of ASD has dramatically increased worldwide according to the Centre for Disease Control and Prevention (CDC). It is estimated that one in 54 children around the globe has been diagnosed with ASD (CDC, 2020). It happens on average four times less often in girls when compared with boys and occurs in all racial, ethnic, and socio-economic groups (Bateman, 2013). Actually, in South Africa, little data if any are available on the prevalence of ASD (Malcolm-Smith et al., 2013). However, it is estimated that one in every 100 children is born with ASD within this country (Bateman, 2013). Many parents are raising a child with ASD in South Africa despite the shortage of prevalence data (Schlebusch, 2016).

Using the term “autism”, Kanner described a child who presented with repetitive behaviours, an absence of language and social interest from infancy, a resistance to change as well as a need for sameness (Kanner, 1943; Volkmar et al., 2012). Hans Asperger observed that several children presented the behaviours defined by Kanner, whereas they could communicate effectively, which led to the term “Asperger’s syndrome” (Asperger, 1991). The latter forms part of the new ASD diagnosis and is no longer held to be a separate diagnosis (Verhoeff, 2013). In this study, I investigated the experiences and challenges of parents raising a child with ASD on different levels of the spectrum, however I refer to all children as children with ASD in order to keep with the new terminology.

Parenting practices around the world share three major goals: transmitting cultural values, ensuring children’s health and safety, and preparing them for life as productive adults (Abraham, 2017). For children with ASD to function successfully in society, parents play a crucial role in developing the essential skills they need. However, in countries where numerous support services are limited, parenting a child with ASD is a stressful and challenging experience (Shattnawi et al., 2020; Wang et al., 2021). For healthy development of the child, a high-quality parent-child relationship is critical (Abraham, 2017). In South Africa, parents face a range of challenges, including poverty which, in particular, constitutes

a risk to optimal parenting (Schlebusch, 2016). The lack of financial resources affects the ability of parents to
provide nutrition, health care and education, which makes parenting itself considerably more difficult (Schlebusch, 2016).

As established by Statistics South Africa in 2019, about 20% of all children in this country did not live with their parents, while 33% lived with both. Most children, however, lived only with their mothers (42.0%), while a much smaller percentage (4,0%) lived only with their fathers (Statistics South Africa, 2019). Furthermore, 15% of households contained three generations, while 4.5% were skip-generation households in which grandparents lived alone with their grandchildren (Statistics South Africa, 2019). Parenting typically-developed children is challenging; taking care of a child with ASD increases general stress levels (Cohrs & Leslie, 2017; Estes et al., 2012; Hayes & Watson 2013). The challenges are engendered by various factors, including mental health comorbidities, the intensive interventions needed, the chronicity and severity of the condition, and the difficulty obtaining services (Barroso et al., 2018; Bonis, 2016; Costa, et al., 2017). In South Africa, socioeconomic challenges place a significant further burden on most parents and is likely to be intensified amongst those raising children with ASD (Schlebusch, 2016).

In 2018, the South African unemployment rate was around 26.9%, which increased to 28.5% in 2020 (Plecher, 2020). Due to this high unemployment rate, a tremendous financial burden was placed on many parents, including those with children with ASD (Schlebusch, 2016). In traditional African families, limited financial resources were allocated towards disability related services (Schlebusch, 2016). Additional parenting skills and support are required for a child with ASD to flourish (Shattnawi et al., 2020). At present, and likely for some time still to come, the world is challenged by a serious and devastating global pandemic (WHO, 2021). In 2020, the World Health Organisation (WHO) declared Covid-19 to be a global pandemic (WHO, 2021). In fact, in October 2021, 240 million cases were confirmed around the world and more than 4.8 million deaths were reported across almost 200 countries (WHO, 2021). In South Africa, in October 2021, 3 million cases were confirmed and 88 506 reported (WHO, 2021).

Covid-19, designated SARS-Cov-2, is caused by a novel virus that results in many symptoms such as severe respiratory illness, coughing, shortness of breath, sore throat, and/or fever (Manning, 2020). Reported illnesses have ranged from infected people with little to no symptoms to people who were severely ill and dying (WHO, 2021). The spread of the disease is thought to occur mainly via respiratory droplets (WHO, 2021). To date, there is no specific antiviral treatment available, thus a vaccine was designed to provides immunity against the virus while preventing severe symptoms and death (WHO, 2021). In South Africa, the national Covid vaccination program was officially rolled out in February 2021 (Department of Health, 2021). The virus has rapidly spread due to person-to-person transmission. South Africa has confirmed its first case of Covid-19 on the 6th of March 2020 (Department of Health, 2020). On the 15th of March 2020, the Covid-19 pandemic was declared a national disaster by President Cyril Ramaphosa (Department of Health, 2020).

On the 27th of March 2020, the first day of the 21 days of stay-at-home lockdown was announced, which was then extended to flatten the curve of the spreading of the disease in order to prevent a surge of cases (Department of Health, 2021). Subsequently, the country oscillated through various stages and alert levels of lockdown (see appendix A) (Department of Health, 2020). Only essential-services sectors were permitted to provide the necessities of life for everyone, such as medicine, food, fuel, healthcare, energy, internet, banking, and municipal services during lockdown (Department of Health, 2021). In fact, large gatherings were banned to stop the spread of the virus: therefore, workplaces, universities, schools, boarders, and all other non-essential institutions were closed (WHO, 2021). Public entertainment ceased, leaving space for home isolation, and enforced quarantine (WHO, 2021). No alcohol or cigarette sales were allowed during the lockdown in South Africa (Department of Health, 2020). The government opened applications for a special Covid-19 social grant, and individuals who could work remotely from home, did (Department of Health, 2020).

Medical facilities found themselves under increasing pressure (WHO, 2021). Individuals were asked to wear masks and maintain social distancing in order to curb the spread of the virus. On the 13th of January 2021, the government said it had arrested 7 000 people since the end of that December for not wearing face masks (Department of Health, 2021). Citizens were required to wash their hands often, avoid touching their eyes, nose, and mouth with unwashed hands, and clean as well as disinfect frequently touched objects and surfaces (WHO, 2021). Individuals who were tested positive for Covid-19 were urged to keep a distance from others at home and had to isolate when hospitalisation was not necessary (WHO, 2021). Hospitalised individuals were not allowed to receive visits from family or/ and friends. In December 2020, the South African variant that carried a mutation called N501Y, which appeared to make the Covid-19 more contagious, was discovered by scientists, which increased stress in the South African population (Department of Health, 2021).

The Covid-19 outbreak, and concomitant restrictions impacted on people's lives, income and employability resulted in higher levels of psychological distress among the general population and, most importantly, among people suffering from a pre-existing mental health condition such as young individuals with ASD (Manning, 2020). Studies conducted amongst parents with children on the autism spectrum have demonstrated various challenges of parenting a child with ASD during the pandemic (Alhuzimi, 2020; Chen, 2020; Colizzi et al., 2020; Latzer et al, 2021; Manning, 2020). The main challenges identified in various studies were increased parental responsibilities, lack of special education services as well as changes in routine (Alhuzimi, 2020; Colizzi et al., 2020; Latzer et al., 2021; Manning, 2020). For example, in Italy, using an online parent survey, the behavioural and psychosocial impact of Covid-19 in children with ASD was explored in a study conducted by Colizzi et al. (2020). The findings showed that parents had to deal with potential health threats, work from home and, for some, cope with increasing financial pressures, all this while taking the role of being both full-time teachers and caregivers (Colizzi et al., 2020).

During the Covid-19 lockdown, in Tel-Aviv, the experiences of parents of children with ASD were examined, according to a study by Latzer et al. (2021). The findings revealed that various children with ASD experienced worsening in behavioural symptoms, including a lessening in social motivation, bursts of anger, and important disruptions around sleep and food (Latzer et al., 2021; Bruni et al., 2021). In contrast, some children benefitted from these changing conditions, experiencing positive improvements in their life skills as well as an increase in positive mood, according to a study by Cooke et al (2020), conducted in Ireland. The ways in which parents coped during this time influenced children's success or failure (Latzer et al., 2021). The key factor that facilitated effective coping was parents' capacity to respond to their child's needs (Latzer et al, 2021).

1.1. Motivation for the present study

Given the shortage of available studies on parenting a child with ASD in the context of Covid-19 in South Africa, there is a necessity to elucidate these experiences. Previous studies mainly investigated the stress experienced by parents raising a child with ASD (Keenan et al., 2016; Shepherd et al., 2018; Wayment & Brookshire, 2018). Moreover, the majority of the studies on parents of children with ASD who cope with crisis centre on the crises they faced upon receiving their children's diagnosis (Lappe et al.,2018; MacPhee et al., 2015; Yeager,2015; Weiss et al.,2014). There is a lack of studies investigating the coping of children with ASD and parents regarding life crises. In fact, there is a considerable lacuna or set of gaps in extant literature. This present study will write into this lacuna.

Furthermore, most studies have been conducted in high-income countries such as the United States, Italy, Saudi Arabia, and Israel, where socio-economic contexts are different from South Africa's (Alhuzimi, 2020; Colizzi et al., 2020; Latzer et al., 2021; Manning, 2020). A recent search in extant literature (October 2021) showed that little, if any, studies that address parenting children with ASD in the context of Covid-19 have been conducted in developing countries such as South Africa. The knowledge gained in this study will therefore serve as a critically important guide for parents to respond to the needs of their children and assist specialists to support parents and their children with ASD adequately in the context of a pandemic.

Extant studies demonstrate that parents of children with ASD experience elevated psychological distress and caregiving burdens such as health-related problems, lower levels of resilience, and problems around marital and sibling relationships (Estes et al., 2012; Fairthorne et al.,2016, Meadan et al., 2010). However, again, little is known about the experiences of parenting a child with ASD in the context of Covid-19 in South Africa. Additionally, little is reported regarding the support parents obtain and whether this support appropriately prepares them for their role during the pandemic. Thus, understanding what the Covid-19 crisis means to parents of children with ASD can help inform effective preventative and pandemic crisis services.

1.2. Aims and Research question

This study aims to investigate parents' experiences of parenting a child with ASD in South Africa in the context of Covid-19 in order to determine challenges they faced and how they coped with these. As such, the overarching research question (RQ) reads as follows:

RQ: How did South African parents having a child diagnosed with ASD experience parenting in the context of Covid-19?

1.3. Objectives of the study

- To explore the ways in which Covid-19 disease containment measures affected the lives of children with ASD according to their parents' perspectives.
- To explore the ways in which parents collaborated/ interacted with their child with ASD during the pandemic in South Africa.
- To understand in what ways Covid-19 influenced the routine of parents and children with ASD.

- To explore the ways in which parents balanced/ managed their own work against the needs of their children with ASD.
- To explore the sources of support (if any) made available to and accessed by parents of children with ASD during the lockdown.
- To explore the coping strategies employed by parents of children with ASD in South Africa during the lockdown.

1.4. Overview of chapters

Chapter 2 offers a summary of the literature relevant to understanding ASD and parenting a child with this disorder as well as parenting a child with ASD in the context of Covid 19. I discuss ASD by summarising the disorder, together with Asperger’s syndrome, as indicated. Furthermore, I identify the challenges, support systems, coping strategies as well as limits and benefits of the pandemic experienced by parents of children with ASD. In Chapter 3, I describe the theoretical aspects of this study and the research paradigm within which it is located. In Chapter 4, I outline the methodology I used, including the sampling procedure, data collection and data analysis as well as the methodologically related components of trustworthiness, transferability, dependability, confirmability, reflexivity, and ethical considerations. In Chapter 5, I report on the findings by expounding demographics and establishing themes and subthemes. Chapter 6 presents the research findings, including the implications of the results and directions for future practice and research, upon which I conclude the study.

CHAPTER 2

LITERATURE REVIEW

In this section, I provide a review regarding the literature pertaining to the topic of my research. To begin with, I provide a summary of ASD in children, focusing on the core characteristics associated with ASD as well as comorbidities, the causes, and the treatments available for the disorder. Subsequently, I provide a description of parenting a child with ASD, which includes the various challenges associated with this role. I also discuss known support systems and coping strategies used by parents to manage and support their children. I then provide a review of available literature specific to parenting a child with ASD in the context of Covid-19. In that section, I provide an overview of the impact of Covid-19 on parents of children with ASD as well as the impact of the pandemic on children with ASD themselves. Lastly, I will provide an overview of the guidelines for parents of children with ASD suggested by the South African Health Department during the initial lockdown.

2.1. Autism Spectrum Disorder (ASD)

2.1.1. Origins of the term Autism and its Prevalence

The word “autism” originates from the Greek term “autos” which means “self” (Gillberg, 2010). It refers to a condition where individuals might be removed from social communication and interactions, leaving them isolated or alone (APA, 2013). ASD is a complex developmental condition that involves persistent challenges in speech, social interaction, and nonverbal communication, as well as repetitive/restricted patterns of behaviours. ASD is four times more common among boys than girls (Lai et al., 2015). In the 1960s and 1970s, two to four cases of ASD per 10 000 children were reported in Europe and the United States, which led to the impression that ASD was a rare childhood disorder (Baio et al., 2014). The diagnosis of ASD increased dramatically, however, according to estimates made by the Centre of Disease Control and prevention: currently, about one in 54 children has been identified with ASD (CDC, 2020). It has been estimated that one in every 100 children are born with ASD in South Africa (CDC, 2020).

The severity of symptoms and the effects of ASD are different in each child. Symptoms often change over time and can range from mild to severe. ASD is usually first diagnosed in childhood between the ages of two and three (Gillberg, 2010). As indicated, the word “autism” was invented by Dr. Bleuler (Manouilenko & Bejerot, 2015). Dr. Kanner borrowed the term in 1943, and highlighted precise aspects of the disorder (Fitzgerald, 2012; Bleuler, 1950).

In 1944, in Austria, after observing that a couple of children who demonstrated symptoms of ASD had milder symptoms, Dr. Asperger coined the term “Asperger’s syndrome.” He spoke of autistic intelligence as being that of true creativity. Dr. Asperger added that a dash of autism is essential for success in science or art (Fitzgerald, 2012; Volkmar et al., 2012). In fact, although no people with the more severe form of ASD appear to have savant abilities, it is estimated that approximately one-third of individuals with ASD have these (Coleman & Gillberg, 2012). The savant syndrome is a rare condition in which individuals with ASD or other mental disabilities have extraordinary skills. Savant skills are typically confined to five areas: mathematics, calendar calculating, art, music, and mechanical/ spatial skills. These exceptional skills appear to be the result of highly focused attention and possessing superior working memory (Mash & Wolfe, 2019). According to Fitzgerald (2012), a number of intellectual giants were autistic. In fact, he demonstrated that Lewis Carroll, Andy Warhol, Charles Darwin, Einstein, Isaac Newton, as well as Michelangelo had Asperger’s syndrome.

2.1.2. ASD Classification systems

Before 2013, the diagnostic and statistical manual of mental disorders (DSM-4) which has since been updated to the DSM-5, described ASD as one of several pervasive developmental disorders. This category includes childhood disintegrative disorder, Asperger’s syndrome, and those pervasive developmental disorders that are not otherwise specified (Mash&Wolfe,2019). As of 2013, the DSM-5, the new and revised edition, removed these terms and replaced them with ASD (see appendix B) (APA, 2013). ASD includes all the previous pervasive developmental disorders, but it is measured on a scale or a spectrum. A disorder new to the DSM 5-social pragmatic communication disorder includes the difficulties in social communication seen in ASD but without restricted, repetitive patterns of behaviour (APA, 2013). These individuals do not easily learn social rules when communicating with others: for instance, they interrupt, talk too loudly, or do not listen to others (APA, 2013; Sadock et al., 2015).

2.1.3. Clinical description

In the DSM-5, two major characteristics of ASD are defined: (1) impairment in social communication and social interaction and (2) restricted, repetitive patterns of behaviour, interests, or activities (APA, 2013). In addition, the DSM-5 recognises that the impairments limit daily functioning and are present in early childhood. The DSM-5 introduces three levels of severity. Level-1 is that of “requiring support.” Level-2 is that of “requiring substantial support.” And Level- is that of “requiring very substantial support” in order to accommodate the range of difficulties engendered by the two symptoms clusters, that is, again, social/ communication interaction and restricted, repetitive patterns of behaviour, interests, or activities (appendix B) (APA, 2013).

2.1.4. Impairment in social communication and interaction

Failing to develop age-appropriate social relationships is one of the defining characteristics of children with ASD (Mash & Wolfe, 2019). Difficulties with social interaction and communication are defined by three aspects: non-verbal communication, initiating and maintaining social relationships, as well as problems with social reciprocity; all three aspects of which must be present to be diagnosed with ASD (APA, 2013). Deficits in social-emotional reciprocity range from reduced sharing of interest, affect and emotions to an abnormal social approach and failure of normal conversations. Social reciprocity for children with more severe symptoms of ASD includes a failure to respond to or initiate social interactions as well as the inability to engage in joint attention (Mash & Wolfe, 2019). Children with milder symptoms of ASD (previously diagnosed with Asperger’s disorder) present with a lack of social reciprocity by appearing self-focused and not showing interest in things other people care about (Sadock et al., 2015).

Deficits in non-verbal communicative behaviours used for social interaction range from poorly integrating non-verbal and verbal communication to abnormalities in body language, eye contact or a deficit in the understanding and use of gestures to a total lack of non-verbal communication and facial expressions (APA, 2013). About 25% of children with ASD do not develop language proficiency sufficiently to communicate their needs effectively. Those with some language capabilities tend to have echolalia, that is, repetition of the speech of others (Hadjikhani, 2014). Children with ASD can be verbal, but because of their tendency to have restricted interest and social deficits, they often have one-sided conversations about their topics of interests appearing to others to be socially disengaged (Hadjikhani, 2014). Deficits in maintaining, understanding, and developing relationships range from challenges around changing behaviours to fit different social contexts on the one hand, to difficulties in making friends on the other (Mash & Wolfe, 2019).

2.1.5. Restricted repetitive patterns of behaviours interest or activities

Restricted repetitive patterns of interest, behaviours, or activities include repetitive motor movements, such as echolalia, idiosyncratic phrases, flipping objects or lining up toys (APA, 2013). It also includes inflexible adherence to routines, insistence on sameness, difficulties with transitions, distress at small changes, greeting rituals, inflexible thinking patterns, or a need to eat same food every day (Joyce et al., 2017). Moreover, children with ASD have highly fixated, restricted interests that are abnormal in focus or intensity such as excessively circumscribed or perseverative interest or strong attachment to or preoccupation with unusual objects (Factor et al., 2016). Furthermore, they have uncommon interests in sensory features of the environment or a hypo- or hyper-reactivity to sensory input such as visual fascination with movement or lights, excessive smelling or touching of objects, adverse responses to specific textures or sounds and apparent indifference to pain/ temperature (Ryan, 2018).

2.1.6. Comorbidities of ASD

ASD is frequently accompanied by other conditions ranging from mental-health issues to physical diseases; these are called co-occurring conditions or comorbidities (Bellardinelli et al., 2016). ASD comorbidities include attention-deficit/ hyperactivity disorder (ADHD), depression, Down syndrome, language disorders, disrupted sleep, feeding issues, anxiety, gastrointestinal (GI) problems, epilepsy, and motor difficulties (Bellardinelli et al., 2016). ADHD affects 6 to 7% of the general population, while affecting an estimated 30 to 60% of children with ASD. ADHD involves a persistent pattern of inattention, hyperactivity and/ or impulsivity that interferes with learning and daily life, causing difficulty remembering things as well as trouble around managing time and organizational tasks (Antshel et al., 2016) Symptoms of ADHD can overlap with those of ASD; therefore, ADHD can be difficult to position on the spectrum (Antshel et al., 2016). Treatment may include medication for ADHD and behavioural strategies.

Approximately 3% of children in the general population have anxiety while 40 to 60% of those with ASD are diagnosed with anxiety, especially social anxiety (Llanes et al., 2018; Rodgers et al., 2011). Social anxiety can be defined as the extreme fear of social situations, crowds, and new people, which is especially common among children with ASD (Van Steensel et al., 2011). In addition, several children with ASD face challenges controlling anxiety once triggered. Anxiety can be triggered by different activities, including some that were previously enjoyable. Behavioural and cognitive therapy, medications, as well as relaxation techniques can all be used to treat the anxiety (Wood & Gadow, 2010). About 2% of children in the general population are diagnosed with depression while it affects an estimated 7% of children with ASD. However, depression in children with ASD can be masked by communication-related challenges (Bellardinelli et al., 2016). Symptoms of depression include chronic feelings of sadness, worthlessness, loss of interest in activities, a noticeable worsening in hygiene, hopelessness, and irritability (Mash & Wolfe, 2019).

Gastrointestinal (GI) disorders are nearly eight times more common among children with ASD when compared to others (Buie et al., 2010). These include gastroesophageal reflux, abdominal pain, chronic constipation, and bowel inflammation. Around seven of ten children with ASD are affected by eating- and feeding problems (Bellardinelli et al., 2016). These issues can include aversions to certain tastes and textures and extremely restricted food habits (Patten et al., 2013). These challenges often stem from a strong need for sameness or/ and ASD-related hypersensitivities (Factor et al., 2016). Approximately as many as four in five children with ASD have one or more chronic sleeping problem (Gillberg, 2010,). These sleep issues tend to interfere with learning, worsen behavioural challenges, and decrease overall quality of life. Medications such as Melatonin and sleep strategies are often used as treatments (Bellardinelli et al., 2016). Around one in three children with ASD suffer from epilepsy (seizure disorder); by contrast, it affects only 1 to 2% of the general population (Cawthorpe, 2016).

Language delay occurs when young children have difficulties using spoken language and/ or linguistic understanding (Mash & Wolfe, 2019). If a child suffers from a language delay, it might be a sign of a developmental language disorder. Children with these disorders struggle to read and have language difficulties that affect their everyday lives. Approximately 25 to 50% of children with ASD cannot communicate verbally (Bellardinelli et al., 2016). Speech pathologists can help children with language and speech problems by teaching them other ways to communicate such as key-word signing or by employing speech-generating devices as well as pictures or picture boards (Mash & Wolfe, 2019). It is estimated that children with ASD are ten to 25 times more likely to be diagnosed with Down syndrome (Versaci et al., 2021).

Children with motor deficiencies might have difficulties around gross motor skills, including clumsiness, balance problems, or walking problems (Mash & Wolfe, 2019). These difficulties caused by muscle weakness might be related to fine motor skills, including problems with writing, grasping objects, or using cutlery (Licari et al., 2020). However, some children have difficulties with coordination even though their muscles are fine. About 80% of children with ASD have some form of motor difficulty (Bhat, 2021). Motor difficulties can happen in babies and often before autism characteristics become obvious. Researchers demonstrated that these difficulties might be early signs of ASD. Early intervention that includes physical and occupational therapy is used to help children with motor difficulties (Bellardinelli et al., 2016).

2.1.7. Causes of ASD

The causes of ASD encompasses a combination of genetic, neurobiological, and environmental influences (Coleman & Gillberg,2012). The exact genes involved in the development of ASD remain vague. Parents that have one child with ASD have about a 20% chance of having another child with the disorder. However, older parents are more likely to have a child with ASD (Gillberg, 2010). In fact, parents over the age of 40 years are five times more likely to have a child with ASD. Regarding genetics, children with ASD actually have a larger amygdala (Mash & Wolfe, 2019). The amygdala is the core of the neural system when it comes to processing fearful stimuli; therefore, the theory proposed is that the amygdala in children with ASD is enlarged early in life, causing fear and excessive anxiety, which perhaps contribute to their social withdrawal (Lyall et al., 2017).

Some parents think that vaccinating their children could increase the risk of ASD. This is however a false belief. Not vaccinating children leads to a significant increase in cases of rubella, mumps, and measles (Mash & Wolfe, 2019). Some health epidemics in South Africa such as HIV/ AIDS as well as malnutrition, alcohol abuse, and depression place women at risk of having a child with ASD (Tomlinson et al., 2014). Seventy eight percent of pregnant women diagnosed with HIV received antiretroviral medications (UNAIDS, 2020). Antiretroviral treatment aggravates the genetic pre-disposition of ASD (Budd et al., 2018).

2.1.8. Treatments of ASD

Currently, no effective pharmacological treatment exists for ASD. However, for children with ASD to experience improvements in the core symptoms of this disorder, early intervention is crucial (Thomas, 2019). Most therapies consist of school education with special psychological support that help children deal with problems related to communication and socialisation. Specialist interventions and therapies can assist around the problems of self-harming, hyperactivity, and sleep difficulties (Gillberg, 2010). Educational and behavioural programmes can support the learning of social skills. Medication can help with associated symptoms, including melatonin for sleep, SSRIs (selective serotonin reuptake inhibitors) for depression and methylphenidate for ADHD (Stevens, et al., 2016). It is concerning that it may take several years for a child to receive an accurate diagnosis given the importance of early intervention for young children with ASD.

Once diagnosed, children have limited access to interventions and services. For support, many parents rely on their own resources or non-governmental organisations. It has been established by a study conducted in KwaZulu-Natal (Malcom-Smith et al., 2013), for example, that parents consulted an average of seven practitioners over an average period of three years to receive an accurate diagnosis. The average age at which the children were first diagnosed was five; however, one of them was diagnosed at the age of 10. For this reason, the present project was limited by a small sample size (n =7) and by the fact that the parents of the children were not able to afford to consult doctors and specialists, which many South African's do not have the resources to accomplish (Malcom-Smith et al., 2013). The present study highlights the need to address the issue of the diagnosis and treatment of children with ASD in South Africa. Moreover, because of great demands as well as stressors involved in living and caring for such children, parents need support (Malcom-Smith et al., 2013).

2.2. Parenting a child with ASD: Challenges, support structures and coping strategies

Parenting is the activity of bringing up a child. While parenting a neurotypical child can be difficult and stressful, this is often exacerbated for parents of children with ASD (Bonis, 2016). In fact, parenting a child with ASD is accompanied by various challenges. In the subsequent section below, I describe these challenges as well as the support systems and coping strategies used by parents successfully to manage and support their children.

2.2.1. Challenges

Parenting is in itself a challenging experience and will be even more difficult when raising a child with ASD. Due to the severity and chronicity of ASD, mental health comorbidities, and intensive interventions needed by children with this condition as well as the difficulties of obtaining services, meeting the needs of these children can be challenging (Costa et al., 2017). Moreover, studies have suggested that taking care of children with ASD is accompanied by a myriad of additional challenges and stressors due to their behavioural problems and the lack of resources, support systems as well as coping strategies (Barroso et al., 2018; Bonis, 2016; Costa et al., 2017; Lai et al., 2015; Miranda et al., 2019). In South Africa, Alhazmi et al. (2018) demonstrated that the quality of life (QOL) of parents raising a child with ASD is significantly lower across all domains compared to that of parents raising a neurotypical child. According to research, greater stress levels are experienced by families with children with ASD (Barroso et al., 2018; Bonis,2016; Costa et al., 2017). It was demonstrated that there is a positive correlation between the ASD symptoms and behavioural challenges of children with ASD and their parents' stress (Miranda et al., 2019). Bonis (2016) also stated that parents of children with ASD had more symptoms of depression and greater levels of the symptoms of parenting stress than those of neurotypical children.

Research showed that taking care of a child with ASD leads to higher parenting stress than any other neurodevelopmental disorder (Watson et al., 2013). Similarly, it was demonstrated that these parents had enhanced physiological stress and lower subjective well-being. Symptoms exhibited by children with ASD such as aggression, destructiveness, temper tantrums, meltdowns, lack of communication skills, on-verbal communication behaviour, and insistence on sameness are among the most stressful and challenging difficulties experienced by parents (Costa et al., 2017). The main challenges they face include stigma around the disorder, long-lasting symptoms of the condition, and the stressful phase of diagnosis (Costa et al., 2017). Furthermore, parents of children with ASD often describe feeling depressed, overwhelmed, confused, and guilty.

Because manifestations of the disorder are often vague and ambiguous, the phase before diagnosis could be particularly stressful (Brentani, 2013). Parents' early concerns include eye contact, behaviour problems, pointing and awareness, speech, language, as well as rituals, which they often become aware of months before professionals diagnose their child (Bretani, 2013). During this period, parents find it difficult to understand their child's development, therefore they experience feelings of stress, anxiety, and confusion (Bluth et al., 2013). In fact, upon receiving an ASD diagnosis, parents often react with depression, anxiety, guilt, distress, and mental-health related issues which may develop into a crisis (Chan et al., 2018; Weiss et al., 2014). These feelings are experienced as parents are wading into an unknown territory (of parenting a child with ASD) and feel somehow responsible for having a child with ASD (Bluth et al.,2013).

Parents of children with ASD tend to be stigmatised for their child's ASD diagnosis because of various beliefs that may be prevalent in their culture (Sarrett, 2015). Further, parents feel embarrassed and nervous about people's reactions to the child's behavior in public (Sarrett, 2015). However, parents usually feel relieved and gain greater awareness of the child's needs after receiving a diagnosis (Dababnah et al., 2019). Some parents seem to experience acceptance only after having experienced and worked through some of the emotions mentioned above (Dababnah et al., 2019). Acceptance is felt when parents feel some control over the situation and their feelings about it (Dababnah et al., 2019).

Limited support and social awareness lead to parents not understanding the behaviours of their child (Kelley et al, 2019). Furthermore, while the emotions and/ or behaviour of children with ASD are the most visible factors that affect the well-being and stress of the parents, other factors such as financial difficulties related with the expenses on special education and interventions as well as severity of ASD symptoms may also play a role in this regard (Da Paz et al., 2018). The psychological well-being and stress of mothers seemed to be impacted more than those of fathers, even though fathers also experience considerable amounts of stress (Da Paz et al., 2018). According to researchers there is a significant difference due to gender roles and differences. For example, mothers spend more time doing tedious chores like cooking, cleaning, and monitoring the child's behaviour while fathers spend more play and leisure time with the child after work (Da Paz et al., 2018).

Another factor that is related to emotional well-being and stress of parents of children with ASD is the quantum of social support available to them, concomitant with the ease with which they can access and obtain support from qualified experts in mental health (Meyer, 2012; Vohra et al., 2014). Moreover, support for children with ASD (health-wise, educationally, or otherwise) does not appear to be comprehensive, and does not reach all (Kelley et al., 2019).

2.2.2. Access to support systems

For parents raising children with ASD, having access to support systems is crucial. Indeed, research has demonstrated that parents of children with ASD cope better with access to both formal support, for instance support from medical specialists and psychologists and informal support, for instance support from social network and community (Lee & Gardner, 2010; Jung, 2010). In fact, the literature on support distinguishes between informal and formal support. Formal support is often offered by people and groups of individuals that are organised to respond to particular family needs (Jung,2010). Formal support is provided by medical specialists, health care providers, therapists and the assistance offered by early intervention programmes. Informal support centres on individuals who are part of the parents' lives (Jung, 2010), such as that provided by the extended family, friends, neighbours, recreational clubs, and churches. According to research (Jung, 2010), parents find the informal social support network the most helpful.

To modulate their coping, parents need support from their extended family members, friends, and social networks (Hartley et al., 2010). Social support also includes the availability of leisure time where they can take part in recreational activities as well as support from specialised schools and professional helpers (Benn, 2012). Social support has been recognised as a crucial aspect when it comes to decreasing the negative psychological effects of raising a child with ASD (Jung, 2010). Lee and Gardner (2010) investigated the importance of grandparents as informal supporters, and they were found to be the main sources of support to parents. In fact, grandparents' support seems to have a considerable effect on the parents' physical and emotional well-being (Lee &Gardner, 2010). Moreover, social support has been identified as a critical factor when it comes to reducing the negative psychological effects of raising a child with ASD. Parents who lack a sense of emotional support from their social networks can feel depressed, isolated, hopeless, or stressed (Jung, 2010), primarily due to them navigating the terrain of parenting a child with ASD without the requisite emotional and social support that would serve as a buffer against the deleterious effect of parenting without much support. In fact, vast literature on the benefits of social support highlight that, when faced with adverse life experiences and acute emotional upheavals, people often find solace from knowing about and utilising social, emotional, and instrumental support from the significant others within the social milieu (Lee & Gardner, 2010; Jung, 2010).

Due to their limited availability for socialising, parents of children with ASD may withdraw from social support activities and progressively lose their friends (Jung, 2010). Furthermore, parents of children with ASD experience a higher risk to divorce which, in part, can be explained by the high level of parenting stress and demands (Lee & Gardner,2010). In South Africa, parents of children with ASD can obtain support services privately or through public institutions (Franz, 2018). Most parents are reliant on school services for occupational and speech therapy (Franz, 2018). However, mainstream public schools are limited in the support that they can provide.

2.2.3. Coping strategies

To overcome the challenges of raising children with ASD, parents make use of various coping strategies (Benn, 2012; Bluth et al., 2013; Cooke et al., 2020). The most common among these are respite- and special education services (Cooke et al., 2020; Franz, 2018). Parents of children diagnosed with ASD in the United States also highlighted the importance of a planned and scheduled routine for their children that included daily exercising and/ or fun activities (Benn, 2012; Bluth et al., 2013). For example, parents who followed a consistent well-defined schedule and routine helped their children diagnosed with ASD enhance their learning abilities and cope better with anxiety (Benn, 2012). Pictographs (for instance of toothbrushes or books) placed in a specific manner could help children with more severe ASD (Bluth et al., 2013).

Bluth (2013) found that parents who took their children with ASD on everyday errands such as a post office run or grocery shopping helped them get used to the world around them, in contrast to parents who exposed their children with ASD minimally to the outside world, dreading the behaviour of their child in public. In fact, parents with children with ASD tend to be stigmatized by the people around them (Alshaigi et al., 2020). In a study by Alshaigi et al. (2020), the authors showed that younger parents usually stayed away from public view and felt discouraged, while older adults proudly went out with their child and stood up for them when the need arose. It was found that the older parents dealt well with these reactions in contrast with the younger parents. Parents of children with ASD highlighted that religious and spiritual faith assisted them with stress reduction and acceptance. A study conducted in South Africa demonstrated that caregivers of children with ASD used distraction activities such as calming techniques, adherence to routines, and outings in order to cope with their child's behavioural symptoms (Dawson, 2011; Fewster, 2014; Matenge, 2013; Reddy et al., 2019).

A study by Cooke et al. (2020) found that, by making use of respite services, parents coped with their children with ASD. In fact, respite services, which can come in many forms, are designed to give parents a break from taking care of their child. Someone might take the child out to an activity group or day centre or look after the child on a regular basis (Cooke et al., 2020). Respite services were considered to be a crucial coping strategy that facilitates family adaptation. Indeed, respite services reduce stress and social isolation as they allow parents to go to work, have time for self-care as well as moments together and with friends. Parents also make use of special education services in order to encourage their child to interact with other children (Cooke et al., 2020).

2.3. Parenting a child with ASD during Covid-19

At the time of the initial lockdown, Dr Zweli Mkhize, the former Minister of Health, defined the fight against the pandemic as an individual's combat against the disease: "We will defeat the pandemic on the basis of collective social behavioural change, that creates a whole new culture of distancing, of use of masks, cough etiquette and ensuring that everybody is cautious of their individual roles, because unless our citizens themselves take responsibility of infection control, then off course we will not be able to win" (Department of Basic Education, 2020, p.3). The rise of Covid-19 changed the life of every parent, especially those living with a child with ASD (Altable, 2020). Because ASD is a disorder that occurs on a spectrum, not all parents face the same difficulties. In addition, parents who face similar challenges experience them to varying degrees. Given the symptoms of ASD and the different and unique ways in which it happens in children, preparing them for the kind of restrictions associated with a global pandemic required special consideration (Altable, 2020).

2.3.1. Impact of Covid-19 on parents of children with ASD

As the Covid-19 pandemic spread across the globe, South Africa, like many other countries, declared a national state of disaster under Section 3 of the Disaster Management Act 57 of 2002 on the 15th of March 2020 (Department of Co-operative Governance and Traditional Affairs, 2020). Parenting a child with ASD in typical circumstances can be stressful, and the Covid-19 pandemic created a high degree of disturbance to the lives and stress-coping levels of parents (Altable, 2020; Wang et al.,2021). In South Africa, information given to parents of children with disabilities was not tailored to their specific needs (Ned et al., 2020). Available studies suggest that the Covid-19 pandemic created a high degree of anxiety, fear of falling ill, and feelings of isolation, which impaired parents' emotional well-being (Alhuzimi, 2020; Chen, 2020; Colizzi et al., 2020). Parents of children with ASD experienced unavoidable stress during the pandemic (Rose et al., 2020; Wang et al., 2021). During the pandemic, social services were on significant demand, therefore the collective effort of parents to educate their children with ASD was a challenge (Cahapay, 2020).

Regardless of the child's ASD severity level, all parents were upset about the special education time their child would lose and the possible development repercussion this might have (Latzer et al., 2021). Moreover, parents mentioned that they lacked the resources and skills to meet their child's developmental needs (Latzer et al., 2021). Parents mentioned the recurrence of problematic behaviours and felt helpless. (Latzer et al., 2021). In China, through the online parent education and training (PET) programme developed during the pandemic to offer home-interventions strategies, parents of children with ASD found help and support (Chen, 2020). Parents who worked from home had to adjust their program to help their child. A number of parents expressed the need to constantly be facilitating and supervising their child in order for them to engage in their work (Chen, 2020). A study in Tel-Aviv highlighted that online meetings were not tolerated well by children, highlighting the necessity to direct the focus during these times on improving parents' skills around using appropriate therapeutic disciplines and instructing them (Latzer et al., 2021).

As the spread of the Covid-19 continued, governments around the world established policies enforcing exceptional quarantine measures (WHO, 2019). For example, the lockdown that was imposed by the government in Tel-Aviv in order to contain the pandemic comprised procedures, such as home confinement and the shutting down of special education systems (Latzer et al., 2021). Similarly, during the lockdown in Italy, no type of service utilization was accessible and there was a shutdown of all the educational systems which led to the loss of a support network consisting of healthcare professionals, teachers, and social workers (Colizzi et al., 2020). Parents were worried regarding their capacity to support and educate their child. Parents lost a vital support network because of the shutting down of special education systems and had to be full-time caregivers despite lacking the skills to cope with this new situation (Chen, 2020).

Parents had to take the role of being both full-time educators and caregivers as they lacked sufficient tools and the option of recruiting family help. All this while dealing with financial pressures and potential health threats, as well as managing their job from home (Latzer et al., 2021). Parents had to be babysitters, teachers, and therapists, for their child with ASD, on top of their jobs and daily duties (Colizzi et al., 2020). Limited job flexibility, especially for mothers, led to a decrease in quality of life for parents and children (Ueda et al.,2021). Assistance was interrupted by restricted travel methods, fear of contracting Covid-19 from the caregiver, and not having stay-in caregivers, according to Ned et al. (2020). Moreover, caregivers were also in need of public transport to get to work, which increased the risk of infection. Finding a reliever if another one was off duty and changing caregivers were risky endeavours during this time. Due to the fear of the virus, some caregivers were also observing lockdown regulations, while others (including domestic helpers) could not get permits to work (Ned et al., 2020).

Individuals did not understand all the information provided to them. There were false news items and information linked to social media platforms, as well as significant information overload (Ned et al, 2020). As such, there was misinformation about the Covid-19 crisis in addition to experiencing this pandemic (WHO, 2021). For instance, in a study conducted by Ned et al. (2020) in South Africa, parents received unsatisfactory feedback concerning the ways in which teachers would enforce physical distancing of learners in special schools. During the Covid-19 lockdown, the main challenges that parents faced while raising their children with ASD was the lack of special education services, the change in routine, food- and sleep-related issues, as well as limited physical space (Bruni et al., 2021; Latzer et al., 2021). The changes in routine led to a lack of the ability to entertain oneself and, as a result, boredom (Latzer et al., 2021).

The lack of space for children in which to expand their energy led to various levels of psychomotor agitation. During the pandemic, the food provided by parents was different from what children with ASD were used to as they spent their day in educational systems before the lockdown (Alhuzimi, 2020). Selectivity and refusal of food resulted in exacerbated behavioural issues, severe nutrient deficiencies, frustrated family interactions, and financial burdens. Parents also mentioned sleep difficulties for children who suffered from night terrors and frequent awakenings, therefore they would give their child Melatonin (Bruni et al., 2021; Latzer et al., 2021). Additional challenges mentioned were the lack of service access, isolation, and the extended time spent providing proxy services while caring for their child with ASD in addition to other family needs (Latzer et al.,2021). Alhuzimi (2020) found that, during the Covid-19, the severity of the children's ASD symptoms changed, which impacted the well-being of parents.

The majority of the parents stated that their emotional well-being had been impacted and their stress levels increased because of the pandemic (Alhuzimi, 2020; Wang et al., 2021). According to Colizzi et al. (2020), most parents of children with ASD experienced the pandemic as challenging and requiring more commitment than before. In fact, the Covid-19 pandemic was experienced as a challenging period by 94% of parents raising a child with ASD (Colizzi et al., 2020). Furthermore, approximately 78% of parents raising a child with ASD faced challenges in organising daily activities. Various studies suggested that parents should be guided in the method of structuring a flexible routine personalised to meet the child's unique needs during the pandemic (Colizzi et al., 2020; Latzer et al., 2021; Narzisi, 2020). For example, it might involve structured and semi-structured activities, as well as saving time slots for free play that could reduce stress (Narzisi, 2020).

Most support was delivered by private therapists, local healthcare services, as well as school services: however, about half of the parents reported needing support from healthcare services, especially in-home services (Colizzi et al., 2020). Furthermore, parents were concerned about their child's evolution. In fact, they stated that their child with ASD regressed in many developmental fields (Latzer et al., 2021). Because of the lockdown, parents were worried about the absence of social interaction, therefore various special education programs tried to resolve this issue by meeting virtually. However, some children did not participate or stepped away from the screen, while others lost interest quickly and found it hard to handle (Latzer et al., 2021). Parents were frustrated and frightened by their children's negative behaviours such as destruction and aggression. Moreover, because of ongoing sibling rivalry and fighting, many parents experienced challenges (Latzer et al., 2021; Toseeb,2021). Interestingly, almost one in every five parents reported that the loosening of restrictions and the end of the lockdown helped to alleviate some of these problems (Colizzi et al., 2020).

Parents experienced complications when it came to explaining the Covid-19 protection measures to their child diagnosed with ASD (Chen, 2020). A common difficulty was to explain to them the uncertainty caused by the pandemic. Various studies found that parents had to take on new roles in the context of the Covid-19 crisis (Alhuzimi, 2020; Chen, 2020; Colizzi et al., 2020; Eshraghi et al., 2020). Furthermore, findings from a survey conducted in Italy showed that about one in four parents stopped working because of the pandemic (Alhuzimi, 2020; Colizzi et al., 2020). Moreover, a study conducted by Chen (2020) in China found that parents who worked had to adjust their schedule in order to assist their child with learning at home, a job normally handled by teachers. In order to physically separate school and home, parents mentioned the need to designate a specific work area in the child's room (Chen, 2020).

In China, some structure into the children's lives was reinstituted by e-learning, however this led to new challenges (Chen, 2020). One of these was the transition from one activity another. In fact, this was hard for children with ASD, but the transitions ran easily when a structure in the children's daily routines was created (Chen, 2020). An unpleasant parent-child relationship was created as parents tried to take on the role of a teacher (Chen, 2020). A study in Saudi Arabia found that parents taking new roles created a shadow in one's relationship with the child (Eshraghi, 2020). Moreover, parents noticed that focusing too much on the needs of the child with ASD caused a decrease of family participation in activities and unconsciously relegated the needs of other family members (Chen, 2020). Therefore, parents mentioned the importance of striving for a balance of structure that would maximise the family's happiness and productivity as a whole (Chen, 2020). During the pandemic, parents who had less job stress, anxiety, and depression, managed to maintain a good quality of life (Ueda et al.,2021; Wang et al., 2021). In fact, low parental stress was associated with decreases in challenging behaviour in children with ASD (Ueda et al.,2021; Wang et al., 2021). A study by Varner (2021), conducted in Canada, demonstrated that frontline health care workers with children were already managing a precarious work-life balance before Covid-19, while the pandemic brought new challenges and anxieties such as the fear of contracting the virus.

2.3.2. Impact of Covid-19 on children with ASD

In crisis situations, children with disorders such as ASD tend to be excluded from pandemic responses and emergency interventions as well as around the allocation of relief resources (Narzisi, 2020). This was evidenced by previous cases of pandemics such as cholera, Ebola, and swine flu. Due to children's difficulties around adapting to new routines, receiving medical treatments for their comorbidities, and appraising the situation, they are particularly vulnerable to conditions of prolonged isolation. In fact, their progress may be negatively affected by this. In a study by Narzisi (2020) conducted in Italy, the author explained that during the Covid-19 pandemic, relationships, physical environments, and schedules changed (Narzisi, 2020). An impact on children during this period has been the general concern and inconsistency regarding the pandemic. This inconsistency may have impacted each child, giving rise to additional challenges and complexities. Children with ASD require routine and consistency in development and learning (Altable,2020).

Challenging behaviours may be present in children on the spectrum (Gillberg, 2010). These behaviours often arise out of anxiety or frustration and are not malicious or purposeful (APA,2013). In fact, these behaviours might include exposing saliva and blood through scratching and biting, which may increase the spread of infection risk. Those challenging behaviours increased due to the lockdown and disruptions in routine which led to children with ASD being emotionally dysregulated (Narzisi, 2020). During the pandemic, parental stress was associated with challenging behaviours in children (Ueda et al., 2021, Wang et al., 2021). Additionally, Altable (2020) underlines the importance of routines, as these children are likely to be distressed by any alterations to these. Eshraghi (2020) emphasises that children with ASD are preoccupied with routines. A study in Canada indeed found that the impact of both the pandemic's implications and the measures implemented to lessen transmission of Covid-19 on children with ASD and their families was unfavourable (Smile, 2020). The Covid-19 crisis led to higher levels of psychological distress, especially among people suffering from pre-existing mental health conditions (Colizzi et al., 2020).

Children with ASD are particularly vulnerable to complex and unpredictable changes (Colizzi et al., 2020). In the context of the pandemic, the drastic change of routine was challenging for the majority of children with ASD (Narzisi, 2020). In response, some of them exhibited a decrease in social motivation and good sleep as well as an increase in bursts of anger and ritualized behaviour (Latzer et al., 2021; Bruni,2021). In fact, during the pandemic, the changes in the sleep rhythms of the children with ASD led to a decreased quality of life for both children and parents (Ueda et al,2021; Bruni,2021). Moreover, according to Colizzi et al. (2020), about 40% of children with ASD experienced more frequent and intense behavioural problems, especially while being quarantined. Similarly, children with ASD have difficulties getting used to new habits, therefore they were particularly vulnerable to conditions of prolonged isolation, which were crucial to counteract the pandemic (Narzisi, 2020). In several countries, the routines of children with ASD were affected in various ways during the lockdown (Altable, 2020; Eshraghi et al., 2020).

Because of strict home isolation, symptoms of hyperactivity in children with ASD increased (Narzisi, 2020). Children with ASD who did not receive school support during the Covid-19 pandemic expressed greater levels of intense behaviour problems, suggesting the importance of maintaining contact with the school during the ongoing crisis (Colizzi et al., 2020). Family dynamics seemed to change during lockdown periods (Amaral & De Vries., 2020; Latzer et al., 2021). These changes included separation from grandparents who were usually present, extensive time with a sibling, or the presence of a parent who was habitually not at home (Amaral & De Vries, 2020; Latzer et al., 2021; Toseeb, 2021). Isolation was linked to increased feelings of loneliness and sadness, as there were fewer opportunities for children to interact in person with others that they were previously involved with (Manning, 2020). When transiting from one activity to the next, studying through online platforms created a challenge for school-going children with ASD (Narzisi, 2020).

Challenges were mainly related to the radical transition in a population of children who struggled with handling change (Frantz, 2018). Strict home isolation meant being physically confined to a small area with limited options for the expending of energy and movement (Fontanesi, 2020). Studies found that most children with ASD who experienced the lockdown encountered significant challenges, which were explained by the notion of the prevalent sensory and psychomotor agitation in children with ASD (Fontanesi, 2020; Pellicano & Stears, 2020). Changes and transition in routine can feel very disruptive for children with ASD. For example, in a study by Chen (2020), some parents reported that their children adapted without a major fuss, thinking of it as a school break/ vacation, while other parents reported that their children were disturbed by the transition.

They further said that their children immediately missed the structure of classes, the travel to school, friends, and teachers and felt the effects of a broken routine (Chen, 2020). Loneliness was exacerbated due to the absence of a supportive classroom setting surrounded by peers. Some parents stated that their child’s behaviour and mood rapidly changed, where some children were sad, confused, and angry and showed greater levels of hyperactivity (Chen, 2020). Moreover, children with ASD displayed anger, behavioural problems, and confusion, as they felt a strong discomfort when asked to conform to Covid-19 safety measures, especially when wearing a mask, and sometimes they simply failed to comply with social distancing rules (Cooke et al., 2020). Parents had issues when entering establishments that required masks, as children with ASD felt discomfort wearing these over their faces. Furthermore, a lack of understanding from the community about the challenges children with

ASD faced combined with failure to comply with the social distancing rules, led to a further stigmatising of the disorder (Cooke et al., 2020).

Parents articulated the necessity to ease their children with ASD back into society by having the community or school put on small preparation events where they could practice and learn Covid-19 safety precautions (Chen, 2020). Examples included having teachers write social stories about the importance of wearing masks as well as having their students practice the wearing of masks for short periods of time over Zoom with them and the child's therapist. To decrease stigmatization, it is essential to have community talks and disseminate information regarding the challenges children with ASD could face due to the Covid-19 (Chen, 2020).

2.3.3. Limits and benefits of the pandemic experienced by children with ASD according to their parents

During the Covid 19 pandemic, a number of children experienced worsening of developmental, behavioural, and social domains, while others benefitted from these changing conditions (Colizzi et al., 2020; Cooke et al., 2020; Latzer et al., 2021; Yahya & Khawaja 2020). In fact, some children with ASD not only seemed to overcome the difficulties of changing conditions, but benefited from them (Colizzi et al., 2020). Parents of children with ASD found that a set daily routine as well as their presence at home led to positive improvements in their children's life skills (Cooke et al., 2020). When it comes to chores such as doing laundry, parents have observed an increase in initiation (Chen, 2020). They attribute the positive improvements in life skills to routine and being present and able to provide reminders. Moreover, parents described their children as more relaxed and affectionate, which made it simpler to get along with other members of their family (Chen, 2020).

Even though parents spent more of their own time helping their child with schoolwork, they have been happy about the fact that there was more transparency on their child's progress in school. Interestingly, increasing age as well as living with a separated or single parent was associated with a better outcome in terms of the intensity of behaviour problems (Colizzi et al., 2020). Additionally, parents noticed a decrease of problem behaviours as well as an increase in positive mood (Colizzi et al., 2020). The ways in which parents coped, influenced their child's success or failure (Latzer et al., 2021). The key factors that enabled successful coping were the parents' resourcefulness and creativeness, as well their ability to adapt to their child's needs (Latzer et al., 2021). Some parents "read the map of needs" rapidly and responded with resourcefulness and creativity (Yahya & Khawaja, 2020). This also meant freeing up significant portions of time to spend with their chid, establishing family togetherness, participating in their activities, or making a concerted effort to involve him or her in household tasks.

Latzer et al. (2021) found that there were parents whose situation at home did not seem to be better than others, but they interpreted it as more positive. Those parents expressed joy from discovering new abilities in their child and from the temporary halting of the "race of life". Parents who had a negative outlook on the situation, mentioned feelings of helpless and hopeless. In these households, children subsequently showed worsening of behaviour and/ or regression. Moreover, according to Latzer et al. (2021), investing in a strong support system for parents, is the best way to benefit ASD children caught up in radical changes of their routine lifestyle. The well-being of the child depends on parental response, therefore the support provided should be parent-focused as much as it is child-focused (Cooke et al., 2020). This should include cognitive behavioural therapy that focuses on challenging negative beliefs about the stressful situation while improving their understanding of their child's disorder for parents of children with ASD. This therapy should also emphasise the resources and strategies available for parents (Cooke et al., 2020).

2.3.4. Coping strategies during Covid-19

Some parents combat and positively cope with daily stressors, although parents' stress was increased during these times (Chen, 2020; Wang et al., 2021). Again, all parents did not experience the pandemic in the same way. Some re-adjusted and experienced improvement while others found this time very frustrating and difficult. During this time, most parents prioritised their child's needs. Parents reported negative and positive coping strategies. They mentioned as few coping responses to Covid-19 such as praying, selfcare, exercising, creative outlets, meditation, and talking to friends, family, and even therapists or counsellors (Narzisi, 2020). In order not to get too overwhelmed, parents who had more than one caregiver in the house suggested the idea of switching back and forth on rest breaks. Making time for themselves was hard for some parents (Narzisi, 2020).

When stress became overwhelming, parents mentioned that they found themselves yelling at their child (Latzer et al., 2021; Wang et al.,2021). By adjusting to the child's unique interest, harmony was achieved. In order to explain the pandemic to their child, parents had to be creative. Moreover, parents advised letting their children enjoy themselves (for example, by letting them play outside on the trampoline) and reflect on precious moments one has with one's child (Latzer et al., 2021). When things were not going perfectly, parents gave themselves leeway and did not let the new roles (those of teacher and therapist) cast too much shadow on their relationship with their child. Some parents also explained that it is important to stay strong for the child and seek help from mental health professionals, family, friends, and co-workers when needed no matter how difficult the situation became (Narzisi, 2020).

In order to have a break, parents would delegate responsibilities to the child so that they could feel a sense of independence as they would at school. Information was monitored to decrease feelings anxiety and fear (Narzisi, 2020). The eventual outcome of the situation was affected by various parental approaches to the level of news to which children with ASD were exposed (Chen, 2020). As such, some parents did everything to spare their children from information. Other parents, focusing on a positive point of view, permitted some news about the pandemic to be transmitted, but made sure it was toned down. Some parents believed that full exposure to information would control the fear of their child. Moreover, the family dynamics that had changed due to the necessitated togetherness had a significant influence on coping and outcomes (Narzisi, 2020). A feeling of despair has been developed by a number of parents who experienced difficulties due to ongoing fighting among siblings. However, some parents perceived sibling rivalry as a sign of normalcy (Toseeb, 2021).

A few parents emphasized that positive shifts were brought about by family togetherness (Narzisi, 2020). Family members were together at home for a considerable period due to the public emergency. Hence, most of the family members were involved in the process of home education of children with ASD. The parents took advantage of the online modality of intervention while therapy services were almost inaccessible (Narzisi, 2020). Yarımkaya et al. (2020) offered a guide to promote activities for children with ASD and their parents. They discussed possible strategies and benefits, specifically of physical activities. Some examples of physical activities that were performed were educational games, online exercise class, meditation, and functional exercises. Tips were offered to parents by Narzisi (2020) on how to teach new social realities for children with ASD. For example, as children with ASD exhibit a range of perceptual skills as regards phenomena, he suggested that parents, with the help of therapists, needed to concretely explain the new situation through appropriate strategies such as concept maps.

As an alternative mode of education, many parents of children with ASD were looking into home education as an alternative to public schooling. Parents were positive that, with support, they could help their child reach their full potential despite the many challenges that occurred during the pandemic. Teaching new social realities to children with ASD could involve a concrete explanation of new situations, considering the social impact of the Covid-19 (Narzisi, 2020). In order to share and gain different types of support needed for the continued education of children with ASD at home, it would be necessary to maintain online contact with the teachers, therapists, caregivers, and other parents. All family members were together at home, therefore all of them were involved in the home education of children with ASD in response to the behaviour of these children (Dyson et al., 2019).

Because of the inaccessibility of therapy services as a result of the national lockdown, parents drew interventions for their children with ASD from the internet (Chen, 2020). Although tele-practice provided challenges for parents, it also offered support. In a study by Chen (2020) suggested that parents should use social stories as well as simple language and visual aids in order to explain the pandemic creatively. Dyson et al. (2019) suggested that parents limit their child’s exposure to the news as it might increase stress which could lead to a multitude of related anxiety-provoked behaviours. Moreover, in order for their children to participate in social activity with their peers, parents reported using safe modes of communication such as video conference and email writing. They also planned in advance and communicated honestly and openly with their child to make transitions easier. Furthermore, parents created masks out of the characters their children liked to address the issue of wearing masks during the pandemic (Chen, 2020).

2.3.5. South African guidelines for schools and parents of children with ASD during Covid-19

The present section summarises the guidelines provided by the Department of Basic Education (2020). These guidelines were given to schools and parents of children with ASD during the Covid-19 pandemic. Again, due to disruptions in routine during the lockdown, children with ASD might have been emotionally dysregulated, resulting in challenging behaviours. These children should not be disciplined for these behaviours according to the Department of Basic Education (2020). Moreover, it was found that the spread of infection risk might increase associated behaviours, therefore, to prevent the spread of the virus, there was a need to inform children with ASD of the new measures that had come in place. Communication with children must be mediated through the medium that is accessible to them. This will allow children to understand what is expected of them. Moreover, measures should be explained using signs and gestures for children who have difficulties communicating and who are non-verbal.

The sanitiser must be monitored and kept out of reach in order to ensure that children do not have access to it. As the smell of the sanitiser might also upset some children with ASD, fragrant-free, odourless sanitiser or solution should be used. For younger children, parents should teach hand washing in a playful manner. Furthermore, no child should ever be forced to wear a mask if it causes any distress or anxiety, which is one of the particular challenges these children can be faced with. Different types of face protection should be introduced to children, for instance surgical masks, cloth masks, or face shields. Some children may bite or chew the masks; therefore, parents should always be ready to step in and assist if this occurs. There is a risk of suffocation with the elastic of the mask, therefore parents must make sure that children are safe from this danger. Furthermore, if a mask can be tolerated by the child, it may need to be changed and cleaned more frequently in order to stop the spread of germs. Parents should be advised to keep children who are sick at home.

2.4. Summary of chapter

In this section, I summarised the literature on ASD and parenting a child with ASD in typical circumstance and also during the Covid-9 pandemic. Understanding the uniqueness of each of the ASD levels is crucial for recognising the need for specialised additional support for parents, both before and during the pandemic. Support systems for parents of children with ASD has grown immensely worldwide and in South Africa. However, challenges remain for parents raising a child with ASD. These include the increase in parental responsibilities around having to meet the needs of children with ASD, which is even more challenging in the context of Covid-19. Furthermore, it is obvious that additional support is required although there is a dearth of information available on parenting a child with ASD in the context of Covid-19 in South Africa. However, parents have mentioned a lack in support and resources during the pandemic. Nevertheless, parents play a vital role in the coping strategies and well-being management of children with ASD. To examine the lens through which this research is interpreted, I subsequently turn to the theoretical framework and research paradigm.

CHAPTER 3

RESEARCH PARADIGM AND THEORETICAL FRAMEWORK

3.1. Introduction

In this section, I discuss the research paradigm and theoretical framework that underpin the present project. I start by describing the research paradigm, which is interpretivism. I then explain the parenting style theory. Furthermore, I outline the transactional model of stress-and-coping theory as well as sociocultural theory.

3.2. Interpretivist paradigm

Interpretivism is a branch of epistemology and emphasises the view that truth and knowledge are aspects of individuals' historical and cultural experiences, which are subjective (Cresswell, 2018). A researcher who employs an interpretivist or a constructivist approach explores the perceptions and experiences of others to gain knowledge regarding the way they perceive the world. The influence of the researcher is not ignored by the interpretivist paradigm (Cresswell, 2018). The researcher moves away from the notion of one objective truth to consider his or her subjectivity as part of his or her experiences in interpretivist research. The interpretivist paradigm highlights that reality is multi-layered and complex, therefore a single phenomenon can have multiple interpretations (Thanh et al., 2015). The interpretivist paradigm groups diverse approaches, including phenomenology, hermeneutics, and social constructivism. Interpretivists assume that reality is socially constructed rather than objectively determined (Silverman, 2010).

In order to gain a deeper understanding of a phenomenon in its unique complexity, interpretivist researchers use interviews and observations as their data collection methods. According to the interpretivist framework, the concepts of reality tend to be subjective rather than objective (Silverman, 2010). The present project is embedded in the interpretivist paradigm as it aims to create meaning on the basis of the subjective experiences of parents of children with ASD. This meaning-making is achieved by investigating the experiences parents have of parenting a child with ASD in the context of Covid-19 in South Africa. Therefore, the data generated in interpretivist studies cannot be generalized, since the gathered information is heavily impacted by participants' personal viewpoints (Thanh et al.,2015). The interpretivist paradigm will, in other words, allow me to focus on and understand the subjective experiences of parents raising a child with ASD in the context of Covid-19 in South Africa.

While my study is broadly located within the interpretivist paradigm, I am likely to draw on parenting theory as well as child developmental theories to make sense of my findings. For example, in terms of parenting theory, I will draw on Diana Baumrind's parenting styles theory as some information engendered by the interviews may reveal parenting styles (Baumrind, 1967). I will therefore draw on the work of Lev Vygotsky (1978) in order to determine the ways in which parents collaborated/ interacted with their children. Furthermore, the transactional model of stress-and-coping theory of Lazarus and Folkman (1984) will be explained in order to understand the ways in which parents of children with ASD coped during the Covid-19 pandemic in South Africa.

3.3. Parenting Styles Theory (Baumrind, 1967)

The underlying theoretical understanding of parenting styles commonly used in psychology today is based on the work of Diana Baumrind (1967). In the 1980s, Maccoby and Martin (1983) felt that Baumrind's model was incomplete, therefore they refined it. Baumrind's theory suggests that there is a close relationship between children's behaviour and parenting style. Different parenting styles can lead to different outcomes and child development. Baumrind (1967) established three parenting styles namely authoritative, authoritarian, and permissive. Authoritative parents are defined as being nurturing and reasonable, setting clear and high expectations. Children with parents who demonstrate this style tend to be self-disciplined. According to Baumrind (1967) the authoritative style is thought to be most beneficial to children. In contrast, Baumrind (1966) explained that authoritarian parents provide low responsiveness yet have extremely high expectations of their children.

According to Baumrind (1967), permissive parents are more responsive than demanding. They allow considerable self-regulation while being lenient so as to avoid confrontation. Parenting experts have questioned Baumrind's emphasis on the need for control and firm (not rigid) rules (Lewis 1981, Grolnick, 2003). In 1983, Maccoby and Martin (1983) added a fourth parenting style, namely uninvolved/ neglectful. Uninvolved/ neglectful parents are known to be dismissive, indifferent, or even completely neglectful towards the needs of their child (Maccoby & Martin, 1983). The theory of Baumrind (1967) serves to determine the ways in which parenting styles manifested during the Covid-19 for parents in my study and what might have been the implications of these styles on the behaviours of children with ASD. This theory was used in various studies that explored parenting a child with ASD (Clauser, 2021; Kendall-Jones, 2014; Ventola et al., 2017). For instance, Ventola et al (2017) reported that parents having children with ASD who exhibit higher levels of maladaptive behavioural symptoms are more controlling and allow for less autonomy, likely in response to the significant behavioural dysregulation in their children.

In this study, I will explore parent-child interactions during the Covid-19 pandemic, and some of this information may reveal parenting styles that were adopted during the pandemic, that is, changes to parenting styles under conditions of extreme stress. I will use Baumrind's theory as a lens through which to interpret these data and offer some insights into parents' parenting styles under these exceptional circumstances.

3.4. Sociocultural Theory Lev Vygotsky (1896-1934)

Sociocultural theory grew from the work of seminal psychologist Lev Vygotsky, who believed that caregivers, parents, peers, and the culture at large were responsible for developing higher-order functions in children (Vygotsky, 1978). According to Vygotsky (1978), learning has its basis in interacting with other people. Human development is viewed as collaborative dialogues. Through collaborative dialogues with more knowledgeable members of society, children develop their cultural values, beliefs, and problem-solving strategies. The principle of Vygotsky's work, the zone of proximal development (ZPD) is related to the concept of the more knowledgeable other (MKO) (Vygotsky, 1978). This concept demonstrates the difference between what children can achieve with guidance from a skilled adult and what they can achieve independently (Holzman, 2017). Vygotsky believed that, when children are in the ZPD for a particular activity, providing the appropriate assistance will give them the ability to achieve the task (Holzman, 2017).

In this study, sociocultural theory was found to be a useful lens through which to determine the ways in which parents interacted and collaborated with their children diagnosed with ASD in South Africa in the context of Covid-19. The theory of Vygotsky was used in previous studies to investigate ASD in the school setting (Chalay & Male, 2011). For example, the study of Chalay and Male (2011) demonstrated that the utilisation of the ZPD in schools and special needs schools would ensure adequate teaching which would allow children with ASD to reach their full potential. Rogoff (1990) dismissed the fact that Vygotsky's theory is universal, as it does not account for the slower rate of cognitive growth in some children. Consequently, the theory of Scaffolding, which is highly dependent on verbal instruction, was introduced by Rogoff (1990). The theory of Vygotsky will allow me to understand parents' involvement and the ways in which they helped, guided, and supported their children with ASD in the context of Covid-19 in South Africa.

3.5. The transactional model of stress and coping theory-Lazarus and Folkman (1984)

The theory by Lazarus and Folkman (1984) known as the transactional model of stress and coping, could serve to determine the ways in which parents coped during lockdown and school closure as a result of the restrictions imposed by the Covid-19 pandemic. This theory defines coping as a phenomenon that involves behavioural and cognitive responses that people use in order to manage external and/ or internal stressors perceived to exceed their personal resources. Lazarus and Folkman (1984) define coping as continually varying behavioural and cognitive efforts to deal with internal and external demands. Lazarus and Folkman (1984) created the concept of cognitive reappraisal and appraisal. According to their theory, coping implies a complex process of thinking and assigning meaning to it. Coping strategies are the choices that someone makes in order to respond to a stressor (Biggs et al.,2017).

A strategy can be maladaptive (ineffective or harmful) or adaptive (effective). Coping mechanisms vary from time to time and from person to person. To get over a particular situation, no two people would use the same strategies. The same individual can use two completely different coping strategies to adapt to similar stressors at different points in life (Biggs et al., 2017). The ideal adaptive coping strategy varies depending on the personality traits of the individual responding, as well as the context. Adaptive coping strategies include emotional expression, regulation strategies, help or support-seeking strategies, as well as active strategies or problem-solving. In fact, Lazarus, and Folkman (1984) explain that help or support seeking strategies can aid with overcoming stress with greater ease. Furthermore, daily relaxation practices were found to be an effective way to train the mind to stay calm when facing challenges. Moreover, daily physical exercises aid the release of endorphins and regulates the circulatory system of the body.

As opposed to adaptive coping strategies, maladaptive coping strategies are harmful to peoples' well-being (Biggs et al., 2017). Some examples of maladaptive coping strategies include unhealthy comfort zones, distraction strategies, avoidance, and problem escape, as well as emotional numbing. Resorting to comforting habits like watching television, eating, or surfing the internet for hours is a perceptual error which leads to distress. Emotional numbing is an extreme form of emotional distancing where we separate ourselves from communication and interpersonal relationships, fearing to get hurt again. It strengthens risky behaviours such as substance abuse and causes social isolation (Lazarus & Folkman, 1984). For example, Lai and Oei (2014) investigated coping in parents of children with ASD in Singapore using Lazarus and Folkman's theory. They demonstrated that the most frequent coping strategy used by parents of children with ASD in Singapore was problem-focused coping. This coping strategy involves taking control of the situation by resolving the issue at hand, which is seen as being a positive and adaptive coping strategy according to Lazarus and Folkman (1984). Trenberth and Dewe (2004) criticised Lazarus and Folkman's (1984) theory, explaining that it exhibited a lack of applied research that put theory into practice.

3.6. Conclusion

This study is interpretive in nature, with the aim exploring parents' experiences of parenting a child with ASD in South Africa in the context of Covid-19 in order to determine challenges they faced and how they coped. The research is further interpreted using the parenting theory, the socio-cultural theory as well as the transactional model of the stress-and-coping theory. These theories provide a more structured way of interpreting parents' experiences of raising a child with ASD in the context of Covid-19 in South Africa.

CHAPTER 4

RESEARCH DESIGN AND METHODOLOGY

4.1. Introduction

In this section, I will mention the methodology employed in the present project. I will start by describing the research method, that is, research design, research participants and sampling, data collection method, and data analysis. Subsequently, I will be discussing the trustworthiness of the study as well as my reflexivity throughout the research process. The ethical considerations relevant to this research will also be mentioned.

4.2. Study design

This is an exploratory qualitative study. Understanding how individuals attach meaning to their social world is defines as qualitative research (Cresswell, 2018). It contradicts the idea that experiential statistics and data are required for a study to be reliable and valid (Cresswell, 2018). A qualitative research approach enabled me to explore individual experiences regarding parenting a child with ASD in South Africa within the context of Covid-19 so as to determine what challenges they face and how they coped with these challenges. Qualitative research allows for a degree of interpretations and concepts that allocate mutual meaning to those who participate in the study as well as the researchers involved (Mason, 2012). It explores the possible meanings and understandings of a statement and interprets the concepts compiled within the research (Mason, 2012).

In this qualitative research study, I transcend or suspend prior knowledge to understand parents' experiences of raising a child with ASD in the context of Covid-19 in South Africa (see Tuffour, 2017). I approached and investigated the subjective experiences of parents raising a child with ASD in the context of Covid-19 in South Africa to elicit rich and descriptive data that are helpful for current and future research (Tuffour, 2017). Moreover, I made use of bracketing, a process of setting aside one's beliefs, feelings, and perceptions to be more open to the phenomenon examined. The qualitative approach allowed me to explore the way in which parents of children with ASD made sense of the world around them during the pandemic in South Africa. My task was to interpret and gain an understanding of parent's beliefs, traditions, and views.

4.3. Setting

Following the ethics clearance processes outlined in the section on ethics (to be discussed in detail in 4.13, page 44), I approached the administrator of a South African autism support group on Facebook. I obtained permission to make a post about my study on the support group page (Appendix H). Through this post (Appendix J), I explained the study to the members of the group and asked them to email me if they were willing to participate. After receiving an email from willing participants, I sent them the information leaflet and the consent form (Appendix C). Moreover, I discussed and confirmed individual times and dates with the participants for interviews. I provided participants with the option to conduct the interviews using their preferred method – either by phone calls, Zoom, Skype, or Microsoft Teams. Most of the participants chose WhatsApp calls. I discussed consent, confidentiality, and the voluntary nature of participation prior to commencement of the interviews. Additionally, I audio-recorded the interviews with participants' permission, either using a Dictaphone or the recording feature on each of the online call platforms. Each interview took place for approximately 60 minutes. I started the interview by completing the demographic questionnaire for each participant (Appendix D). I then proceeded with the interview questions.

4.4. Research participants and sampling strategy

In this research, I made use of purposive sampling to recruit eligible participants. Purposive sampling is when the researcher selects a specific group of participants who are best suited to help him or her gather information on the topic needed ((Korstjens & Moser, 2018). Purposive sampling is a non-probability technique used to target a specific group of participants within a population. It is a form of non-probability sampling where precise criteria are established and participants have to meet these to partake (Etikan,2016). I recruited my participants from an online platform for parents with children that have ASD. To be eligible for this study, participants had to be parents of children with ASD between the ages 6 to 12. I chose this age range as it is the most apparent period for the confirmation of the ASD diagnoses and it is also a crucial stage of identity formation for children according to Mash &Wolfe (2019).

One of the limitations of my chosen sampling strategy is that parents who did not have access to the online platform were not informed about the study and were therefore not presented with an opportunity to participate. In total, 23 parents of children diagnosed with ASD in South Africa were interviewed. All parents who were part of the ASD Facebook group were eligible on condition that they had a child with ASD between the ages of 6 to 12. I attained data saturation as I reached the point in the research process where no new information emerged from the interviews (Abdul Majid et al., 2018). This general principle of data saturation is that it happens when no new ideas, themes, or concepts emerge from the data set (Abdul Majid et al., 2018). Each experience is different; therefore, it would be difficult to ever reach data saturation. However, from early on, various patterns were identified in the interview process. I stopped data collection after 23 interviews, as I considered these repetitive trends among interviews. I started analysing my data as soon as I reached data saturation.

4.5. Data collection methods

4.5.1. Semi-structured interviews

In this study, I made use of semi-structured interviews to collect data. A semi-structured interview is defined as a list of open-ended questions used to direct it and attain information on a specific topic (Cresswell, 2018). It enables me to communicate with the interviewee in an informal and open way, using a combination of closed- and open-ended questions (Luo & Wildemuth, 2017). It is helpful, because it is flexible, including pre-set questions that can be adjusted or omitted as the interview unfolds. Moreover, information regarding participants' perspectives and subjective experiences is gained using semi-structured interviews (Luo & Wildemuth, 2017). To get more information or elaborations, researchers conduct semi-structured interviews often making use of probes or follow-up questions, using the operative words such as "why" and "how" (see appendix E) (Adams, 2015). Participants have the freedom to answer the questions in a way they find comfortable due to the open-endedness of semi-structured interviews.

The interviewer gain insight into the thoughts and understanding of the participants and obtains more detailed information from them in a casual way (Adams, 2015). The shortcomings of semi-structured interviews are that they can take considerable time due to selecting questions, making transcriptions, and analysing the data. In addition, the researcher or interviewee should ensure that the responses are clear and that all the research questions are answered. If this is neglected, it may be impossible or difficult to clarify and confirm once the interview has been completed (Adams, 2015; Luo & Wildemuth, 2017). Listing multiple open-ended questions assisted me in focusing the discussion on the topic, while leaving space for participants to include additional necessary information. The interview guide helped me ask and probe questions on the topic. Thus, I remained free to refine questions if needed. I centred the semi-structured interview questions on parenting a child with ASD in South Africa in the context of Covid-19 (see Appendix E). I also centred the questions on the coping strategies and sources of support used by parents of children diagnosed with ASD in South Africa in the context of Covid-19. As mentioned, prior to the interview questions, I completed a demographic information form with each participant (Appendix D). The electronic data from the interviews were then transcribed by me and stored in a safe and secure place. The data were managed electronically by me and backed up on OneDrive.

4.5.2. The interview schedule

The semi-structured interviews were directed by a self-designed aspect. I structured interviews with open-ended questions (See Appendix E). I avoided leading questions and created ones that were clear and easy to understand. I determined questions according to my research objectives. I designed questions that aligned with data collection and data analysis goals. A total of 23 participants were interviewed, as indicated and, on average, the interviews lasted 60 minutes. After completing all the interviews with the participants, I transcribed them by listening and typing them out using Microsoft Word. All transcriptions and recordings are stored electronically on my computer which is protected with a password and only available to my supervisor and I. Hard copies of all data connected to this study are stored in a locked cupboard in my office. The participants received an airtime voucher from the supplier of their choice to the value of R 50.00 as a token of appreciation for their time and willingness to participate in my research study.

4.6. Data analysis

To analyse the data collected, I used reflexive thematic analysis (see Braun & Clarke, 2020). Reflexive thematic analysis is an accessible and adaptable interpretative approach to qualitative data analysis that enables the identification and analysis of patterns or themes that emerge from data. I used ATLAS.ti version 9 software to analyse and code the data. Reflexive thematic analysis can be applied to various qualitative data sets. It is a process used to determine patterns of meaning in a set of data collected from participants in the interview process. Due to its flexibility, thematic analysis is beneficial (Braun & Clarke, 2020). It can be implemented successfully across multiple theoretical frameworks, even though it is not limited to a specific theoretical technique. There are two manners to conduct thematic analysis – the first is using a deductive (theory-driven) approach and the second is an inductive (data-driven) approach (Braun & Clarke, 2020). I used an inductive approach for this research, as I emphasised the role of the data collected by not coding these to pre-existing themes. Various qualitative approaches necessitate comprehensive knowledge about particular theories (for example, discourse analysis or interpretative phenomenological analysis (IPA)), whereas thematic analysis functions independently and allows a wide range of theoretical perspectives and research interests (Braun & Clarke, 2020).

I used the six steps prescribed by Braun and Clarke (2020) to carry out a thematic analysis in relation to the research question and the available data: (1) familiarising myself with the data through repeated reading; (2) generating initial codes; (3) searching for themes; (4) reviewing of themes; (5) defining and naming of themes; and (6) producing the final report. The process of generating themes is no longer considered to be rigid, building from the first phase to the second phase only. The six steps were not performed linearly; rather, Braun and Clarke (2020) suggest that researchers move back and forth between the steps to guarantee accurate and detailed analysis. By systematically organising and identifying the data into themes, I made use of thematic analysis to examine this data. The themes clarified and made sense of the collective data set by recognising overlapping experiences and meanings and by determining the patterns that were relevant to the research question across the data set. By using the six-phase thematic analysis process set out below, I described the shared meaning in the data set (Braun & Clarke, 2020).

Phase 1. This phase started with collecting all the data through online interviews (see Braun & Clarke, 2020). I stored the data safely for use as part of this research project after personally conducting the interviews. Becoming familiar with the collected data was the purpose of the first phase. To understand the depth of what the participants meant by what they are revealing, I fully immersed myself in the whole data set. As it created the basis for the analysis procedure, this phase was imperative to the rest of the process (see Braun & Clarke, 2020). The process of transcribing interview recordings was part of familiarising myself with the data. The task of transcribing offers an important opportunity to become familiar with the data set, even though it is complex, time-consuming, and tedious (Braun & Clarke, 2020). For this project, I used the following transcription punctuation: pause in speaking (..), sounds or other noises in regular brackets such as (laughing), sentence interruptions (-), end of speaking turn (.), other information that may be helpful as discerned by the transcriber in double brackets such as (sigh of relief), pause in sentence followed by continuation of separate sentence (_).

It was necessary to consider the data as a way of making sense and understanding the experiences of an individual throughout the analysis (see Braun & Clarke, 2020). I considered the interview as the transcription was taking place and I transcribed each document carefully while reflecting on what each participant said and writing notes to review at a later stage. The recording of the interviews allowed me to come closer to the data and deepen my comprehension of what was said, it was therefore beneficial (see Braun & Clarke, 2020). To ensure accuracy, I re-read the completed transcriptions while listening to the recordings. I fixed any errors I came across in the transcripts during this time. I created a brief summary of key concepts to start developing themes from the data once I had completed the transcriptions. To gain a more holistic view of what each participant was trying to say, I studied and reviewed the documents with the actual interviews in mind.

Phase 2. I started generating initial codes. Throughout the process of data familiarisation, these codes represented areas of interest that appeared within the data set. I did not have pre-existing themes, since I used a data-driven, inductive approach. To create themes, I coded the data inductively and later grouped codes together. I paid careful attention to each interview in order to start the coding process. It was essential to code as much as I could to ensure any potential interesting and vital information was documented, as I did not have set codes and themes in mind (see Braun & Clarke, 2020). The process of coding was done through ATLAS.ti version 9, as indicated: it is a software program for qualitative research. I descriptively labelled all significant information and organised it in a well-structured manner during coding.

Phase 3. The third phase of data analysis began once I had coded the data set. During this phase, I identified themes across the code groups created (Braun & Clarke, 2020). As such, once the coding process had been finalised, the codes were reviewed to create themes that were broader, combining various codes. To aid this step, Braun and Clarke (2020) suggested the use of visual representation. There are several visual representations that can be used. I created a table to get a clear overview of all the codes for this research. I arranged the table in a chronological manner in order to differentiate the information given by parents regarding their experience of raising a child with ASD before and during the Covid-19 pandemic. I formed different groups once the codes had been established into two different categories, namely before Covid-19 and during Covid-19. Braun and Clarke (2020) further suggested being conscious of an overall theme that may emerge during this point in the data analysis, and a broader theme did indeed emerge which answered each of my objectives.

Phase 4. All the themes had already been identified by phase four. The purpose of this phase was to review the themes that had been created. The review process had to confirm that the themes accurately recorded the meaning of the data (see Braun & Clarke, 2020). Braun and Clarke (2020) emphasised that there should be clear distinctions between various themes and that these should be distinctly identifiable. When selecting a theme, researcher judgement as well as rigidity in approach were required.

Phase 5. The fifth step was to define and name the themes once they all had been refined (Braun & Clarke, 2020). At this level, each theme must have a unique story that fits into the larger narrative of the data and that which the research is attempting to communicate. Each theme must have subthemes addressing the various elements of that theme. I defined each theme carefully during this process. Interestingly, numerous initial themes became subthemes. By constructing a table, this process was also performed. Each theme was divided into subthemes concomitant with citations relevant to each by the use of different colour codes.

Phase 6. Presenting the analysed data in writing was the final phase in this process (Braun & Clarke, 2020). The aim of this is to present the reader with the complete and detailed account of the data. The final written product must be concise and clear, showing the analytical narrative of the data in an easy-to-understand manner as related to the research question (Braun & Clarke, 2020). Displaying the story that the data told, the written aspect of this phase was completed enthusiastically and carefully. The analysis procedure was data-led, allowing the data to lead the writing process as well. I aimed at creating a holistic narrative in order to understand the experiences of those parenting a child with ASD in the context of Covid-19 in South Africa.

4.7. Trustworthiness

Trustworthiness refers to the methods used in the analysis and the assurance of accurate interpretation of data (Connelly, 2016). The trustworthiness of qualitative research was often questioned by positivist researchers. The reason for this distrust is the need for objectivity validity, and reliability, which are terms used to assess research conducted in positivist research paradigms (Cresswell, 2018). However, qualitative research diverges from the traditional positive approach, especially in regard to the assumptions, research purpose, and inferences. Qualitative reliability and validity take place through a process of evaluating the trustworthiness of the research by observing the following four areas: dependability, credibility, confirmability, and transferability (Zhang & Wildemuth, 2017).

4.8. Credibility

In qualitative research, credibility replaces the concept of internal validity (Cresswell, 2018). Internal validity questions whether a test properly verified what it was supposed to. Credibility pursues the interpretation of findings and truthfulness in the study method, as well as questioning whether the results are compatible with reality. There are many ways to guarantee credibility (Korstjens & Moser, 2018). In fact, negative case analysis, continuous observation, peer debriefing, member checks, extended engagement, triangulation, and referential adequacy can be used to guarantee credibility. Moreover, consistent debriefing sessions and well-established research methods also facilitate the insurance of credibility (Korstjens & Moser, 2018).

The credibility of this research was ensured firstly by extended engagement (Connelly, 2016). I was present during all parts of the process as I conducted the interviews myself. Participants gave examples of their situations, which supported their statements, throughout the interviews. Credibility can also be found in the use of an established research method. Before the data collection began within the present project, the questions for the interviews were written in such a way that it would elicit information that would have theoretical underpinnings. The data analysis procedure, which is well-established and well-known, was done step by step, including supervision at intervals for guidance, throughout the process.

4.9. Transferability

External validity observes whether the findings are generalisable by means of statistics, for the positivist researcher (Nowell et al., 2017). Generalisability is impossible, but transferability enables other researchers to benefit from the process and apply it to their unique setting, in naturalist research (Connelly, 2016). With this in mind, the researcher should make use of "thick description." For the research to becomes meaningful to an individual outside of it, the researcher records the broadest possible range of information and incorporates behaviours, contexts, and experiences (Korstjens & Moser, 2018). This section presents a well-defined process to show how this research was done, including details on the various elements and context. The design of the research is set up to be replicated.

4.10. Dependability

Dependability states that the study should be repeatable with similar results should it be replicated under identical conditions (Cresswell, 2018). For other academics to potentially follow the process, the researcher should document the research process in a coherent manner. Credibility and dependability are inextricably connected, suggesting that the display of credibility should achieve dependability (Nowell et al., 2017). The same results should be accomplished if the process is followed in the same environment, although environments and people change. The credibility of this research should lead to dependability as credibility and dependability are linked (Nowell et al., 2017).

4.11. Confirmability

Confirmability is achieved when dependability, credibility, and transferability have all been established (Korstjens & Moser, 2018). To achieve conformability, there should be transparency in the steps taken during the research process, documenting everything from the beginning of the project through its developments, as well as around the end where findings are made (Cresswell, 2018). The maintenance of an audit trail is a necessary step in this process. Here, the researcher keeps detailed notes on the research process, and these often are peer reviewed. Nowell et al. (2017) mentioned that throughout the research, reasons for analytical, methodological, and theoretical choices should be included in order for others to understand the study. Furthermore, throughout this chapter, the research process was clearly outlined. Within each step, I described the processes and the reasons for these processes. Given these levels of transparency, researchers should be able to reach the same conclusions if they had access to the raw data (Nowell et al., 2017). The auditing process included engaging with my supervisor frequently in order to ensure accuracy, especially prior to the data collection process and around finalising the methodology.

4.12. Reflexivity

Reflexivity centres on the process of consistent critical self-reflection around group and individual thoughts and actions, as well as conscious acknowledgement and obvious recognition that this position may potentially influence the qualitative research process and outcome (Nowell et al., 2017). Readers are often curious about what elicited the researcher's interest in the topics that he or she researched and to whom they were reporting and what the researcher personally stands to achieve from a particular study. With a view to this, throughout the research process, I exposed my thoughts by explaining excerpts from the diary that I kept. My hope was that reflexivity would reveal the depth of the meaning of the phenomena researched and increase understanding for the reader, due to the qualitative nature of this research. Reflexivity is also imperative when it comes to attaining neutrality and objectivity in the research process (Nowell et al., 2017). I am passionate about all topics related to clinical psychology, especially children's mental health.

I researched ASD, as it is important to understand it in order to gain knowledge on the larger class of neurodevelopmental disorders. More importantly, through my study I hoped to improve awareness and empathy, while creating greater acceptance of children with ASD. I entered the process knowing that I had to be as objective as possible, particularly during the interview process. Throughout this, I therefore paid careful attention to remaining teachable and receptive to others, especially my supervisor. We met frequently in order to share my thoughts on the interview process. We emphasised neutrality in the process. Throughout the first interview, it became obvious to me that interviewing necessitates a different skillset to that of counselling. Having experienced counselling, I had to make a clear distinction between counselling participants and interviewing them. I learned different skills and had the opportunity to further practice them, therefore this was a pleasant process for me. I noticed after the first interview that some of the questions were phrased in a way that was difficult to understand and answer with regard to the interview questions themselves. Therefore, I rephrased ways of asking the questions to the other parents.

The probing questions were often aimed at engaging with the experience of parents and how they related to their environment and role. Some participants would personally message me to ask for financial, educational, or emotional help, which was outside my ability. With the instruction of my supervisor, I managed to refer these parents to the Welgevellan Clinic for them to receive the assistance they needed (see appendix F). One of the parents I referred to the clinic messaged me back to thank me for referring her; I was considerably encouraged by this. After each interview, parents would thank me for doing this research and promoting awareness of their experience, and they would ask me to send them my thesis and my publication after getting it done. This created a sense of purpose, renewal and, most importantly, belonging.

I felt most emotional when a non-verbal child took the phone from his mom and said “Hi” to me during the interview, which filled my heart with joy. One parent also proudly showed me the dinosaur shapes her son built with playdough. I was so impressed by this little boy’s talent and requested permission from his mom to add this picture to my study (see appendix M). All parents thanked me for doing this research, which increased my determination and motivation. However, despite these mostly positive experiences around my study and the recruitment of my research participants, I did experience a major challenge during the recruitment phase. In keeping with the recommendation of my supervisor and the REC coordinator, I agreed to place this instance in my thesis – as it may help other students and supervisors who navigate participant recruitment through online media platforms.

On the 14th of June 2021, the research ethics coordinator at Stellenbosch University informed my supervisor and I of a complaint made against the study. The complaint came from a concerned parent who had seen my research flyer on a social media platform and was concerned about the legitimacy of the research and the way in which they had been approached about it. In this instance, in addition to placing the flyer on the groups public page, I had also individually contacted, through Facebook Messenger, potential participants in the study. This parent did not appreciate being contacted through Facebook Messenger. On reflection, I had not included in my proposal that I would use Facebook Messenger to contact participants who belonged to the support groups I had permission for – so this was considered by the REC to be a breach of protocol. As such, after discussing the matter with my supervisor as well as the REC, I submitted a protocol deviation to the REC, registering the complaint as well as the corrective steps taken. These entailed a letter of apology in which I addressed the complainant and explained that my study was indeed legitimate, in that I had received REC approval, and that I had apologised for contacting the participant directly through Facebook Messenger. The REC executive reviewed the letter to ensure that the tone and information included was well considered and addressed the complaint raised. The complainant accepted my apology, and the REC gave me permission to proceed with my study. My supervisor played a crucial role in helping me manage this challenge. This helped me shift my focus from achieving perfection to learning and growing through the process, engaging with all aspects of the research, and reading a final product that is not a regurgitation of information, but a true analysis of experiences.

4.13. Ethical considerations

Before data collection commenced, I obtain ethics clearance from both the Department Ethics Screening Committee (DESC) and the Research Ethics Committee (REC). The REC approved the study and designated it to be of a medium risk (see Appendix K and L). This designation was engendered by the fact that the interview questions may have led to personal and/ or emotional responses. However, I informed the participants that a free counselling session offered by Ms. Megan Snow (Department of Psychology, Stellenbosch University) was available to them if needed. Moreover, through the implication of voluntary withdrawal, participants were protected from the possibility of coercion. I posted the flyer on the Facebook group and received emails from willing participants, following the final approval of my research proposal by the REC.

Participation in this research was entirely voluntary, and I mentioned this openly to each parent. As mentioned, the interviews were done online by using either WhatsApp phone calls, Zoom, Skype or Microsoft Teams, depending on the participants' preferences. I clearly explained to each participant that the information obtained during the research process would be kept confidential. During the interviews, I prioritised the physical and psychological well-being of the participants by making sure they were comfortable.

The participants signed an informed consent form before the interview process started. I ensured that all participants signed the consent form and emailed it back to me prior to the interview, where they were made aware that they were taking part in a research study (Appendix C).

The informed consent contained a form that outlined the objective of the study and provided information on how the data would be used and what the study was about (Appendix C). Before the process, the participants were given information on the procedures and were informed that the interview process was entirely voluntary. Moreover, the consent form highlighted that their responses would remain anonymous and that, at any time, they could withdraw from the study without any repercussions. Participants could withdraw from the research at any time and/ or choose not to answer a question, with no consequences. All parents participated fully. By attributing a number to each participant (such as 001, 002, 003 and so forth), confidentiality was ensured. Participants were told that all information gleaned from interviews would only be available to my supervisor and me. I was the only interviewer for this study. As indicated, all parents who participated received a R 50.00 airtime voucher from the supplier of their choice as a token of appreciation for their time (see appendix I).

Once the interview was complete, a contact detail form was displayed, and participants were given the opportunity to withdraw from the study if they wished, which none did. The contact details of my supervisor, Dr. Bronwyne Coetzee, as well as my contact details, were included (see appendix G). The interviews were recorded with the permission of the participants. Moreover, the voice recordings were directly transferred to an electronic device, saved in numbered files, and encrypted, while personal information (such as names) were removed. During the interview, I did not use leading questions and did not divulge personal information. However, probes were used when participants gave vague answers or to elaborate on points that they were making. The goal was to stay as neutral as possible in my role as interviewer and interpreter. Supervision provided conversation and guidance about the thought and research processes. Finally, in order to ensure accuracy in reflexivity, a diary was kept documenting my thoughts throughout the process.

4.14. Conclusion

Throughout this chapter, I discussed the semi-structured interview method used to gather data and the qualitative research design of this study. I clearly described the use of purposive sampling to recruit participants. I elaborated on the process of data analysis, that is, using the thematic analysis procedure for this. I additionally discussed the ways in which trustworthiness was ensured: mainly by exposing my thoughts during the research process. Finally, I unpacked the necessary ethical considerations relating to this study. I now turn to the findings made, having established the motivation for this study, including the aims and objectives, relevant literature, the theoretical framework, and research methodology.

CHAPTER 5

RESEARCH FINDINGS

5.1. Introduction

As indicated, the purpose of this research was to investigate parents' experiences around parenting a child with ASD in South Africa in the context of Covid-19, in order to determine the challenges, they faced and how they coped with these. In order to achieve this aim, I conducted semi-structured qualitative online individual (one-on-one) interviews, with a sample of 23 parents of children with ASD as recruited by using social media. In this chapter, I present the findings following a reflexive thematic analysis of the interview data that I collected. I begin with an overview of participants' demographic characteristics. Subsequently, I present an account of the findings as engendered by my reflexive thematic analysis.

5.2. Participant characteristics

As represented in Table 5.1, 23 parents of children with ASD (21 females and 2 males) participated in this research. Parents' ages ranged from 23 to 49 years (Mean(M)=37.6; Standard Deviation (SD)=6.9). Among these 23 parents, 20 had boys diagnosed with ASD, while three had girls with this diagnosis. The ages of the children ranged from 6 to 12 (M=7.8; SD=2.0). Furthermore, 15 parents (65%) reported being married, 6 (26%) reported being single, and 2 (9%) reported being divorced. Moreover, 20 (87%) parents reported that they were living with other adults and children, while 3 (3%) reported that they were living alone with their children. Additionally, ten children (43%) were attending an autism-only school, five (22%) were attending a special-needs school, four (17%) were attending a mainstream school, two (9%) were being home schooled, and a further two children (9 %) were not attending school.

Additionally, 12 parents (52%) reported being unemployed, eight (35%) reported being employed, and three (13%) reported that they were being employed on a part-time basis. In total, 11 parents (48%) reported earning less than R12 000.00 monthly, eight (35%) reported earning between R10 000.00 to R40 000.00 monthly, and four (17%) were earning between R40 000.00 to R80 000.00 monthly. Most parents reported living in Western Cape and Gauteng. In fact, 11 parents (48%) were living in the Western Cape and 11 (48%) in Gauteng. Only one parent (2.3 %) reported living in KwaZulu Natal. All participants reported speaking English and at least one additional language. However, English was the first language of only eight parents (35 %). Other parents' first language was either Afrikaans, Xhosa, Zulu, or Sepedi. About six parents (26%) reported their first language to be Afrikaans, four (17%) reported it to be isiZulu, four parents' (17%) reported it to be isiXhosa, and one the first language of one parent (2.3%) was reported to be Sepedi.

Table 5.1. Participants' characteristics

Participant	**Age of participant**	**Age of child**	**Gender of participant**	**Gender of child**	**Marital status**	**Living situation**	**Education of chid**	**Work situation**	**Family monthly income**	**Provence**	**First language**	**Second language**
P001	36	7	F	M	Married	Living with other adults and children	Autism-only school	Unemployed	R10 000.00- R40 000.00	Western Cape	English	Afrikaans
P002	36	7	F	F	Married	Living with other adults and children	Home schooled	Employed	R10 000.00 – R40 000.00	Gauteng	English	Afrikaans IsiZulu
P003	40	9	F	M	Divorced	Living with other adults and children	Autism-only school	Employed	R10 000.00- R40 000.00	Western Cape	IsiXhosa	English IsiZulu
P004	30	6	F	M	Single	Living alone with the child	Autism-only school	Unemployed	Less than R12 000.00	Gauteng	IsiZulu	English
P005	43	7	F	M	Married	Living alone with the child	Special-needs school	Employed	R10 000.00- R40 000.00	Gauteng	English	None

P006	49	10	F	F	Married	Living with other adults and children	Autism-only school	Employed	R40 000.00- 80 000.00	Gauteng	English	Afrikaans
P007	36	6	F	M	Married	Living with other adults and children	Autism-only school	Employed	R40 000.00- 80 000.00	Gauteng	Afrikaans	English
P008	41	6	M	M	Married	Living with other adults and children	Autism-only school	Employed	R40 000.00- 80 000.00	Gauteng	Afrikaans	English
P009	34	6	F	M	Divorced	Living with other adults and children	Mainstream school	Employed	R10 000.00-R40 000.00	Western Cape	Afrikaans	English
P010	44	6	F	M	Single	Living alone with the child	Not going to school	Unemployed	Less than R12000.00	KwaIsiZulu-Natal	English	Afrikaans IsiZulu
P011	39	9	M	M	Married	Living with other adults and children	Home schooled	Employed	R40 000.00- 80 000.00	Western Cape	English	Afrikaans

P012	33	9	F	M	Married	Living with other adults and children	Special-needs school	Employed part time	Less than R12000.00	Western Cape	Afrikaans	English
P013	37	8	F	M	Married	Living with other adults and children	Mainstream school	Unemployed	Less than R12000.00	Western Cape	Afrikaans	English
P014	43	12	F	M	Married	Living with other adults and children	Autism-only school	Unemployed	Less than R12000.00	Gauteng	Tswana IsiZulu	English
P015	49	6	F	M	Married	Living with other adults and children	Special-needs school	Unemployed	Less than R12000.00	Western Cape	English	Afrikaans
P016	24	6	F	M	Single	Living with other adults and children	Mainstream school	Unemployed	Less than 12000.00	Western Cape	IsiZulu	English
P017	33	11	F	M	Single	Living with other adults and children	Special-needs school	Unemployed	Less than R12000.00	Gauteng	Sepedi	IsiZulu Tswana
P018	39	7	F	M	Married	Living with other adults and children	Not going to school	unemployed	Less than R12000.00	Western Cape	IsiXhosa	English

P019	29	6	F	M	Single	Living with other adults and children	Mainstream school	Employed part time	R10 000.00-R40 000.00	Gauteng	Afrikaans	English
P020	45	11	F	M	Married	Living with other adults and children	Autism-only school	Unemployed	R10 000.00-R40 000.00	Western Cape	IsiXhosa	English
P021	38	9	F	M	Married	Living with other adults and children	Autism-only school	Unemployed	R10 000.00-R40 000.00	Western Cape	English	Afrikaans
P022	44	11	F	M	Married	Living with other adults and children	Autism-only school	Employed part time	Less than R12000.00	Gauteng	IsiXhosa	English
P023	23	6	F	M	Single	Living with other adults and children	Mainstream school	Unemployed	Less than R12000.00	Gauteng	IsiZulu	IsiXhosa Sesotho English

*F-Female M-Male

5.3. Themes and subthemes

I identified four themes and 12 subthemes as engendered by the examination of the data. These four themes and their subthemes can be found in Table 5.2 below. In the section that follows, I outlined each of theme and its subthemes by generating a description of the experiences of parents. The narrative of the results is augmented by anonymised and supportive quotes where appropriate. I start off the discussion of my results by explaining the ways in which parents of children with ASD experienced the pandemic containment measures as well as the concomitant changes in routine. Then I go onto describing the impact of Covid-19 on interpersonal relationships in the home. Finally, I explore the sources of support and coping strategies parents used during the pandemic.

Table 5.2. Results of the thematic analysis

THEMES	**SUBTHEMES**
• Pandemic challenges – restrictions, routines, and remote working	➢ Children’s understanding of and responses to the restrictions imposed by the lockdown ➢ Adjusting and adapting to the disease containment measures ➢ Structuring the chaos ➢ Work-life (im)balance
• Parenting and interpersonal relationships in conditions of confinement	➢ Parent-child relationship ➢ Siblings’ relationships ➢ Parental relationships
• Help-seeking and sources of support	➢ Family and friends ➢ Community and government ➢ Professionals and workplace
• Finding ways to cope amidst a crisis	➢ Substance abuse, binge eating and isolation ➢ Home activities, music, and television ➢ Faith, acceptance, and communication

5.4. Pandemic challenges – restrictions, routines, and remote working

In this theme I capture parents' experiences of the ways in which their children responded to the lockdown and the various disease containment measures that were implemented. Furthermore, I describe how the disease containment measures impacted on the routine of children and parents. In this section, I also describe how adjusting and adapting to the disease containment measures impacted on parents' work and their ability to balance their work needs against their children's needs.

5.4.1. Children's understanding of and responses to the restrictions imposed by the lockdown

In terms of the lockdown, parents explained that their children initially had difficulty understanding what exactly the lockdown was and why it was necessary. Parents reported that their children did not seem to understand the reasons why they were asked to stay home. They also explained that their children were confused and constantly questioned them regarding these conditions. One parent stated:

> *She had no understanding of what a virus is, what is the police, what is the government, why we can't go out, and why we can't see people. She's a single child so there was no interaction with kids. She would ask why she wouldn't see other kids (P009).*

Parents with children who were non-verbal explained that the lockdown was especially difficult to manage because their children's ASD symptoms were more difficult to manage than those who enjoyed high-functioning ASD. As one parent explained:

> *I explained to him [child with high functioning ASD] the virus, he started watching the news and understood that we had to stay home. He accepted it and got used to it (P003).*

Further, parents who had children with comorbidities such as ADHD or Down syndrome, explained that their child did not have enough space to expand their energy which, in turn, increased hyperactivity symptoms. One parent stated:

> *The hardest part is that he also had ADHD with ASD so during the lockdown he would constantly jump and run everywhere is the house shouting and breaking things (P023).*

However, parents reported that, while children with high functioning ASD were better able to understand COVID-19, the lockdown and associated restrictions also brought about heightened levels of anxiety – as one parent explained:

> *When I would cough, he would ask me if I had Covid, he was very worried. People that we know died. People that we know get infected, his friend got sick, and he worried for him. My best friend was diagnosed with Covid, and he thought that she was going to die. Her child is my child's friend and he also got Covid. My son cried when he knew that his friend got the Covid. He was overly stressed(P013).*

Parents also reported that the unpredictability of the pandemic left them feeling quite powerless and helpless since they were not able to reassure their children that things would be fine . One of the parents explained:

> *It was horrible, because I wanted to help and make him understand that everything will be okay even if something is different. I felt helpless because he couldn't understand and didn't feel safe (P009).*

Parents explained that, as a consequence of their children's inability to grasp that the lockdown meant that they had to stay at home, their children would become severely frustrated and act out, which further exacerbated their feelings of helplessness. One of the parents stated:

> *It was very difficult because he didn't understand why he can't go to the park and why he can't go outside. He had a lot of tantrums and a lot of meltdowns (P004).*

Another parent stated:

> *He broke the TV and throws everything around the house. He broke everything in the house(P018).*

Parents also explained that the implementation of the disease containment measures by law enforcement in the communities in which they resided created much fear and worry in their children and as parents, it remained difficult to explain what was happening to their children. One parent stated:

> *He would often hear police and ambulances on the streets or see the military come in the community to ask people to stay indoors and that would give him a lot of anxiety. He did not understand what was going on and why was this happening (P011)*

Parents reported that, in some instances, the anxiety, meltdowns, and tantrums would escalate and worsen to the point where children began to hurt themselves out of sheer frustration and wanting to go outside. One parent explained:

> *During the Covid period, one day my daughter wanted to go outside. She started banging her head against the door and she eventually broke the door from banging so badly (P002).*

Another parent explained:

> *During the lockdown, because he was 24/ 7 at home he got frustrated and broke the glass with his hand, he had stiches and was admitted to the hospital for 3 days (P014).*

Parents whose children engaged in self-harming behaviours explained that they had to become more vigilant in terms of their supervision of their children, which was not always possible.

> *During the lockdown, I had to look after him every time and watch him because he would hurt and strangle himself (P017).*

Parents explained that the frustration around being confined meant children would also attempt to run away from home, which would lead to heightened anxiety in parents. One parent explained:

> *He ran away from the house, and I found him 2 hours later. Luckily, there were no cars on the road because he was on the road because it was the lockdown. I was so scared because he can't speak or say his name, he is non-verbal. It was very scary(P010).*

Parents explained that being confined at home had a serious emotional impact on their children which, in turn, affected their own mental health as well. One parent said:

> *His behaviour changed completely during the lockdown, he started crying often. When I ask him why he is crying, he says that he doesn't know. When he had a tantrum, it wasn't easy to calm him down and I ended up crying myself because I didn't know what to do (P009).*

In contrast to children who were negatively impacted by the lockdown conditions, others benefitted from staying at home. One parent said:

> *The lockdown helped him manage his sensory issues, he is less overwhelmed and less stressed because the places are less crowded (P017).*

5.4.2. Adjusting and adapting to the disease containment measures

In terms of the disease containment measures, parents reported experiencing numerous challenges around getting their children to adhere to mask wearing, sanitising and social distancing. They explained that their child experienced behavioural and emotional challenges when asked to wear a mask. Children who had a sensory problem as a comorbidity experienced additional challenges handling the mask. In order to get their child to feel more comfortable with the mask, some parents would privilege certain mask materials in order for their child to wear them. One parent stated:

> *Every time I would put the mask on for him, he would have a tantrum and get aggressive. He cannot handle the face mask; he takes it off and bites it(P010).*

Another stated:

> *He struggles to wear the mask, so I had to get him surgical masks because he can't breathe through other masks because it's heavy. If it's a light mask, then it's okay and if it's not too tied around his face (P019).*

As their child could not handle the face mask or could only handle it for a short period of time, parents experienced challenges going out with their children even when the lockdown was eased. While certain schools enforced the mask on children with ASD, some parents preferred removing their child from school or sending their child to school without a mask, which put them at risk for the virus. One parent explained:

> *He can't wear a mask, we tried everything. He's not compliant, the educational department said that they don't need to wear a mask because they are unable to(P021)*

In contrast to children who struggled to handle the face mask, others did not only adapt but integrated the wearing of the mask into their new routine and would even be the ones reminding their parents when they would forget to give them their mask. In fact, children adapted to the wearing of the mask as parents found innovative and creative ways to teach them and encourage them to wear a mask. One parent explained:

> *I taught him how to wear a mask. I did paintings for him to understand how to wear a mask. I received instructions from the Autism Group, and I even sent them to his teacher (P020).*

Another parent explained:

> *When he goes to school, he doesn't want to take out his mask. He is the one who reminds me when I forget to give him his mask. I got him a mask with his favourite Disney character on it. He tells me: mom my uniform is not complete(P017)*

In terms of social distancing, parents explained that their child did not understand this rule and therefore they could not take them to public spaces because they would be criticised or stigmatised.

One parent stated:

> *He can't do social distancing so I can't take him to the shops. People do not understand that he has ASD. I ask my neighbours to help me with groceries shopping(P010).*

In terms of hand sanitising, some parents explained that their child with ASD was scared of sanitisers and would not understand the utility of it, especially those who were non-verbal. Other parents explained that their child mimicked their behaviour or understood the preventive measures, especially those children with high functioning ASD, and integrated it into their routine. One parent stated:

> *He is very scared and frustrated when I spray his hands, therefore I got him the gel sanitiser which works better for him(P006).*

Another parent stated:

> *He is very intelligent, he took note of what was going on around the world by himself, he watches the news all the time, he sanitises his hand and respects social distancing as well. He is the one who holds our hands so that we sanitize them(P013).*

5.4.3. Structuring the chaos

Parents reported that, before the Covid-19 pandemic, their children had a very set routine on which they relied heavily for daily structure. Having a set routine allowed children to be calmer and easier to manage. Parents explained that a typical day would see their children going to school, perhaps attending a doctor’s appointment, or seeing their therapist. Parents also explained that a typical day would involve a series of outdoors activities and family time in the evening. Parents stated that the set and clear routine at school and at home helped their children with ASD participate in and engage more successfully in activities, which often reduced stress and problematic behaviours like meltdowns and tantrums.

One parent explained:

> *He would have a typical day routine at school while I would be at work. We had a lot of appointments with doctors, psychologists, and speech therapist, which helped a lot. On weekends we would spend time together and enjoy outdoors activities(P007).*

Parents explained that, even before the pandemic, if there was a change in the daily schedule it would significantly disrupt the day and lead to an increase in the frequency of meltdowns, tantrums, and aggressive behaviours. One parent said:

> *Challenging days would be when we had something different to do which is not part of his routine. Any change of the schedule gives him a meltdown, he doesn’t like it. He likes knowing his schedule every day(P009).*

However, during the lockdown schools were closed, appointments with doctors were cancelled or done online and outdoors activities were prohibited. Consequently, parents described that the lockdown resulted in chaos at home, especially in the initial days when parents had no set or clear routine with their child.

One parent stated:

> *There was no routine in a day, it was extremely difficult, it was a total nightmare, she was miserable most of the days(P002).*

Another parent stated:

> *During the lockdown, we couldn't go anywhere, he had no exposure to the world. There were no easy days at all during the lockdown. We were at home 24/ 7, we did not have a routine. Every day was the same him and the baby fighting as we were all confined in the same area (P021).*

While some parents did not see any easy days during the lockdown, others mentioned that they experienced some easy days during this time especially since they were able to spend quality time with their child - as one parent said:

> *During the lockdown, I spent more time with my son and understood him more(P015)*

Parents who said that their child struggled with the changes in routine also explained that the Covid-19 conditions set their child's ASD back in different areas. For example, parents mentioned that their child experienced problems around not being at school and online schooling during the lockdown and others seemed to regress developmentally, as was reported by the following parent:

> *Not being at school is a negative impact on the learning side. It sets him back. He also had a very bad toilet training regression. Covid-19 impacted my child very negatively because it set back my child's development(P009).*

Another parent said:

> *We did one online school class, but it didn't work as she wasn't familiar with the process and with the online tutor(P006).*

Parents stated that, in addition to the lack of routine, the transition from one lockdown level to another as well as the inconsistency and unpredictability of the pandemic were extremely difficult to manage for children with ASD. Parents explained that it was as though, as soon as their child adapted to the situation, the government would change the lockdown levels and restrictions. In fact, parents stated that these constant changes negatively affected the child as they could not adapt to a set routine.

One parent said:

> *It was very difficult because he was used to his school schedule, he would insist every day to go to school. He got meltdowns and it became very difficult for me to calm him*

> *down, he wanted his routine back. He eventually adapted to the situation, but then when the school reopened, he did not want to go to school anymore because he was used to being at home. It was really complicated because he did not know what was expected from him(P017)*

Another parent said:

> *The transition was horrific. What was worse was that the school would only open 3 days a week, Monday, Wednesday, and Friday, and that broke his brain because he could not understand that. It had a very negative impact on him (P009)*

Parents reported that, while some children experienced difficulties with the transition from school to home and from one lockdown level to other, others were better able to adjust to the situation. Children who were able to adjust to the situation were either those diagnosed with high-functioning ASD or those who initially did not follow a set routine. One parent explained:

> *The transition was a bit difficult, but he is very intelligent, he understood and adapted. My son's autism is very mild, and his IQ level is very high (P013)*

Another parent said:

> *We don't have a routine because I teach my child to adapt in any situation that's how he adapted easily to the pandemic conditions (P020).*

Another challenge parents faced other than the transitional ones were related to food. Children engaged in food selectivity as they were used to the food provided to them by their school, which was different from that provided by their parents at home. The changes in food routine also created an increase in negative behaviours in children with ASD. Moreover, parents reported that their children engaged in overeating, as they were at home 24/ 7 and bored. The selectivity and overeating led to emotional stress for parents who experienced difficulties handling their child's behaviour. Parents also experienced financial challenges, as they had to get specific foods in bigger quantities than they used to before the pandemic. One parent described this as follows:

> *We were responsible now for giving them breakfast and snacks, but he would also complain about the food. He only eats one specific type of yogurt, and if I didn't buy that specific type of yogurt, he would get a meltdown (P019).*

Another parent said:

> *Because he is just at home, he started eating a lot. He was constantly eating and that is expensive because I had to buy food regularly. It was cheaper when he was at*

> *school, he ate at school. It takes a lot of my energy to take care of my child while before Covid he used to stay 8 hours at school(P003).*

While some children experienced food-related challenges during the lockdown, others learned to become independent, as they spent more time at home and learned to do house chores such as cooking.

One parent said:

> *During the lockdown, my son learned to make his own food. He wouldn't come and ask me to make him food. I would just see him walking around making his own food(P017).*

As children's school routine and food habits changed, so did their sleeping patterns. In fact, due to the lack of routine, children experienced sleep-related issues. In order to combat this challenge, parents reported that they medicated their children during the lockdown to help them sleep. They explained that medications were helpful when it came to managing the sleeping patterns and behaviour. One parent explained:

> *His eating habits changed and his sleeping pattern as well because he was always home not doing anything. Before the lockdown he would fall asleep easily from exhaustion after school and outdoor activities(P017).*

Another parent explained:

> *Since the lockdown I give him medications to sleep, now he sleeps very nicely at night (P018).*

In contrast, parents who managed to get their children to sleep during the lockdown seemed to be those who were able to maintain their child's sleeping routine and who were able to spend more time with their children and understood them more.

One parent said:

> *We maintained a solid bedtime routine, we sing a song, I read a story, we do kisses and hugs and then he goes to sleep (P009).*

Another parent said:

> *The lockdown actually helped a lot; he stopped his melatonin as he managed to sleep on his own because I learned to communicate and understand him better(P015).*

The lack of routine also led to boredom and lack of the ability to entertain oneself. The task of giving children the stimulation they needed was very challenging for parents. Some of them tried to reconstruct a sense of consistency for their children by home-schooling them during the pandemic.

One parent stated:

> *Trying to give my daughter enough stimulation was the biggest challenge. My child would get meltdowns when she was bored(P002).*

Another parent stated:

> *During the lockdown I had to develop a weird learning style and a very strict routine because I learned that he needs a routine (P019).*

5.4.4. Work-life (im) balance

In terms of work from home, parents explained that they experienced challenges managing their own work against the needs of their child. In fact, before the lockdown, parents explained that going to work was a way for them to enjoy their own space and time away from their children. Having their own work responsibilities allowed them to release tension and take a break from parenting responsibilities and keep a well-balanced life. Working from home was a challenge for parents, as they were constantly having to respond to their children who demanded their attention. Parents explained that, in order to secure time to themselves, they resorted to hiding away, bringing their child into online meetings, working late nights, or taking their full annual leave. One parent explained:

> *When I was in a meeting, and she would want to speak to me, and I would tell her that I can't speak to her now as I'm in a meeting, she would try to attack me physically while I'm in a meeting. I would lock the door of my office and put her in the passage, then she would nearly break the door of my office. She would go to the kitchen, take a knife and do some weird things in the house to get my attention*. Work *was extremely stressful. I had to take my full-year annual leave and divide it up over each week. It was very stressful coming out of the lockdown period, I had no single day leave left. I had to catch up work at night and work on weekends (P006).*

Another parent explained:

> *It was really difficult because sometimes when I had an important meeting, I had to go hide in the garage so that he couldn't get to me. It was so difficult that at some stage I had to ask the company to go to the office because it wasn't working from home, and they granted me the access to the offices so that I could get some work done(P007).*

Other than work responsibilities, parents had to play different roles during the pandemic in order to meet the increase in responsibilities. Taking new roles created much tension between children and parents. Parents experienced difficulties managing their child's needs against their everyday duties, especially those whose children had comorbidities like ADHD.

Consequently, parents reported experiencing an increase in stress, as they had no time to rest or relax and had more responsibilities than they had before the pandemic. One parent explained:

> *It was very stressful and there was a lot of hard work. I had to be mom, teacher, cleaner, and a sales manager as I am. I still had to do my own work as well(P007).*

Another parent said:

> *I could not have my time and relax doing my duties in the house, cleaning, and making food as he was constantly crying, throwing things around the house, and fighting with his brother(P001).*

One parent, who was at the frontline of the pandemic, reported that they experienced additional stress as they were forced to go to work and be far away from their child during the initial eight weeks of lockdown. This parent had to leave their child in an institution, as they feared being fired or experience salary cuts. The parent said:

> *I work as a soldier. It was extremely stressful, we had direct contact with people who came in to have medication for Covid. It was very stressful; it was a built on feeling of being in a threat situation. I had no physical contact with my child and physical contact is important for him, he liked it. It used to upset him as I left him in a full care institution in order to work. My direct supervisor told me that she doesn't know any concessions given to parents like that. She also told me that if I don't come to work, I will be fired. One of my biggest worries was that something happens to me and that I can't raise my boys, especially him because no one understands him(P005).*

Parents who did not face many challenges were those who were used to staying at home with their child. In fact, some parents explained that they had quit their jobs a while prior: in fact as soon as they had received their child's ASD diagnosis. One parent said:

> *Nothing changed because we are used to be at home, I quit my job when I received his diagnosis. There is no difference, the only thing that changed are the restrictions that we need to follow when we go out, but we are home most of the time(P020).*

5.5. Parenting and interpersonal relationships in conditions of confinement

In this theme I explain family dynamics in the home before and during the Covid-19 pandemic in South Africa.

5.5.1. Parent-child relationship

Parents said that, before Covid-19, they felt as though they had a good relationship with their child. They explained that part of the reason for this good relationship was that their relationship was balanced around some time together during the day, but also some time apart. They further explained that, when time was spent together, –it was often to engage their children in enjoyable outdoors activities after school or during the weekends. One parent stated:

> *Our relationship was pretty good before the lockdown. We had our own personal space; it was more of an appreciative nature. I would drop him to school and go to work. He had most of his stimulation at school and we would do things over the weekends (P011).*

However, while parents mostly reported a good relationship with their child before the pandemic, this relationship became strained and difficult during lockdown – mostly due to a lack of personal space and minimal time apart from each other.

> *We used to see each other like 5 to 6 hours per day, and now we see each other like 16 hours a day. There is more tension and more anxiety from both sides. We need space from each other(P011).*

Parents reported that, as a result of lockdown and spending more time at home with their children, an expectation was created for the children that they would be more available to them. Parents reported that their children were confused when seeing their parents at home working and not spending time with them, as they were used to this during the weekends when they were at home before the Covid-19 pandemic.

> *Our relationship was very strained, because she didn't comprehend that even though we are at home, it's not the weekend. It really upset her that we did not give her the attention she used to have when we were at home on the weekends. Therefore, our relationship was full of tensioning. She would try to get our attention by screaming and having meltdowns, which I was not able to handle(P002).*

Correspondingly, parents who worked at the frontline of the pandemic (n=2) such as health care workers or those who worked in essential services, also felt distant from their child, which affected the parent-child relationship. A parent explained:

> *Our relationship became distant because I had no physical contact with him. It used to upset him to only see me on a video call. Therefore, his psychologist asked me not to call anymore. When I came back, I was too scared to discipline him because he was away for too long (P005).*

Other than the lack of space or physical contact, parents reported that their presence or absence at home during the pandemic created confusion and tension for their child, as he or she was not used to it. In fact, children's behaviour would affect their parents emotionally and create a strained relationship. One parent explained:

> *Covid made my relationship with my daughter much worse. The parent that she related more with was not here, so I was at home with her often. She would get frustrated and violent with me, and I didn't deal with it in the best possible way. I would also get frustrated, and tensed, I would cry. She is partially verbal, but we got our fights, it got rough, we were frustrated with each other (P006).*

Parents reported immense frustration with their children during lockdown, which affected the parent-child relationship negatively. While some parents tended to get frustrated with their children, others avoided conflicts and meltdowns by becoming much more lenient towards them. One parent explained:

> *When he wanted something, I would give it to him, it doesn't matter what it is. Because we were confined, I was trying to avoid conflicts and meltdowns(P007).*

Parents who had more than one child explained that it became increasingly difficult to divide their attention equally between all of them and tended to prioritise their children with ASD - consequently impacting on their relationship with their other children. One parent said:

> *He takes all my attention; I focus much more on him than on my other children. He takes all the attention(P015)*

While some parents reported difficult relationships with their children, others reported benefitting from these changed conditions, as they spent more time with their child and understood their condition better.

> *The lockdown actually helped me a lot to understand him and allowed him to stop taking the medications. I started communicating more with him and understand him better. He is non-verbal, I interacted with him more than before(P015).*

5.5.2. Siblings' relationships

Parents reported both positive and negative impacts on sibling relationships during the lockdown. They reported that their children with ASD would display destructive and aggressive behaviours towards their siblings, presumably out of frustration and limited space and stimulation. Parents reported that sibling fights affected them emotionally as it was difficult to manage. One parent described it as follows:

> *He fought and hurt his baby brother every day during the lockdown because we were confined. He didn't have his own space and his baby brother was always in his face.*

> *These fights were difficult to handle. It made me not want to be a mum anymore because I was forced to stay with my children 24/ 7(P021).*

Moreover, some children preferred to be alone and would isolate themselves from the entire family and stay alone.

> *He doesn't like to play with me or his siblings, he likes to play alone. He is always alone, as soon as he eats, he goes to his bedroom and watch football on TV. He loves football(P014).*

Other parents reported that sibling relationships improved during lockdown and even promoted social development. One parent said:

> *His relationship with his brothers improved during the lockdown because they spent more time together as they were locked in the house 24/ 7. They played a lot more with him during the lockdown, it improved his social skills(P007).*

One parent explained how understanding her son was towards his sister with ASD:

> *They had a very good relationship prior to Covid and during the Covid. My son was my rock during the time of Covid. My son is so accepting of her uniqueness and her condition. The only thing that used to affect my son was when my daughter had meltdowns, it was a bit hard for him to study at home, but he never got upset with her for what was happening. He knew that it was difficult for her. He loves his sister, so he supported her the whole way through (P002).*

5.5.3. Parental relationships

Parents also experienced challenging relationships with their partners as they spent more time together and did not have the space they used to before the lockdown. Moreover, the uncertainty of the pandemic increased tension between partners. Furthermore, arguments arose when parents would understand and cope with their child differently during the pandemic. One parent said:

> *My relationship with my wife was affected by the Covid, it was a strained relationship. We argued more because we were on each other face. You are making me realise that I definitely need a counselling session. I'm about to cry, it is very emotional talking about it because you realise how real it is(P011).*

Another said:

> *When our son shouts then my husband will also shout at him, so it will make it worse. I keep telling my husband that the more he shouts, the more our son will shout (P001)*

Similarly, parents explained that, even before the lockdown, their partner did not accept their child's condition, which led to emotional distress. While some parents experienced challenges with the partner, others got closer and supported each other. One parent explained:

> *We used to live at his father's house until the day we were kicked out because he said that in his family, they don't have children who have ASD (P004).*

Another parent said:

> *It was nice spending more time with my partner. We supported each other and communicated well. We really enjoyed the times that we had together(P006).*

5.6. Help seeking and sources of support

In this theme, I describe the support systems that were available to my participants during the lockdown. The main sources of support were family and friends as well as community and professional services. Furthermore, most parents in this study received financial support in the form of a grant from the government.

5.6.1. Family and friends

Parents reported that they received much of their needed support during lockdown and, subsequently, through their informal social networks such as their husbands, partners, families, and friends. An important part of emotional support before and during Covid-19 for most families occurred on a parent-to-parent basis. This source of support was even more important during the lockdown, as both parents were at home. Female caregivers in particular reported relying heavily on their partner/ husband for support. One parent said:

> *My husband was home which usually was not the case before lockdown. Before lockdown, my husband had his business and used to work away in the week, and he was only home on weekends. During the lockdown, he was home in the week as well, so it was very nice as his father helped me a lot with him(P021).*

Furthermore, even though some parents mentioned their partners as their main sources of support, other parents did not feel supported enough regarding childcare responsibilities by their partner and felt overwhelmed with childcare and financial responsibilities.

One parent explained:

> *My husband doesn't fully understand the condition of our child. He tries to help me but at the end of the day it's all on me as a mother I'm the one who is always 24/ 7 with him, as my husband doesn't know anything about the medication or how to handle him when he has meltdowns(P001).*

Other than partner-to-partner support, neuro-typical siblings also played a significant role in the parents' support structure through their involvement with their ASD sibling. One parent said:

> *His Brother was very helpful during the lockdown as he didn't go to school, he would help me and look after him and play with him while I was busy, but not all the time because he still had homework to do (P007).*

Parents reported the grandparent was also an important source of support, but only if this did not pose risks to his or her health. One parent explained:

> *My mother helps me a lot and during the lockdown I decided to move to her house so that she can help me look after him(P021).*

Another parent explained:

> *I couldn't ask my mom to assist me. Both of them are asthmatic so we weren't exposing them to anybody during the pandemic (P002)*

Parents reported that relaying on extended family was important for support as well, but only when those family members understood their child. One parent said:

> *I can't even leave him with my own sister because she doesn't understand him. She is going to hit him and say he is naughty and spoiled. Even though my sister has her own son who is Autistic, but he is not the same as my son(P007).*

Parents also reported relying on their friends for emotional support and guidance, but this was not always easy, as people's lives became difficult and complicated as a result of the pandemic. One parent explained:

> *My friend who is 30 minutes away from me, both her sons are Autistic, she got both variant of Autism so I would phone her a lot. She has experienced it all, so I would ask her for advice(P021).*

Another parent explained:

> *The friends I used to speak to weren't there, because they were also busy with their child and have also lost all support. There were in the same situation as us. We used to go out with our children before Covid, and I lost that support because of the lockdown as we couldn't meet up as usual(P006)*

5.6.2. Community and government support

Parents found support from their community (neighbours and church) especially helpful during the Covid-19 pandemic.

One parent explained:

> *My church helped me a lot, they would drop me a food parcel once a week(P015).*

While some parents received help from their neighbours' during the lockdown, other parents mentioned that they experienced stigma and lack of understanding from their neighbours and community during the lockdown when their child would have increased episodes of meltdowns. In fact, parents were suspected of child abuse. A parent said:

> *The fact that he shouts and has meltdowns make it difficult with neighbours. They looked at me funny, especially during the lockdown. He screams at the top of his lungs; other people think I'm hitting him, they don't understand(P010).*

In addition to support from neighbours, several parents (n=8) received a grant from the government, which helped them financially before and especially during the lockdown. For some parents, the grant was their only source of income during the lockdown, which was not sufficient. One parent said:

> *I received a monthly grant from the government, it's R1200, but it's not enough, it's not even enough to carry his transport fees to the school where he is situated. His dad used to cover it all but he caught Covid so he couldn't work anymore so it's all on me now. The school is very expensive, and I need to buy him clothes and shoes. I would have also like financial support to buy groceries (P012).*

Parents felt both supported and unsupported by the government in terms of restrictions posed during lockdown. One parent explained feeling unsupported when public spaces were closed, which limited places for her child to play and release frustration, while others were grateful that childcare institutions remained open during the lockdown. These institutions were major sources of support, especially for parents who were at the frontline of the pandemic. One parent explained:

> *I put him in a full-time institution during the lockdown, I don't know what I would have done if the government had closed that (P005).*

In addition to neighbours, church and governmental support, social media platforms were used by parents as tools to find emotional support, seek out advice, and create important social connections for themselves and their children. All of the parents in this study were part of the ASD group on Facebook and reported that it was a major source of support for them on an emotional level. One parent said:

> *I am part of the ASD support group on Facebook, we could bring comfort to each other, phoning and video calling each other. It would calm me down. It is the support group on Facebook that helped me find a school for him(P001).*

Another parent said:

> *I received food parcels and vouchers from the ASD group during the lockdown(P015).*

Whereas some parents found the ASD support group on Facebook helpful, others did not (n=3).

One parent explained:

> *I didn't find any Facebook or WhatsApp group very helpful because every person's situation is different, and I did not want to disturb the group with my issues as they also have a child with ASD and their own problems (P006).*

5.6.3. Professionals and workplace

Parents held support received from mental health professionals to be crucial for their child's development.

One parent explained:

> *Before the pandemic he used to spend a lot of time in therapy. Even during the lockdown, he went to therapy every Friday (P014).*

Another parent explained:

> *At least he had online sessions with his school therapist, it was a new way of doing things that we adapted to (P005).*

While some parents were grateful their child's therapy could continue, even if online, others explained that children who relied on therapy they received at school were not getting the support they needed. One parent said:

> *The school was closed so he missed all his speech therapy, that was not good for him at all. I was worried because his discipline and development went backwards(P009).*

Another parent said:

> *Our psychologist caught Covid and got very sick, we were not able to visit her anymore (P006).*

Parents did not only express the need for therapy for their child, but also the need for therapeutic, emotional, and psychoeducational support for themselves in order to gain more knowledge about ASD and be able to manage their child effectively (n=15). One parent explained:

> *I would have liked mental health care professionals to chat to specifically about my situation at work. That would have been very helpful to speak about the emotional sides and speak about the collapse of our support group. It would have been a big bonus for me(P005)*

In addition to mental health care support, parents benefited from home care workers' support before and during the pandemic, which allowed them to manage their daily duties against the needs of their child. In contrast to parents who were relieved as they benefited from the support of home care workers during the lockdown, others lost the support from their home care workers which, in turn, led to parenting struggles and challenges. Parents felt overwhelmed and tired, and they would have liked childcare support during the pandemic One parent explained:

> *I have a full-time nanny that stayed with us during the lockdown. My nanny was my saving grace because if she had not been in the picture, I would not have been able to manage and that is definite(P002).*

Another parent explained:

> *Before lockdown we had two full-time employees helping us. One was helping with the kids and the housework and the other one was a facilitator who helped us with the schooling. During the lockdown, we lost the help of both of these people. We are tired, we need someone to help with our child so that we can rest(P011).*

Other than mental health care and childcare support, parents also mentioned support from their workplace. While some benefited from work support which relieved a great amount of parenting stress and eased the difficulties of the pandemic, others lacked support from their work, which increased their parenting stress. One parent stated:

> *Members with children who have issues should be given concessions, but the chief of defence didn't give any guidelines as what could have been done about it. When I was at work, my direct supervisor told me that she doesn't know any concessions given to parents like that. She also told me that if I don't come to work, I will be fired(P005).*

Another parent stated:

> *It's a very supportive company allowing extra understanding and clarity about flexibility of working hours. It was very positive; the flexibility of working hours was extra support (P011)*

5.7. Finding ways to cope amidst a crisis

5.7.1. Substance abuse, overeating and isolating

Parents experienced an increase in mental distress during the lockdown. One parent stated:

> *During the pandemic I had to borrow money to buy food. I was also very stressed because I could not cope with his tantrums and meltdowns. Most of the time I cried in*

> *the bathroom because I could not deal with it. I went to the doctor, and he gave me medications for depression(P004).*

Another parent stated:

> *Covid-19 made me not want to be a mum anymore, I cry a lot because I feel like a failure. I'm forced to stay with my children 24/ 7 and the financial stress is terrible, so it has broken us apart as a family(P021).*

Parents explained that, in order to cope with these mental health challenges, they experienced that they turned to substances such as alcohol and cigarettes. Parents explained that, before Covid-19, they used to cope by doing outdoors activities, but now relied on substances to relieve their stress.

One parent stated:

> *Before the lockdown I would go for a run to relieve my stress but I could not do that during the lockdown so I would drink alcohol every night to relax because I did not know what else to do. It was extremely hard during the lockdown when I could not get alcohol, not that I can make my own(P011).*

Another parent stated:

> *I cried a lot and smoked a lot during the lockdown because I did not know what else to do." (P021).*

While some parents turned to alcohol and cigarettes during the lockdown, others started overeating or/ and isolating in order to relieve their stress and anxiety. One parent explained:

> *My coping strategy during the pandemic is eating. I eat excessively when I am stressed and that helps(P009).*

Another parent explained:

> *I become frustrated and stressed to such an extent that I wouldn't want to see my son. I would just lock myself in my bedroom and cry myself to sleep. I could not cry or stress in front of him because he picks up on my energy when I am stressed, he is stressed and when I am relaxed, he is relaxed(P017).*

5.7.2. Home activities, music, and television

Parents explained that, before the Covid-19 pandemic, most of their children's activities if not all were outdoors. Therefore, during the lockdown, they faced challenges stimulating their child through indoors activities. In order to distract their children, parents had to be creative. They explained that they would privilege practical arts activities. One parent explained:

> *She mainly played with Legos and puzzles but giving my daughter enough stimulation was the biggest challenge it really was. I did not know what to turn to, what I to follow, it was a complete disaster. It was very stressful as a parent(P002).*

Another parent explained:

> *During the lockdown he started doing practical activities and I saw that he is gifted with play dough. He does all forms of dinosaurs' shapes, I will send you the pictures, he is very intelligent P012.* (Pictures included in appendix with parent's permission).

Parents who faced financial challenges found it more difficult to distract their child. Whereas some parents could afford arts tools, others had to be even more creative, finding objects to replace art tools. Moreover, parents explained that their child tended to be bored at home as they could not afford a computer or a television to distract them. One parent explained:

> *I got him colourful things like clothes because I could not get him toys so I would give him different colours of garments. He would then pack them in a row forming different shapes in the yard, it would keep him distracted and calm(P015).*

Another parent explained:

> *I can't afford to buy a computer to keep my son busy. He gets frustrated and keep complaining that he is bored since the pandemic. I would have liked to receive parcel of toys for my child to play with when he gets bored, I can't afford to buy a laptop(P022).*

In addition to arts activities, parents would share valuable time with their child dancing, listening to music, and exercising, which was calming and fun for both the parent and the child. Moreover, parents explained that coping became easier as the lockdown was eased, and children could get back to outdoors activities. One parent said:

> *When we were on level 1and 2, he was able to go outside and ride his bicycle. Even though he wouldn't interact with other kids, he would ride his bicycle around the neighbourhood (P023).*

Other than arts and exercising, parents initiated their child to culinary activities and house chores, which allowed their child to feel more responsible, independent, and organised. One parent stated:

> *During the lockdown I was happy spending more time with him. I tough them how to cook and he started making his own food(P003).*

Another parent stated:

> *I try to teach him to become independent. He enjoyed learning how to wash dishes, I am happy, but he is using a lot of soap (P020).*

In addition to arts, exercising, cooking, and engaging in house chores, parents used digital devices as means to distract their child and have free time. In contrast to parents who coped by allowing their child to use digital devices and television, others would describe this coping strategy as having a negative impact on their child's behaviour, especially during the lockdown. One parent explained:

> *When I have to take care of my house duties, I put for him cartoons on TV or give him my phone to distract him from bothering me. He is a very digital child, he likes tablets, phones and TV, anything that has a screen. He can stay on the phone playing games or watching TV for 3 to 4 hours. That's how I manage(P023).*

Another parent explained:

> *Before Covid, he would play with all of us when he wanted. During Covid, he watched a lot of TV and YouTube. It made him isolate himself even more(P009***)**

5.7.3. Faith, acceptance, and communication as coping strategies

Parents reported that faith (belief) and prayers (practice) were their main coping mechanisms, especially during the lockdown (n=10). Spirituality empowered parents by providing inner strength, optimism, peacefulness, wisdom, and determination. Parents mastered anxiety through resistance to being subdued by fear. However, in contrast to parents who found strength through spirituality, others experienced spiritual doubts. One parent explained:

> *I am Christian so I would find myself praying more during the pandemic and reading God's words. I felt lost neglected and abandoned sometimes and I had all these responsibilities. My husband and I coped by praying because it calmed us and gave us hope that things are going to get better. God is our counsellor. We also meditate to understand and control our situation(P015)*

Another parent stated:

> *Sometimes I question God: why me? That's my first child. I expected a lot, so when the days are not going well, I feel defeated(P017).*

In terms of acceptance, tolerance of the child's uniqueness brought peacefulness to parents as they noticed that their anxiety decreased as soon as they acknowledged and tolerated their child's condition, as opposed to times when they rejected the diagnosis. Contrary to parents who accepted their child's conditions, others were still in denial, which made it more difficult for them to manage. One parent said:

> *I gained patience when I accepted what I could not change. I was in denial; I didn't want to hear about ASD. Now I'm more accepting of information, I have accepted it. I learned to accept him for who he was and not my expectations of him. I used to be a closed book. My stress was very high when I was in denial. I'm still stressed but it's much better(P013).*

Another parent said:

> *It is not easy, it is very difficult, it is terrible and exhausting. I never really accepted the diagnosis, I'm still in denial. I'm going through life, but I have not accepted that he has ASD (P003)*

Parents explained that, when their child accepted the lockdown conditions, they experienced fewer meltdowns, which made it easier for parents to cope. One parent stated:

> *He accepted the fact that he was locked in the house. After 3 weeks, he was conditioned, he started calming down, he didn't cry anymore to go out which made it easier for me to manage(P007)*

Accepting their child's condition allowed positive parenting practices. In fact, after receiving and accepting their child's diagnosis, parents changed their disciplinary methods and, instead of shouting or giving hidings to their child, they would communicate with them. Parents realised that communication was the most effective coping strategy when it came to raising a child with ASD. Communicating with their child did not only make it easier for them to cope but, most importantly, benefitted their children academically, socially, and emotionally. One parent explained:

> *Before I thought he was a very naughty boy so I would shout at him. Communication helped, he used to battle to talk but now he is becoming verbal(P016)*

Another parent explained:

> *When I knew that he was diagnosed with autism, I realised that I was doing it all wrong so instead of shooting, giving him hidings and screaming at him, I decided to communicate with him. Everything changed, I talk to him and listen to him, and I understand his behaviour. I talk him through things, I prepare him, and that is how he is exceling at school (P012)*

However, during the pandemic some parents were under pressure, which made it difficult for them to be patient and communicate with their child. In contrast, other parents maintained communication as their main coping mechanism during the pandemic. These parents seemed to cope better when compared to those who shouted on their child while under pressure during the pandemic. One parent said:

> *Honestly speaking, because of the lockdown, it made me more of an emotional person because of all the pressure. It was too much for me, so I was mainly shouting and screaming at him, but it would just make it worse. The more I shout, the more my son will shout(P001).*

Another parent said:

> *Being able to talk about the issues has helped me a lot. That is one of my biggest coping strategies(P009).*

5.8. Summary of research findings

These research findings demonstrate that the pandemic in South Africa created many issues for parents and their child with ASD. According to parents, children experienced many difficulties around understanding the restrictions imposed by the lockdown. Moreover, they highlighted that, in addition to the lockdown, children with ASD had difficulties adapting to containment measures. These were especially challenging for children who were non-verbal or those who had comorbidities such as ADHD. Thus, the children who adapted to the lockdown as well as the containment measures were mainly those who had been diagnosed with high-functioning ASD. Moreover, parents mentioned that the lack of routine during the pandemic and the transitions from one level to another negatively affected children’s behaviour. Working from home was difficult for them, as they experienced challenges balancing their work against the needs of their child. Interpersonal relationships in the house were negatively affected by confinement.

Some parents explained that spending more time with their children was one of the main positive aspects of the pandemic, as it increased their child’s warmth and communication skills. Moreover, while some parents mentioned that they enjoyed support from family, friends, community, government, and professionals, others felt unsupported and overwhelmed. While lacking sources of support and resources, parents engaged in maladaptive coping such as substance use, isolation, and overeating. In contrast to this, some parents privileged adaptive coping such creative activities, faith, acceptance, and communication, which allowed them to manage their child effectively during the pandemic. Most parents experienced the need for financial support, grocery parcels, therapeutic support, psychoeducation support, respite services, safe spaces to visit, educational support as well as greater support from family and friends.

CHAPTER 6

DISCUSSION AND CONCLUSION

In this study, I investigated the experiences of parenting a child with ASD in the context of Covid-19 in South Africa. To my knowledge and at the time of this writing, this is the first study in South Africa that explored this particular topic. In this chapter, I discuss the findings by using an objective-by-objective approach within the context of extant literature, while drawing on theory where needed. At the end of this chapter, I provide a section on the implications of the results as well as on the recommendations for future research. Moreover, I include a section on the strength and limitations of this research.

6.1. Brief overview of main findings

The findings of this study showed that parents experienced the pandemic as overwhelming and difficult to manage. The general experiences of parents varied, where some parents experienced parenting during the pandemic as positive. Thus, during the pandemic, other parents experienced many challenges and demands as part of their role. Parents stated that their actual roles required much more from them than was the case before the Covid-19 pandemic. The results suggest that there was no one-size-fits all when it came to parenting a child with ASD during the Covid-19 pandemic, as each child had unique requirements that asked of the parents to be adaptable and flexible in their roles. There were various elements that affected parents' experiences during the Covid-19 pandemic, as expressed in all the themes in the data. Parents were asked whether they had any support and what support they had during the pandemic.

Parents faced several challenges and demands. The way they coped with and managed these was often through support structures they created individually or that had been offered to them by key role players. This research found that each parent had their own unique experience during the Covid-19 pandemic. Some had more positive experiences than others, which was often due to better coping strategies, support structures and relationships formed in the home environment. Moreover, parents with children diagnosed with high-functioning ASD coped better than those who had children who were non-verbal or had a comorbid disorder in addition to ASD, such as ADHD or ASD.

6.2. Objective 1: Covid-19 disease containment measures impacting the lives of children with ASD according to their parents

The first objective of my study was to explore the ways in which Covid-19 disease containment measures affected the lives of children with ASD according to their parents' perspectives. A few containment measures were introduced by the National Corona Virus Command Council (NCCC). Lockdown measures were put in place to contain the spread of the virus. Wearing a face mask in public places is obligated and hand hygiene as well as social distancing were necessary.

6.2.1. Lockdown challenges

In this study, it was established that parents initially demonstrated concerns due to the implications of the stay-at-home orders. They explained that their children were confused and initially had difficulty understanding what exactly the lockdown was and why it was necessary to stay home. Moreover, parents described that a child who was non-verbal or who had comorbidities such as ADHD experienced the lockdown as extremely challenging, because it negatively increased their symptoms of hyperactivity and impulsivity, due to the lack of space. In fact, the lockdown meant being confined to small spaces with limited options for the expending of energy. Thus, according to parents in this study, the strict home isolation was a significant challenge for children with ASD due to psychomotor-agitation symptoms. These findings resonate with those of recent literature. For example, Narzisi (2020) showed that symptoms of hyperactivity were increased due to strict home isolation. Another study found that a number of children with ASD experienced worsening in behavioural symptoms such as a decrease in social motivation and out bursts of anger (Latzer et al.,2021).

Parents of children with high-functioning ASD explained that their children understood and adapted to the lockdown fairly well. However, these children experienced anxiety, as they feared the consequences of the virus as well as the unpredictability of the pandemic. The present study demonstrated that all parents, including those who had a child diagnosed with high-functioning ASD, experienced some level of difficulty at the beginning of the lockdown. These findings again resonate with the literature. For example, in a study by Dyson et al (2019) found that parents limited children’s exposure to the news as it led to increased anxiety, which triggered a multitude of related anxiety-provoked behaviours such as obsessive and ritualistic behaviours as well as stimming and resistance to changes in routine. Ned et al. (2020) explained that there had been significant information overload as well as false news during the pandemic, which increased parents’ and children’s anxiety.

Parents in this study felt quite powerless and helpless around not being able to reassure their children that things would be OK. These findings are also echoed in the literature. For example, in a study by Chen (2020), parents stated that their main challenge was to explain the uncertainty of the pandemic to their children. Another study, by Colizzi et al. (2020), demonstrated that, due to the unpredictability of the virus, it was difficult for parents to reassure their children regarding the Covid 19 pandemic as well as the lockdown conditions.

Parents in this study reported that being confined at home due to the lockdown had a serious emotional impact on their children: in some instances, the anxiety, meltdowns and tantrums would escalate and worsen to the point where children began to hurt themselves or tried to run away from home out of sheer frustration. Consequently, parents had to be more vigilant in their supervision, which would affect their own mental health leading to a heightened sense of responsibility and, concomitantly, anxiety in parents. They mentioned that children who had sensory issues seemed to benefit from the lockdown condition, though, as places were less crowded, which decreased their symptoms. This finding is similar those found in extant literature. For example, Cooke et al. (2020) explain that some children benefitted from these changing conditions by experiencing positive improvements.

6.2.2. Face mask, social distancing, and hand hygiene challenges

In terms of mask wearing, parents explained that their child experienced behavioural and emotional challenges when asked to wear a mask, especially those who had sensory issues. These findings resonate with the literature. For example, Latzer et al (2021) showed that children with ASD displayed behavioural problems, anger, and confusion, as they felt strong discomfort when wearing a mask. Consequently, some parents preferred removing their child from school or sending their child to school without a mask, which put them at risk for the virus. In this study, parents explained that, even though the lockdown was eased, they still experienced challenges going out with their children, as they could not wear a mask or adhere to social distancing. This finding seemed to be in contrast to that which is available in the literature. For example, Colizzi et al (2020) reported that, at the end of the lockdown, the loosening of restrictions helped parents and children with ASD, as they could go out.

In contrast to children who struggled to handle the face mask, others did not only adapt but integrated the wearing of the mask into their new routine. Parents explained that teaching their child to wear a mask using fun strategies or privileging certain masks in terms of design and/ or material helped. In terms of hand hygiene, parents explained that their children would either be scared of sanitisers or would not understand its utility. Children who managed to regularly sanitise their hands were mostly those with high-functioning ASD or those who mimicked their parents’ behaviour.

Vygotsky believes that, when children are in the ZPD for a particular activity, providing the appropriate assistance will give them the ability to achieve the task (Holzman, 2017). Through guidance from a skilled adult, that is, the MKO, children manage to complete an activity or task (Holzman,2017). In fact, parents in this study, that is, the MKOs, explained that providing guidelines to their children regarding the containment measures through descriptive images such as a painting helped them understand and adapt to these measures. Further, Silver (2011) provides scaffolding of instruction guidelines in order to help children achieve a required task. These guidelines include providing instructions such as breaking the activity into small, more manageable tasks. In fact, this could allow children with ASD reach their full potential.

6.3. Objective 2: Parenting and interpersonal relationships in conditions of confinement

The second objective of my study was to explore the ways in which parents collaborated/ interacted with their child diagnosed with ASD during the pandemic in South Africa.

6.3.1. Parent-child relationship

Parents said that, before Covid-19, they felt as though they had a good and balanced relationship with their children where they spent some time together during the day but also some time apart. A high-quality parent-child relationship is critical for healthy development (Gillberg,2010). However, this relationship became strained and difficult during the pandemic for the participants in the present project, mostly due to a lack of personal space and time apart from each other. This finding is again echoed in the literature. For example, Narzisi (2020) explains that the change in physical environments affected those relationships. These changes included the presence of a parent who was usually absent from home or extensive time shared with a parent (Narisizi,2020; Latzer et al., 2021)

In fact, due to the changes in the physical environment, parents and children became frustrated with each other, which negatively affected their relationship. While some parents tended to get frustrated with their child during the pandemic, others avoided conflicts and meltdowns by changing the ways in which they interacted with their child, reporting greater leniency on their side. The literature on parenting a child with ASD in times of crisis mirrors these findings. For example, in a study by Ueda et al. (2021) conducted in Japan, /assessed the quality of life of 136 school-aged children with neurodevelopmental disorders including ASD (intellectual quotient ≥ 50) and their parents through completion of questionnaires. The authors demonstrated that, in a situation of crisis, parents experienced a lack of agency as well as adjustment difficulties, and therefore struggled to handle their child's behaviour. This lack of control of the crisis situation led to increased stress levels, which decreased the quality of life of both parents and children (Ueda et al., 2021).

Children who had parents who were at the frontline of the pandemic, such as health care workers or those who worked in essential services, felt lonely, as their parents had to leave them in a childcare institution in order to work during the lockdown. Being far away from each other affected the parent-child relationship. This once more resonates with the literature. For example, in a study by Varner (2021) conducted in Canada, the author explains that the need to isolate from their children due to their career was extremely difficult for parents who were at the frontline of the pandemic. Similarly, parents in this study mentioned that the main positive aspect of putting their child in an institution was that he or her became warmer and more accepting of strangers. In contrast to parents who noticed that their relationship with their child was negatively affected by the pandemic, though, some benefitted from the changing conditions, as they spent more time with their child and understood their condition better. These findings are similar to those found in a study by Latzer et al. (2021), who demonstrate that the pandemic made children more affectionate and relaxed, which made it easier to get along with other members of the family.

Unemployed parents did not see any changes in the relationship with their child, as they are used to being at home together. Parents experienced challenges giving equal attention to all the other family members during the pandemic, as they experienced an increase in responsibility and mostly focused on their child who was diagnosed with ASD, neglecting other family members. These findings are similar to those found in the literature. For example, in a study by Chen (2020), it was found that parents noticed that focusing too much on the needs of the child with ASD unconsciously made them relegate the needs of other family members and decrease family participation in activities.

6.3.2. Siblings' relationship

During the lockdown, parents experienced sibling rivalry due to the lack of space and stimulation, which was emotionally challenging as well as difficult to manage. For example, in a study by Toseeb (2021), the author explains that parents experienced difficulties due to ongoing sibling fighting and bullying, as children harmed each other during the lockdown. Children with ASD would display destructive and aggressive behaviours towards their siblings. In contrast, some children spent more time with their siblings, which made them closer and even improved their communication skills. For example, Toseeb (2021) found that family togetherness brought positive shifts to the family dynamics. In fact, neurotypical children understood their neurodiverse sibling to a greater extent, which positively affected their relationship and helped parents cope. These finding are echoed in the literature. Pellicano and Stears (2020) suggest the importance of moments spent together between children with ASD and their family members, explaining that it could help reduce maladaptive behaviour and stress as well as and maintaining social development.

While the pandemic changed siblings' relationship in a positive or negative way, some parents explained that the relationship among their children was not affected by the pandemic. Moreover, some children preferred to be alone and would isolate themselves from the entire family and stay alone. This dovetails well with extant literature. Manning (2020) indicates that isolation was linked to increased feelings of sadness and loneliness, as there were fewer opportunities for children to interact in person with others that they were previously involved with. Latzer et al (2021) suggest that special attention should be directed to parents in terms of encouraging the social engagement of siblings and attempting to resolve sibling discord.

6.3.3 Parental relationships and parenting styles

Furthermore, parents experienced challenging relationships with their partner, as they spent more time together and did not have the private space they were used to before the lockdown. In fact, arguments arose, as parents would understand and cope with the child differently during the pandemic. Some parents explained that, even before the lockdown, their partner did not accept their child's condition, which led to emotional distress. This finding is consistent with those of extant literature. For example, Lee and Gardner (2010) found that parents of children with ASD experienced a prolonged period of vulnerability to divorce which, in part, could be attributed to the constant high level of parenting demands and stress. In this study, while some parents experienced challenges with their partner, others got closer and supported each other.

During the pandemic, and likely as a result of stress and feeling overwhelmed, it seemed as though several parents resorted to negative parenting styles such as permissive or authoritarian ones (Baumrind, 1967). According to Baumrind (1967), authoritarian parents are extremely strict and focus on discipline, control, and obedience rather than nurturing. In fact, in this study parents explained that they found themselves shouting at and punishing their child more in order to discipline and control their behaviours, which were difficult to manage during the pandemic. According to Baumrind (1967), permissive or authoritarian parenting styles are likely to have a negative effect on children's behaviour, and ultimately (if left unchanged) their development. Negative parenting styles are thus likely to lead to increased aggressivity, impulsivity, anti-social behaviours, emotional dysregulation, decreased self-discipline and poor academic performance (Baumrind, 1967).

6.4. Objective 3: Routine

The third objective of my study was to understand the ways in which Covid-19 influenced the routine of parents and children with ASD.

6.4.1. Structuring the chaos

Parents reported that, before the Covid-19 pandemic, their children had a set routine on which they relied heavily for daily structure that would lessen their negative behaviours such as meltdowns and tantrums. Similarly, Benn (2012) established that a set routine helped children with ASD cope with anxiety and enhanced their learning abilities. In the present study, parents explained that a typical day as well as an everyday routine would consist of children going to school, getting involved in a series of outdoors activities, and perhaps attending doctor’s appointment or seeing their therapist. Moreover, parents explained that, even before the pandemic, if there was a change in their daily schedule it would significantly disrupt the day and lead to an increase in the frequency of meltdowns, tantrums, and aggressive behaviours. However, during the lockdown schools were closed, appointments with doctors were cancelled or done online and outdoors activities were prohibited.

According to parents, children with ASD had difficulties adapting to changes in routine and schedule in addition to separation from teachers and peers at school as well as the new home environment, where parents and siblings were then constantly present. In fact, parents described that the lockdown resulted in chaos at home, especially in the initial days, when parents had no set or clear routine with their child. Similar findings are reported in Latzer et al. (2021): for most of children with ASD the radical alteration of routine was hard to accept. Narzisi (2020) found that, due to a lack of routine, children with ASD were emotionally dysregulated, as their scheduled changed. In this study, parents explained that the transition from one lockdown level to another as well as the inconsistency and unpredictability of the pandemic were extremely difficult to manage for children with ASD, who are known to struggle with handling change. As soon as the child adapted to the situation, the government changed the lockdown instructions. In fact, these constant changes negatively affected the child, as he or she could not adapt to a set routine. These findings are consistent with the literature. For example, Fontanesi (2020) explains that the difficulties that emerged in the pandemic were principally related to the drastic transition, which children with ASD find particularly difficult to manage.

6.4.2. Children's regressions

In this study, parents explained that, in response to these constant changes, children experienced setbacks on different levels: emotionally, socially, and academically, over and above an increase in negative behaviours such as aggressivity, meltdowns, isolation, sleep, and the maintenance of food issues. Therefore, parents were concerned about the challenges ahead and the developmental regressions of their children in view of these changes, including the cessation of mental health care and interventions. These worries are understandable, as the treatment provided for children with ASD are aimed at reducing maladjusted behaviours, improving social skills, and instructing parents (Mash & Wolfe, 2019). Colizzi et al. (2020) highlight that there was a clear description of regression in children with ASD that had occurred as well as behavioural issues that were intensified during the pandemic. In fact, children experienced food-related issues, sleep deregulation, and lack of stimulation, which were major sources of difficulties for parents. Latzer et al. (2021) determined that children with ASD engaged in food selectivity as they were used to the food provided by their school, which was different from that provided by their parents at home. In this study, parents explained that changes in food routine also created an increase in negative behaviours in their child with ASD.

Some parents allowed unhealthy eating, including those usually prohibited by doctors, in order to avoid tantrums and meltdowns. Children overate as they were confined to their home and bored. Food selectivity and overeating led to emotional stress for parents, who experienced difficulties handling their child's behaviour. Parents also experienced financial challenges, as they had to get specific food and in bigger quantities than they used to before the pandemic. Literature confirms the validity of these findings. Sharp et al. (2013) explain that selectivity and refusal of food could result in severely exacerbating behavioural issues, nutrient deficiencies, financial burdens for parents, and frustrated family interactions. In addition, Latzer et al (2021) suggest that guidance had to be given for balancing the ASD child's diet as much as possible due to the unique food-related challenges that arose during the pandemic, and parental awareness was to be increased by healthcare professionals. This might include treatment with nutritional supplements if required as well as strategies for offering foods that the child did not habitually eat (Latzer et al., 2021).

Due to the lack of routine, children experienced sleep-related issues. In order to combat this challenge, parents medicated their children during the lockdown to help them sleep. They explained that medications were helpful to manage their child's sleeping pattern and behaviour. Bruni et al. (2021) indeed explained that, during the lockdown, children with ASD experienced a significant increase of sleep disturbances, especially in terms of falling asleep, anxiety at bedtime, sleep terrors, and daytime sleepiness. The task of giving children the stimulation they needed was very challenging for parents. Some parents tried to reconstruct a sense of familiarity for their child by home-schooling them during the pandemic, which was helpful. In fact, parents had to take on different roles, which was overwhelming and increased their responsibilities. Latzer et al. (2021) found that parents had to take the role of educators and caregivers, while trying to handle their own jobs from home, coping with mounting financial pressures, and dealing with potential health threats. Children who were able to adjust to the situation were either those diagnosed with high-functioning ASD or those who initially did not follow a set routine.

6.4.3. Children's improvements

While some parents said that their children experienced regressions in various areas, others explained that their children's behaviour improved. In fact, parents explained that, by maintaining a routine at home and spending quality time with their child, he or her became more affectionate and independent. For example, parents who managed to get their child to sleep during the lockdown were mainly those who maintained their child's sleeping routine and those who spent quality time with their children and understood them better. Colizzi et al. (2020) suggest that parents should be guided in order for them to create a flexible routine tailored to their children's needs during Covid-19. Moreover, as mentioned, participants of the present project explained that their child's communication skills and warmth improved as he or she spent more time with their siblings and other family members. Some children learned to become independent, as they spent more time at home and learned house chores such as cooking which, again, is consistent with the literature. Chen (2020) explains that parents observed an increase of initiation when it came to house chores, which they attributed to being at home and able to provide reminders as well as improvements in life skills.

6.5. Objective 4: Work-life (im) balance

The fourth objective was to explore the ways in which parents managed their own work against the needs of their children with ASD in South Africa in the context of Covid-19.

6.5.1. Working from home

In terms of working from home, parents explained that they experienced challenges managing their own work against the need of their child. In fact, before the lockdown, going to work was a way for parents to enjoy their own space and time away from their child. Having their own work responsibilities allowed them to release their tension and take a break from parenting responsibilities so as to keep a well-balanced life. Working from home was a challenge for parents, as they were constantly disturbed by their children who wanted attention. In fact, in order to have their parents' attention, children would engage in negative behaviours. Therefore, in order to be able to work without being disturbed, parents had to hide, bring their child into a meeting, work late nights, or take their full annual leave. Other than their work responsibilities, parents had to adopt different roles during the pandemic and therefore experienced an increase in responsibilities. Those parents who did not face as many challenges were the ones who were used to staying at home with their child for prolonged periods of time. In fact, some parents quit their job as soon as they received their child's diagnosis and decided to stay at home and take care of their child. These findings are echoed in the literature. For instance, in Pennsylvania, Cidav et al. (2012) noticed that parents of children with ASD tended to face a significant economic burden as it was 9% less likely for both to be working.

6.5.2. New roles

Adopting new roles created much tension between children and parents. Parents experienced difficulties managing their child's needs against their everyday duties, especially those who had children diagnosed with ASD and another comorbidity such as ADHD or Down syndrome. Consequently, parent experienced an increase of stress, as they had no time to rest or relax and had more responsibilities than they had before the pandemic. These findings are consistent with the literature. For example, Wang et al. (2021) explain that the increase of parental stress creates a vicious circle that can have a negative impact on both parents and children's mental health. Moreover, participants in the present project were worried about their capacity to support and educate their child as well as the possible long-term effects of the pandemic. These worries are echoed in the literature. In fact, Hall (2012) underlines the importance of offering informal and formal care for the well-being and competency of parents of children with ASD.

6.5.3. Parents working at the frontline of the pandemic

Parents who were on the frontline of the pandemic experienced additional stress, as they were forced to go to work and be far away from their child during the eight weeks of lockdown. These parents explained that they had to leave their child in an institution, as they feared being fired or experiencing salary cuts. These parents also feared getting sick. Similar findings are shown in a study by Varner (2021), in that frontline health care workers with children were already managing a precarious work-life balance before Covid-19, while the pandemic brought about new challenges and anxieties, such as the fear of contracting the virus.

6.6. Objective 5: Sources of Support

The fifth objective of my study was to explore the sources of support (if any) made available to and accessed by parents of children with ASD during the coronavirus crisis in South Africa.

6.6.1. Support from family and friends

Parents reported that they received the majority of their support during lockdown via their informal social networks including their husbands, partners, friends, and families. These findings resonate with the literature. For example, Jung (2010) explains that parents find support most beneficial when it comes from the informal social support network that includes the social network of family, friends, neighbours, and community. An important part of emotional support before and during Covid-19 for most families occurred on the parent-to-parent level. In the present study, female caregivers in particular reported relying heavily on their partner/ husband for support. However, some parents did not feel supported sufficiently regarding childcare responsibilities by their partner and felt overwhelmed with childcare and financial responsibilities.

Through their involvement with their ASD sibling, neurotypical siblings also played a crucial role in the family support structure. In addition, parents reported that grandparents were important sources of support, but only if this did not pose risks to their health. These findings correlate with those found in the literature. For example, Lee and Gardner (2010) outline the important role grandparents have in the support system of parents regarding their emotional and physical well-being. Moreover, parents reported that relying on extended family was important for support as well, but only when those family members understood their child. These finding are echoed in the literature. For example, Kinnear et al. (2016) explain that parents with children with ASD tend to be stigmatized by others, including their own family members. Parents also reported relying on their friends for emotional support and guidance, but this was not always easy, as people's lives became difficult and complicated as a result of the pandemic.

6.6.2. Support from the community and the government

Another main source of support for parents during the pandemic was help from their community, in particular neighbours and the church. While some parents received help from their neighbours during the lockdown, others mentioned that they experienced a stigma and lack of understanding from their neighbours and community when their child would experience an increase in meltdown episodes. Several parents (n=8) received a grant from the government, which helped them financially before and especially during the lockdown. For some parents, the grant was their only source of income during the lockdown, which was not sufficient. Parents felt both supported and unsupported by the government in terms of restrictions posed during lockdown. Parents explained feeling unsupported when public spaces were closed, which limited places for their child to play and release frustration, while others were grateful, as the government allowed childcare institutions to remain open during the lockdown. These institutions were a major source of support, especially for parents who were at the frontline of the pandemic.

Social media platforms were used by parents as tools to find emotional support, seek advice, and create important social connections for themselves and their children. All of the parents in this study were part of the ASD group on Facebook and reported that it was a major source of support for them on an emotional level. However, some parents did not find the group helpful, as they could not relate to members or did not want to share their experiences. Parents expressed the importance of support received from mental health professionals as crucial for their child's development. Literature resonates with these findings. For example, Jung (2010) demonstrates that parents of children with ASD coped better with access to formal support such as that received from medical specialists and psychologists and informal support such as that received from social networks and community. While some parents were grateful that their child's therapy could continue, even if online, others explained that children who relied on therapy they received at school were not getting the support they needed.

6.6.3. Support from professionals and workplace

Parents did not only express the need for therapy for their child, but also the need for therapeutic, emotional, and psychoeducational support for themselves in order to gain more knowledge about ASD and be able to manage their child effectively. In contrast to the literature (Colizzi et al., 2020), parents also benefited from home care workers' support before and during the pandemic, which allowed them to manage their daily duties against the needs of their child. Some parents lost the support from their home care workers which, in turn, exacerbated parenting struggles and challenges. These findings resonate with the literature. For example, Ned et al. (2020) explained that assistance was interrupted by restricted travel methods as well as the fear of contracting Covid-19 from home care workers. Parents felt overwhelmed and tired, and they would have liked childcare support during the pandemic. Moreover, parents also mentioned support from their workplace. While some parents benefited from work support, which relieved a great amount of parenting stress and eased the difficulties of the pandemic, others lacked support from their work, which increased their parenting stress. The literature outlined that online learning was a source of support when it came to helping parents around their child's education. For example, eLearning is a source of support for parents of children with ASD according to a study by Latzer et al. (2021). The present study found that children did not tolerate and were not compliant with any type of learning online in contrast to some of these recent literatures.

6.7. Objective 6: Coping strategies

The last objective of my study was to explore the coping strategies employed by parents of children diagnosed with ASD in South Africa during the Covid-19. Parents experienced an increase in mental distress during the lockdown.

6.7.1. Substance use, overeating and isolation

Coping with the pandemic posed additional demands and stress on parents of children with ASD. Some mentioned that, before Covid-19, they coped with their anxieties by making use of substances such as alcohol or cigarettes, while other parents explained that they coped by practicing activities outdoors. However, due to lockdown conditions, outdoors activities were prohibited. Therefore, parents could not relive their stress through outdoor exercising, and some turned to substance use in order to relieve their anxiety. Moreover, parents who used substances before the lockdown explained that their use of these increased during this period. These findings are echoed in the literature. In fact, a study conducted by De Backer (2021) in South Africa established the detrimental impact on mental health due to the Covid-19 pandemic in addition to the recent violence in the country and the economic fallout from these.

The author highlighted that many South African started using over-the-counter medication and alcohol in order to deal with the crises in the county, which led to an increase in substance use (De Backer 2021). Thus, in attempting to manage and cope with the COVID-19 pandemic, the South African government prohibited the sale and transportation of cigarettes and alcohol during the lockdown. This legislation negatively affected parents who used substances to cope with their distress, which increased symptoms of anxiety and depression. De Backer (2021) urged individuals who are either struggling and/ or recovering from substance use to seek support from healthcare professionals, the church, friends, and the community, who remained easily accessible through online groups to all those committed to healing and the mental health of fellow South Africans.

Moreover, some parents started overeating and/ or isolating themselves in order to relieve their stress and anxiety, which negatively impacted their mental well-being.

6.7.2. Home activities, music, and television

During the lockdown, parents faced challenges around stimulating their child through indoor activities. In fact, parents had to free up a significant portion of time in order to entertain their child and get them to participate in enjoyable activities. Parents explained that, in order to stimulate their child during the pandemic, they had to respond rapidly with resourcefulness and creativity. Therefore, parents privileged practical creative arts activities to distract their children during this time. They discovered that their child had certain outstanding skills they had not known of. These findings are echoed in the literature. For example, Latzer et al. (2021) explain that parents’ creativity was the key factor that enabled successful coping. Whereas some parents could afford arts tools, others had to be even more creative by finding objects to replace these.

Parents explained that their child tended to be bored at home as they could not afford a computer or a television to distract them. They explained that they shared valuable time with their child dancing, listening to music, and exercising, which would be calming and fun for both parent and child. Moreover, parents initiated their child to culinary activities and house chores, which allowed their child to feel more responsible, independent, and organised which, in turn, established family togetherness. These findings resonate with the literature: a study by Narzisi (2020) explains that parents mentioned these as coping mechanism to Covid-19: exercise, selfcare, and creative outlets. In addition, parents used digital devices as means to distract their child and have free time. In contrast to parents who coped by allowing their child to use digital devices and television, parents would describe this coping strategy as having a negative impact on their child's behaviour, especially during the lockdown.

6.7.3. Faith, acceptance, and communication

As indicated, parents reported that faith (belief) and prayers (practice) were their main coping mechanisms, especially during the lockdown. Spirituality empowered parents by providing inner strength, optimism, peacefulness, wisdom, and determination that was consistent. These findings dovetail with those found in the literature. Latzer et al (2020) explain that parents mastered their anxiety by using prayers to avoid subdued by fear. However, in contrast to parents who found strength through spirituality, others experienced spiritual doubt. In terms of acceptance, tolerance of the child's uniqueness brought peacefulness to parents as they noticed that their anxiety decreased as soon as they acknowledged and tolerated their child's condition as opposed to the time when they rejected the diagnosis.

Contrary to parents who accepted their child's conditions, others were in denial, which made it more difficult for them to manage; this is also consistent with the literature. For instance, Dababnah et al.2019 explain that parents in denial had increased anxiety in comparison to parents who accepted their child's diagnosis. Accepting their child's condition allowed positive parenting practices. In fact, after receiving and accepting their child's diagnosis, parents changed their disciplinary methods and, instead of shouting or giving hidings to their child, they would communicate with them. Parents who were accepting of their child's condition and the pandemic situation experienced the Covid-19 context in a more positive manner when compared to parents who had a negative view of the circumstances, which led to feelings of hopelessness and helplessness. Consequently, the children in these households showed an increase of behavioural symptoms and/ or developmental setback.

Parents realised that communication was the most effective coping strategy when it came to raising a child with ASD. Communicating with their child was not only easier for them but, most importantly, benefitted their children academically, socially, and emotionally. However, during the pandemic some parents were under pressure, which made it difficult for them to be patient and communicate with their child. In contrast, some parents-maintained communication as their main coping mechanism during the pandemic, as indicated. These parents seemed to cope better when compared to those who shouted at their child while being under pressure. Parents explained that, when their child accepted the lockdown conditions, they experienced fewer meltdowns, which made it easier for these parents to cope with the situation.

Lazarus and Folkman (1984) explain that coping strategies can be adaptive (effective) or maladaptive (ineffective or harmful). Adaptive coping strategies include problem-solving or active strategies, daily relaxation, exercising, emotional expression, and regulation strategies as well as help or support-seeking strategies. Maladaptive coping strategies are harmful to individual well-being (Biggs et al., 2017). Some examples of maladaptive coping are escape and avoidance, distraction strategies, unhealthy comfort zones as well as emotional numbing. Resorting to comforting habits such as eating, watching television, or surfing the internet for hours involve perceptual errors and negative coping strategies that lead to distress (Lazarus& Folkman, 1984). In this study, parents made use of adaptive and maladaptive coping strategies. However, they seemed to use maladaptive coping strategies such as substance use, isolation, resorting to comforting habits, isolation, and denial to a greater extent, in contrast to adaptive strategies such as communication, faith, acceptance, and physical exercising.

6.8. Implications of the findings

The first major practical contribution of my research is that it provides much-needed data on the challenges parents faced during the pandemic as well as the support systems they enjoyed (or not) and how they coped with the pandemic. This information is important, given that very little if any study has been conducted regarding raising/ parenting a child with ASD in South Africa in the context of Covid-19. Recounting the experiences of parents will allow mental health care workers, teachers, governmental institutions as well as other parents of children with ASD to comprehend the issues at hand. I believe that my research is especially timely, as the pandemic is still ongoing. The emergence of the pandemic and the rapid transition that occurred led to the negligence of children that required particular care. Based on my research, it seems relevant that future research and interventions as well as policy be oriented towards addressing and responding to the needs of children with ASD and their caregivers during a crisis. This recommendation is similar to the main findings of a pertinent research on parents of children with ASD in Tel-Aviv, whose primary goal was to influence future governmental and current policies regarding these challenges (Latzer et al., 2021). As I have understood from the context of the Covid-19 crisis, children with ASD who were at risk because of their developmental and medical challenges, were especially vulnerable to disturbances.

Specialists should aim at understanding parents' internal resources that need to be developed or those already present, their subjective appraisal of the situation, and whether there is a gap between available resources and parental needs. Strengthening parents' abilities to adjust and offering them support could be particularly helpful at the time of a pandemic/ crisis. Furthermore, for parents to get help to manage challenging conditions and express their concerns, the South African health department could establish support services such as helplines and counselling dedicated only to parents of children with ASD. Additionally, the extent of ASD support provided through formal channels for children with this disorder could be increased by the South African health department. Moreover, in order to guide parents in ways and means of dealing with certain behaviours characteristic of children with ASD and increase their awareness of this disorder, the South African department of health can provide psychoeducational training for parents.

6.9. Limitations and recommendations

6.9.1. Limitations

This study had various limitations. In the wider South African context, the sample of participants was not representative of parents of children with ASD. The subjective and lived experiences are explored qualitatively from within the participants' context. This study was limited by the sample of participants, who were recruited from online social media groups. While the participants were heterogenous in terms of their socio-economic status, gender, age, marital status, sexual orientations, work situation, level of child ASD severity, and education, they were recruited from a single platform. The sample consisted of parents of children with ASD who were on a Facebook group: therefore, parents who were not on this social media group were not part of the study. In South Africa, in 2021, only 60% of the population had access to internet; some parents did not have access to social media (Statistics South Africa, 2021). Furthermore, only parents who had children between the ages of 6 to 12 were interviewed. Therefore, parents who had children outside this age group were excluded from the study. Moreover, the sample size was mainly composed of mothers of children with ASD, therefore there was a shortage of fathers who took part in the study.

My research was designed to analyse parents' subjective experiences through open-ended questions, which allowed for flexibility, but which could also have created a varied range of answers. While some parents gave brief and generalized responses, others gave detailed and elaborate responses. Furthermore, it is crucial to note that the interviews were conducted in English. Even though all participants spoke English, this was not their first language. Not being able to conduct the interviews in other languages limited the potential pool of participants who could take part in this study.

6.9.2. Recommendations

Future research could include the experiences of raising adolescents with ASD in the context of Covid-19 in South Africa. Also, future research might focus on assessing the emotional well-being and stress of parents of children with ASD – and under different levels of restriction. Moreover, there is little research available on parenting a child with ASD in the context of Covid-19 in South Africa in both underprivileged and affluent communities. Acknowledging the impact of the pandemic in South Africa, more research centred on this would improve parenting a child with ASD in this context. Interviews were of a once-off nature, leaving little room for enough rapport building. Participants could be more vulnerable about their experiences if better rapport is built (Elliot & Martin, 2013).

Have focus group interviews with participants on the basis of various parenting experiences could be another possibility for future research. They could discuss and compare their experiences in this platform. Moreover, time did not allow for the data to be confirmed by the participants of the present project. Participant verification necessitates that the themes and transcriptions that emerged from the thematic analysis are sent to them for verification and authentication. Thus, to ensure the credibility of the research, this method should be applied in future research. Thus, credibility was guaranteed in the present project through familiarisation with the parents of children with ASD and the Facebook group as well as a sound research method.

6.10. Conclusion

Once more, the primary aim of my research was to explore parents' experiences of parenting a child with ASD in South Africa in the context of Covid-19 in order to determine challenges they faced and how they coped with these. I pursued this aim by directly interviewing 23 parents of children with ASD in South Africa in the context of Covid-19. This revealed that parental emotional well-being and the stress of parents of children with ASD in South Africa significantly deteriorated during the Covid-19 pandemic. The main difficulties encountered by children with ASD according to their parents were related to lockdown conditions, preventive measures imposed, change in routine, lack of space as well as sibling rivalry and fights. In fact, the pandemic negatively affected the children's behaviours leading to regression. Moreover, the parent child-relationship was negatively affected by the pandemic. Non-verbal children and those diagnosed with a comorbidity such as ADHD or Down syndrome had much more difficulties coping than those diagnosed with a high-functioning ASD. In contrast to parents and children who experienced difficulties during this period, some experienced this period as being beneficial and even positive.

Parents’ capacity to respond to their children’s needs as well as a resourceful and creative problem-solving orientation and a general positive outlook were main elements that allowed effecting coping. While some parents used maladaptive coping, others used adaptive coping. Parents who used the former allowed their children to adapt to the preventive measures and integrated them in their daily routine. While some parents felt supported during the pandemic, others lacked support and felt overwhelmed. The main needs of parents were financial and educational support. Moreover, they expressed the need for more grocery parcels. Providing these needs, especially in times of a pandemic, may be helpful for preventing behavioural regression and negative symptoms such as running away from home, destroying objects, and head banging.

Providing solutions for these needs may decrease parental frustration. My findings expand the knowledge of coping strategies of children with ASD and their parents in times of a pandemic. In such times, programmes that are not only parent-focused but also child-focused should aim at enhancing the resilience of parents. For example, providing cognitive behavioural therapy for parents that is focused on improving their understanding of their children’ disorder in the context of Covid-19 in South Africa as well as challenging their negative beliefs about the stressful situation could empower them with resourceful strategies and strengthen the family unit as a whole.

REFERENCES

Abdul Majid, M. A., Othman, M., Mohamad, S. F., & Abdul Halim Lim, S. (2018). Achieving data saturation: evidence from a qualitative study of job satisfaction. *Social and Management Research Journal* (SMRJ), 15(2), 65-77.

Adams, W. C. (2015). Conducting semi-structured interviews. In Newcomer, K. E., Hatry, H. P., & Wholey, J. S (Eds.), *Handbook of practical program Evaluation* (2nd ed., pp. 492–505). Jossey-Bass.

Alhazmi A, Petersen R, Donald KA. (2018). Quality of life among parents of South African children with autism spectrum disorder. *Acta Neuropsychiatry*.

Alhuzimi, T. (2020). Stress and emotional wellbeing of parents due to change in routine for children with autism spectrum disorder (ASD) at home during COVID-19 pandemic in Saudi Arabia. *Research in Developmental Disabilities*, 1-12.

Alshaigi, K., Albraheem,R., Alsaleem,K., Zakaria,M., Jobeir,A., & Aldhalaan,H.(2020). Stigmatization among parents of autism spectrum disorder children in Riyadh Saudi Arabia.

Altable, M. (2020). Child and adult autism spectrum disorder in COVID-19 pandemic.

Amaral, D. G., de Vries, P. J. (2020). COVID-19 and autism research: Perspectives from around the globe. *Autism Research*, 13(6), 844–869. https://doi.org/10.1002/aur.2329

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

Antshel, K. M., Zhang-James, Y., Wagner, K. E., Ledesma, A., & Faraone, S. V. (2016). An update on the comorbidity of ADHD and ASD: A focus on clinical management. *Expert Review of Neurotherapeutics*, 16(3), 279–293. https://doi.org/10.1586/14737175.2016.1146591

Asperger, H. (1991). 'Autistic psychopathy' in childhood (U. Frith, Ed.). *Cambridge University Press*. https://doi.org/10.1017/CBO9780511526770.002

Baio, J., Wiggins, L., Christensen, D. L., Marnner, M. J., Daniels, J., Warren, Z., KursiusSpencer, M., Zahorodny, L., Robinson Rosenberg, C., White, T., Durkin, M. S., Imm, P., Nikolaou, L., Yeargin-Allsopp, M., Lee, L., Harrington, R., Lopez, M., Fitzgerald, R. T., Hewit, A., Pettygrove, S … Dowling, N. F. (2014). Prevalence of autism spectrum disorders among children aged 8 years – autism and developmental disabilities monitoring network, 11 sites, United States, 2014. MMWR Surveillance Summary, 67(6), 1-23. http://dx.doi.org/10.15585/mmwr.ss6706a1

Baumrind, D. (1967). Childcare practices anteceding three patterns of preschool behaviour. *Genetic Psychology Monographs*, 75(1), 43-88.

Barroso, N. E., Mendez, L., Graziano, P. A., & Bagner, D. M. (2018). Parenting stress through the lens of different clinical groups: A systematic review & meta-analysis. *Journal of Abnormal Child Psychology*, 46(3), 449–461.

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

Bellardinelli C, Raza M, Taneli T (2016). Comorbid behavioural problems and psychiatric disorders in autism spectrum disorders. *Journal of childhood and developmental disorders,1-9.*

Benn, R. (2012). Mindfulness training effects for parents and educators of children with special needs. *Developmental Psychology*, 48 (5), 1476.

Bhat, A (2021). Is motor impairment in autism spectrum disorder distinct from developmental coordination disorder? *Physical therapy.*

Biggs, A., Brough. P, Drummond, S. (2017) The Handbook of Stress and Health: *A Guide to Research and Practice*, 349-364.

Bleuler, E. (1950). Dementia praecox; or, The group of schizophrenias. *International Universities Press.*

Bluth, K., Roberson, P. N., Billen, R. M., & Sams, J. M. (2013). A stress model for couples parenting children with autism spectrum disorders and the introduction of a mindfulness intervention. *Journal of Family Theory & Review*, 5(3), 194–213.

Bonis, S. (2016). Stress and parents of children with autism: A review of literature. Issues in *Mental Health Nursing*, 37(3), 153–163.

Braun, V. & Clarke, V. (2020). Thematic analysis: A practical guide. London: Sage.

Brentani, H. (2013). Autism spectrum disorders: An overview on diagnosis and treatment. *Brazilian Journal of Psychiatry*, 35, S62–S72.

Bruni O, Melegari MG, Breda M, Cedrone A, Finotti E, Malorgio E, Doria M, Ferri R (2021). Impact of COVID-19 lockdown on sleep in children with autism spectrum disorders. *Journal of Clinical Sleep Medicine ,18(1):137–143.*

Budd, M. A., Calli, K., Samson, L., Bowes, J., Hsieh, A. Y. Y., Forbes, J. C., Bitnum, A., Singer, J., Kakker, F., Alimenti, A., Maan, E. J., Lewis, M. E. S., Gentile, C., Côte, H. C. F., & Brophy, J. C. (2018). Blood mitochondrial DNA content in HIV-exposed uninfected children with autism spectrum disorder. *Molecular Diversity Preservation International*, 10(77), 1–16. https://doi.org/10.3390/v10020077

Buie, T., Campbell, D. B., Fuchs, G. J., III, Furuta, G. T., Levy, J., VandeWater, J., Whitaker, A. H., Atkins, D., Bauman, M. L., Beaudet, A. L., Carr, E. G., Gershon, M. D., Hyman, S. L., Jarapinyo, P., Jyonouchi, H., Kooros, K., Kushak, R., Levitt, P., Levy, S. E., Lewis, J. D., Murray, K. F., Natowicz, M. R., Sabra, A., Wershil, B. K., Weston, S. C., Zeltzer, L., & Winter, H. (2010). Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. *Pediatrics, 125*, S1–S18.

Cahapay, M. B. (2020). How Filipino parents’ home educate their children with autism during COVID-19 period. *International Journal of Developmental Disabilities*.

Cawthorpe, D. (2016). Comprehensive Description of Comorbidity for Autism Spectrum Disorder in a General Population. *Frontiers in Psychiatry*.

Centers for Disease Control and Prevention (CDC). (2020). *Data & Statistics on Autism Spectrum Disorder*. Retrieved from *Centers for Disease Control and Prevention*: https:/ / www.cdc.gov/ ncbddd/ autism/ data.html

Chalay,C., & Male,D. (2011). Applying Vygotsky's zone of proximal development and peer collaboration to pupils with profound and multiple learning difficulties and severe learning difficulties: two case studies. *Research Gate*.

Chan, K. K. S., Lam, C. B., Law, N. C. W., & Cheung, R. Y. M. (2018). From child autistic symptoms to parental affective symptoms: A family process model. *Research in Developmental Disabilities*, 75, 22–31.

Chen.Y. (2020). The Experience of Parents of Children with Autism Spectrum Disorder During the COVID-19 Pandemic: A Qualitative Analysis. Research Square, 1-13.

Clauser,P. (2021). Parenting styles, parenting stress, and behavioural outcomes in children with autism. *School Psychology International*.

Colizzi, M., Sironi, E., Antonini, F., Ciceri, M. L., Bovo, C., Zoccante, L. (2020). Psychosocial and behavioral impact of COVID-19 in autism spectrum disorder: An online parent survey. *Brain Sciences*, 10(6), 341. https://doi.org/10.3390/brainsci10060341

Cohrs, A.C., Leslie, D.L. Depression in Parents of Children Diagnosed with Autism Spectrum Disorder: A Claims-Based Analysis. *Journal of Autism and Developmental Disorders* 47, 1416–1422 (2017).

Coleman, M., & Gillberg, C. (2012). The Autisms (Fourth ed). *Oxford University Press*, Inc.

Connelly, L. M. (2016). Trustworthiness in qualitative research. *MEDSURG Nursing*, 25(6), 435–436

Cooke, E., Smith, V., & Brenner, M. (2020). Parents' experiences of accessing respite care for children with autism spectrum disorder (ASD) at the acute and primary care interface: A systematic review. *BMC Pediatrics*, 20(1), 1–12.

Costa, A. P., Steffgen, G., & Ferring, D. (2017). Contributors to well-being and stress in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 37, 61–72.

Creswell, J. (2018). Qualitative inquiry and research design: Choosing among five approaches. USA: *SAGE Publications*, Inc.

Dababnah, S., Habayeb, S., Bear, B. J., Hussein, D. (2019). Feasibility of a trauma-informed parent-teacher cooperative training program for Syrian refugee children with autism. Autism, 23(5), 1300–1310. https://doi.org/10.1177/1362361318805368

Da Paz NS, Siegel B, Coccia MA, Epel ES. (2018). Acceptance or Despair? Maternal Adjustment to Having a Child Diagnosed with Autism. *Journal of Autism and Dev Disorders*, *48(6):1971-1981.*

Dawson N (2011). An ecological perspective on parents' experiences of having a child with autistic spectrum disorder (ASD) in the South African context. University of Witwatersrand.

Department of Basic Education. (2020). Guidelines for schools with autistic learners returning to school during Covid-19.

Department of Co-operative Governance and Traditional Affairs. (2020).Disaster management act.

Department of Health (2020). Covid-19/ Novel Coronavirus.

Department of Health (2021). Covid-19/ Novel Coronavirus.

Dyson, M. W., Chlebowski, C., & Brookman-Frazee, L. (2019). Therapists' Adaptations to an Intervention to Reduce Challenging Behaviours in Children with Autism Spectrum Disorder in Publicly Funded Mental Health Services. *Journal of autism and developmental disorders*, *49*(3), 924–934.

Eshraghi, A. A., Li, C., Alessandri, M., Messinger, D. S., Eshraghi, R. S., Mittal, R., Armstrong, F. D. (2020). COVID-19: Overcoming the challenges faced by individuals with autism and their families. *Lancet Psychiatry*, 7(6), 481–483. https://doi.org/10.1016/S2215-0366(20)30197-8

Estes, A., Olson, E., Sullivan, K., Greenson, J., Winter, J., Dawson, G., et al. (2012). Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain & Development*, 35, 133–138.

Etikan, I. (2016). Comparison of Convenience Sampling and Purposive Sampling. American *Journal of Theoretical and Applied Statistics*, 5(1), 1.

Factor, R. S., Condy, E. E., Farley, J. P., Scarpa, A. (2016). Brief report: Insistence on sameness, anxiety, and social motivation in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46(7), 2548–2554. https://doi.org/10.1007/s10803-016-2781-x

Fairthorne J, Jacoby P, Bourke J, de Klerk N, Leonard H (2016). Onset of maternal psychiatric disorders after the birth of a child with autism spectrum disorder: A retrospective cohort study.

Fewster DL. (2014). A qualitative study to understand the experiences and coping processes of primary caregivers of children with autism spectrum disorder. University of KwaZulu-Natal.

Fitzgerald, M. (2012). Schizophrenia and autism/ Asperger’s syndrome: Overlap and difference. *Clinical Neuropsychiatry*, 9(4), 171–176.

Fontanesi L, Marchetti D, Mazza C, Di Giandomenico S, Roma P, Verrocchio MC. (2020). The effect of the COVID-19 lockdown on parents: A call to adopt urgent measures. *Psychol Trauma*.

Franz, L. (2018). Providing early detection and early intervention for autism spectrum disorder in South Africa: stakeholder perspectives from the Western Cape province. *Journal of Child and Adolescent Mental Health*, 30(3): 149–165.

Gillberg, C. (2010). The ESSENCE in child psychiatry: Early symptomatic syndromes eliciting neurodevelopmental clinical examinations. *Research in Developmental Disabilities*, 31(6), 1543–1551. https://doi.org/10.1016/j.ridd.2010.06.00

Grolnick, W. S. (2003). The psychology of parental control: How well-meant parenting backfires. Mahwah, NJ: Lawrence Erlbaum Associates.

Hayes SA, Watson SL. (2013). The impact of parenting stress: a meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43, 629-642.

Hartley, S., Barker, E., Seltzer, M., Greenberg, J., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449-457.

Holzman, L. (2017). Vygotsky at work and play (2nd ed.). New York, NY: Routledge.

Joyce C, Honey E, Leekam SR, Barrett SL, Rodgers J (2017). Anxiety, Intolerance of Uncertainty and Restricted and Repetitive Behaviour: Insights Directly from Young

People with ASD. *Journal of Autism and Developmental Disorders, 47, 3789–3802.* https://doi.org/10.1007/s10803-017-3027-2.

Jung, L. (2010). Identifying families' support and other resources. In R. McWilliam, & R. McWilliam (Eds.), Working with families of young children with special needs.

Kanner, L. (1943). Autistic disturbances or affective contact. Nervous Child, 2, 217–250.

Keenan, B.M., Newman, L.K., Gray, K.M. *(2016).* Parents of Children with ASD Experience More Psychological Distress, Parenting Stress, and Attachment-Related Anxiety. *Journal of Autism and Developmental Disorders, 46(9):2979-91*

Kelly B, Williams S, Collins S, (2019). The association between socioeconomic status and autism diagnosis in the United Kingdom for children aged 5-8 years of age: Findings from the Born in Bradford cohort. Autism; 23 (1): 131-140

Kendall-Jones, Rowan (2014). An investigation into the differential diagnosis of autism spectrum disorder and attachment difficulties. University of Birmingham.

Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. European Journal of General Practice, 24(1), 120–124.

Lai, M. C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/gender differences and autism: Setting the scene for future research. *Journal of the American Academy of Child and Adolescent Psychiatry*, 54(1), 11–24. https://doi.org/10.1016/j.jaac.2014.10.003

Lai, W.W., Oei, T.P.S (2014). Coping in Parents and Caregivers of Children with Autism Spectrum Disorders (ASD). *Journal of Autism Developmental Disord*ers 1, 207–224.

Lappe, M., Lau, L., Dudovitz, R. N., Nelson, B. B., Karp, E. A., & Kuo, A. A. (2018). The diagnostic odyssey of autism spectrum disorder. *Pediatrics*, 141(Suppl. 4), S272–S279.

Latzer T, Leitner Y, Karnieli-Miller O (2021). Core experiences of parents of children with autism during the COVID-19 pandemic lockdown.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York: Springer.

Lee, M., & Gardner, J. (2010). Grandparents' involvement and support in families with children with disabilities. *Educational Gerontology*, 36, 467-499.

Lewis, C. C. (1981). The effects of parental firm control: A reinterpretation of findings. *Psychological Bulletin.*

Licari, M.K., Alvares, G.A., Varcin, K., Evans, K.L., Cleary, D., Reid, S.L., Glasson, E.J., Bebbington, K., Reynolds, J.E., Wray, J. and Whitehouse, A.J.O. (2020), Prevalence of Motor Difficulties in Autism Spectrum Disorder: Analysis of a Population-Based Cohort. *Autism Research*, 13: 298-306.

Llanes, E., Blacher, J., Stavropoulos, K., & Eisenhower, A. (2018). Parent and teacher reports of comorbid anxiety and ADHD symptoms in children with ASD. *Journal of Autism and Developmental Disorders*, 50(5), 1520-1531. https://doi.org/10.1007/s10803-018-3701-z

Luo, L., & Wildemuth, B. M. (2017). Semistructured interviews. In Wildemuth, B. M (Ed.), Applications of Social Research Methods to Questions in Information and Library Science (2nd ed., pp. 248-256). Libraries Unlimited.

Lyall, K., Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., Mandell, D. S., Miller, L. A., Pinto-Martin, J., Reaven, J., Reynolds, A. M., Rice, C. E., Schendel, D., & Windham, G. C. (2017). The epidemiology of autism spectrum Stellenbosch University https:/ / scholar.sun.ac.za 127 Disorders. *Annual Review of Public Health*, 28(1), 235–258. https:/ / doi.org/ 10.1146/ annurev. publhealth.28.021406.14400

Maccoby, E. E., Martin, J. A. (1983). Socialization in the context of the family: Parent-child interaction. In P. H. Mussen (Ed.), *Handbook of child psychology* (Vol. 4, pp. 1-101). New York: Wiley.

MacPhee, D., Lunkenheimer, E., Riggs, N. (2015). Resilience as regulation of developmental and family processes. *Family Relations*, 64(1), 153–175.https://doi.org/10.1111/fare.12100

Malcolm-Smith, S., Hoogenhout, M., & Thomas, K. (2013). Autism Spectrum Disorders Global challenges and local opportunities. *Journal of Child and Adolescent Mental Health*, 25(1), 1-5.

Manning, J. (2020). Perceptions of Families of Individuals with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 1-9.

Manouilenko, I., Bejerot, S. (2015). Sukhareva: Prior to Asperger and Kanner. Nordic *Journal of Psychiatry*, 69(6): 1761-1764

Mash, E., & Wolfe,D. (2019). Abnormal Child Psychology (7th Edition). London: Thomson Wadsworth.

Mason, J. (2012). Qualitative research (2nd ed, ch.4). *SAGE publications*.

Matenge B.(2013). An exploration of the lived experiences of mothers raising children with autism. University of Cape Town.

Meadan H, Halle JW, Ebata AT. Families with Children Who Have Autism Spectrum Disorders: Stress and Support. *Exceptional Children*. 2010;77(1):7-36.

Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019). Parenting stress in mothers of children with autism without intellectual disability. Mediation of behavioural problems and coping strategies. *Frontiers in Psychology*, 10, 464.

Narzisi, A. (2020). Handle the autism spectrum condition during coronavirus (COVID-19) stay at home period: Ten tips for helping parents and caregivers of young children. *Brain Sciences*, 10(4), 207. https://doi.org/10.3390/brainsci10040207

Ned,L. McKinney, E., Swartz, L. (2020). COVID-19 pandemic and disability: essential considerations. *Social and Health Sciences.*

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1), 1–13. https://doi.org/10.1177/1609406917733847

Patten E, Ausderau KK, Watson LR, Baranek GT (2013). Sensory Response Patterns in Nonverbal Children with ASD. *Autism Res Treat*.

Pellicano, E., & Stears, M. (2020). The hidden inequalities of COVID-19. *Autism*, *24*(6), 1309–1310. https:/ / doi.org/ 10.1177/ 1362361320927590

Plecher, H. 2020. *South Africa: Unemployment rate from 1999 to 2020*. Retrieved from Statista: https:/ / www.statista.com/ statistics/ 370516/ unemployment-rate-in-south-africa.

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*.

Rodgers, J., Glod, M., & Connolly, B. (2012). The relationship between anxiety and repetitive behaviours in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 42(11), 2404-2409. https://doi.org/10.1007/s10803-012-1531-y.

Rogoff, B. (1990). Apprenticeships in thinking. New York: Oxford University Press.

Rose,J., Willner,P., Cooper, V., Langdon,P., Kroese,S., (2020). The effect on and experience of families with a member who has Intellectual and Developmental Disabilities of the COVID-19 pandemic in the UK: developing an investigation, *International Journal of Developmental Disabilities.*

Ryan, G. (2018). Introduction to positivism, interpretivism and critical theory. *Nurse Researcher*, 25(4), 14–20. https://doi.org/10.7748/nr.2018.e146

Sadock, B. J., Sadock, V. A., & Ruiz, P. (2015). Synopsis of Psychiatry: Behavioural Sciences/ Clinical Psychiatry (11th ed.). Wolters Kluwer.

Sarrett, J. C. (2015). “Maybe at birth there was an injury”: Drivers and implications of caretaker explanatory models of autistic characteristics in Kerala, India. *Culture, Medicine and Psychiatry*, 39(1), 62–74.

Schlebusch, L. (2016). South African families raising children with autism spectrum disorders: Relationship between family routines, cognitive appraisal and family quality of life. *Journal of Intellectual Disability Research* , 60(5):412-423.

Shattnawi KK, Bani Saeed WM, Al-Natour A, Al-Hammouri MM, Al-Azzam M, Joseph RA. (2020). Parenting a Child With Autism Spectrum Disorder: Perspective of Jordanian Mothers. *Journal of Transcultural Nursing*,32(5):474-483.

Shepherd D, Landon J, Taylor S, Goedeke S. (2018). Coping and care-related stress in parents of a child with autism spectrum disorder. Anxiety Stress Coping.

Silal, S. P., Penn-Kekana, L., Harris, B., Birch, S., & McIntyre, D. (2012). Exploring inequalities in access to and use of maternal health services in South Africa. *BMC Health Services Research*, 12(1). https://doi.org/10.1186/1472-6963-12-120

Silver, D. (2011). Using the ‘Zone’ Help Reach Every Learner. Kappa Delta Pi Record, 47(sup1), 28-31.

Silverman, D. (2010). Doing Qualitative research, (3rd ed). Jay Gubrium, University Florida: Sage.

Smile, S. C. (2020). Supporting children with autism spectrum disorder in the face of the COVID-19 pandemic. *Canadian Medical Association Journal,* 192(21), E587. https://doi.org/10.1503/cmaj.75399

Statistics South Africa (2019). General Household Survey 2019.

Stevens, T., Peng, L., & Barnard-Brak, L. (2016). The comorbidity of ADHD in children diagnosed with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 31, 11–18. https://doi.org/10.1016/j.rasd.2016.07.003

Thanh, N. C., Thi, T., & Thanh, L. (2015). The interconnection between interpretivist paradigm and qualitative methods in education. *American Journal of Educational Science*, 1(2), 24–27. http://www.aiscience.org/journal/ajes

Thomas, S. (2019). Young Children with ASD Participate in the Same Level of Physical Activity as Children Without ASD: Implications for Early Intervention to Maintain Good Health. *Journal of Autism and Developmental Disorders*.

Tomlinson, M., O’Connor, M. J., le Roux, I. M., Stewart, J., Mbewu, N., Harwood, J., & Rotheram-Borus, M. J. (2014). Multiple risk factors during pregnancy in South Africa: The need for a horizontal approach to perinatal care. *Prevention Science,* 15(3), 277– 282. https://doi.org/10.1007/s11121-013-0376-8

Toseeb, U. (2021). Sibling Conflict during COVID-19 in Families with Special Educational. Needs and Disabilities. *British Journal of Educational Psychology.*

Trenberth L, Dewe P (2004). Work stress and coping: Drawing together research and practice. *British Journal of Guidance & Counselling.*

Tuffour, I. (2017). A Critical Overview of Interpretative Phenomenological Analysis: A Contemporary Qualitative Research Approach. 2(4), 52(1) –52(5).

Ueda, R., Okada, T., Kita, Y. (2021). The quality of life of children with neurodevelopmental disorders and their parents during the Coronavirus disease 19 emergency in Japan. *Sci Rep* 11, 3042

UNAIDS. (2020, October 03). South Africa. https:/ / www.unaids.org/ en/ regionscountries/ countries/ southafrica

Van Steensel, F. J. A., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children amd adolescents with autistic spectrum disorders: a meta-analysis. *Clinical Child and Family Psychology Review*, 14(3), 302-317.

Varner,C.(2021)Parents on the front lines of COVID-19 face tough choices. CMAJ.

Ventola P, Lei J, Paisley C, Lebowitz E, Silverman W. (2017) Parenting a Child with ASD: Comparison of Parenting Style Between ASD, Anxiety, and Typical Development. *Journal of Autism and Developmental Disorders*, *47*(9), 2873–2884

Verhoeff, B. (2013). Autism in flux: A history of the concept from Leo Kanner to DSM-5. *History of Psychiatry*, 24(4), 442–458. https://doi.org/10.1177/0957154X13500584

Versaci TM, Mattie LJ, Imming LJ. (2021) Down Syndrome and Autism Spectrum Disorder Dual Diagnosis: Important Considerations for Speech-Language Pathologists. *Am J Speech Lang Pathol.*

Vohra R, Madhavan S, Sambamoorthi U, St Peter C (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. Autism.

Volkmar, Fred. R; Reichow, Brian; McPartland, J. (2012). No Title. *Dialogues in Clinical Neuroscience*, 14(3), 229–237. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3513678

Vygotsky, L. S. (1978). Mind in society: The development of higher psychological processes. Cambridge, MA: Harvard University Press.

Wabiri, N., Chersich, M., Zuma, K., Blaauw, D., Goudge, J., & Dwane, N. (2013). Equity in maternal health in South Africa: Analysis of health service access and health status in a national household survey. *PLoS ONE*, 8(9). https://doi.org/10.1371/journal.pone.0073864

Watson, D., Bayliss, P., & Pratchett, G. (2013). Pond life that ‘know their place’: exploring teaching and learning support assistants’ experiences through positioning theory. *International Journal of Qualitative Studies in Education*, 26(1), 100-117. https://doi.org/10.1080/09518398.2011.598195

Wang, L., Li, D., Pan, S. (2021). The relationship between 2019-nCoV and psychological distress among parents of children with autism spectrum disorder. *Global Health* 17, 23.

Wayment HA & Brookshire KA (2018). Mothers' Reactions to Their Child's ASD Diagnosis: Predictors That Discriminate Grief from Distress. *J Autism Dev Disord.*

Weiss, J. A., Wingsiong, A., & Lunsky, Y. (2014). Defining crisis in families of individuals with autism spectrum disorders. *Autism: the international journal of research and practice*, *18*(8), 985–995. https:/ / doi.org/ 10.1177/ 1362361313508024

Whitman, T. L. (2010). Autism symptom topography and maternal socioemotional functioning. *Journal Information*, 115, 234-249.

WHO. (2021). Coronavirus disease (COVID-19) pandemic. Retrieved from World Health Organisation: https:/ / www.who.int/ emergencies/ diseases/ novel-coronavirus-2019

Wood, J. J., & Gadow, K. D. (2010). Exploring the nature and function of anxiety in youth with autism spectrum disorders. *Clinical Psychology Science and Practice*, 17(4), 281- 292.

Yahya, A. S., Khawaja, S. (2020). Supporting patients with autism during COVID-19. *Primary Care Companion to CNS Disorders*, 22(4), 20com02668. https://doi.org/10.4088/PCC.20com02668

Yarımkaya, E., İlhan, E. L. and Karasu, N. 2017. An investigation of the changes in the communication skills of an individual with autism spectrum disorder participating in peer mediated adapted physical activities.

Yeager, K. R. A. (2015). Crisis intervention handbook: Assessment, treatment, and research (4th ed.). *Oxford University Press*.

Zhang, Y., & Wildemuth, B. M. (2017). Unstructured interviews. In Wildemuth, B. M. (Ed.), Applications of Social Research Methods to Questions in Information and Library Science (2nd ed., pp. 239-247). Libraries Unlimited

APPENDICES

APPENDIX A

Level	Dates
1	1 March 2021 to 30 May
3	29 December 2020 to 28 February 2021
1	20 September to 28 December 2020
2	15 August 2020
3	1 June to 14 August 2020
4	1 to 31 May 2020
5	26 March to 30 April 2020

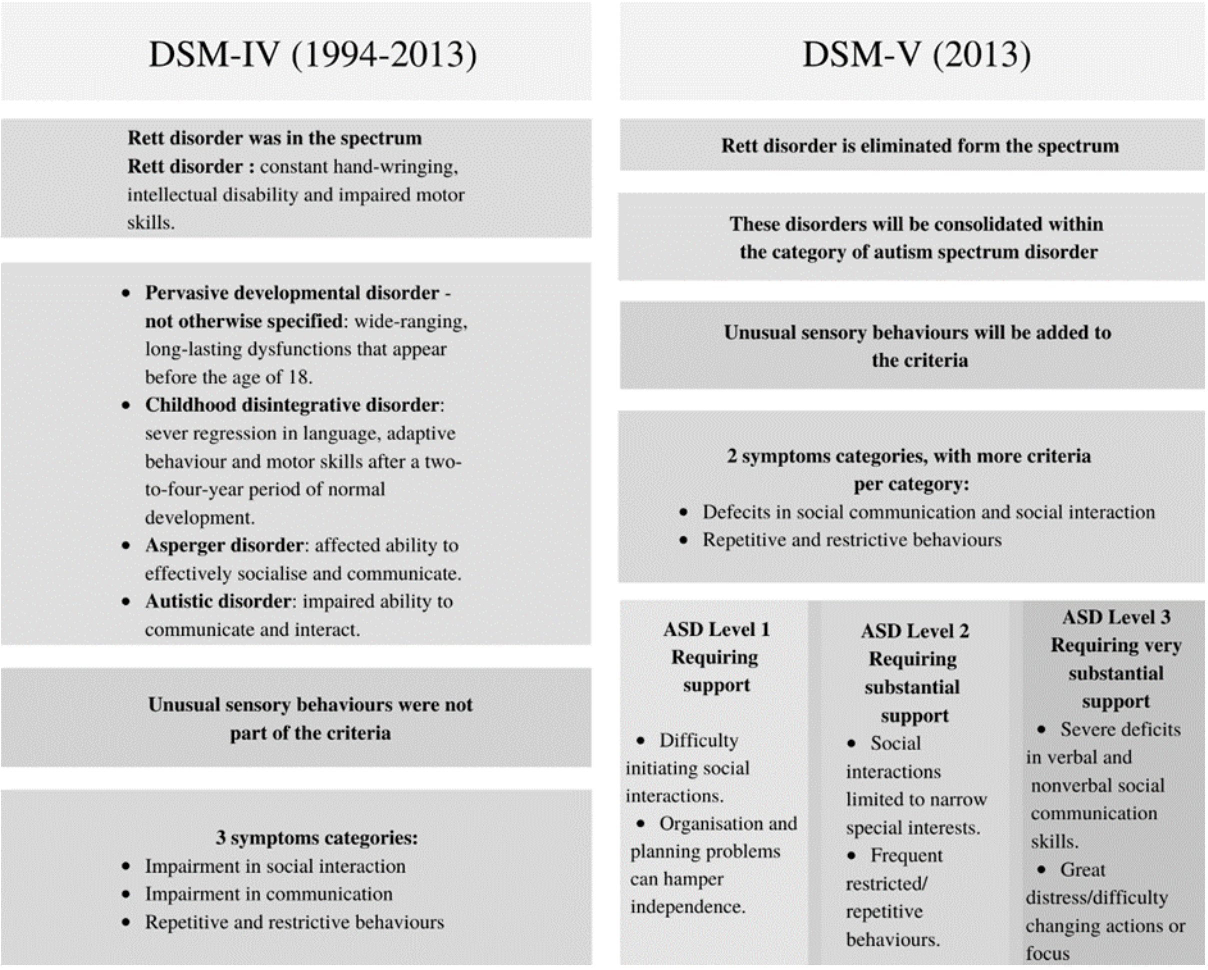
Table 1.1. Lockdown levels and dates in South Africa

Alert Level 5	Alert Level 4	Alert Level 3	Alert Level 2	Alert Level 1
OBJECTIVE				
-High virus spread, and/ or low health system readiness -Drastic measures to contain the spread of the virus and save lives -Lockdown: only essential services are permitted -Public transports may operate at restricted times of the day with limitations on vehicle capacity and stringent hygiene requirements -No inter-provincial movements	-Extreme precautions to limit community transmission and outbreaks while allowing some activity to resume -All essential services are permitted -Confined to own residence from 8PM to 5AM -Public transports may operate at restricted times of the day with limitations on vehicle capacity and stringent hygiene requirements	-Moderate virus spread with moderate readiness -Restriction on many activities including workplaces and socially to address a high risk of transmission - Public transports may operate at restricted times of the day with limitations on vehicle capacity and stringent hygiene requirements - No inter-provincial movements	-Moderate virus spread with moderate readiness -Physical distancing and restrictions on leisure and social activities to prevent resurgence of the virus -Domestic air travel is restored -Car rental services are restored -Movement between provinces at level 1 and 2 restrictions	-Moderate virus spread with high readiness -Most normal activity can resume with precautions and health guidelines followed at all times -Population prepared for an increase in alert levels if necessary -All sectors are permitted -All modes of transport with stringent hygiene conditions in place -Inter-provincial movement is

	-No local or inter-provincial movements -Wearing of a mask in public is compulsory -Cycling, jogging, and walking is allowed between 6AM to 9 AM within 5KM of your residence and not in a group.			allowed with restrictions on international travels

Table 1.2. Summary of alert levels in South Africa

APPENDIX B



DSM-IV (1994-2013)

Rett disorder was in the spectrum
Rett disorder : constant hand-wringing, intellectual disability and impaired motor skills.

- **Pervasive developmental disorder - not otherwise specified**: wide-ranging, long-lasting dysfunctions that appear before the age of 18.
- **Childhood disintegrative disorder**: sever regression in language, adaptive behaviour and motor skills after a two-to-four-year period of normal development.
- **Asperger disorder**: affected ability to effectively socialise and communicate.
- **Autistic disorder**: impaired ability to communicate and interact.

Unusual sensory behaviours were not part of the criteria

3 symptoms categories:

- Impairment in social interaction
- Impairment in communication
- Repetitive and restrictive behaviours

DSM-V (2013)

Rett disorder is eliminated form the spectrum

These disorders will be consolidated within the category of autism spectrum disorder

Unusual sensory behaviours will be added to the criteria

2 symptoms categories, with more criteria per category:

- Defecits in social communication and social interaction
- Repetitive and restrictive behaviours

ASD Level 1 Requiring support

- Difficulty initiating social interactions.
- Organisation and planning problems can hamper independence.

ASD Level 2 Requiring substantial support

- Social interactions limited to narrow special interests.
- Frequent restricted/ repetitive behaviours.

ASD Level 3 Requiring very substantial support

- Severe deficits in verbal and nonverbal social communication skills.
- Great distress/difficulty changing actions or focus

Figure 1.1. DSM5 and levels

Diagnostic criteria of autism spectrum disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for

example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures: to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/ temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if;

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(**Coding note**: Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioural disorder

(**Coding note**: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioural disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia).

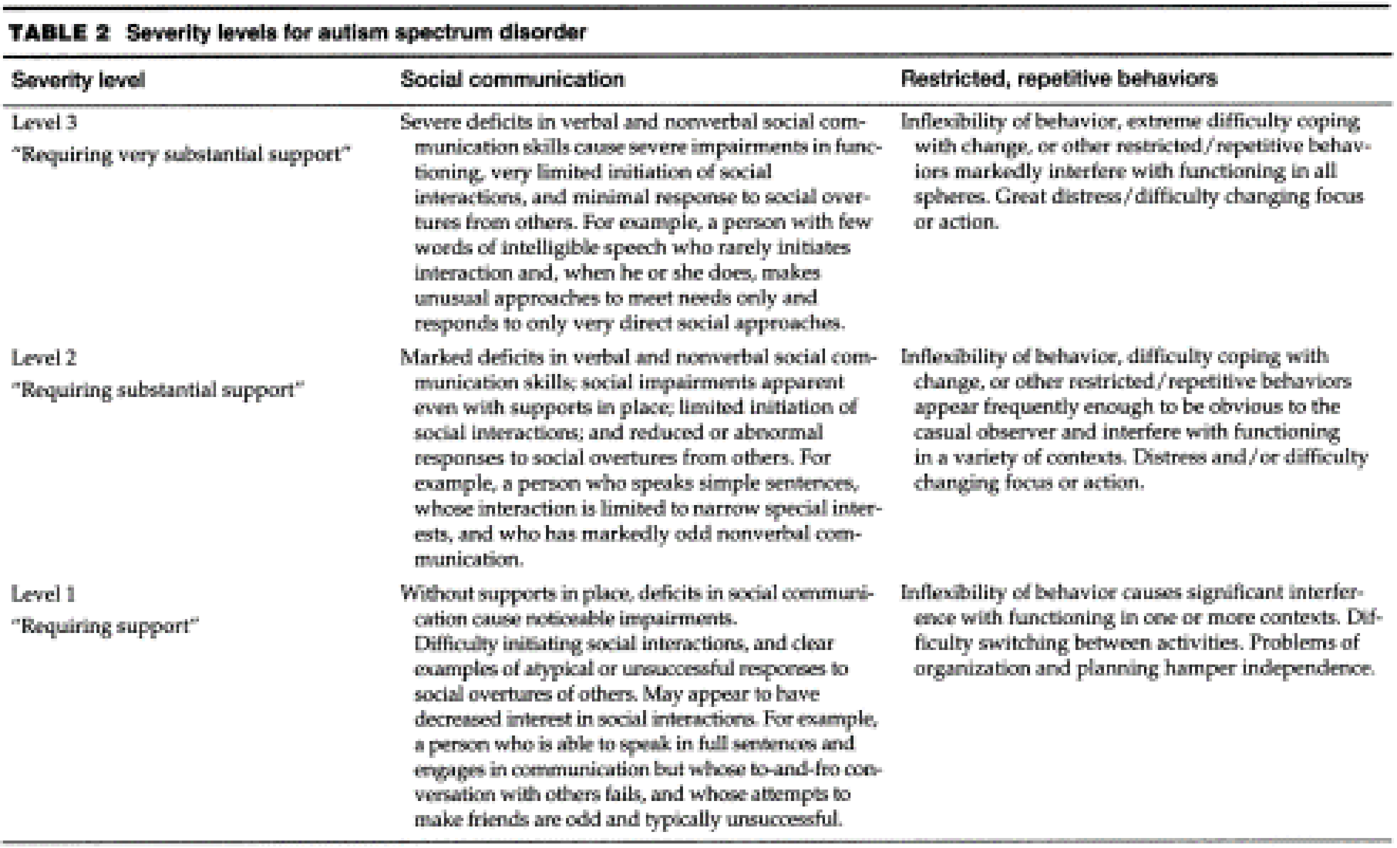


TABLE 2 Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

APPENDIX C

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

PARENTING A CHILD WITH AUTISM SPECTRUM DISORDER (ASD) IN THE CONTEXT OF COVID-19 IN SOUTH AFRICA: A QUALITATIVE STUDY

PRINCIPAL INVESTIGATOR:
MIRIAM KARRIT

EMAIL ADDRESS:
miriamkarrit@hotmail.fr

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study researcher any questions about any part of this project that you do not fully understand. It is important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary**, and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by **the Research Ethics Committee (REC) at Stellenbosch University.**

What is this research study all about?

The following study aims to gather perceptions and experiences of raising a child with ASD during covid-19 in South Africa. The following study will be conducted at over zoom, skype, Microsoft teams or over a call according to participants preferences. Approximately 20 participants will be invited to take part in this study. The results of this study will help psychologists develop strategies to support parents to manage challenges associated with parenting a child with ASD under restricted conditions, such as those imposed by the COVID-19 pandemic. If you agree to participate in this study, you will complete a demographic information sheet and attend a 60-minute interview over the online platform of your choice.

Why have you been invited to participate?

You have been invited to participate in this study because:

1. You have a child between the age of 6 to 12 years old who has been diagnosed with ASD
2. You are a member of the Autism Support Group South- Africa on Facebook.

What will your responsibilities be?

As a participant in this study, you will have no direct responsibilities.

Will you benefit from taking part in this research?

As a participant it is not intended that you will benefit directly from this research. However, your responses will provide insights into the challenges and coping strategies used by parents in the context of a pandemic. Your participation will help the researcher further their understanding of ASD, and contribute to the completion of a master's degree in Psychology

Are there in risks involved in your taking part in this research?

There are no foreseeable risks, and you may stop your participation at any time. You can withdraw at any time during the interview without consequence and your data gathered up to that point will be deleted. Should you become distressed at any point during your participation in this study you will be given information about where to seek a free counselling session. I have arranged for at least 1 free counselling session by a mental healthcare professional associated with the Welgevallen Psychology clinic in Stellenbosch.

If you do not agree to take part, what alternatives do you have?

If you do not wish to participate in the study, you are not obliged to continue in anyway.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study, but you will receive a R50 airtime voucher from the supplier of your choice to thank you for your participation. There will be no costs involved for you if you do take part.

You can contact **Miriam Karrit** at cell: **0837662757 if** you have any further queries or encounter any problems. You can contact the **Research Ethics Committee** at 021 808 9185- if you have any concerns or complaints that have not been adequately addressed by the researcher of this study. You will receive a copy of this information and consent form for your own records.

DECLARATION BY PARTICIPANT

By signing below, I ……………………………………….………… agree to take part in a research study entitled **Parenting a child with Autism Spectrum Disorder (ASD) in the context of COVID-19 in South Africa: A qualitative Study**

I declare that:

I have read this information and consent form and it is written in a language with which I am fluent and comfortable.☐

I have had a chance to ask questions and all my questions have been adequately answered.☐

I understand that taking part in this study is voluntary and I have not been pressurised to take part.☐

I may choose to leave the study at any time and will not be penalised or prejudiced in any way.☐

I may be asked to leave the study before it has finished, if the study researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.☐

I consent to my interview being recorded.☐

I consent to being contact for a follow up interview in the instance that the researcher wishes to clarify a response with me.☐

Signed at (place) ………………………….

On (date)……………………………. **2021**.

Signature of participant ………………….

Signature of witness ………………………

DECLARATION BY RESEARCHER

I Miriam Karrit declare that:

- I explained the information in this document to ………………………………
- I encouraged him/ her to ask questions and took adequate time to answer them.
- I am satisfied that he/ she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (place)……………………

On (date) …………....………. 2021.

Signature of Researcher…………...

Signature of Witness ……………….

APPENDIX D

Demographic questionnaire

RESEARCH STUDY ON PARENTING A CHILD WITH AUTISM SPECTRUM DISORDER (ASD) IN THE CONTEXT OF COVID-19 IN SOUTH AFRICA: A QUALITATIVE STUDY

Thank you for agreeing to participate in this study. You have been asked to participate in this study because you are parenting a child with ASD in the context of Covid-19 in South Africa.

You are free to refuse to participate in this study or to stop answering this questionnaire at any time.

All of the information you provide us will remain confidential. No one will have access to the data except for the Stellenbosch research staff. **No one else** will see your responses to the questions.

All data will be managed electronically and backed up on OneDrive. If the data are used in any publications, you will not be identified by name.

Where necessary: Please mark your answer with an X

When complete please email it to: miriamkarrit@hotmail.fr

001_age	**Please write the required age:**	**Your child's age?**	**Your age?**
002_gender	Please mark the gender?	Your gender: Male ☐ Female ☐ Other ☐	Your child's gender: Male ☐ Female ☐ Other ☐
003_mstatus	What is your current marital status?	Single	Widowed
		Separated	Divorced
		Married or living with a significant other in a marriage-like relationship	Other

004_living	What is your current living situation?	Live with children only	Live with other adults and children (please specify) Other
005_edu	Please select the school option your chid is attending?	Not going to school	Going to a general education school (private or public)
		Going to a special needs school (private or public)	Going to an autism-only school (private or public)
006_work	What is your current work situation?	Employed full time	Employed part time
		Unemployed	Homemaker
		Disabled	Student
		Retired	Other
007_income	Which of the following best describes your approximate monthly family income from all sources before taxes?	Less than R12,000	R110,001-R170,000
		R10,001-R40,000	R170,001-R240,000
		R40,000-R80,000	R240,001 and above
		R80,001-R110,000	Do not know Do not wish to answer
008_pob	Where do you currently live (Town/ City)?		

09_lang	What is your first language?		
010_other	Which other language do you speak?		

APPENDIX E

Semi-structured Interview

DEBRIEFING

Good day, I am a Psychology Masters Student at the university of Stellenbosch. Thank you for agreeing to participate in my research for my thesis. I would like to assure you that all the information that will be gathered will be strictly used only for the purpose of my research project and measures will be put in place to ensure our confidentiality. I would like to know if I could please record our interview for the purpose of data collection and transcription. This recording will strictly be used and only listened to by myself and my supervisor. Measures will be put in place to store the recording in a safe place, where it can only be accessed by myself and my supervisor. I would like to emphasise that you can voluntarily withdraw at any time within the study. Thank you very much for kindly agreeing to voluntarily participate in this study and interview process. As mentioned previously, all identifying information regarding yourself will remain confidential. I am going to give you the contact details of a counselling centre. You can contact Ms. Megan Snow if you feel that this interview has negatively affected you in any way. In order to thank you for your time and participation you will be receiving a R50 airtime voucher from the supplier of your choice (MTN, Vodacom, Cell-C).

INTERVIEW QUESTIONS

Part 1- Parents and children Routine

- Can you describe to me a typical day for you and your child in the days before the Covid-19 pandemic?
- In March 2020, we experienced a national lockdown due to the Covid-19 pandemic. What was your day-to-day routine like during this time?
- Can you talk specifically about your interaction and relationship with your child prior to, during and after the lockdown?
    - Can you please describe what a typical day looks like for you and your child - what your typical interactions together are like?
    - Can you please describe what a typical day was like for you and your child during lockdown-what your typical interactions together as parent and child were like?
    - How do you think your child experienced your interaction and relationship during this time (before and during lockdown)?
    - How did your child interact with other family members?
    - Could you describe a difficult day?
        - Can you tell me about a day that was particularly challenging for you as a parent, and how you responded to your child during this time?
    - Could you describe an ‘easier’ day?
        - Can you tell me about a day that went well for you and your child? Please could you describe such a day before and during lockdown.

Part 3-Parents work management against the need of their Child.

- Can you tell me about what you do for a living?
- What was work like during the lockdown and once all the restrictions came in?
- Can you tell me about work and childcare responsibilities during this time? What was this like?

- How did other family members they helped you manage your work against the need of your child?

Part 4-Sources of Support

- What sources of support were available to you during lockdown days – and can you tell me about the ways in which you felt supported/ unsupported during this time.
- Who would you call in a crisis?
- Professionals-How do they support you? Can you give me an example? Did it change during the pandemic? Are there any gaps?
- Family members-How does family contribute to the support you are receiving?
- Friends -How does friends contribute to the support you are receiving?
- We have spoken about professionals, your family, and friends that all contribute to your support structure. Is there anyone else that you feel is supporting you that we have not spoken about?
- Do you feel that you are receiving enough support? How can you feel more supported during this Covid-19 pandemic?
- Thank you for sharing that with me. It looks like you have/ do not have a great support system. You have mentioned that you also have another child, how could you describe his or her role in your support structure at home?

Part 5-Coping Strategies

- Earlier you described a difficult day – how did you manage days like that?
    - Would you consider these as coping strategies? What would you call it?
    - What would you describe as your coping strategies for difficult days – what works and what does not work?
    - What about your child – what would you say are/ were their coping strategies.
    - How did other family members contribute to coping during this time?
    - How have these changed (if at all) to how you used to deal with things pre-covid?

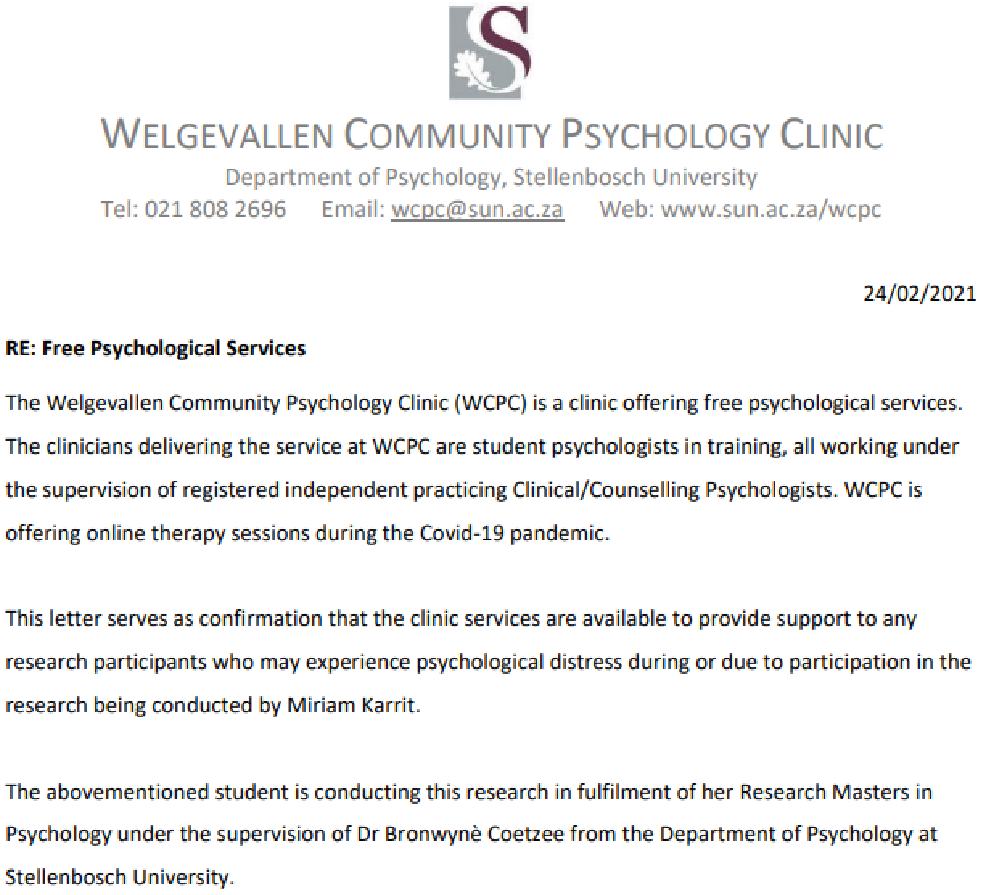
Part 6-Impact of Covid 19

- Does your child understand the Covid-19 pandemic and preventive measures?
- What is the impact of Covid 19 on you and your child?
- Negative-Is there any positive aspect of this pandemic?
- Positive-where there any negative aspect of this pandemic?

Thank you for the valuable information that you have shared with me. I have learned a lot from you and appreciate the time that you put aside to participate in my study.

APPENDIX F

Psychological services



WELGEVALLEN COMMUNITY PSYCHOLOGY CLINIC
Department of Psychology, Stellenbosch University
Tel: 021 808 2696 Email: wcpc@sun.ac.za Web: www.sun.ac.za/wcpc

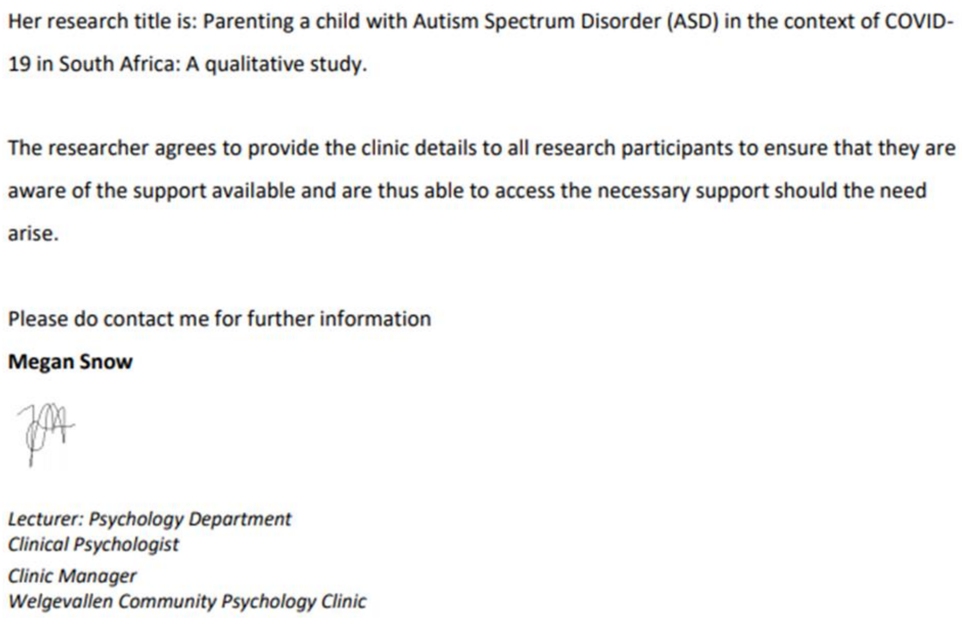
24/02/2021

RE: Free Psychological Services

The Welgevallen Community Psychology Clinic (WCPC) is a clinic offering free psychological services. The clinicians delivering the service at WCPC are student psychologists in training, all working under the supervision of registered independent practicing Clinical/Counselling Psychologists. WCPC is offering online therapy sessions during the Covid-19 pandemic.

This letter serves as confirmation that the clinic services are available to provide support to any research participants who may experience psychological distress during or due to participation in the research being conducted by Miriam Karrit.

The abovementioned student is conducting this research in fulfilment of her Research Masters in Psychology under the supervision of Dr Bronwynè Coetzee from the Department of Psychology at Stellenbosch University.



Her research title is: Parenting a child with Autism Spectrum Disorder (ASD) in the context of COVID-19 in South Africa: A qualitative study.

The researcher agrees to provide the clinic details to all research participants to ensure that they are aware of the support available and are thus able to access the necessary support should the need arise.

Please do contact me for further information

Megan Snow

Lecturer: Psychology Department
Clinical Psychologist
Clinic Manager
Welgevallen Community Psychology Clinic

APPENDIX G

Contact Details

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study.

Researcher name	Miriam Karrit
Researcher number	0837662757
Researcher email address	miriamkarrit@hotmail.fr

Supervisor name	Dr. Bronwyne Coetzee
Supervisor number	021 808 3979
Supervisor email address	bronwyne@sun.ac.za

Masters Psychology (Thesis) Coordinator name	Dr. Chrisma Pretorious
Masters Psychology (Thesis) Coordinator number	021 808 3453

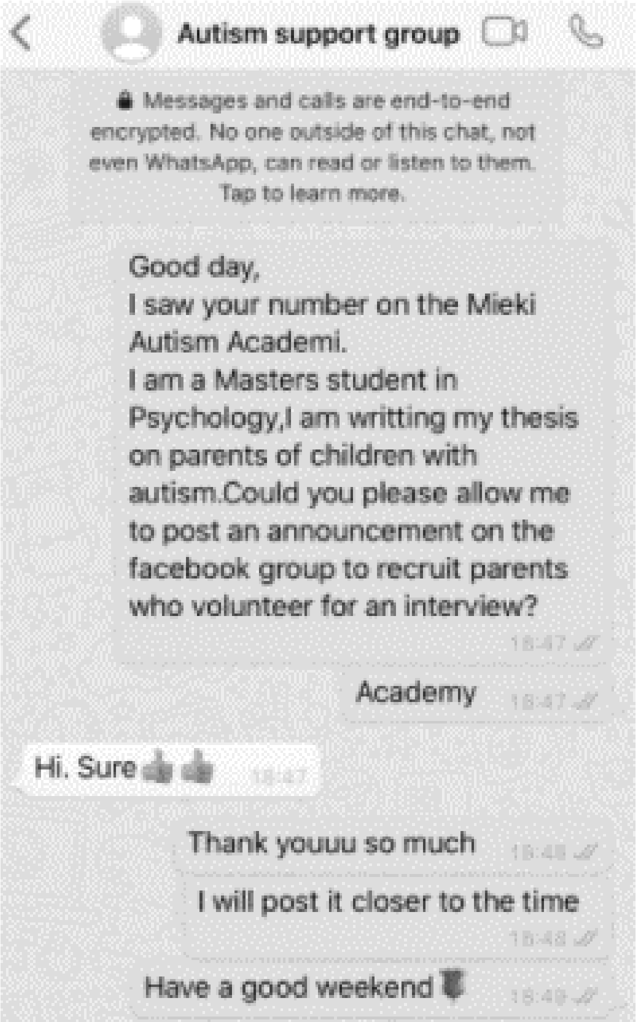
Masters Psychology (Thesis) Coordinator email address	chrismapretorius@sun.ac.za

Research Ethics Committee Coordinator name	Ms Clarissa Graham
Coordinator phone number	021 808 9183
Coordinator email address	cgraham@sun.ac.za

Psychologist name	Ms Megan Snow
Psychologist number	021 808 2696
Psychologist email Address	snow@sun.ac.za

APPENDIX H

Permission to make a post on the facebook group (Autism Support Group South Africa)



🔒 Messages and calls are end-to-end encrypted. No one outside of this chat, not even WhatsApp, can read or listen to them. Tap to learn more.

Good day,
I saw your number on the Mieki Autism Academi.
I am a Masters student in Psychology,I am writting my thesis on parents of children with autism.Could you please allow me to post an announcement on the facebook group to recruit parents who volunteer for an interview?
18:47

Academy 18:47

Hi. Sure👍👍 18:47

Thank youuu so much 18:48

I will post it closer to the time 18:48

Have a good weekend 18:49

APPENDIX I

Budget of the study

Participants	Airtime voucher in Rand

A	R50
B	R50
C	R50
D	R50
E	R50
F	R50
G	R50
H	R50
I	R50
J	R50
K	R50
L	R50
M	R50
O	R50
P	R50
Q	R50
R	R50
S	R50
T	R50
U	R50
Total number of Participants	**Total budget**

APPENDIX J

Flyer

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UNIVERSITY

Parents of children (6 to 12 years old) with Autism
Please join this study!

Parenting a child with Autism Spectrum Disorder (ASD)
in the context of COVID-19 in South Africa

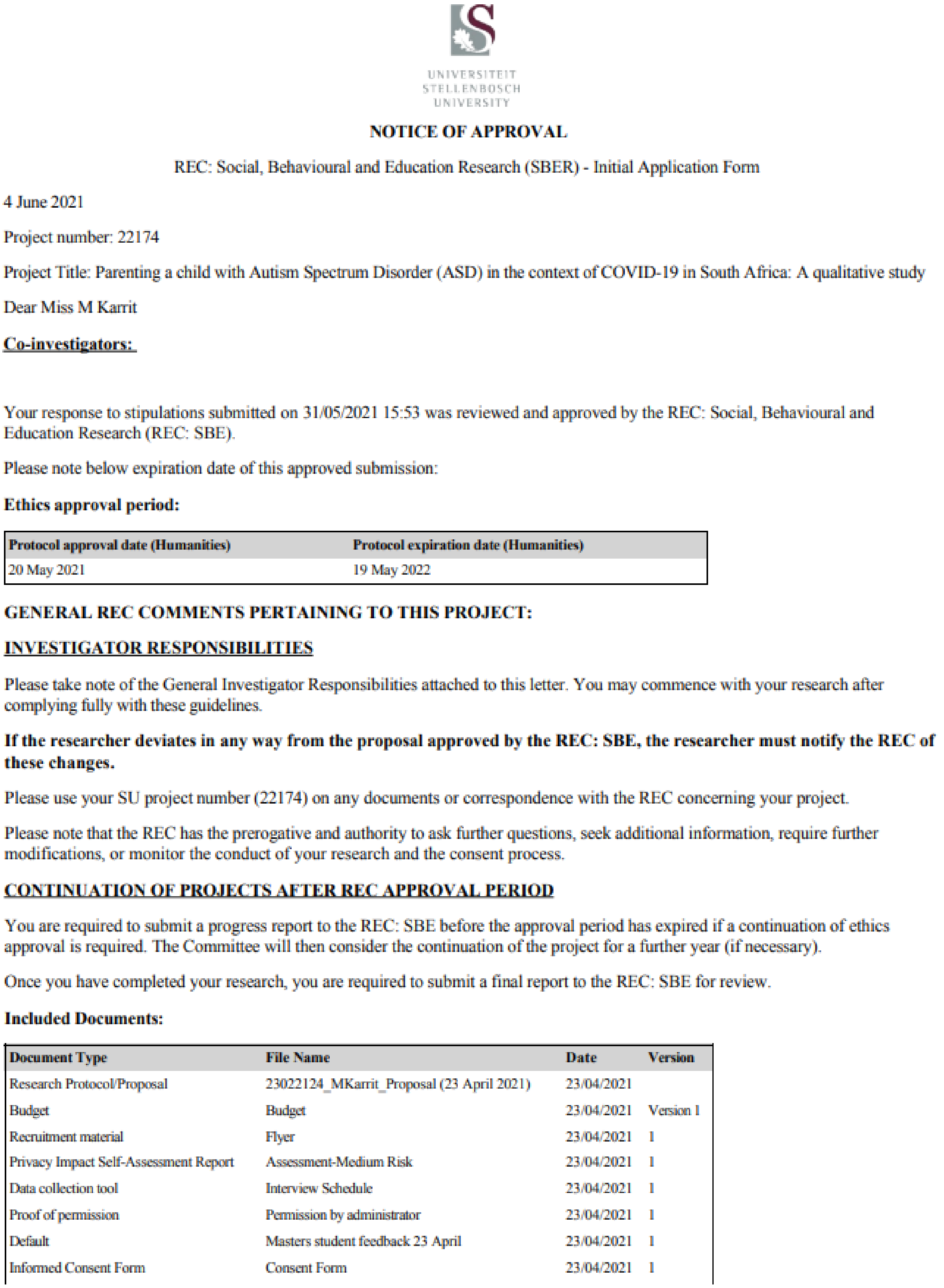
You are invited to participate in a study conducted by Stellenbosh University!

All you have to do is participate to an interview and complete a few forms.
You will receive a R50 airtime voucher from the supplier of your choice!

Interrested ?
Please email :
miriamkarrit@hotmail.fr

APPENDIX K

Ethical approval 1



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NOTICE OF APPROVAL

REC: Social, Behavioural and Education Research (SBER) - Initial Application Form

4 June 2021

Project number: 22174

Project Title: Parenting a child with Autism Spectrum Disorder (ASD) in the context of COVID-19 in South Africa: A qualitative study

Dear Miss M Karrit

Co-investigators:

Your response to stipulations submitted on 31/05/2021 15:53 was reviewed and approved by the REC: Social, Behavioural and Education Research (REC: SBE).

Please note below expiration date of this approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
20 May 2021	19 May 2022

GENERAL REC COMMENTS PERTAINING TO THIS PROJECT:

INVESTIGATOR RESPONSIBILITIES

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: SBE, the researcher must notify the REC of these changes.

Please use your SU project number (22174) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

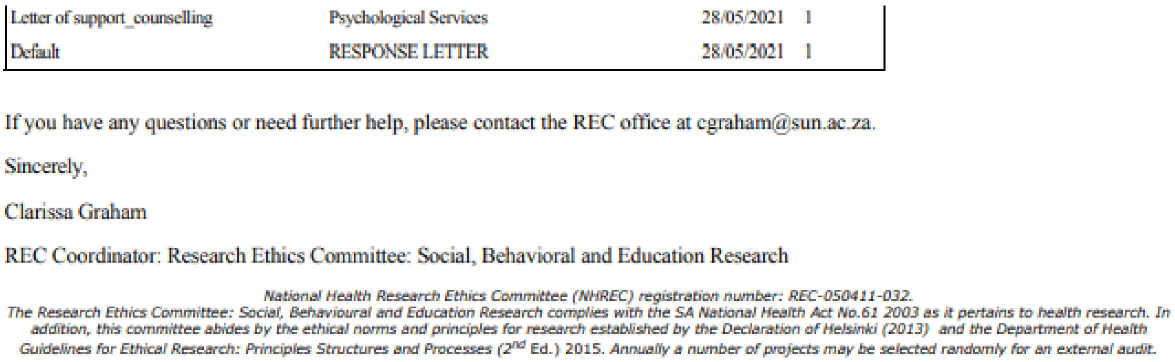
CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

You are required to submit a progress report to the REC: SBE before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary).

Once you have completed your research, you are required to submit a final report to the REC: SBE for review.

Included Documents:

Document Type	File Name	Date	Version
Research Protocol/Proposal	23022124_MKarrit_Proposal (23 April 2021)	23/04/2021	
Budget	Budget	23/04/2021	Version 1
Recruitment material	Flyer	23/04/2021	1
Privacy Impact Self-Assessment Report	Assessment-Medium Risk	23/04/2021	1
Data collection tool	Interview Schedule	23/04/2021	1
Proof of permission	Permission by administrator	23/04/2021	1
Default	Masters student feedback 23 April	23/04/2021	1
Informed Consent Form	Consent Form	23/04/2021	1



Letter of support_counselling	Psychological Services	28/05/2021	1
Default	RESPONSE LETTER	28/05/2021	1

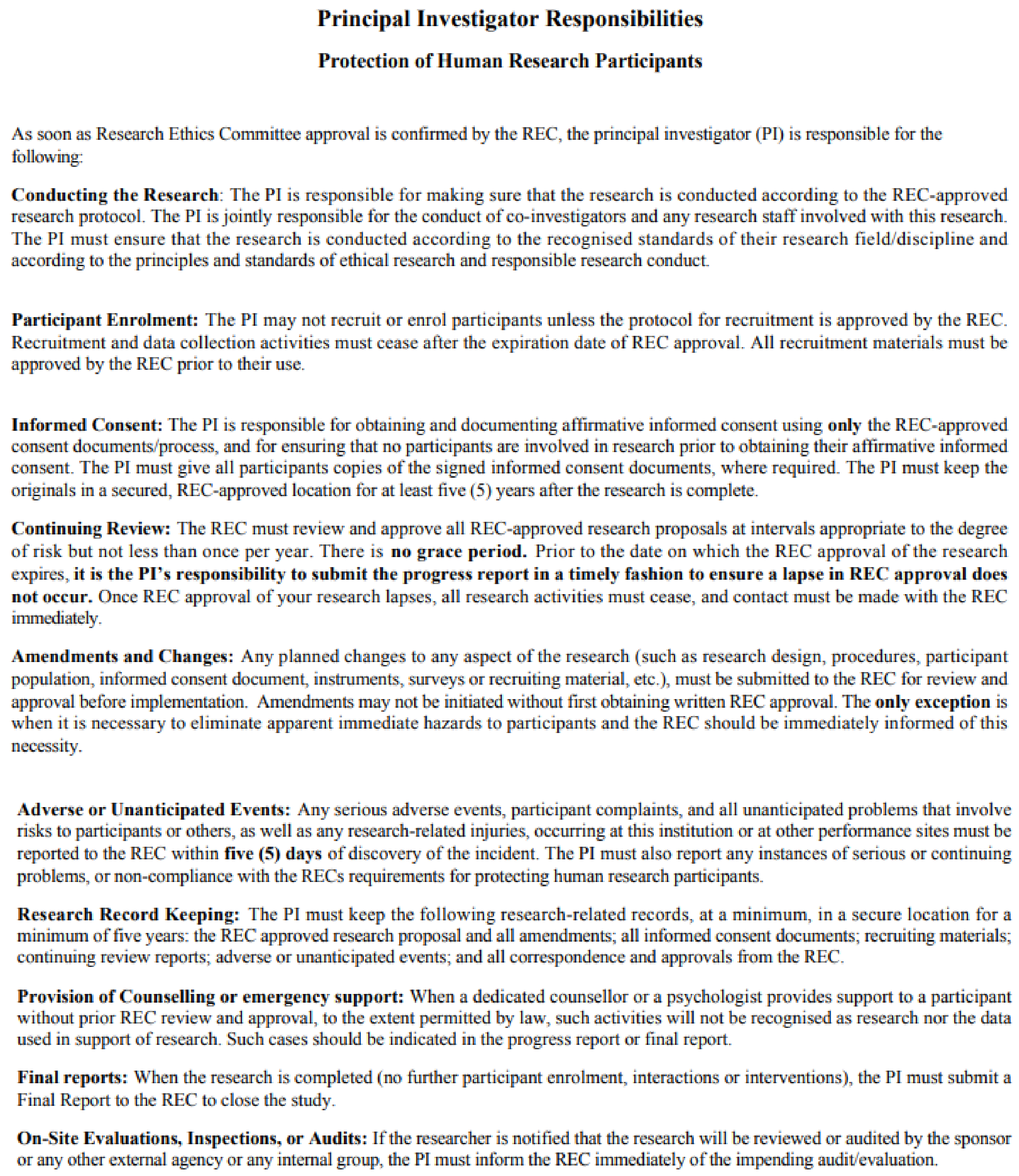
If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Social, Behavioral and Education Research

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Social, Behavioural and Education Research complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.



Principal Investigator Responsibilities

Protection of Human Research Participants

As soon as Research Ethics Committee approval is confirmed by the REC, the principal investigator (PI) is responsible for the following:

Conducting the Research: The PI is responsible for making sure that the research is conducted according to the REC-approved research protocol. The PI is jointly responsible for the conduct of co-investigators and any research staff involved with this research. The PI must ensure that the research is conducted according to the recognised standards of their research field/discipline and according to the principles and standards of ethical research and responsible research conduct.

Participant Enrolment: The PI may not recruit or enrol participants unless the protocol for recruitment is approved by the REC. Recruitment and data collection activities must cease after the expiration date of REC approval. All recruitment materials must be approved by the REC prior to their use.

Informed Consent: The PI is responsible for obtaining and documenting affirmative informed consent using **only** the REC-approved consent documents/process, and for ensuring that no participants are involved in research prior to obtaining their affirmative informed consent. The PI must give all participants copies of the signed informed consent documents, where required. The PI must keep the originals in a secured, REC-approved location for at least five (5) years after the research is complete.

Continuing Review: The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the REC approval of the research expires, **it is the PI's responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur.** Once REC approval of your research lapses, all research activities must cease, and contact must be made with the REC immediately.

Amendments and Changes: Any planned changes to any aspect of the research (such as research design, procedures, participant population, informed consent document, instruments, surveys or recruiting material, etc.), must be submitted to the REC for review and approval before implementation. Amendments may not be initiated without first obtaining written REC approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

Adverse or Unanticipated Events: Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the REC within **five (5) days** of discovery of the incident. The PI must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants.

Research Record Keeping: The PI must keep the following research-related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence and approvals from the REC.

Provision of Counselling or emergency support: When a dedicated counsellor or a psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

Final reports: When the research is completed (no further participant enrolment, interactions or interventions), the PI must submit a Final Report to the REC to close the study.

On-Site Evaluations, Inspections, or Audits: If the researcher is notified that the research will be reviewed or audited by the sponsor or any other external agency or any internal group, the PI must inform the REC immediately of the impending audit/evaluation.

APPENDIX L
Ethical approval 2

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NOTICE OF APPROVAL

REC: SBER - Protocol Deviation form

29 July 2021

Project number: 22174

Project Title: Parenting a child with Autism Spectrum Disorder (ASD) in the context of COVID-19 in South Africa: A qualitative study

Dear Miss M Karrit

Co-investigators:

Your REC: SBER - Protocol Deviation form submitted on 16/06/2021 22:58 was reviewed and approved by the REC: Social, Behavioural and Education Research (REC: SBE).

Please note below expiration date of this approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
20 May 2021	19 May 2022

GENERAL REC COMMENTS PERTAINING TO THIS PROJECT:

INVESTIGATOR RESPONSIBILITIES

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: SBE, the researcher must notify the REC of these changes.

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Once you have completed your research, you are required to submit a final report to the REC: SBE for review.

Included Documents:

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Social, Behavioral and Education Research

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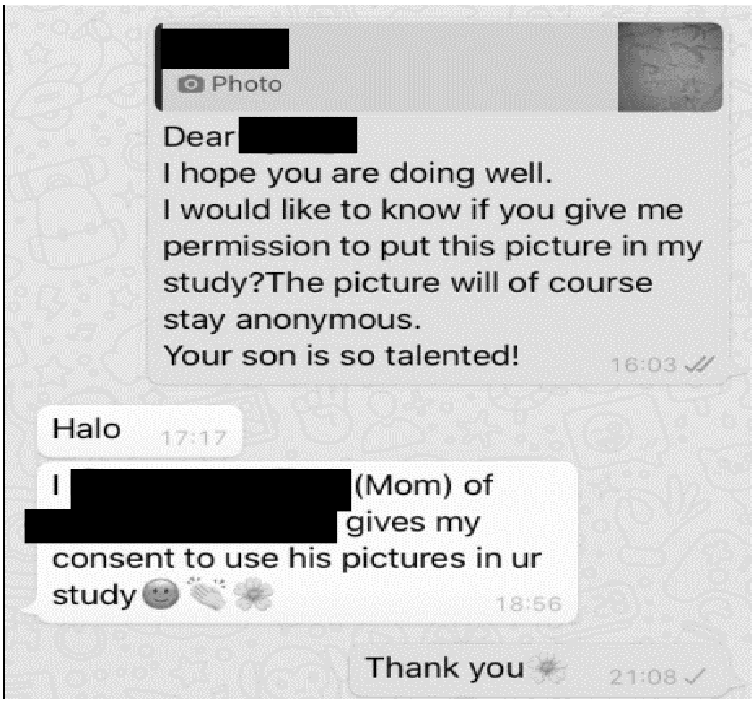
APPENDIX M
Approval of parent to post picture



[redacted]
Photo

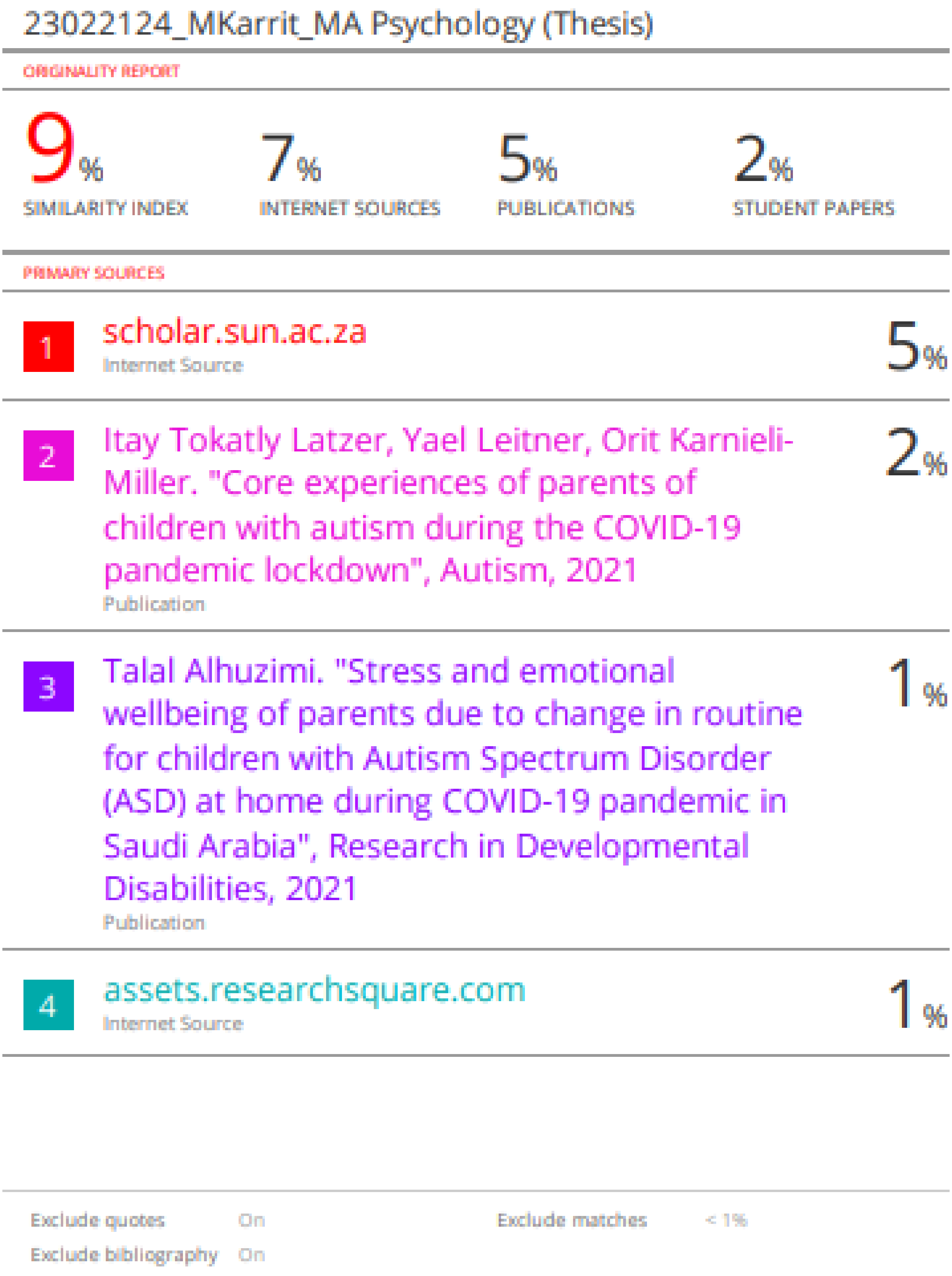
Dear [redacted]
I hope you are doing well.
I would like to know if you give me permission to put this picture in my study?The picture will of course stay anonymous.
Your son is so talented! 16:03 ✓✓

Halo 17:17

I [redacted] (Mom) of [redacted] gives my consent to use his pictures in ur study 🙂👏🌼 18:56

Thank you ✨ 21:08 ✓

TURNITIN REPORT



23022124_MKarrit_MA Psychology (Thesis)

ORIGINALITY REPORT

9%	7%	5%	2%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	scholar.sun.ac.za Internet Source	5%
2	Itay Tokatly Latzer, Yael Leitner, Orit Karnieli-Miller. "Core experiences of parents of children with autism during the COVID-19 pandemic lockdown", Autism, 2021 Publication	2%
3	Talal Alhuzimi. "Stress and emotional wellbeing of parents due to change in routine for children with Autism Spectrum Disorder (ASD) at home during COVID-19 pandemic in Saudi Arabia", Research in Developmental Disabilities, 2021 Publication	1%
4	assets.researchsquare.com Internet Source	1%

Exclude quotes	On	Exclude matches	< 1%
Exclude bibliography	On		