Raising a child with autism spectrum disorder: Black South African parents’ reported lived experiences

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A research proposal submitted in partial fulfilment of the requirements for the degree of BA Masters (Clinical Psychology) in the Faculty of Humanities, University of the Witwatersrand, Johannesburg.

Declaration

I declare that this research report is my own, unaided work. It is submitted for the degree of Master of Arts in Clinical Psychology at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other university.

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Ogone Magape

_____28/01/2025____________________

Date

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Abstract

Autism Spectrum Disorder (ASD) is increasingly becoming a significant public health concern in developing countries, particularly in South Africa, where cultural factors significantly affect perceptions and diagnoses of ASD. This presents challenges for early identification and support. Parenting a child with ASD brings considerable physical, emotional, social, and financial challenges. To understand the impact of raising a child with ASD on parents, a qualitative research design was implemented, utilising semi-structured interviews for data collection. A total of six interviews were conducted for this study, focusing on the experiences of black South African parents raising children with ASD. The study aimed to explore the experiences of black South African parents raising children with ASD, focusing on their beliefs and social experiences, as well as the impact on family dynamics.

Findings revealed significant gaps in knowledge about ASD, which impeded early identification and management. Parents experienced long waits for diagnoses and often turned to traditional healers for understanding. The study indicated that raising a child with ASD impacts interpersonal relationships, particularly emphasising gender roles where men felt pressured to be emotionally strong for their partners, resulting in difficulty expressing their feelings. Financial strain was a common challenge reported by all parents.

Research findings of the current study revealed that increased awareness of ASD in black South African communities is crucial. Psychoeducation could empower parents, counter misconceptions, reduce stigma, and enhance support systems. Additionally, there is a pressing need for healthcare professionals to provide more comprehensive care and understanding of ASD implications for families. Expanding the number of ASD-specialised healthcare professionals in South Africa is also essential.

Keywords: ASD, culture, community awareness, parental experiences, socioeconomic factors

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CHAPTER 1: INTRODUCTION AND RATIONALE

Autism spectrum disorder is a lifelong neurodevelopmental disorder that is characterised by persistent deficits in reciprocal social communication and social interaction including impairments in nonverbal communication, and restricted and repetitive behaviour (American Psychiatric Association (APA), 2022). Autism spectrum disorder (ASD) is increasingly becoming a public health concern in developing countries (Pillay et al., 2022; Woodgate et al., 2015). However, there is limited knowledge about ASD particularly in Africa (Aderinto et al., 2023). Only recently has many developing countries begun to recognise and diagnose ASD (Wallace et al., 2012). Despite this recognition, there is still a lack of awareness, identification, and adequate services for people with ASD, and their parents in developing countries (Wallace et al., 2012). The identification and effective management of ASD remains a challenge in African communities due to the limited healthcare resources, restricted access to mental health services, and poverty (Aderinto et al., 2023). Furthermore, culture also influences how ASD is perceived and understood further making it challenging to generalise existing knowledge about ASD to the African context (Aderinto et al., 2023), which calls for more research to be conducted within the African context.

Autism spectrum disorder is one of the most severe childhood disorders and has long term devastating effects on an individual's functioning (Eapen et al., 2014; Fewster et al., 2020). The World Health Assembly drew up the WHA67.8 resolution in 2014 which calls governments to make comprehensive and coordinated measures to manage and improve the quality of life of children with ASD and their families (World Health Organisation (WHO), 2014). In a study that explored the perspectives of key government stakeholders in Western Cape, South Africa (SA), and their recommended solutions to meet the needs of children with ASD and their families, it was suggested that government and civil society work together to break down barriers and improve access to services for children with ASD (Pillay et al., 2022). Therefore, learning and understanding parents' experiences may help to meet the WHA67.8 resolution, reduce barriers to access treatment, improve quality of treatment, as well as the quality of life of children with ASD and their parents.

Raising a child with ASD has a significant impact on the individual, family, and society; however little research about ASD and how it affects family functioning has been conducted in SA. Therefore, to bridge the gap between evidence and practise, further research needs to be conducted within the South African context (Wilford, 2013). Furthermore, the focus of ASD intervention tends to be on the child while the health and wellbeing of the primary caregiver or parent tends to be overlooked as part of the holistic management of the child (Fewster et al., 2020). Understanding the experiences of parents with a child with ASD may help in developing effective interventions aimed at improving the mental health and overall wellbeing of the parents. The improved overall wellbeing and quality of life of parents also enhance the potential of the child with ASD to achieve a better quality of life (Catalano et al., 2018).

Research studies have indicated that there are racial and ethnic disparities in the recognition of intellectual and developmental disabilities with black children being identified less frequently in comparison to white children (Guler et al., 2017; Mandell et al., 2002; Mkabile & Swartz, 2020). Delays and discrepancies in the diagnosis of ASD may result from differences in parents' knowledge and understanding of typical development across different racial, ethnic and socioeconomic status (Campbell et al., 2018). South Africa is a multicultural country with diverse indigenous understandings of illness. Therefore, there is a need for research that seeks to understand cultural understandings of ASD that goes beyond western understanding of ASD. Additionally, understanding parents' experiences can help reduce barriers to treatment and enhance its quality.

Most research that has been conducted in the area of ASD is quantitative research studies which have shown that parents of children with neurodevelopmental disabilities are likely to experience more stress and parental challenges compared to parents of children without a disability (De Clercq et al., 2022). Children with ASD need more medical, educational, and social support compared to children without a disability (McCarty & Frye, 2020). This extra support oftentimes puts a financial strain on parents and affects the family's quality of life (McCarty & Frye, 2020). Thus, the need for research studies such as the current study to further our understanding of the impact that raising a child with ASD has on parents.

According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR), it is understood that individuals diagnosed with the same mental disorder may not display identical behaviours (APA, 2022). Therefore, in this research paper, the term "ASD" will be used to refer to Autism Spectrum Disorder, recognising that it exists on a spectrum (APA, 2022). Additionally, the DSM-5-TR recommends avoiding stigmatising language (APA, 2022). Consequently, this research report will employ person-first language, referring to participants as "parents raising a child with ASD" rather than "parents raising an autistic child." This approach is adopted to mitigate the impact of medical labels on the perception and inclusion of individuals with disabilities in society and to help prevent the perpetuation of stigma against those with mental health disorders or disabilities (Vidal et al., 2024).

Research aims

The primary aim of this research study was to explore the reported lived experiences of black South African parental caregivers who are raising a child with ASD. The intention was to explore these parents' understandings and beliefs about ASD. The study also aimed to gain insight into these families and their social experiences, and how raising a child with ASD may impact their family dynamics and social relations.

Research report outline

This chapter has explored some of the challenges that developing countries face with regards to the diagnosis and treatment of ASD which includes lack of awareness, identification, and adequate services for children with ASD and their families. Furthermore, in a country such as South Africa culture influences how ASD is perceived, understood, and diagnosed, further making it challenging to generalise existing knowledge about ASD to the African context which further poses a challenge with regards to early identification and diagnosis of ASD (Aderinto et al., 2023). Research studies have shown that parents of children with neurodevelopmental disabilities are likely to experience more stress and parental challenges compared to parents of children without a disability (De Clercq et al., 2022). However, not much research has been conducted with regards to how raising a child with ASD affects parents including their familial and social relations as well as how black South Africans, in particular understand ASD. Therefore, the next chapter explores how disability is understood within African families, diagnostic features of ASD, its prevalence, development, and course, including risk and prognostic factors. It further explores treatment services for children with ASD, the experience of parenting a child with ASD, impact of culture in how ASD is understood, the familial grief associated with ASD diagnosis within the family, parents support systems, as well as ASD awareness and knowledge within black African communities. After that, chapter three details the methods of the project. In chapter four, the findings of the study are presented which includes themes from the data. Chapter five provides a discussion of the research findings. Chapter six concludes the thesis and discusses the implications of the research findings, limitations of the study as well as recommendations for future research.

CHAPTER 2: LITERATURE REVIEW

Disability

Over time various models of disability have been developed, and the two most common models of disability are the medical and social models. According to the medical model, disability is believed to be as a result of physical impairments that are a result of disease, injury, or health conditions, thus interventions tend to be primarily medical which include rehabilitation and institutional care (Palmer & Harley, 2011). The social model views disability as socially constructed and part of social life, thus placing emphasis on interaction and how society excludes people with disabilities (Palmer & Harley, 2011). The social model has been successful in de-medicalising and de-individualising disability; as a result, social change is perceived as the primary remedy for disability (Palmer & Harley, 2011). Both models have been criticised. The medical model has been criticised for not addressing how disability affects social participation, while the social model has been criticised for being dismissive of impairment (Palmer & Harley, 2011). Black South Africans believe in the spirit of ubuntu which is about shared humanity and interconnectedness and disability from this perspective can be understood as the ‘other’ that is different from what is perceived to be normal according to the shared societal norms (Berghs, 2017). Furthermore, in some cultures disability can also be understood from a spiritual realm whereby disability may be perceived as a curse, form of punishment, or bewitchment (Aderinto et al., 2023; Berghs, 2017). Thus, the need for research studies such as the current one to further our understanding on how ASD may be understood across different cultural backgrounds.

The social model of disability has influenced the WHO’s definition of disability. The WHO’s (2021) policy on disability defined disability as “the outcome of the interaction between individuals with a health condition (e.g., cerebral palsy, Down syndrome or depression) and personal and environmental factors (e.g., negative attitudes, inaccessible transportation and public buildings, and limited social supports)” (p. 10). Persons with disability are defined as individuals with long-term physical, mental, intellectual, or sensory impairments which affect how they interact and participate in the society (WHO, 2021). Therefore, in this research study WHO’s definition of disability was used, since the study was interested in understanding parents’ experiences, including family and social relations, in raising a child with ASD and how they understand ASD.

Living with a child with a disability tends to affect family functioning which can have negative and positive effects. Furthermore, the extent to which an individual experiences disability in their daily life differs and is oftentimes dependent on how their impairment or health condition affects their interaction with society (WHO, 2021). Positively, raising a child with disability can make family members more aware of their inner strengths, enhance family cohesion, as well as promote and improve relations with community groups (Reichman et al., 2008). On the negative side, it can be straining financially, emotionally, physically, and time demanding, especially for parents (Reichman et al., 2008; Schlebusch & Dada, 2018). Majority of children when they grow up, tend to leave their parents, and become independent. However, for children with a disability their care tends to be life long, sometimes even after the death of their parents (Reichman et al., 2008). Those who cannot gain independence usually require enormous resources (Reichman et al., 2008).

The term 'disability' tends to also carry a social stigma, and, in some African cultures disability may be seen as a curse or punishment which as a result may lead to under-reporting of disabilities or delay the process of families seeking a diagnosis or treatment for their child (Aderinto et al., 2023; Mkabile & Swartz, 2020; Schlebusch & Dada, 2018). This avoidance is often associated with fear of social stigma which may lead to isolation and discrimination.

Autism spectrum disorder and diagnostic features

Autism spectrum disorder is a lifelong neurodevelopmental disorder which is characterised by impairments in social settings, non-verbal and verbal communication deficits, and stereotypical repetitive behaviours (APA, 2022). Stereotypical repetitive behaviours may include inflexibility to change in routines, repetitive motor movements, strong attachments to unusual objects, repetitive speech, ritualized patterns of verbal or nonverbal behaviour and hyperactivity to sensory input (APA, 2022). The definition of ASD has evolved overtime. It was first defined in 1980 in the Diagnostic Statistical Manual of Mental Disorders (DSM) the third edition, it was then revised and divided into three subcategories in the DSM-IV, and it was redefined again in the DSM-5 as one disorder with a spectrum of severities (McCarty & Frye, 2020). Specific core features such as lack of social communication abilities, repetitive behaviours, and restrictive interests remained the same and have always been used to define ASD (APA, 2022).

According to the Diagnostic Statistical Manual of Mental Disorders Fifth Edition, Text Revised (DSM 5-TR) the features of ASD need to cause a clinically significant impairment in important functioning areas of an individual including social and occupational functioning to be diagnosed with ASD (APA,2022). Additionally, impairments must be marked based on the developmental level of the individual (APA, 2022). The DSM-5 is used as a diagnostic reference for ASD; however, it is not used as a formal test for ASD because it only provides the criterion for diagnosis of ASD (McCarty & Frye, 2020). Therefore, caregiver interviews, questionnaires and clinical observations are often used to diagnose ASD, and these are used together to improve the reliability of the diagnosis (APA, 2022). During the caregiver interview, the caregiver provides insights into the child's developmental and behavioural symptoms (McCarty & Frye, 2020). Thus, it is important that parents' experiences and their understanding of ASD are studied.

Prevalence of autism spectrum disorders

Over the past three decades the prevalence of ASD has significantly increased (McCarty & Frye, 2020). It is believed that 1 in 160 children worldwide are diagnosed with ASD (Fewster et al., 2020; Reddy et al., 2019; Wilford, 2013). Although in Africa the prevalence of ASD is still unknown, it is estimated that 2 percent of the population in SA has ASD (Reddy et al., 2019). In a retrospective review that consisted of 1010 medical records in 2013 it was projected that over 270,000 people in SA are living with ASD with 5000 new cases per year (Springer et al., 2013). The increasing prevalence of ASD may be linked to the increase of ASD awareness and research done in recent years as well as secular changes in the diagnostic practices and development of key diagnostic features of ASD (Wallace et al., 2012; Yoon et al., 2020). Factors such as misdiagnosis, delayed diagnosis or underdiagnosis of ASD particularly for individuals from some ethnoracial backgrounds may affect the reported prevalence of ASD (APA, 2022). However, the increasing number of ASD cases does call for more research to be conducted, particularly in SA. Majority of research that has been done on ASD stems from high income countries, however, there is limited research done in African countries, including SA (Viviers et al., 2020).

Development and course of autism spectrum disorder

According to global research, ASD is usually first diagnosed when the child is still an infant and during early childhood from as young as 18 months (McCarty & Frye, 2020). Autism spectrum disorder usually emerges before the age of 3 years (Viviers et al., 2020). Moreover, symptoms of ASD usually become recognisable in the second year of life (APA, 2022). When developmental delays result in severe symptoms, they may become visible prior to the child turning one and in cases where symptoms are subtle, they may be noted later after the child has turned two years (APA, 2022). The pattern of onset description may include delays in social communication which would typically happen between 12 and 24 months (APA, 2022). It is however noted that it may be difficult to diagnose ASD at an early age as factors such as lack of social communication skills often emerge after the child has turned one (McCarty & Frye, 2020). Furthermore, some behaviours during early infancy are considered typical initially and only become atypical when they continue into later infancy or beyond (APA, 2022). Some abnormal behaviours such as repetitive and restrictive behaviours/interests may develop or become evident at a later stage when the disorder has already established (McCarty & Frye, 2020). Additionally, factors such as age, gender, and cultural norms should be understood and measured against typical developmental milestones when developing, maintaining, and understanding deficits associated with ASD (APA, 2022).

Many people with ASD tend to have poor adult psychosocial functioning such as being able to live independently and gain employment (APA, 2022). However, some individuals particularly those with lower levels of impairment may be able to work independently, however, they may have problems with organising practical work independently (APA, 2022). Therefore, for individuals that may not be able to live independently this would mean that parents would need to continue caring for them, thus putting strain on parents.

Risk and prognostic factors of autism spectrum disorder

The etiological determinants of ASD are still unclear (Yoon et al., 2020). However, it is believed that genetic and environmental factors are associated with ASD. Genetic factors underlying ASD are believed to have a stronger association with ASD compared to environmental factors (Yoon et al., 2020). This was shown in a twin study with monozygotic twins having a concordance rate of 92 percent of ASD compared to dizygotic twins with a 10 percent concordance rate (Yoon et al., 2020). Furthermore, about 15 percent of cases of ASD have been shown to be associated with a known genetic mutation (APA, 2022). Additionally, there seems to be different de novo mutations in specific genes in different families (APA, 2022).

Although various genetic and epigenetic risk factors associated with ASD have been suggested, no clear pathogenesis and specific diagnostic features have been identified (Yoon et al., 2020). It is however suggested that understanding epigenetics associated with ASD is important as they regulate gene expression, thus they can help in developing ASD therapies that control epigenetic states (Yoon et al., 2020). Some ASD related genes are believed to be associated with other neurodevelopmental syndromic disorders which includes fragile X syndrome and Rett syndrome (Yoon et al., 2020). Environmental factors such as advanced parental age, extreme prematurity, in utero exposure to valproic acid, prolonged lack of zinc during pregnancy and low birth weight are some factors associated with ASD (APA, 2022; Yoon et al., 2020).

Autism spectrum disorders manifest in complex phenotypes; thus, they tend to be accompanied by comorbidities (Yoon et al., 2020). Epilepsy is one of the comorbidities and is associated with lower verbal ability and intellectual disability (APA, 2022). Presence or absence of intellectual disability and language impairment are considered some of the prognostic factors within ASD (APA, 2022). Often an individual that has functional language by age 5 years is usually perceived as having a good prognosis (APA, 2022).

Treatment for children with autism spectrum disorder

Treatment of ASD tends to be lifelong and is usually provided by highly skilled professionals which tends to be expensive thus putting a financial strain on parents raising children with ASD (Guler et al., 2018). Additionally, factors such as poverty and the cost of medication cannot be overlooked when considering the use of medication in individuals with ASD (Aderinto et al., 2023). The high cost of psychotropic medications including limited access to financial assistance and mental health resources significantly contributes to the disparities in healthcare and limits access to appropriate treatment for children with ASD (Aderinto et al., 2023).

Early intensive behavioural intervention is the most commonly used treatment for children with ASD (McCarty & Frye, 2020). Early intensive behavioural intervention is based on the principles of applied behaviour analysis which is believed to improve cognitive functioning and language skills of children with ASD, thus improving their social skills and behaviours (Genovese & Butler, 2020). However, this type of treatment tends to be long as it is usually done for several years on a weekly basis (20 - 40 hours a week) (Genovese & Butler, 2020). Therefore, the amount of time required for this treatment can place great financial and time strain on parents. This financial strain can then limit parents' access to evidence-based interventions, thus compelling families to rely on alternative therapies with unproven efficacy (Aderinto et al., 2023). This reliance on alternative therapies may further exacerbates challenges of accessing appropriate and effective treatment for children with ASD (Aderinto et al., 2023).

It has been found that the effectiveness of the child's behavioural treatment interventions decreases when the mental health needs of parents are not met (Catalano et al., 2018). Therefore, it is important that parents' experiences are understood and taken into consideration to avoid parents developing negative thoughts or being resistant towards their child's treatment. For instance, in a study that was conducted in 2018 by Wetherston et al., it was found that parents had negative feelings towards healthcare professionals who were treating their children with ASD. These feelings were because parents felt as though their concerns regarding treatment of ASD were not shared by healthcare professionals and their information was not used in a collaborative manner. Such thoughts can result in parents being resistant towards the treatment of their children. Furthermore, these thoughts highlight the need for healthcare professionals to be aware and culturally sensitive of the different beliefs that parents have (Shilubane & Mazibuko, 2020). Parents play a vital role in the selection and implementation of treatment of ASD for their children, therefore it is important that their views are taken into consideration otherwise they may withdraw from treatment (Wetherston et al., 2018).

The most common theme about ASD treatment is that when intervention is started early it has long-term benefits for the child (McCarty & Frye, 2020). However, late identification, long waiting lists, insufficient infrastructure, and delayed diagnosis can hinder accessing early treatment which further exacerbates the challenges that children with ASD and their families face (Aderinto et al., 2023; McCarty & Frye, 2020). Parents are usually the first to notice any developmental delays or behaviours in their children that may not be typical, thus prompting them to have their children screened, however, their lack of awareness or knowledge may delay the treatment process. Additionally, during the initial clinical evaluation for ASD, parents are interviewed to provide insight about the presenting problem (Genovese & Butler, 2020). Therefore, their insights are important in the diagnosis and treatment of their children with ASD. Thus, it is important to gain insight into their lived experiences of raising a child with ASD and their understanding of ASD.

Parenting a child with autism spectrum disorder

Parenting is complex and can be emotionally draining, which has a noteworthy impact on parents' wellbeing (De Clercq et al., 2022). Parenting a child with ASD can be challenging physically, emotionally, socially, and financially (Eapen et al., 2014). Parents as primary caregivers of a child with ASD means that they need to provide complex care to their child while also having to balance other family aspects and work commitments, which may put a strain on them (Woodgate et al., 2015). In pursuit of caring for their child with ASD, their other children may feel neglected (Mosia & Tseeke, 2021). Children with ASD tend to be inflexible with regards to routine changes and lack of support which may restrict parents' ability to work or advance in their desired career and often parents then need to adjust their lives, aspirations, and sometimes future plans when they have a child with ASD (Ooi et al., 2022). This may thus put more financial strain on parents (Schlebusch & Dada, 2018).

According to research, parents caring for children with ASD are most likely to experience increase in stress, anxiety, depression, and stigma compared to parents of able-bodied children (Adams et al., 2020). The study by Martins et al. (2013) found that fathers of children with ASD expressed that parenting their child negatively affected their social lives, relationships with their spouses, and how they view themselves as fathers which may contribute significantly to their stress. Externalising behaviours such as hyperactivity and conduct problems of children with ASD have consistently been found to contribute to parental distress and poor physical health (Catalano et al., 2018). Additionally, children with ASD have a high likelihood of having comorbid conditions, such as obsessive-compulsive disorder, specific phobias, or attention-deficit hyperactivity disorder which may make it even more difficult for parents to manage their children's behaviour (Catalano et al., 2018). Therefore, the complexity of parenting a child with ASD and the wellbeing of parents is increasingly becoming a public issue (Woodgate et al., 2015). Given the complex role that parents raising children with ASD must take, there is a need for additional support and resources, however, there is a lack of adequate services and support systems that help parents raising children with ASD (Adams et al., 2020). Research findings further support that there is need for primary caregivers to also be considered as the silent client when providing intervention for children with ASD (Fewster et al., 2020; Wilford, 2013).

Raising a child with ASD also puts parents under financial strain due to high assessment costs, special diets which may be expensive, and education services (Mosia & Tseeke, 2021). For low-income families with limited resources who may have already been struggling to support their family financially, this may put further strain on them (Schlebusch & Dada, 2018). It has been suggested that gaining parents' insights about the needs of their children could be helpful in informing ASD treatment practices by providing insight about factors that support or hinder service delivery which could help in reducing financial and human resource barriers to evidence-based treatment in low resource countries such as SA (Guler et al., 2018; Mereoiu et al., 2015).

Behavioural feeding difficulties and atypical eating are one of the most challenging behaviours children with ASD have, greatly impacting family mealtimes (Viviers et al., 2020). These behaviours thus create tense family interactions and increases parents' stress levels (Viviers et al., 2020). Furthermore, such feeding difficulties and atypical eating behaviours may also lead to nutritional deficiencies, increased risk for other diseases, and significant health problems like rickets, while also negatively affecting quality of life (Viviers et al., 2020). Learning and understanding parents' experiences in this regard can thus help in developing effective coping strategies for parents and help them to better support their children's diet. Furthermore, in a qualitative study that explored the importance of context in early ASD intervention in SA, parents expressed that they needed to be equipped with necessary skills to help them deal with the variety of challenges of raising a child with ASD (Guler et al., 2018).

Culture and autism spectrum disorders

Although culture, socioeconomic status, or geographical region do not cause ASD they do however inform how ASD is understood across different contexts (Wetherston et al., 2018). South Africa is a multicultural and multiracial country, thus factors such as culture and linguistic background of the family are important to understand as they may affect the quality of treatment the child with ASD receives, as well as the experiences of the parents. Different cultures have different norms about social interaction, non-verbal communication, and relationships; such factors are usually used to mark impairment in ASD (APA, 2022). A South African retrospective case review noted racial variation in language ability in ASD, with about 94 percent of black African children being non-verbal at presentation when compared to mixed race children with 77 percent and 42 percent for white children (Springer et al., 2013). The racial variations in verbal ability were suggested to be due to socio-economic factors that serve as barriers to care (Springer et al., 2013). Therefore, cultural and socioeconomic factors may affect when an ASD diagnosis is made which can oftentimes lead to late or under diagnosis of

ASD (APA, 2022). Thus, understanding parents' experiences and their understanding of ASD can be useful in providing insights on how ASD is understood across different contexts in SA, specifically black South Africans in this case.

Cultural and superstitious beliefs about ASD are important to understand particularly within the African context as they influence and shape attitudes towards ASD and its treatment which may lead to delays in parents seeking medical attention or relying on alternative treatments (Aderinto et al., 2023; Mosia & Tseeke, 2021). In African cultures it is common for parents to take their children to traditional healers first before they seek medical assistance which further delays the diagnosis process (Shilubane & Mazibuko, 2020). Some parents may rely on prayers to deal with every day challenges including challenges in caring for their children. For example, in a study by Shilubane and Mazibuko (2020) parents reported that prayer helped them accept their children's diagnosis of ASD. Although some of these practices may be helpful in helping parents accept their children's diagnosis it can sometimes lead to delays in seeking medical intervention which may affect the effectiveness of treatment.

In a study that explored the importance of context in early ASD intervention within the South African context, caregivers expressed the need for service providers to understand that they are culturally different to them, and thus need to be sensitive to their cultural background and include such knowledge when treating their children (Guler et al., 2018). Furthermore, one participant in the same study reflected how her mother as well as other women in her community discouraged her son from getting a diagnosis as they believed the son was trapped in evil spirits that needed to be released through traditional practices which left her feeling confused. Therefore, such cultural beliefs may lead to discriminatory and stigmatising behaviours which may sometimes be due to lack of knowledge and understanding. Cultural beliefs that view mental health and developmental disorders as caused by supernatural factors or as taboo tend to perpetuate stigma against ASD and other disorders (Aderinto et al., 2023). Additionally, cultural beliefs such as believing that the child's ASD may be a curse or that the parent is to blame for their child's ASD often lead to parents being isolated and shamed which limits parents' access to social support (Aderinto et al., 2023; Guler et al., 2018). Thus, it is important that there is ASD awareness otherwise parents' support systems are limited. This is particularly important in a country like SA with so many varied cultural and racial groups.

Culture influences thoughts and behaviour, therefore, it plays a noteworthy role in how parents understand their children's development and behaviours which will ultimately influence the extent to which parents are willing to adhere to their children's treatment (Mandell & Novak, 2005). It is also important to note that due to genetic and environmental factors, there might be cultural differences in how symptoms of ASD may be understood (Mandell & Novak, 2005). For example, in some black South African cultures the child's repetitive behaviours may be perceived as being disrespectful while some may see it as the child being cursed (Guler et al., 2018). Culture also influences intervention compliance (Adams et al., 2020). However, factors such as the availability of treatment in the child's first language tends to be complicated and limited in SA (Wetherston et al., 2018). When working with children it is also important to consider parent's needs, therefore, a family-centred approach is required when developing an intervention for children with ASD (Adams et al., 2020).

Grief and ASD diagnosis within the family

A diagnosis of ASD in the family often comes with a painful assimilation process which can be compared to a grieving process in which the family grieves the loss of a 'typical child' (Bravo-Benítez et al., 2019). This type of grief has been considered chronic sorrow and non-finite grief (Bravo-Benítez et al., 2019). The concept of chronic sorrow is defined as profound sadness that parents with children with mental disabilities feel when they experience the loss of the fantasised child which brings about feelings of sorrow (Olshansky, 1962; Teel, 1991). Non-finite grief is used to refer to families that are experiencing loss as a result of chronic illness, disability, or accident (Bruce & Schultz, 2001). Families with a child with a disability often face challenges such as interpersonal difficulties, chronic physical and emotional crises, adapting to routine changes and financial burden (Krishnan et al., 2017). As a result, parents may go through chronic sorrow throughout their life span (Olshansky, 1962). Yet, parents tend to not be included in the treatment of their child with a disability (Krishnan et al., 2017).

In the context of parents raising children with ASD this kind of loss tends to be re-experienced by these families when their children do not reach expected developmental milestones (Krishnan et al., 2017). The sadness is defined as constant and that it gets triggered during critical periods of development of their children when parents recognise the disparity between their child and their fantasised child (Teel, 1991). According to Boushey (2001), due to the chronic nature of their children's diagnosis, parents tend to experience a complicated form of non-infinite loss and grief. Thus, chronic sorrow and sadness recur throughout the parent's and child's lifetime (Teel, 1991). Other authors adapted the concept of ambiguous loss which refers to an 'incomplete and uncertain loss' in which although the child is physically present, they are emotionally absent or distant (Boss, 1999). For most parents, particularly those with children with disabilities, this phenomenon is reported not to be outside the range of normal experience and may not require medical intervention, however, it is suggested that if provided with long-term support by professionals it can help parents accept the chronic sorrow as a normal response to loss in order for parents to achieve increased comfort in raising their children (Olshansky, 1962).

Support systems

Supporting parents who are caring for children with ASD has been identified as an important part of treatment plans (Shepherd et al., 2020). This is important because most ASD-related interventions are implemented at home and lack of support increases parents stress which then negatively impacts the quality of care the child receives which in return may then create a cycle increasingly harmful parent-child and parent-parent relationships (Shepherd et al., 2020). Therefore, support received from family, peers, and school has been found to play a crucial role in assisting parents deal with the challenges that are associated with caring for a child with ASD (Krishnan et al., 2017; Shilubane & Mazibuko, 2020). This kind of support has been found to be helpful in enhancing parents' emotional wellbeing (Shilubane & Mazibuko, 2020).

Social support has been suggested to be as a protective factor against parenting stress of raising a child with ASD and helpful in assisting parents adjust psychologically to their child's diagnosis (Shepherd et al., 2020). Furthermore, the negative impacts that raising a child with ASD has on parents can be mitigated through social support systems (Shepherd et al., 2020). Additionally, family relationships and the marital relationship have been identified as important sources of support to parents raising children with ASD (McStay et al., 2015). Spousal support has been linked to fewer depressive symptoms, greater child acceptance in the family, as well as higher relationship quality (Mcstay et al., 2015).

Both formal and informal support have been identified as an important source of support. Formal supports include support that is usually provided by professional services which mostly tends to require payment, while informal support is usually provided by non-professionals such as family and friends and requires no payment (Shepherd et al., 2020). Parents tend to mostly access informal sources of support and relying on this kind of support may be important to help parents cope with the everyday demands of raising a child with ASD most especially when there is limited access to treatment (Sharabi & Marom-Golan, 2018; Shepherd et al., 2020).

Parents raising children with ASD may be motivated to use online groups as an opportunity to share their experiences, make sense of the diagnosis and provide mutual support and encouragement (Abel et al., 2019). Social media has been found to provide a user-friendly platform that parents use to seek advice or support 24 hours a day (Shepherd et al., 2020) which means that parents may receive multiple replies and perspectives from different kind of people which may increase the risk of incorrect information being shared. This further highlights the need for increased ASD awareness as although such groups may be helpful, they can also be harmful when incorrect information is shared.

In a study by Abel et al. (2019) which analysed the content and purpose of numerous ASD-related Facebook groups, they found that the majority of the groups, about 60%, provided emotional support by sharing of stories. Similarly, in the study by Shepherd et al. (2020) parents rated social media as the highest provider of emotional support and helpful in reducing parenting stress than formal sources of support. In a study by Smith-Young et al. (2022) it was found that parents when faced with uncertainty they engaged in advocacy work as a way to raise awareness and seek help. In raising awareness, parents wanted to share their experiences as well as educate others through their lived experiences (Smith-Young et al., 2022). Advocacy was also found to be used by parents as a coping mechanism to help parents accept their children's diagnosis (Smith-Young et al., 2022).

Autism spectrum disorder knowledge among black African parents

Parents are often responsible for children's healthcare management which includes understanding and sharing delays in children's development; therefore, parents play a crucial role in the early detection of child developmental delays (Campbell et al., 2018). However, for children who live in poverty or whose parents have lower levels of education, their parents tend to notice the delays at a much later stage due to the lack of knowledge (Sharabi & Marom-Golan, 2018). The lack of knowledge about ASD often leads to delay in parents seeking medical interventions (Campbell et al., 2018). Furthermore, the lack of awareness and understanding amongst the general population also tends to create sigma and discrimination which then hinders access to essential support and resources for parents raising children with ASD (Aderinto et al., 2023). Research has found that lack of ASD knowledge to be a common theme among black parents' experiences who are raising children with ASD. For example, in a study by Mthimunye and Mazibuko (2020) parents reported that they were not adequately informed about ASD, while for some they learned about ASD when their children were diagnosed before then they had never heard about it.

Conclusion

Raising a child with ASD has a significant impact on the individual, family, and society; however little research about ASD and how it affects family functioning has been conducted in SA. Furthermore, South Africa is a multicultural and multiracial country, thus factors such as culture and linguistic background of the family are important to understand as they may affect the quality of treatment the child with ASD receives, as well as the experiences of the parents. Culture influences thoughts and behaviour, therefore, it plays a huge role in how parents understand their children's development and behaviours which will ultimately influence the extent to which parents are willing to adhere to their children's treatment (Mandell & Novak, 2005). However not much research has been conducted to explore and gain understanding on how culture influences how ASD is understood within black African families. It is however important to understand the role of culture and how a diagnosis of ASD affects family and social functioning of black African parents as their experiences will influence their adherence to treatment. This leads to **research questions** of this study:

1. What are black South African parents' experiences of raising a child with autism spectrum disorder?
    - 1.1. What are black South African parents' familial experiences of raising a child with autism spectrum disorder?
    - 1.2. What are black South African parents' social experiences of raising a child with autism spectrum disorder?
2. How do black South African parents understand autism spectrum disorder?
    - 2. 1 What are black South African parents' beliefs about autism spectrum disorder?

CHAPTER 3: METHODOLOGY

Research design and paradigm

The primary focus of this research study was to understand parents' experiences of raising a child with ASD; thus, a qualitative research design was utilised. Qualitative research designs put emphasis on experiences, understanding, and meaning making within context and how people interpret and make meaning based on their experiences (Merriam & Tisdell, 2016). Furthermore, it focuses on understanding how people experience and manage a particular situation (Willig, 2008). Revealing and understanding people's values, belief systems, rules of living, and their interpretative schemes can be achieved through qualitative research (Omona, 2013). Therefore, this research design allowed me to understand the complexities that parents experience when raising a child with ASD from their viewpoint and in rich detail.

To understand parents' experiences as lived by them, an interpretative paradigm was used. An interpretative paradigm emphasises discovering how people understand their lives (Omona, 2013). An interpretative paradigm states that to discover the subjective experiences and how participants make sense of those experiences, the focus of researchers should be on understanding how participants interpret their subjective experiences. Furthermore, it is also believed that research that is focused on discovering, gaining insight, and understanding people's experiences as lived by them can also make a great difference in people's lives (Merriam & Tisdell, 2016). Therefore, the qualitative, interpretative paradigm allowed for an in depth understanding of how parents experience raising a child with ASD.

Sample and sampling

The study consisted of six individuals who have a biological child with ASD. Their children were diagnosed with ASD at least two years prior to the parent participating in the study. This allowed for parents to be able to reflect on and provide rich descriptive information on their lived experience of raising a child with ASD. All parents were over the age of 18 years and also were living with their child with ASD on a fulltime basis which allowed for parents to share some in-depth experiences of raising a child with ASD. The children of the participants were diagnosed with ASD by a relevant medical professional. Furthermore, all participants were black and South African. All interviews were conducted in English.

Purposeful sampling was used. The aim of this sampling technique is to obtain insight and understanding, therefore, this sampling technique allowed me to purposefully select individuals that met the study's criteria and characteristics (Omona, 2013).

Various organisations that work with children with disabilities and Autism were approached to obtain the sample. Obtaining the sample proved to be difficult and social network sites such as *Facebook* were thus used. A poster was created (please see Appendix C) and shared with various *Facebook* groups and community *Facebook* groups. Once parents indicated interest and willingness to participate in the study, Participant Information Sheets and Consent Forms (please see Appendix D and E) were then sent to participants before the interview.

Table 1: Research participant characteristics

					Child			
Participant no	**Parent role**	**Relationship status**	**Employment status**	**Intervention facilities**	**Sex**	**Age**	**Age when diagnosed**	**Number of other children in family**
1	Mother	Single	Employed	Private then went public	Boy	8	5	1
2	Father	Married	Employed	Private and public (school)	Boy	14	4	1
3	Mother	Single	Employed	Private	Boy	5	3	0
4	Mother	Married	Employed	Private	Boy	17	2	2
5	Mother	Traditionally married	Self employed	Public then went private	Boy	14	4	1
6	Mother	Single	Employed	Hybrid (mostly private)	Twins (boys)	12	L=5 K=8	0

Data collection method and procedure

One-on-one semi-structured interviews were conducted with participants. Formats that are less structured assume that individuals have unique ways of defining and understanding the world (Merriam & Tisdell, 2016). Therefore, the use of semi-structured interviews allowed for the exploration of how different parents experience raising a child with ASD. Semi-structured interviews allowed for flexibility and for the interviewee to respond to new ideas, unique worldviews of participants, as well as the situation at hand (Willig, 2013). The use of semi-structured interviews also allowed for follow-up questions to gain in depth understanding of parents' experiences of raising a child with ASD (Merriam & Tisdell, 2016). Furthermore, it also provided parents with an opportunity to enter into in-depth reflection of their experiences, as well as freedom of expression.

After reviewing relevant literature, an interview schedule was designed (please see Appendix B). An interview schedule is a carefully constructed set of questions developed by the researcher to redefine the topic under investigation to help the researcher not to lose sight of the original research question/s (Willig, 2013). The interview schedule comprised of open-ended questions to allow for in-depth information and follow up questions when needed. The research supervisor of the study reviewed the schedule. This was important to ensure that the schedule aligns with the research questions and check the appropriateness of the questions (Adams et al., 2020). Furthermore, the first two interviews were used as pilot interviews to improve the validity and reliability of the interview schedule. After the first interview I reviewed the interview with my supervisor and one additional question was added to the demographic questions.

The initial plan was for interviews to be conducted in person; however, not enough participants were found to be interviewed in person. Therefore, only one interview was held in person and all other interviews were conducted online using Microsoft teams. All interviews were audio recorded and transcribed verbatim for data analysis. As the researcher, I transcribed the data myself, this allowed me to become familiar with the data while protecting confidentiality of participants. All transcribed scripts of the interviews were anonymised by removing all identifying particulars of participants, except in cases where participants expressed that they would like their names or children's names to be used. Only the researcher had access to the recordings. The supervisor had access to the anonymised transcribed scripts. The anonymised transcribed scripts were password protected and stored in a password protected device.

Data analysis

Reflexive thematic analysis was used to analyse the data. Reflexive thematic analysis is a flexible interpretative approach to qualitative data analysis that allows for themes to be discovered within the data set (Braun & Clarke, 2013). Furthermore, it also highlights the researcher's active role in the interpretation and analysis of the data (Braun & Clarke, 2013). Thematic analysis is not rooted in any pre-existing theoretical framework, and thus this allowed for flexibility (Braun & Clarke, 2013). The inductive approach was utilised so that the data best represent meaning and parents' experiences as communicated by them (Braun & Clark, 2013). An inductive approach is not rooted in any pre-convinced theoretical framework; therefore, codes are mainly a reflection of the content of the data to best represent meaning as communicated by participants (Braun & Clarke, 2013; Bryne, 2022). Therefore, it allowed me to reflect the reality of parents' experiences of raising a child with ASD in rich detail and identify common emerging themes and what information they provide in terms of meeting the research aims of the study. The following steps of Braun and Clarke's thematic analysis technique were followed:

Step 1: I familiarised myself with the data. The interviews were transcribed manually by myself, and this allowed for deep immersion into the data as well as helped me to identify appropriate information that was relevant to the research question and aims. After transcribing the data, I then read and re-read each transcript. While familiarising myself with the data I also noted down my thoughts and feelings with regards to the data and what seemed to be most common responses.

Step 2: This step entailed generating initial codes through organising the data into meaningful groups. Extracts from the data were used to demonstrate the codes to ensure quality of the analysis. I copied and pasted quotes from the data into a separate word document and began to evaluate whether the different codes could combine to form a sub-theme and eventually form into a logical main theme. During this stage, I looked for thematic meaning instead of looking for individual meanings of the codes which helped in deriving main themes.

Step 3: This step entailed searching of themes through sorting the various codes into potential themes and putting relevant coded data extracts into identified themes. During this stage I ensured that there was consistency among participants' responses and chosen data extracts to form themes. Mind maps were used to connect and understand the relationship between the identified codes and candidate themes.

Step 4: This step included reworking on my candidate codes by checking whether the themes formed a coherent theme, there was validity between my themes and the data set, and then create a thematic map to see how all the different themes fit together and what this says about the data. The development of these themes involved some level of interpretation.

Step 5: In this step the themes and subthemes were named and defined so that I could refine them for analysis. I highlighted what each theme and subtheme was about and what they say about the data set in relation to the research questions.

Step 6: This step entailed the final analysis and writing of the report which took place once all the themes had been identified. Each theme was analysed and discussed in detail.

Ethical considerations

Ethical clearance was obtained from the University of the Witwatersrand's Human Research Ethics Committee (non-medical) (MClin/23/02). Parents were presented with participant information sheets and informed consent forms (please see Appendix D and E) before the interviews. Written consent was obtained from each participant. No identifying information was revealed. In order to ensure confidentiality and final anonymity each participant has been given a pseudonym except in cases where participants expressed that they would like their names to be used.

The study required parents to share about their lived experiences in raising a child with ASD. For some parents it may have invoked intense emotions, thus before the end of each interview I conducted a debriefing session (please see Appendix B) to check if participants feel fine to end the interview. Furthermore, participants were reminded that they can go to the Emthonjeni Centre at the University of the Witwatersrand for free counselling services if they needed to discuss their emotions further. Contact details of free ASD specific service providers were also included in the participant information sheets (please see Appendix D).

Methodological Rigour

Qualitative research tends to be based on the subjective interpretations of the researcher, therefore, to evaluate quality of my research study measures such as using researcher reflexibility, credit checks with my supervisor, documentation, grounding analysis in examples and the use of direct participant quotations, as well as reference to existing similar studies were used. Grounding my analysis in examples extracted from the data was used to ensure the validity of my interpretations and that they fit with the data (Sandelowski, 1993). Documentation of the analytic process was done by explaining how reflexive thematic analytic steps were used to analyse the data. Furthermore, during the data analysis stage I looked for consistency among participants' responses and used existing research studies to check consistency with other similar studies which also helped with understanding and making meaning of the data and validating my analysis (Sandelowski, 1993). All aspects of methodology and data analysis were detailed to ensure dependability. Confirmability was established through reflexivity to reduce the risk of bias (Adams et al., 2020), please see the section below. Documentation of the data analysis process included explaining how thematic steps, as proposed by Braun and Clarke (2013), was used to analyse the data.

Researcher reflexivity

Some participants shared with me how upsetting and difficult it was for them when they did not receive good treatment from health professionals when searching for answers for their children's behaviours. This led to me being left with feelings of guilt as I felt that I was in some way responsible and that my identity as a clinical psychology student emotionally triggered them in some way. To deal with these feelings during the interview I reminded myself of my role in the research as researcher and used my therapy skills in holding what was mine while reflecting the participants' feelings. Additionally, I consulted my own personal therapist to deal with those feelings. I also noted that during the interviews, there were points where I felt the pull to want to use my therapy skills and identity as a clinical psychology student to provide some counselling to those parents perhaps also as a way to deal with those feelings of guilt. I dealt with such feelings by again reminding myself of my role in the study, that I am a researcher and not a psychologist here and referring the parents to the Emthojeni Centre and helped them in getting referral forms in this regard. Consulting my personal therapist to deal with my own feelings also helped me during the analysis process so that I interpret, and report parents' experiences as shared by them without my own feelings of guilt clouding my judgement. As a black researcher who grew up in a black society, I was familiar with some of the cultural beliefs that participants shared, while some I was not familiar with, which at some points during the interview made me question some of those beliefs. Therefore, credit checks with my research supervisor was also helpful in ensuring that my analysis and interpretation of the data was based on the data received and this also helped in reducing personal bias in assuming similarity with the participants because I am also black.

CHAPTER 4: RESEARCH FINDINGS

Themes

1. Pre diagnosis	1.1 Milestones 1.2 Waiting period 1.3 Lack of knowledge
2. Diagnosis	2.1 Receiving a diagnosis 2.2 Making sense of the diagnosis 2.3 Cultural and religious factors
3. Post diagnosis	3.1 Family dynamics 3.2 Interpersonal relationships 3.3 Financial challenges 3.4 Culture and community

1. Pre-diagnosis

This theme captured parents' experiences before their children were diagnosed with ASD. Participants reported that this stage was filled with confusion as they did not understand or know what was happening with their child. Parents reported the pre diagnosis period to be difficult for them.

1.1 Milestones

Parents in the study reported that not reaching certain child developmental milestones at certain ages raised a concern that there might be something wrong with their child. The experiences were shared as being:

> *... so, the first thing for me was the milestones, he was not reaching his milestones…he didn't crawl, he basically just walked, so it was, he wasn't developing like any other child (participant 1)*
>
> *…when we needed to start, to get to communication milestones, it really became a struggle (participant 6)*

Several parents reported that their children met expected developmental milestones until there was a sudden change and their child stopped reaching certain milestones, or they regressed. This sudden change alerted them to the fact that there was something wrong with their child. Some parents expressed that the switch was difficult for them, as illustrated in this extract:

> *Before he used to…say few words…then he went mute…the child was fine, the child was okay, counting and doing all these things, he was just a bright child and then boom autism and the switch. Yoh the switch was just a strain, it was so painful (participant 3)*

One parent reported that although the change alerted him that there was something wrong with his child, he was in denial at first which made him take longer to get his child assessed. This wait to attend to his child is linked to being black in participant 2's mind:

> *…he was developing well as a child, like any normal child would do but I think at the age of 4, 4/5 you started to see that he was regressing. There were few things that were changing, his speech was no longer the same and you could see he had so much energy. But you think as a child, all the kids have energy so there is nothing wrong and you also, as a parent sometimes you are in denial, you know I think it's us like black people sometimes. You know with white people as soon as they see something wrong with the child they will take them to specialist, but with us we think you know the child will be okay and that's the same attitude we had, we didn't think there was anything wrong…*

One parent who is raising twins, reported that her children were diagnosed at different ages and that with the one twin they did not think he had ASD, and they took him to mainstream school until later when he started displaying signs of autism. She described the experience as confusing because she was not sure if it was signs of ASD or he was mimicking his twin, the experience was reported as:

> *…you are not quite sure if they're just mimicking each other's behaviour or there is something to respond to, so it definitely took a while to identify his and in fact again, that's why his diagnosis took so long because I really had to process it and be like okay maybe we need to consult… (participant 6)*

1.2 Waiting period

Following their children not reaching certain milestones and regressing, parents then took their children to get assessed. Some parents in the study reported that they had to wait long periods of time, for some it took years before they could get a formal diagnosis of autism spectrum disorder:

> *I would say Aobakwe was 4 when he had, when we realized that he has autism but to get a professional diagnosis he was 6, 6 years when he got the doctor writing down that yes, he is autistic (participant 2)*
>
> *Eventually when I got the diagnosis because with Doctor ... there was a 2 1/2 year waiting period (participant 1)*

Participants attributed the waiting time to how long it took within the public sector more especially in big cities for their children to get diagnosed. They described this period as stressful because they needed the diagnosis for school placement. Due to this, one parent reported that they decided to go to a town in the Free State province to receive a diagnosis as they felt that because it is a small town it may increase their chances of getting a diagnosis earlier unlike when they are in Johannesburg. The experience was shared as:

> *…unfortunately, with Joburg at that time it was hustle to get a diagnosis…I realized it's not gonna happen this year, it's gonna take more than two years for us to get a diagnosis and get the child into school and I was not gonna wait for my child to be 8 to start schooling. So, a friend of mine, his mom is a nurse in a rural area of Free State, a small place next to Thaba'Ntsho so she said no bring the child here let's see what we can do… I think within six months if I still remember we had the diagnosis (participant 2)*

Participant 3 described this waiting period as painful and stressful as she did not understand what was happening and when asked at her child's school, she had no answers to say what is wrong with her child:

> *…waiting for your appointment to meet this pediatrician neurologist, it is just painful because when they ask you, you go to a parent meeting and people will just be talking and talking, and with you when they ask you, you will be like guys I don't know what is happening, I am not sure, my child is not yet diagnosed…*

1.3 Lack of knowledge

During the pre-diagnosis period, several parents mentioned that they did not know anything about ASD, they only learnt about it after their child was diagnosed. They described this period as difficult as they were confused as to what could be happening with their child. Most of the participants reported that they did not know about ASD, but rather knew about physical and learning disabilities. These experiences were described as:

> *Yoh, I didn't even know how to write autism, I was just so surprised that there is something called autism, I was more familiar with physical disability but with mental disorders I just did not know anything (participant 5)*
>
> *I first suspected that something was wrong with him you know when he was not hitting his milestones, I just did not have a word for what it was (participant 1)*
>
> *I only knew about the hyperactive one, the Down syndrome you know, I only knew about that this one about slow learners, I only knew about that, so I didn't know that there is autism (participant 3)*
>
> *I did not know about autism spectrum disorder honestly speaking uhm before my child was diagnosed (participant 4)*

Due to the lack of knowledge and understanding, one parent reported that she consulted a sangoma[1] and other alternative options with the hope that getting a cultural insight might offer an understanding of what was happening with her child and hopefully get a solution:

> *… before I got my diagnosis, I tried everything, I went from sangomas, church everything, I have tried everything. (participant 1)*

One parent shared that due to the confusion and lack of understanding his wife and her family suspected that his family had done something to the child which caused tension in the house:

> *My wife's family was saying this, and my wife was also saying this to say your family did something to the baby that's why there are issues with the child and that's before anyone thought of autism. (participant 2)*

Participant 5 shared that because she did not know or understand what was happening to her child, she just thought maybe her child was crazy:

> *I was just like everyone else who thought it was just a person who is crazy. (participant 5)*

These experiences show how this period was painful and confusing for most parents and how the lack of knowledge and understanding caused tension in families which further made the

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A sangoma is a spiritual healer (Geiselhart,2018) experience more painful. These experiences also suggest that some participants began to rely on specific cultural beliefs and practices in order to make sense of their child's presentation.

2. Diagnosis

This second theme captures parents' experiences during the diagnostic phase, how parents reacted, challenges they experienced, support structures they turned to, and how they learnt more about ASD after their children received a diagnosis.

2.1 Receiving a diagnosis

Following the experiences of confusion and not understanding what may be happening with their child, as well as difficulties they had with school placements, parents went for medical intervention in the hope of receiving clarity. Some parents reported the experience to be frustrating as some doctors were not sure what the problem could be, encountering long waiting periods, while also being stressed and worried about school placement:

> *…unfortunately with Joburg at that time it was hustle to get a diagnosis because everyone gave you their own reason why this child is like that… you need to go through the process of getting a letter from the clinic and from the clinic they will refer to the hospital… we went there and I think they checked in around March and they said the next appointment would be around September (participant 2)*

> *I consulted this other doctor, then he did the investigations and then he said he doesn't know what is happening… I had to get that diagnosis and then I consulted a pediatric neurologist, and he diagnosed that yes, it is autism (participant 3)*

> *….I didn't understand myself by that time why my son is not developing like other children but I could get the sense that even the nurses didn't know because if they knew something they would have just pointed it out … it was really frustrating eeh remember I was trying to get something to hold on to, to say okay this is what is wrong with my son, so if I am getting different answers… (participant 5)*

Participant 1 said that because she did not know much about ASD, she was advised by the principal at her child's school to seek out help and have her child assessed:

> *At the daycare that he went to I was speaking to the principal and telling her my concerns and that's when she recommended that I go to doctor because her grandchild was autistic that's how I got to start the whole process.*

One parent reported that she was told by family members that her child has ASD, however she did not take kindly to that. She described this experience as difficult and isolating since she did not know or understand the disorder. She described the experience as:

> *so the first reaction was really horrible, so my sister in law walks in and says this child is autistic, and I don't know what autism is….I was like, you walk into my house and you are not even a doctor or what…I did not take kindly okay and uhm my mother-in-law reaches out to my mother, and says uhm, so my mother-in-law she is a nurse and she asks my mother uhm 'do you have an experience of delayed mental whatever in your family?' And my mother is asking why are you asking me that, and she says 'no, I picked up that you know my son is like 1 2 3'…I think the way the thing unfolded and this and that, and I just felt a little bit isolated and I felt like people are not understanding me in as much as I don't understand. But at the time I felt like no there is no support here, you get what I am saying? So it was difficult, it was extremely difficult (participant 4)*

Participant 2 reported that due to his work and the long diagnostic process, he took his son to his grandmother to help them go through the diagnostic process while he was at work. The experience was described as:

> *….so, the truth is that with us, I was in Joburg, and everything was taken care of by my mom, so we were supporting financially…*

These experiences highlight the frustrations parents felt with having to wait to get answers that they desperately needed in order for their children to get placed in school as well as for them to understand what was going on with their child. These accounts also illustrate the role the greater family plays in black cultures in South Africa.

2.2 Making sense of diagnosis

Receiving a formal diagnosis of ASD was a relief to some parents as it helped them to understand what was happening with their child and gave them hope that something can be done. Although it was a relief, parents also shared that they were scared and heartbroken. The extracts below capture parents' initial emotionally-laden reactions when they received the diagnosis:

> *For me because I knew something was wrong, I was happy that there is actually, an answer and way forward because you are parenting someone who you are not sure what's wrong with the child. So, for me, having a diagnosis was firstly a relief and then secondary emotion um heartbreaking (participant 1)*
>
> *mmm to be honest I was relieved but scared and just worried about how am I going to handle him because there was just a lot of information, it was so confusing at the same time so yeah. But I felt relieved because I always knew that there was something wrong with my son, so I needed something to hold on to, to say okay this is what it is wrong with my son… (participant 5)*
>
> *I think it was disappointment, uhm obviously followed by frustration, followed by anger, followed by resentment of some kind… (participant 4)*
>
> *…I was like God what happened? ...you are like what did I do wrong? And then you ask so many questions, you cry for days but I just decided that as long as there is hope… (participant 3)*

One parent who is raising twins had different reactions to the diagnosis as her children were diagnosed at different times. She described the first diagnosis as a relief and the second diagnosis was hard to accept. The experience was shared as:

> *I must say the diagnosis was a was a relief. The first time was with Omphile when I was told about autism…So, I think denial would be it, it definitely was denial, I was lucky in the sense that I had help…with Kgotso that was hard, that was hard because I think like with stages of grief, I think I was bargaining with God to say I could deal with it here but why are you giving it to me twice ... so it was harder, but also it was free in the sense okay it can be the same condition but it presents differently… (Participant 6)*

Following the diagnosis, parents in the study reported that they went through a period of having to accept that they might not be able to do some things with their children. These experiences highlight how a diagnosis of ASD in the family can be followed by grief. Parents described the experience as hard and painful:

> *It's a, it's a constant grief that you carry and your grief as a family will never be the same (participant 6)*

> *I was saying you don't know what you have until you don't have it anymore, you know. Because you know you look at like for me when my friends were having kids I always imagined that my son is gonna graduate from grade R, he is gonna go to normal school, he gonna play sports he gonna do this and that but when you have special needs child you, you forget you, some of the things that you will never be able to do…I can't take him to go get a haircut because he can't deal with the environment and it overwhelms him you know, people take that for granted … people take being able to go on holiday with your child for granted I can't do that, he needs to uhm go to the place a couple of times firstly he needs to see the environment, understand the environment before we can even think of sleeping there you know so Eish its hard, yoh it's hard (participant 1)*

> *He is still young but then to think that we are raising two different parts of, we are in different parts of experiencing life with our children so I would, to remind myself that I am on the other side of town but sometimes I get that thing of comparing how if my son didn't have autism he would be in high school, those things will come…I would wonder how it would have felt like to see my son going to high school for the first time and so forth, would he have matured because I could sense that other parents are at the stage of adolescence and their children are starting to date and sometimes I would just want to have that feeling but anyway I am having my unique journey so I need to appreciate that and yeah (participant 5)*

Oftentimes black African families, particularly fathers take pride in having a son because they believe the son will continue the family name (Mudau & Obadire, 2017). Participant 2, who is a father, shared how his son's diagnosis meant that he had to adjust his own dreams that he had for his son to the reality of his son's disability:

> *The emotional part uhm I would say as a black person, uhm especially as a guy, when you have a boy or a son you already have dreams you are thinking I am gonna worry about girlfriends now you know it's a nice stress kind of stress you know what Eish … and the worse part, Aobakwe looks exactly like me even if you saw him passing through you, you can actually that's Paseka's son, that's how identical I look with him so I always have that thing to say you know what I want my son to be this, I want my son to do this, I want my son to achieve more than I achieved and you start saving money, you start doing things and boom your son has autism, now you have to align your dreams (participant 2)*

Following the diagnosis, several parents in the study reported that they learnt about ASD after their children were diagnosed. Majority of the parents reported that they used the media, particularly the internet, to educate themselves about the disorder and to understand their child:

> *I do a lot of research, I actually watch YouTube videos (participant 2)*

> *…. I started googling, I love Google… I just went home and googled, and I saw that there are stages, the signs to say these are the signs for this stage and I just saw that mine is below severe, I only researched, and I was like ohh okay... (participant 3)*

> *I used the internet… (participant 6)*

Some parents reported that seeing public figures and celebrities that have autism or who are raising children with ASD was encouraging and helped them to accept the diagnosis. The experiences were shared as:

> *…I went to who is this Zakes Batweni's wife, Zakes Batweni also has a ASD child and then I also look at those things and they just talk about their experiences and all that, and then yeah I just googled people in South Africa who had experienced such things and that's how I knew that okay this is it, it differs, it is not the same, it has different categories and stuff (participant 3)*

> *…if Tommy Hilfiger, a person that has all this money, cannot cure their child with autism, who are we? (participant 2)*

These experiences highlight the positive influence of media and how it gives parents a sense of control when they are faced with the unknown and helped them to not feel alone as well as feel empowered with regards to receiving an ASD diagnosis for their child.

2.3 Cultural and religious contributions

Following the diagnosis, some parents reported that they were in denial, and they found it difficult to accept the diagnosis and some questioned and blamed God. Some parents looked to God for comfort and guidance to help them accept the diagnosis:

> *My mom was also a big Christian and uhm she encouraged me to pray about it and hence I was able to accept it sooner rather than later… I had already accepted it because when I first figured that something is not right, I prayed a lot, and I asked God to help me accept him …. (participant 1)*

> *my mother was the one sole person that was there with me all the time, she was praying with me…she tried every little that could be done including uhm let's go to pastor … we spend a lots of nights crying, praying and looking for answers … (participant 4)*

One parent who is raising twins, reported that the second diagnosis was hard at first to accept and she bargained and questioned God why it was given to her twice. She described the experience as hard but that it also helped her to understand ASD more and how it can present differently:

> *….That was hard, that was hard because I think like with stages of grief, I think I was bargaining with God to say I could deal with it here but why are you giving it to me twice yoh so it was harder, but also it was free in the sense okay it can be the same condition but it presents differently… (participant 6)*

Participant 2 reported that they did not believe in traditional medicine or healers, however after they got the diagnosis it was hard to accept so they then went to consult with a sangoma with the hope that their son would be helped and when it did not work, their experience helped them to accept their son's diagnosis and that it is not curable. His experience was shared as:

> *I have never been a person that believes in African medicine or Sangomas or traditional healers …. we took our child to a traditional healer because we were getting advice from different people so when you are desperate you do anything although I didn't believe it ..so I had to change my mentality around traditional healers and traditional medicine just for the sake of maybe my son getting help, it is only later on that my wife and I decided that you know what these things are not going to work, it is autism, it doesn't have cure, we are wasting money here…we also didn't want to believe it is autism although we knew… (participant 2)*

These experiences highlight how out of feelings of helplessness and denial, parents can sometimes seek cultural and religious interventions. However, after failed trials with cultural interventions it helped them to accept the diagnosis, while for some parents' prayer helped them to accept that their child has ASD. These experiences highlight the role of religion and culture in helping these parents accept their children's diagnosis, particularly in black African families.

3. Post-diagnosis

Raising a child with ASD has a significant impact on the individual, family, and society, as well as affecting family functioning. This third theme explored parents' experiences post diagnosis and how they have had to adjust their lives.

3.1 Family dynamics

Raising a child with ASD deeply impacts the family system, routines, and mealtimes. These themes were evident in the study, in that post the diagnosis period participants have had to make routine changes to accommodate their child. Such changes caused tension as the family was still trying to understand and adjust to their new lives, however, after a while, parents in the study reported that their families accepted their new reality and things improved:

> *I think from the home set up; lot of things had to change… we began to change the diet in the family…. so, you can imagine that you are subjecting other people to a very difficult environment…my husband was very supportive, but I could feel as well that he was very much frustrated … (participant 4)*

As a result of routine changes that parents have had to make as well as the level of support their child requires, some parents reported that they have also had to make career changes or leave their jobs so that they can be able to be there for their children:

> *I had to leave a high paying job to settle for a job that allows me to be able to one pick him up from school, two should I get a call I am able to go at a moment's notice…so I had to stop pursuing my dream to become a mother so yeah, those challenges… (participant 1)*

> *my wife is unemployed right now because when we realized our son had autism one of*
>
> *us had to look after the child while the other is looking for a job, so I found a job and my wife had to sit at home… (participant 2)*

> *… I got a job, I think it was at spar (grocery store), we used to work long hours till 8 o'clock in the evening and my issue that made me stop working was I would have so many appointments and they wouldn't let me to go to, I had to choose, it is either I go to for one for the neurology and I don't attend the other one … so yeah it was again difficult, then I had to stop working (participant 5)*

As part of change in family dynamics, parents in the study reported that raising a child with ASD also impacted their marriages. Their experiences were shared as:

> *I had to break up with my partner because he couldn't accept that the child is like this… the treatment was not the same and I never ever want my child to feel like an outsider at home, it's bad enough that the world will treat him like an outsider and I just didn't want that at home especially in the, in my house, I just didn't want that so that's why I made that decision of walking away from everything (participant 1)*

> *we separated with my son's dad because he could see, because I was also communicating with him to say there is something wrong with our son, what could be wrong, but he didn't want that part he just wanted to have a nice life with a son who doesn't have problems, so he pulled out of the relationship slowly but surely, he was out (participant 5)*

> *On a relationship, definitely I mean I have an 11-year-old who holds my hand more than any other 11-year-old would, that definitely strains a relationship … uhm I broke up with my children's father long before diagnosis and uhm even him he doesn't understand but it also makes dating difficult (participant 6)*

> *uhm relationship wise I felt like I needed to spend more time with the child and so on, and you begin to neglect your marriage … I think my husband was just quiet, just sitting there, observing the situation, and hoping that we are gonna get the best out of these interventions, but it was quite strenuous (participant 4)*

Participant 1 described that although she took the decision to break up with the father of her son, it has been emotionally straining to raise her child as a single parent:

> *… motherhood is not what it's put out there to be, you know um, it looks like you can do it without a man, you can but it is emotionally taxing… I have the money but emotionally it is still hard, emotionally it strains you know, like sometimes when you wanna have someone to talk to …*

Black African men often pride themselves in being the leader of the family and that in times of adversities they need to be strong for their families and although they may be experiencing emotional distress, they tend to not share that with their spouses (Masemola et al., 2022).

Participant 4 described how she and her husband dealt with the diagnosis differently, she was talking about it, but her husband found solace in alcohol:

> *…. the fact that he was not able to admit, I was crying, I was admitting, I was messed up and this and that, and at that time I think he felt like he needed to compose himself and be the stronger one and be more supportive, but actually he was finished himself and uhm because he couldn't cry, he couldn't do this and that, somehow he found consolation in alcohol, he did not become an alcoholic but he spent most of his time drinking, because he couldn't open up and I think it was only when his sister spoke to me or I got to know that he was talking to his father and he was crying like you know it is really hitting him*

Interestingly, participant 2 shared that their child with ASD helps him and his wife get along and that he is the reason they would never get divorced out of fear that other people may not understand their son:

> *the stress that comes with married people especially young people so when we have these fights we would actually not talk to each other….but because we had Aobakwe, especially Aobakwe because he would actually see, he would actually notice that something is different, sometimes he would take my wife's hand and my hand and hold them against each other, sometimes he would want to get a group hug and all those things and we realized when we were getting along that we actually only get all these group hugs, the holding of hands when we are fighting or we are not getting along…. we did say that you know what with us we can only fight, we know that we cannot get divorced because I don't think I will be happy to see another man taking care of Aobakwe, they might not, they will do things that I don't think Aobakwe should be doing and they might not understand his condition and my wife was saying the same thing about me (participant 2)*

Another parent expressed that she enjoys being a single mom as she can independently make decisions regarding her child with ASD:

> *I will actually say luckily, I'm a single parent I have got to acceptance on my own, I make decisions on my own (participant 6)*

Parents reported that the diagnosis of their child impacted the family system and how they parented their other children. The theme of overcompensating and guilt were evident in how they felt and related to their other children, as illustrated in the following extracts:

> *I think oh with her I think that I have um I will say overcompensated for the fact that my son is the way that he is you know because and in essence I think I'm parenting two toddlers because he needs so much support from me, and she understands but at the same time I overcompensate you know….I feel guilty at times and I sometimes think maybe what I did was … actually a selfish move to have another child when this child, when the first one still needs you so much… (participant 1)*

> *….sometimes I wanted to go out with my little girl, go do things but I won't because I got this one to take care of and she knew the dad will take her to the shops and she will do this and that uhm yeah so it was quite demanding … (participant 4)*

These experiences show how a diagnosis of ASD in the family affects the family system and relationships within the family causing tension and thus making the experience of raising a child with ASD full of emotional reactions.

3.2 Interpersonal relationships

Parents reported that raising a child with ASD has also impacted their social relations which made the journey for some of them lonely:

> *it affects your relationship with everybody, with everybody, with your friends, with your work colleague…. (participant 6)*

> *…. I become very much withdrawn and sometimes it was even difficult to host a party for the older daughter because you knew the son was going to be there, he is the brother and so on but how will people even get to understand the environment, so it was a little bit difficult (participant 4)*

> *You lose friends because people judge me without understanding what autism is…it does get lonely … (participant 1)*

> *As a friend, if you can say that my child is mute and that I am in denial, it means that you are not in support, and you are not going to give me support so I just cut ties and even relationships from childhood I just cut ties… (participant 3)*

> *I think at the time (of having a child with ASD) I had one or two people that I knew as friend and uhm I don't think that they also understood…they just saw a little bit of withdrawal, spending time with my child and so on, so I guess it did affect … (participant 4)*

> *What can I call the people that did not support me? Should I call, continue calling them friends? No (participant 5)*

Although raising a child with ASD had an impact on these parents' social relations as they lost friends, several parents in the study reported that being part of support groups with parents that were also raising children with ASD was helpful, encouraging, and made them feel like they are not alone since they have people that they can relate to and understand them:

> *… all the kids it might not be the same exact challenge but it's something similar so you draw from that…so going to the early foundation for those classes it helps because they work with him, and they see what happens and what reinforcements I can use to make him understand that no mommy is angry … (participant 1)*

> *Autism SA program helped me a lot …it was an eye opening for me if it wasn't for the program, I think I would have taken long to understand autism … it has helped me help my son to develop into the man that he is today … (participant 5)*

> *I think having communities like that then I think the oldest autistic I know now, now black autistic I know right now is like 45 years old and it helps to be able to have … with autism is like wearing a lens of a spectrum everything in life is a spectrum and it's beautiful because you actually get to see that the other levels that you didn't learn and then you get all the mothers who say I did all, I did the stem cell, went to do the oxygen whatever … and that kind of peace can only come from another parent or somebody who have walked the journey (participant 6)*

> *…. it made me see that I am not alone so when people talk it makes you feel like: no girl you are okay, you are not the only one because sometimes when they talk, I will be like Yoh no you know and even at the previous school… I made friends and … remember you have people whom you can speak the same language yeah unlike having a person who is experiencing a different thing and then they are too judgemental … (participant 3)*

Other forms of support that parents received was support from family and loved ones. One parent reported that she had to move closer to her family so that she can get more support:

> *… I moved back home so that I can have a family structure with my family, with my mom and my dad and my sisters helping with him and also teaching people about autism and the effect, the effect it has on you as the mother (participant 1)*

Another participant shared how although she had support from her family, not being a part of a support group of parents experiencing similar challenges was difficult and isolating:

> *support groups there were really not there … it was difficult at a social level because uhm there wasn't people that could identify with what you feel, like I could belong to this uhm part of the community uhm yeah so it was really difficult, you felt like aah this thing it is just happening to me and everyone else is sitting there, they are raising the kid and everything is fine … (participant 4)*

These experiences highlight how raising a child with ASD does not only impact the family system but social relations as well which makes the journey isolating and more painful. These participants' accounts also highlight the impact and role that support groups have in giving parents a sense of belonging and making their journey less lonely and isolating.

3.3 Financial challenges

Autism spectrum disorder is a lifelong disorder and treatment is usually long and expensive thus placing great financial strain on parents (Guler et al., 2018). Parents shared their experiences in this regard:

> *It is all about financial difficulty, and never-ending financial difficulties… it's a financial chokehold, there is no keeping up… (participant 6)*

> *… when I first started, I went to the private route …. it was quite expensive hence I ended up having to move to the public sector because actually I simply could not afford it (participant 1)*

> *…. remember you had a child and you think the child is normal and then the next thing remember ASD affects you financially, everything is money, you go to the paediatrician neurologist just the consultation is R 2500, every after 6 months you pay R 1500, the creche is R 6500 you need to pay that, OT you need to pay that, speech therapist is how much? Like right now I am paying R8000 per month and then OT is R475 and then the ST is about R120 or R210 after the child goes to creche, from 07h30 to 13h00, then after that, you pay for aftercare, aftercare is R1350, you still need to make a lunch box, you still need to pay GPs it is a lot … there is always a shortage (participant 3)*

> *uhm all the interventions that we were doing, they were very expensive, and I think my husband and I, we just committed to say we will do, even our savings (participant 4)*

> *I was not working so financially wise Yoh it was just too much because I had to take my son for his clinic visits and for speech therapy, neurology checkups so it was just too much for me…I remember there would be days where I didn't have money for transport… the situation would get so deep that I would sell whatever I could sell in the house that belonged to me just to have money to take my son to his monthly checkups (participant 5)*

One parent shared that because of these financial challenges, sometimes parents may feel like a failure when they cannot afford to do some things they want to do for their children:

> *… it's a lot, it's a lot and you are like as a parent mostly feel like you are a failure because you can't keep up (participant 6)*

As a result of these financial strains, participant 2 shared that they also had to adjust as a family and try to not consult but rather get over the counter medication when they are sick so that they can save the medical aid funds for treatment for their child with ASD:

> *when we are sick, we don't go to the doctor we just go to Dischem, buy over the counter medication because we are saving the savings for Aobakwe to be able to get his medication because it is a bit expensive, so if you misuse your savings they will be finished and without his medication he goes hyper.*

Treatment for children with ASD tends to also consist of a special school to support the child's learning of social skills. Parents reported that their child's schools have been helpful in improving their child's social and communication skills, however it has also placed a financial strain on them:

> *it's been it's been good… he in an autistic specialized school, they understand autism, they know how to help him you know become the best that he can be and it also helps me because I am also trying to help him so you all have the same goal so the school is good…it has been a big helpful and he's in a government school so it's very helpful I don't want to lie (participant 1)*

> *I think the school they have been in now; it is a government school has been very good for them… (participant 6)*

> *obviously, I told you that we took him to a school which at some point we paid about R20 000 rand a month, uhm nobody would have that kind of money and uhm all the interventions that we were doing, they were very expensive … (participant 4)*

These experiences illustrate how raising a child with ASD puts a great financial strain on parents which in return also impacts the family's quality of life and family system.

3.4 Culture and community

A diagnosis of ASD does not only affect the immediate family system but also has an impact on how the family relates with extended family and community. This subtheme captures parents' experiences of family and community reactions when they learnt about their child's diagnosis and how community cultural beliefs and norms formed part of those experiences. A great challenge that parents experienced was family not understanding their child which made them feel unsupported:

> *… with family, they don't understand it you know… I feel like they don't understand and if you don't understand my child, you won't be able to give me the support so for you to give the support, you need to understand… (participant 3)*
>
> *… from immediate family relations again, it was very difficult in the sense that they don't understand what was going on with the child and some of them just felt like you are poor at parenting, the child is not disciplined you get what I am saying uhm it was like you are not teaching the child appropriately, you are not, you know those kind of things … (participant 4)*

Another challenge parents experienced was community members saying that they are bewitched, or their child is bewitched, which seems particularly tied up with the participants being black Africans:

> *the first biggest comment I think is bewitched, oh I took somebody's husband or maybe I slept with somebody's husband, so they bewitched my womb so the first one my son is bewitched, second one my womb is bewitched, the third one is crazy (participant 1)*
>
> *I had one nanny who said she didn't know that she was coming to work with children who are demons… (participant 6)*
>
> *the stigma around my son, my neighbours not understanding my son it was just a lot (participant 5)*

Parents described these experiences as painful. Some parents believed that their families and communities were saying such things due to the lack of knowledge and understanding about ASD:

> *I think in terms of our black African culture we are not clued up in terms of ASD and stuff… it is like people are not informed, people are not clued up because like remember in the olden days if you get a child like this, it will be like wa tlhanya (he is crazy) ….*
>
> *so, I don't think that we as blacks, we are not clued up in terms of the autism until it happens to you, until it happens in your family… (participant 3)*
>
> *….. they just don't have knowledge … (participant 4)*

As a result of lack of understanding and knowledge, several parents reported that they felt that it was their responsibility to educate their families and communities about ASD while some even opened nongovernmental organisations to create a safe environment for other parents:

> *… I decided to open my own organization so it's Aobakwe Centre of autism, we haven't done any work but uhm I am doing it in Free State because I am thinking, everything is in Joburg if you go to Free State and ask about autism you will struggle maybe you will get to the suburbs and private hospitals, that's when you will hear people talking about it but ekasi nje (at townships) talking to people, you won't hear anyone saying autism (participant 2)*
>
> *I feel like I have a very huge responsibility to reach out… to the members of the community out there to say look this is what we are dealing with, when you see a child of this nature please support the family, please support you know because I have seen families broken (participant 4)*

As part of educating people about ASD many participants reported that most people found it easier to understand the disorder when they would explain their child's behaviours instead of describing what ASD is:

> *…. I realized that we had to explain it in a different way just to speak to someone that actually doesn't understand, that is not educated it is very difficult we rely on their symptoms to explain it and that's why I am one of those, even when I read it for the first time I didn't know how to explain it because when you are with all these people and*

> *you say all these things, people will say aah this guy can't even explain it … (participant 2)*

> *I would tell them that, remember some are verbal, some are non-verbal there has just been some delays in child developmental stage yeah so some maybe speech, so they delay everything, they crawl at the age of 12 months you know they differ (participant 3)*

> *…. anybody that asks me I would say it is a brain-mind disconnect … but our brains are very much connected but our bodies are failing us, that's it that's what he says and that is his explanation it is not my explanation, he says our brains are very much intact but our bodies are failing us and he says don't judge us based on our bodies, judge us based on our brain (participant 4)*

> *I always say to other parents that uhm autism is more about the behaviour and about how your child communicates and also again most of the time I just like to emphasize a lot on the sensory issues that they have because I think most parents are confused about the sensory issues …(participant 5)*

> *… so with autism … hot water like when you open the tap when you put it there your brain tells you that the water is gonna burn you neh, so with autism there is a disconnect he will, the water will still be hot but your brain will not be able to communicate with your part … there is a disconnect hence if they don't speak, their smelling, their taste and the hearing senses are heightened are more higher than how you would normally… if I were to use big words hence I say my English now is small words you know basic English and when I am talking to someone I use you know anxiety I use um you know uh I don't know how to say it in English but batho bamo imela (people are heavy for him) you know simple words so that the next person that does not know what autism is they understand it, but you win some you lose some (participant 1)*

Based on these experiences and how communities including church can be unsafe spaces for parents and their children with ASD, the most common advice that parents in the study said they would give to other parents is to love, accept, and create safe spaces for their children at home as well as to educate people around them about ASD:

> *I think acceptance is a very important thing, uhm because autism is not something that you can change or cure … (participant 4)*

> *I always tell other parents to create a safe space for your child … and creating a safe space for your child means telling people about your son's condition so that they understand ... (participant 5)*

> *I would say parents needs to love their kids unconditionally, they need to pay attention to what their kids are doing and give them time, they also have to accept, acceptance is the most important when it comes to autism…. (participant 2)*

Some parents, particularly those that live in gated communities had a different experience in that they mostly experienced others as understanding their child with ASD. Several participants shared that living with people in the middle class and those that went to university and thus had a specific level of education made their experiences better as they were more willing to learn about their child and understand their child's ASD:

> *… my neighbours, so we stay in a complex ... my neighbours are okay, the other one is a doctor, she is a paediatrician, so they were okay, like they were so supportive ... (participant 3)*

> *well fortunately uhm because we don't live in the open community and interacting with neighbours and things like that, it is just really family and friends and so on, so the child did not land into an environment where ... where everybody will talk like there in the townships, that would have been the case or in rural areas, that would have been the case… (participant 4)*

> *… I'm in the middle class you know black community where we, a lot of people in my generation started going to school ... to become your doctors, your lawyers, your accountant, your teachers whatever and it was easier to convince people in my circle than convince people who were actually from an impoverished background you know, because a lot of black people, you know, I mean like they look at something as depression as being bewitched not understanding how depression works, you know, it's bad but what can you say? It plays a big role I think the black community needs a way forward (participant 1)*

These experiences highlight how culture, socioeconomic status, and education play a significant role in how families and communities react to the participants' children's diagnosis. One parent shared how she feels like black people have lost the spirit of Ubuntu in which people would help and support each other in times of need:

> *I think people have lost that Ubuntu part of helping each other I have seen it a lot, I have been to malls where my son was just having meltdowns and people would just stare and not even ask, mommy, can we help you? (participant 5)*

All parents in the study reported that there was no existing psychology or psychiatric disorder in the family, some however said due to the lack of understanding or knowledge about psychological disorders in black communities they could have been one, but they do not know. Some parents reported that due to this lack of knowledge or previous experiences in the family it made it difficult for their families to understand their child and their ASD.

Summary of results

The pre-diagnosis period was filled with confusion for parents. They reported long waiting times and a lack of knowledge, which intensified their frustration during this phase. African traditional themes that emerged during this period was parents consulting sangomas and alternative options with the hope of getting answers to understand their child’s behaviour. Parents reported that they went this route due to the lack of knowledge about ASD. During the diagnostic phase, parents expressed feelings of helplessness and denial, leading them to seek cultural and religious interventions. However, after experiencing unsuccessful trials with these cultural methods, many found that it ultimately helped them to accept the diagnosis. For some, prayer played a significant role in coming to terms with their child having ASD. These experiences underscore the importance of religion and culture in aiding parents' acceptance of an ASD diagnosis, particularly within black African families. Additionally, during the diagnostic phase, parents shared that family members and teachers encouraged them to seek assessments for their children. One parent reported taking his son to his grandmother for assistance in getting his son’s diagnosis due to the long diagnostic period. These accounts highlight the significant role that extended family plays in the cultures of black South Africans. Frustration with healthcare professionals and the long waiting periods were common themes in parents' experiences. They also noted the positive impact of media in helping them learn more about ASD, providing a sense of community and empowerment as they navigated their child’s diagnosis.

Parents reported that raising a child with ASD significantly impacted their marriages, relationships, and careers. For those with other children, themes of overcompensating and feelings of guilt in their interactions with siblings were also evident. All six parents noted that raising a child with ASD placed a substantial financial strain on their families, which in turn affected their overall quality of life and family dynamics. Additionally, parents reflected on how community cultural beliefs and norms influenced their experiences. Some faced comments suggesting they were bewitched or that they were not disciplining their child with ASD properly due to the child's behavioural symptoms. These remarks stemmed from a lack of knowledge and understanding about ASD. As a result, parents felt it was their responsibility to educate their communities about ASD by sharing their own lived experiences.

CHAPTER 5: DISCUSSION

This study aimed to explore black South African parents’ experiences of raising a child with ASD as well as their understanding and beliefs about ASD. The study examined parents' experiences during the pre-diagnosis, diagnosis, and post-diagnosis periods. In the context of the current study, results revealed that ASD diagnosis is a complex process, and it does not exclusively occur within the medical model of disability. All six participants held cultural and religious beliefs that influenced their experiences in the three phases, particularly in accepting their children’s diagnosis. Some parents reported consulting with traditional healers and after unsuccessful attempts, it helped them accept their child’s diagnosis, while for some praying to God about it helped them to accept the diagnosis. Four participants reported that they did not know about ASD until their child was diagnosed and one reported that she consulted a sangoma and people at church with the hope of getting an understanding of what was happening to her son. Several parents reported being advised by family members to get their children assessed, while one reported that she was advised by the school principal to get her child assessed for ASD. This chapter thus comprises a detailed discussion of the results of the data.

1. Pre-diagnosis

This theme explored parents' experiences before their children were diagnosed with ASD. Parents reported this period to be difficult and confusing as they did not understand what was happening to their child. Three subthemes were generated, namely: milestones, waiting period and lack of knowledge.

1.1 Milestones

Parents are usually the first to notice early signs of mental illness and distress in their children (Saade et al., 2023). In the current study, parents reported that their children not reaching certain developmental milestones at certain ages raised a concern that there might be something wrong with their child. Several parents reported that their child met expected developmental milestones until there was a sudden change and their child stopped reaching certain milestones or regressed. This sudden change alerted them to the fact that there was something wrong with their child. Participant 1 and 5 reported that this sudden change happened when their children were about two years. These findings are consistent with research findings that children met expected developmental milestones as an infant and then lost their skills and displayed ASD symptoms after at least 2 years of normal development (APA, 2022). The pattern of onset description usually includes delays in social communication which would typically happen between 12 and 24 months (APA, 2022). Similarly in the current study, most parents reported that their child not reaching expected communication milestones was one of the first signs that alerted them to the fact that there was something wrong with their child.

1.2 Waiting period

Following their children not reaching certain milestones and regressing, parents then took their children to get assessed by a healthcare practitioner. Early diagnosis has been identified as important to minimise the impact and emotional effect the diagnosis has on parents and for early intervention for children (Bravo-Benítez et al., 2019). However, in the current study receiving early diagnosis was a challenge for parents. Parents reported that it took an average of two years before they could get a formal diagnosis of ASD. Long waiting lists tend to lead to delays in receiving a diagnosis further exacerbating the challenges that children with ASD and their families face (Aderinto et al., 2023). In the current study, parents reported that the long waiting periods also delayed school placements for their children. They described this period as stressful and painful. Due to the long waiting period to receive an ASD diagnosis, many South African children may remain undiagnosed (Guler et al., 2018).

1.3 Lack of knowledge

This sub-theme explored parents' knowledge of ASD before their children were diagnosed. The findings revealed that parents had limited understanding or knowledge about ASD before their children were diagnosed which brought about overwhelming feelings of confusion. Parents reported that they did not know about ASD, but rather knew about physical and learning disabilities. These findings are consistent with research findings that although there has been an increase in the recognition and diagnosis of ASD in developed countries, there is still a lack of awareness and knowledge about ASD in developing countries, such as SA (Campbell et al., 2018; Wallace et al., 2012).

Participant 5 reported that due to the lack of knowledge, she thought her child was 'crazy', this illustrates that although the participant was aware that there was something wrong with her child, she did not have a term to describe what was going on with her child. It further illustrates how the lack of knowledge about ASD can lead to stigmatising beliefs. This is consistent with the findings found in a scoping review by Saade et al. (2023), that stigma is often associated with the lack of understanding and knowledge about mental health conditions which may act as a barrier to seeking mental health services. In the current study, the lack of knowledge was found to be associated with delays in seeking mental health services. Participant 2 reported that his wife and her family accused him and his family of performing traditional rituals that made their son behave in an unusual manner, which was actually behavioural symptoms linked to ASD. This blame created tension and conflict in their family.

Due to the lack of knowledge and understanding, participant 1 reported that she consulted a sangoma and other alternative options with the hope that getting a cultural insight might offer an understanding of what was happening with her child and hopefully get a solution. This finding is consistent with existing literature that having a child with ASD often involves an extensive process of searching for viable decisive help (Mthombeni & Nwoye, 2018). It further shows the role of culture in helping parents when faced with the unknown and uncertainty. These results are congruent with literature that found that within the African context, cultural beliefs and attitudes towards disability as well as mental health disorders influence the diagnosis of ASD (Aderinto et al., 2023). This suggests that cultural beliefs of viewing disability as a curse or punishment may lead to families seeking alternative options as they may not see their child's behaviour as needing medical attention (Aderinto et al., 2023; Mkabile & Swartz, 2020; Schlebusch & Dada, 2018). Therefore, such cultural beliefs and practices may lead to delays in seeking medical attention as people may rely more on alternative treatments (Aderinto et al., 2023; Mosia & Tseeke, 2021). It is, however, important that mental healthcare professionals take into consideration such factors as they play such a crucial role in how parents make sense of their child's presentation. Furthermore, the results highlight the need for increased ASD awareness among the general public.

2. Diagnosis

This theme explored parents' experiences during the diagnostic phase. The theme of 'diagnosis' has been divided into three subthemes, namely: 'receiving a diagnosis', 'making sense of diagnosis' and 'cultural and religious contributions'.

2.1 Receiving a diagnosis

The diagnosis of ASD typically involves a lengthy, costly, and stressful process (Manono & Clasquin-Johson, 2023). In the study, parents reported experiencing long waiting periods before their children received a diagnosis of ASD. These extended waiting lists often lead to delayed diagnoses, which significantly contribute to inadequate treatment and exacerbate the challenges faced by children with ASD and their families (Aderinto et al., 2023). Parents expressed that these long waiting periods were stressful, particularly as they impacted school placements. Additionally, some reported frustration because some doctors were uncertain about their child's condition. These findings align with other research indicating that diagnosing ASD in Africa presents significant challenges due to a limited number of trained professionals and restricted access to resources (Aderinto et al., 2023; Wallace et al., 2012). Moreover, a consistent theme regarding ASD treatment is that early intervention yields long-term benefits for the child (McCarty & Frye, 2020). However, late identification and diagnosis can hinder access to early treatment (McCarty & Frye, 2020). Therefore, these findings underscore the urgent need for more trained professionals to ensure the early identification and diagnosis of ASD in South Africa.

Most of the parents in the study were told by either family members or teachers to get their children assessed for ASD. Two parents, participant 4 and participant 6, reported that their families told them that their children displayed signs of ASD because they were working within the healthcare sector and were therefore familiar with the disorder. While for others, their family members told them to get their child assessed as they could see that there was something wrong with their child but did not have a word for it. One parent, participant 1 reported that she was told by her son’s school principal to get her son assessed for ASD as she had a grandchild with ASD and could therefore identify some of the symptoms. These experiences highlight the role of families or communities in helping parents identify delayed developmental milestones or behaviours in their children that are outside the norm and to seek help. They are also consistent with the belief that black South Africans believe in the spirit of ubuntu which is about shared humanity and interconnectedness (Berghs, 2017). These experiences underscore the significant lack of awareness regarding ASD within black African communities. This issue is particularly pronounced among families with no background in the healthcare sector or mental health. One parent, participant 2, reported that due to his work and the long diagnostic process, he took his son to his grandmother to help them go through the diagnostic process while he was at work. These accounts illustrate the role the greater family plays in black cultures in SA and highlight the importance for greater families to also be included in the treatment plan of children with ASD.

2.2 Making sense of diagnosis

Upon receiving confirmation of an ASD diagnosis, parents experienced a range of emotions including relief, fear, disappointment, frustration, anger, resentment, and self-blame, while some parents were heartbroken. These experiences highlight how complex a diagnosis of ASD can be for parents. Although some parents reported feeling relieved, they were also overwhelmed by the lifelong implications of the ASD diagnosis. One parent, participant 6, who is raising twins, had different reactions to the diagnosis as her children were diagnosed at different times. She described the first diagnosis as a relief and the second diagnosis as hard to accept. For some parents, the diagnosis gave them hope that something could be done. The hope that parents held onto made them resilient. Similarly, in a study by Oprea and Stan (2012) that explored experiences of mothers raising children with ASD, hope was also identified as a protective factor for reducing anxiety.

Parents also reported that this period was confusing as they only learned about ASD after their child was diagnosed. Similarly, in a study by Mthimunye (2014), it was found that parents felt that they were not adequately informed about ASD, while some never heard about it until the day their child was diagnosed with ASD. Most parents in the current study reported that they used the media, particularly the internet, to educate themselves about the disorder and understand their children. In a study by Campbell et al. (2014), about one-third of their sample also reported that they learned about ASD through media outlets, while others heard about it from their family members. These experiences highlight the importance of increased ASD awareness and utilising media to educate the general public about ASD. In the current study, parents also reported that seeing public figures and celebrities who have ASD or are raising children with ASD was encouraging and helped them to accept the diagnosis. These experiences highlight the influence of media and how it gives parents a sense of control when they are faced with the unknown and helps them not to feel alone as well as feel empowered with regards to receiving an ASD diagnosis for their child (Ammari & Schoenebeck, 2015). Healthcare professionals, except those that were family members, were not identified as sources of information. This further speaks to the importance of utilising other methods aside from traditional materials to educate the public about ASD.

Parents in the study acknowledged experiencing emotions related to grief and accepting that they will not be able to do some things that they would have loved to do with their child. One parent, participant 6, described it as the *"constant grief that you carry"*. These findings are also consistent with previous studies on how a diagnosis of ASD in the family is often associated with feelings of grief (Bravo-Benítez et al., 2019; Krishnan et al., 2017). However, while families are dealing with these feelings of loss, applying traditional models of grief is often difficult to apply to this kind of loss as they are grieving their idealised child (Bravo-Benítez et al., 2019). Thus, it is important that when working with children with ASD there are programs that are aimed at helping families process their feelings of loss. It should also be noted that receiving the diagnosis of ASD was also empowering for parents as it provided them with answers and gave them hope that something could be done (Manono & Clasquin-Johson, 2023; Oprea & Stan, 2012).

2.3 Cultural and religious contributions

Parents in the study reported that they relied on religious and cultural practices such as praying and consulting spiritual leaders including traditional healers to seek answers for their child's diagnosis. Parents chose this route out of feeling helpless and being in denial of their child's diagnosis. However, after failed trials with cultural interventions, it helped them to accept the diagnosis, while some parents' prayer helped them to accept that their child has ASD. Similarly, in a study by Shilubane and Mazibuko (2020), parents reported that prayer helped them accept their children's diagnosis of ASD. Previous studies have found that cultural interventions influence intervention compliance and can sometimes lead to late or underdiagnosis of ASD (Adams et al., 2020; Mandell & Novak, 2005; Mosia & Tseeke, 2021). The findings in the current study revealed that cultural and religious interventions also helped parents in accepting their child's diagnosis. Thus, it is important that when working with families raising children with ASD, healthcare professionals also consider their cultural beliefs as they tend to influence treatment compliance.

3. Post-diagnosis

This theme explored parents' experiences after their children were diagnosed with ASD and four subthemes emerged, namely: 'family dynamics', 'interpersonal relationships', 'financial difficulties' and 'culture and community'.

3.1 Family dynamics

The results of this study provided support to existing literature that raising a child with ASD deeply impacts the family system, routines, and parents' aspirations (De Clercq et al., 2022; Ooi et al., 2022; Woodgate et al., 2015). Parents in the current study reported that these changes brought tension in the family. This finding is consistent with existing literature that receiving a diagnosis of ASD in the family often puts strain on family relationships (Mcstay et al., 2015; Reddy et al., 2019). The strength of the relationship between family members and the strength of the marital relationship has been identified as important forms of support to families raising children with ASD (McStay et al., 2015), however, in the current study, parents reported that receiving a diagnosis of ASD put a strain on their relationships. For some participants, receiving a diagnosis led to relationship breakups which further made their experience stressful. One participant, parent 2, reported that his wife accused him and his family of performing traditional ritual to their child that made him behave unusually. However, after processing and accepting their child’s diagnosis it helped them get along and they reported that their child is the reason they would never get divorced out of fear that other people may not understand their son. These experiences highlight how a diagnosis of ASD can be complex. One parent, participant 1, described that although she decided to break up with the father of her son, it has been emotionally straining to raise her child as a single parent. This finding is consistent with research studies that spousal support is an important form of support particularly for families raising children with disabilities (McStay et al., 2015).

Black African men often pride themselves in being the leader of the family and that in times of adversity, they need to be strong for their families and although they may be experiencing emotional distress, they tend not to share that with their spouses (Masemola et al., 2022). One parent, participant 4, described how she and her husband dealt with the diagnosis differently, she was talking about it, but her husband found solace in alcohol. This finding highlights the importance of understanding gender roles within black African families particularly when working with parents raising children with ASD since men and women within different cultures may deal with their child’s diagnosis differently which can further put a strain on the spousal relationship. In addition to spousal relationships, a diagnosis of ASD within the family can also put a strain on parents’ relationship with typically developing siblings (Reddy et al., 2019). The theme of overcompensating and guilt were evident in how parents felt and related with their other children in the current study.

3.2 Interpersonal relationships

Parents’ challenges with raising a child with ASD are often associated with adverse psychosocial impacts due to the lack of social support, being judged by others, personal distress, and their perceptions of loss (Manono & Clasquin-Johson, 2023). Parents in the current study reported that raising a child with ASD significantly affected their social relations as some lost friends while others became withdrawn in their friendships as they felt misunderstood and not supported by their friends. Similarly, in a study by Martins et al. (2013), it was found that fathers of children with ASD expressed that parenting their child negatively affected their social lives, relationships with their spouses, and how they view themselves as fathers which may contribute significantly to their stress. These results highlight the need for increased awareness in communities as the lack of ASD awareness also limits parents' support systems. Support received from family, peers, and school has been found to play a crucial role in assisting parents cope with the challenges that are associated with caring for a child with ASD (Shilubane & Mazibuko, 2020).

Social support has been identified as a protective factor against the parenting stress of raising a child with ASD and helpful in assisting parents adjust psychologically to their child's diagnosis (Shepherd et al., 2020). In addition, social support systems can be helpful in mitigating the negative impacts raising a child with ASD has on parents (Shepherd et al., 2020). Several parents in the current study reported that being part of support groups with parents who were also raising children with ASD was helpful and encouraging. It made them feel like they were not alone since they had people they could relate to and who could understand them.

Social media or social network sites have been found to provide a user-friendly platform that parents use to seek advice or support 24 hours a day (Shepherd et al., 2020). This means that parents receive multiple perspectives from different sources which can also result in incorrect information being shared thus there is a need for increased awareness of ASD. Parents in the current study used WhatsApp support groups for emotional support and to also share their experiences of raising a child with ASD. These findings are consistent with other research studies that parents rated social media as the highest provider of emotional support, as well as a better reliever of parenting stress than formal sources of support (Abel et al., 2019; Shepherd et al., 2020). Furthermore, the findings from the current study also revealed that participants relied more on informal sources of support. The study did not investigate reasons for this however it found that relying on this kind of support was important to help parents cope with the everyday demands of raising a child with ASD most especially when there is limited access to treatment (Shepherd et al., 2020). One parent, participant 4, in the current study shared how although she had support from her family, not being part of a support group of parents experiencing similar challenges to her was difficult and isolating.

3.3 Financial challenges

Financial difficulties were expressed in all the interviews. Parents expressed the varied treatments their children need which leaves them with the financial strain that they must bear. Parents reported that their children tend to be selective with regards to the food they want to eat. In addition, the therapy sessions that they need are expensive, and oftentimes parents then need to pay the difference when medical aid funds get exhausted. These findings are consistent with existing studies, suggesting that raising a child with ASD is associated with a financial burden (Aderinto et al., 2023; Eapen et al., 2014; Genovese & Butler, 2020; Guler et al., 2018;

Schlebusch & Dada, 2018). One parent, participant 2, shared that they also had to adjust as a family and try not to consult but rather get over-the-counter medication when they are sick so that they can save the medical aid funds for their ASD child's treatment. This highlights how a child's diagnosis of ASD affects the whole family system. In a study by Mazibuko et al. (2020), participants shared that children with ASD have a lot of financial needs and sometimes they are unable to cover all the costs. Similarly, in the current study, one parent, participant 6, shared that because of the financial challenges they need to bear, sometimes parents may feel like a failure when they cannot afford to do some things they want to do for their children. This reveals that raising a child with ASD and the financial burden it has on parents can impact parents' wellbeing and sense of self. These findings support research findings that involving parents in the treatment delivery of their children with ASD may reduce financial burden and human resource barriers to evidence-based treatment in low-resource countries such as SA (Guler et al., 2018).

3.4 Culture and community

A diagnosis of ASD does not only affect the immediate family system but also has an impact on how the family relates with extended family and community. Family reactions regarding the child's diagnosis have been identified as one of the major factors that contribute to the long-term emotional wellbeing of parents raising a child with ASD (Manono & Clasquin-Johnson, 2023). In the current study, the most common challenge that parents experienced when their communities and extended family members learned about their child's diagnosis was the family not understanding their child which made them feel unsupported which further increased their stress levels. One parent, participant 4, reported that her family members felt she was not disciplining her child which affected her sense of self as a parent. Parents reported that they felt their families were not supportive because they lacked knowledge about ASD. These findings thus highlight the importance of increased ASD awareness within communities. Increased understanding of ASD among community members can also lead to increased support for parents and families raising children with ASD. Research has found that support received from family can enhance the emotional wellbeing of parents of children with ASD (Shilubane & Mazibuko, 2020).

Another challenge that parents in the study experienced as a result of the lack of knowledge about ASD is that community members would say they are bewitched. Similarly in a study by Guler et al. (2018), one participant reflected on how her mother as well as other women in her community discouraged her son from getting a diagnosis of ASD as they believed the son was trapped in evil spirits that needed to be released through traditional practices which left her feeling confused. Although parents in the current study believed that their families were saying such things due to the lack of knowledge and understanding about ASD, they described these experiences as painful which further increased their stress levels. These findings show how such cultural beliefs and lack of knowledge can lead to discriminatory and stigmatising behaviours leading to parents being isolated and shamed (Aderinto et al., 2023). Thus, there is a need for increased ASD awareness, particularly in a country like SA with so many varied cultural and racial groups.

As a result of the lack of understanding and knowledge, several parents in the current study reported that they felt that it was their responsibility to educate their families and communities about ASD. Similarly in a study by Smith-Young et al. (2022), parents viewed advocacy as a moral obligation or expectation while some parents used it a coping strategy to help them come to terms with their child's diagnosis. In the current study, advocacy was used to raise ASD awareness by sharing their stories as well as providing support for parents experiencing similar challenges. As part of educating people about ASD, many of the parents reported that most people found it easier to understand the disorder when they explained their child's behaviours instead of describing what ASD is. This finding highlights the importance of involving parents as part of the treatment plan and when educating others about ASD and using language that is easily accessible to community members when educating them about ASD. Based on these experiences and how communities including church can be unsafe spaces for parents and their children, the most common advice that parents in the study said they would give to other parents is to love, accept, and create safe spaces for their children at home as well as to educate people around them about ASD.

Some parents, particularly those that live in gated communities such as complexes had a different experience in that they mostly experienced others as understanding their child with ASD. Several participants shared that living with people in the middle class and those who went to university and thus had a specific level of education made their experiences better as they were more willing to learn about their child and understand (Sharabi & Marom-Golan, 2018). These findings highlight how different factors such as educational level and socioeconomic status play a role in how people understand and make sense of mental and neurodevelopmental health. They further highlight the need for increased ASD awareness, particularly in less advantaged communities.

CHAPTER 6: CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

Autism spectrum disorder (ASD) is increasingly becoming a public health concern in developing countries (Pillay et al., 2022; Woodgate et al., 2015). The results from the current study revealed that the lack of knowledge about ASD remains a challenge towards early identification and management of ASD in SA. Four parents in the current study reported that they did not know about ASD until their child was diagnosed, which delayed their decision to seek intervention. Furthermore, consistent with existing literature adequate services for children with ASD, and their parents in developing countries still remains a challenge (Aderinto et al., 2023; Wallace et al., 2012). In the current study long waiting periods at public hospitals was a prominent experience of parents during the pre-diagnosis period. Consequently, some parents sought help from traditional healers and churches with the hope of gaining an understanding of what was happening to their children. The lack of knowledge about ASD influenced parents' experiences through the pre diagnosis, diagnosis, and post diagnosis phase. In addition, healthcare professionals, except those that were family members, were not identified as sources of information. Parents reported using social media for education about ASD, highlighting the need for increased awareness to prevent the dissemination of false information. The findings also emphasized the importance of families and communities in helping parents recognize delayed developmental milestones or behaviours that deviate from the norm and encouraging them to seek assistance. This aligns with the belief among many Black South Africans in the concept of ubuntu, which highlights the role of extended family members within African communities (Berghs, 2017).

Consistent with existing literature (Krishnan et al., 2017; Martins et al., 2013), parents in the study reported that raising a child with ASD significantly impacted their interpersonal relationships. Some parents separated from their partners, while those who remained married experienced changes in their relationship dynamics. A recurring theme was that men felt the need to be strong for their families, highlighting the importance of understanding gender roles within African families. This understanding is particularly relevant when working with parents raising children with ASD, as men and women from different cultures may respond differently to their child's diagnosis. These differences can further strain spousal relationships. Additionally, all parents in the study reported experiencing financial strain associated with raising a child with ASD.

LIMITATIONS OF THE STUDY

The findings of this study cannot be generalized due to the small sample size and the qualitative nature of the research. Furthermore, all participants were from the same geographical area, which means that the results may not represent the experiences of all parents raising children with ASD, particularly those living in less advantaged communities. Additionally, all participants were recruited from a single social media support group, increasing the likelihood that the parents in the group shared similar feelings. Another limitation is the lack of gender diversity among participants, as there was only one father involved. If more fathers had participated, their insights could have broadened the research findings, especially regarding gender roles within Black African families and how these roles influence the experiences of different genders in raising a child with ASD.

RECOMMENDATIONS

Future research should attempt to explore possible gender differences with regards to parenting a child with ASD. Additionally, there is a need for more research studies to be conducted more especially in less advantaged communities to gain more understanding on how black African parents in disadvantaged communities experience raising a child with ASD as well as factors that may hinder their access to ASD treatment services.

CLINICAL IMPLICATIONS

The results of this study highlight the need for increased ASD awareness particularly among black South African communities. Psychoeducation for black South African parents including their greater family members may be useful in helping parents feel empowered as well as in counteracting the existing misconceptions about ASD that are held in black South African communities. Additionally, it will also be useful in reducing the stigma, enhance support systems for parents, improve the effectiveness of ASD treatments, and alleviate financial barriers to accessing support. Parents in the study also shared feelings of grief and the impact raising a child with ASD had on their interpersonal relations. This highlights the necessity for greater care and support from healthcare professionals to help parents process their child's diagnosis. Additionally, it is crucial for healthcare professionals working with black South African families to explore and understand what an ASD diagnosis means to these parents and their families, as this understanding significantly influences their overall experience in raising a child with ASD. The study also revealed a pressing need for more healthcare professionals specialising in ASD in South Africa.

REFERENCES

Abel, S., Machin, T., & Brownlow, C. (2019). Support, socialise and advocate: An exploration of the stated purposes of Facebook autism groups. *Research in autism spectrum disorders*, *61*,10-21. https://doi.org/10.1016/j.rasd.2019.01.009

Adams, S. N., Verachia, R., & Coutts, K. (2020). A blender without the lid on': Mealtime experiences of caregivers with a child with autism spectrum disorder in South Africa. *South African Journal of Communication Disorders*, *67*(1), 1-9. http://dx.doi.org/10.4102/sajcd.v67i1.708

Aderinto, N., Olatunji, D., & Idowu, O. (2023). Autism in Africa: prevalence, diagnosis, treatment and the impact of social and cultural factors on families and caregivers: a review. *Annals of Medicine and Surgery*, *85* (9), 4410-4416. https://doi.org/10.1097/MS9.0000000000001107

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). American Psychiatric Publishing. https://doi.org/10.1176/appi.books.9780890425787

Ammari, T., & Schoenebeck, S. (2015, April). Networked empowerment on Facebook groups for parents of children with special needs. In *Proceedings of the 33rd annual ACM conference on human factors in computing systems* (pp. 2805-2814).http://dx.doi.org/10.1145/2702123.2702324

Berghs, M. (2017). Practices and discourses of ubuntu: Implications for an African model of disability?. *African Journal of Disability*, *6*(1), 1-8.

Boss, P. (1999). Ambiguous loss research, theory, and practice: Reflections after 9/11. *Journal of Marriage Family*, *66*,551-566. https://doi.org/10.1111/j.0022-2445.2004.00037.x

Boushey, A. (2001). The grief cycle: One parent’s trip around. *Focus on Autism & other Developmental Disabilities*,*16* (1), 27-30.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braun, V. & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners.* London : Sage.

Bravo-Benítez, J., Pérez-Marfil, M. N., Román-Alegre, B., & Cruz-Quintana, F. (2019). Grief experiences in family caregivers of children with autism spectrum disorder (ASD). *International journal of environmental research and public health*, *16* (23),1-18. https://doi.org/10.3390/ijerph16234821

Bruce, E. J. & Schultz, C. L. (2001). Nonfinite loss and grief: A psychoeducational approach. *Family Therapy*, *29* (3), 183

Byrne, D. (2022). A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality & quantity*, *56*(3),1391-1412. https://doi.org/10.1007/s11135-021-01182-y

Catalano, D., Holloway, L., & Mpofu, E. (2018). Mental health interventions for parent carers of children with autistic spectrum disorder: Practice guidelines from a critical interpretive synthesis (CIS) systematic review. *International journal of environmental research and public health*, *15*(2),1 - 23. https://doi.org/10.3390/ijerph15020341

Campbell, J.M., Greenberg, D., Gallagher, P.A., Stoneman, Z., Simmons, C. (2018). Knowledge of autism for parents of low income with low literacy: description and relationship to child development knowledge. *Advances in Neurodevelopmental Disorders*, *3*, 1 – 16. https://doi.org/10.1007/s41252-018-0079-z

De Clercq, L. E., Prinzie, P., Swerts, C., Ortibus, E., & De Pauw, S. S. (2022). "Tell Me About Your Child, The Relationship with Your Child and Your Parental Experiences": A Qualitative Study of Spontaneous Speech Samples Among Parents Raising a Child with and without Autism Spectrum Disorder, Cerebral Palsy or Down Syndrome. *Journal of Developmental and Physical Disabilities*, *34*(2),95 - 329.

Eapen, V., Črnčec, R., Walter, A., & Tay, K. P. (2014). Conceptualisation and development of a quality of life measure for parents of children with autism spectrum disorder. *Autism research and treatment*, *2014*,1 – 1. https://doi.org/10.1155/2014/160783

Fewster, D. L., Uys, C., & Govender, P. (2020). Interventions for Primary Caregivers of Children with Autism Spectrum Disorder: A cross-sectional study of current practices of stakeholders in South Africa. *South African Journal of Occupational Therapy*, *50*(1), 41 - 48. http://dx.doi.org/10.17159/2310-3833/2020/vol50no1a7

Genovese, A., & Butler, M. G. (2020). Clinical assessment, genetics, and treatment approaches in autism spectrum disorder (ASD). *International journal of molecular sciences*, *21*(13), 4726 - 4743. https://doi.org/10.3390/ijms21134726

Geiselhart, K. (2018). Reasoning matters: Transrational traits of healing in competing medical epistemes in Botswana. *South African Journal of Philosophy*, *37*(2), 178-192. https://doi.org/10.1080/02580136.2018.1443775

Guler, J., de Vries, P. J., Seris, N., Shabalala, N., & Franz, L. (2018). The importance of context in early autism intervention: A qualitative South African study. *Autism*, *22*(8), 1005–1017. https://doi.org/10.1177/1362361317716604

Krishnan, R., Russell, P.S.S. & Russell, S. (2017). "A Focus Group Study to Explore Grief experiences among Parents of Children with Autism Spectrum Disorder". *Journal of the Indian Academy of Applied Psychology*, *43* (2), 267-275.

Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental retardation and developmental disabilities research reviews*, *11*(2), 110-115. https://doi.org/10.1002/mrdd.20061

Manono, M. N., & Clasquin-Johnson, M. G. (2023). 'Yebo, it was a great relief': How mothers experience their children's autism diagnoses'. *African Journal of Disability*, *12*, 1-10.

Martins, C. D., Walker, S. P., & Fouché, P. (2013). Fathering a child with autism spectrum disorder: An interpretative phenomenological analysis. *Indo-pacific journal of phenomenology*,*13*(1), 1- 19. https://doi.org/10.2989/IPJP.2013.13.1.5.1171

Masemola, H. C., Moodley, S. V., & Shirinde, J. (2022). Perceptions and attitudes of black men in a rural district of South Africa towards depression and its treatment. *South African Family Practice*, *64*(1), 5557. https://doi.org/10.4102/safp.v64i1.5557

McCarty, P., & Frye, R. E. (2020). Early detection and diagnosis of autism spectrum disorder: why is it so difficult? *In Seminars in Pediatric Neurology*, *13*,1 -7. https://doi.org/10.1016/j.spen.2020.100831

McStay, R., Trembath, D. & Dissanayake, C. (2015). Raising a Child with Autism: A Developmental Perspective on Family Adaptation. *Current Developmental Disorders Rep*, *2*, 65–83. https://doi.org/10.1007/s40474-014-0037-z

Mereoiu, M., Bland, C., Dobbins, N., & Niemeyer, J. A. (2015). Exploring perspectives on child care with families of children with autism. *Early Childhood Research & Practice*, *17*(1),1-13.

Merriam, S., & Tisdell, J.E. (2016). *Qualitative Research: A Guide to Design and Implementation (*4th ed.*)*. Jossey-Bass.

Mithimunye, B. S., Roman, N. V., & Pedro, A. S. (2018). Factors Which Enhance or Hinder Meeting the Educational Needs of Autistic Children in Western Cape Province, South Africa: A Parents' Perspective. *International Journal of Special Education*, *33*(2), 279-294.

Mkabile, S., & Swartz, L. (2020). 'I waited for it until forever': Community barriers to accessing intellectual disability services for children and their families in Cape Town, South Africa. *International journal of environmental research and public health*, *17*(22), 1-13. https://doi.org/10.3390/ijerph17228504

Mosia, P. A., & Tseeke, M. (2021). Explaining parents' experiences of raising children with autism spectrum disorders in Lesotho. *African Identities*, *22*(2),307–322. https://doi.org/10.1080/14725843.2021.2018990

Mthombeni, Z. C., & Nwoye, A. (2018). Black South African caregivers' understanding and responses to their children with autism spectrum disorder symptoms: A qualitative study. *South African Journal of Psychology*, *48*(1), 99-111. https://doi.org/10.1177/0081246317696453

Mudau, T. J., & Obadire, O. S. (2017). The role of patriarchy in family settings and its implications to girls and women in South Africa. *Journal of Human Ecology*, *58*(1-2) 67-72. https://doi.org/10.1080/09709274.2017.1305614

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social casework*, 43 (4),190-193. https://doi.org/10.1177/1044389462043004

Omona, J. (2013). Sampling in qualitative research: Improving the quality of research outcomes in higher education. *Makerere Journal of Higher Education*, *4*(2),169-185. https://doi.org/10.4314/majohe.v4i2.4

Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric disease and treatment*, *12*,745-762. https://doi.org/10.2147/NDT.S100634

Oprea, C., & Stan, A. (2012). Mothers of autistic children. How do they feel?. *Procedia-Social and Behavioral Sciences*, *46*, 4191-4194. https://doi.org/10.1016/j.sbspro.2012.06.224

Osterling, J., Dawson, G. (1994). Early recognition of children with autism: A study of first birthday home videotapes. *Journal of Autism Developmental Disorders*, *24*,247–257. https://doi.org/10.1007/BF02172225

Palmer, M., & Harley, D. (2012). Models and measurement in disability: an international review. *Health Policy and Planning*,*27* (5), 357-364. https://doi.org/10.1093/heapol/czr047

Pillay, S., Duncan, M., & de Vries, P. J. (2022). 'We are doing damage control': Government stakeholder perspectives of educational and other services for children with autism spectrum disorder in South Africa. *Autism*,*0*, 1-11. https://doi.org/10.1177/13623613221142111

Reddy, G., Fewster, D. L., & Gurayah, T. (2019). Parents' voices: experiences and coping as a parent of a child with autism spectrum disorder. *South African Journal of Occupational Therapy*, *49* (1), 43-50. http://dx.doi.org/10.17159/2310-3833/2019/vol49n1a7

Reichman, N.E., Corman, H. & Noonan, K. (2008). Impact of Child Disability on the Family. *Maternal and child health journal*, *12*,679–683. https://doi.org/10.1007/s10995-007-0307-z

Saade, S., Lamarche, A.P., Khalaf, T., Makke, S., Legg, A. (2023). What barriers could impede access to mental health services for children and adolescents in Africa? A scoping review. *BMC Health Services Research*, *23* (348) 1-6. https://doi.org/10.1186/s12913-023-09294-x

Sandelowski, M. (1993). Rigor or rigor mortis: the problem of rigor in qualitative research. *Advances in nursing science*, *16* (2), 1-8.

Schlebusch, L., & Dada, S. (2018). Positive and negative cognitive appraisal of the impact of children with autism spectrum disorder on the family. Research in Autism Spectrum Disorders, 51, 86-93. https://doi.org/10.1016/j.rasd.2018.04.005

Sharabi, A., & Marom-Golan, D. (2018). Social Support, Education Levels, and Parents' Involvement: A Comparison Between Mothers and Fathers of Young Children With Autism Spectrum Disorder. *Topics in Early Childhood Special Education*, *38*(1), 54-64. https://doi.org/10.1177/0271121418762511

Shepherd, D., Goedeke, S., Landon, J., & Meads, J. (2020). The types and functions of social supports used by parents caring for a child with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *50*,1337-1352.https://doi.org/10.1007/s10803-019-04359-5

Shilubane, H., & Mazibuko, N. (2020). Understanding autism spectrum disorder and coping mechanism by parents: An explorative study. *International journal of nursing sciences*, 7 (4), 413-418.https://doi.org/10.1016/j.ijnss.2020.08.003

Springer, P. E., Van Toorn, R., Laughton, B., & Kidd, M. (2013). Characteristics of children with pervasive developmental disorders attending a developmental clinic in the Western Cape Province, South Africa. *South African Journal of Child Health*, *7* (3),95 - 99. https://doi.org/https://hdl.handle.net/10520/EJC141485

Smith-Young, J., Chafe, R., Audas, R., & Gustafson D, L. (2022). "I Know How to Advocate": Parents' Experiences in Advocating for Children and Youth Diagnosed With Autism Spectrum Disorder. *Health Services Insights,15*, 1-11. https://doi.org/10.1177/11786329221078803

Teel, C.S. (1991). Chronic sorrow: analysis of the concept. *Journal of Advanced Nursing*, *16*,1311-1319.

Vidal, V., Urra, P., Diez, M. F. C., León, C. B., Alarcón, M. C. R., & Cortés, J. P. (2024). Revealing conflicting ideologies: A critical discourse analysis of autism terminology in academic journals. *Topics in Language Disorders*, *44*(1),5-24.

Viviers, M., Jongh, M., Dickonson, L., Malan, R., & Pike, T. (2020). Parent-reported feeding and swallowing difficulties of children with Autism Spectrum Disorders (aged 3 to 5 years) compared to typically developing peers: A South African study. *African Health Sciences*, *20* (1), 524 - 532. https://doi.org/10.4314/ahs.v20i1.59

Wallace, S., Fein, D., Rosanoff, M., Dawson, G., Hossain, S., Brennan, L., Como, A & Shih, A. (2012). A global public health strategy for autism spectrum disorders. *Autism Research*, *5* (3),211-217. https://doi.org/10.1002/aur.1236

Wetherston, V., Gangat, S., Shange, N., Wheeler, K., Karrim, S. S., & Pahl, J. (2017). The views and knowledge of parents of children with autism spectrum disorder on a range of treatments. *South African Journal of Child Health*, *11* (3),117-121. https://doi.org/10.7196/SAJCH.2017.v11i3.1274

Wilford, A. (2013). Cultural variations in behaviours related to ASD in South African children. *Human Sciences Research Council Conference* (pp. 1 - 15). Boksburg: Human Sciences Research Council.

Willig, C. (2013). *introducing qualitative research in psychology*. UK: McGraw-hill education.

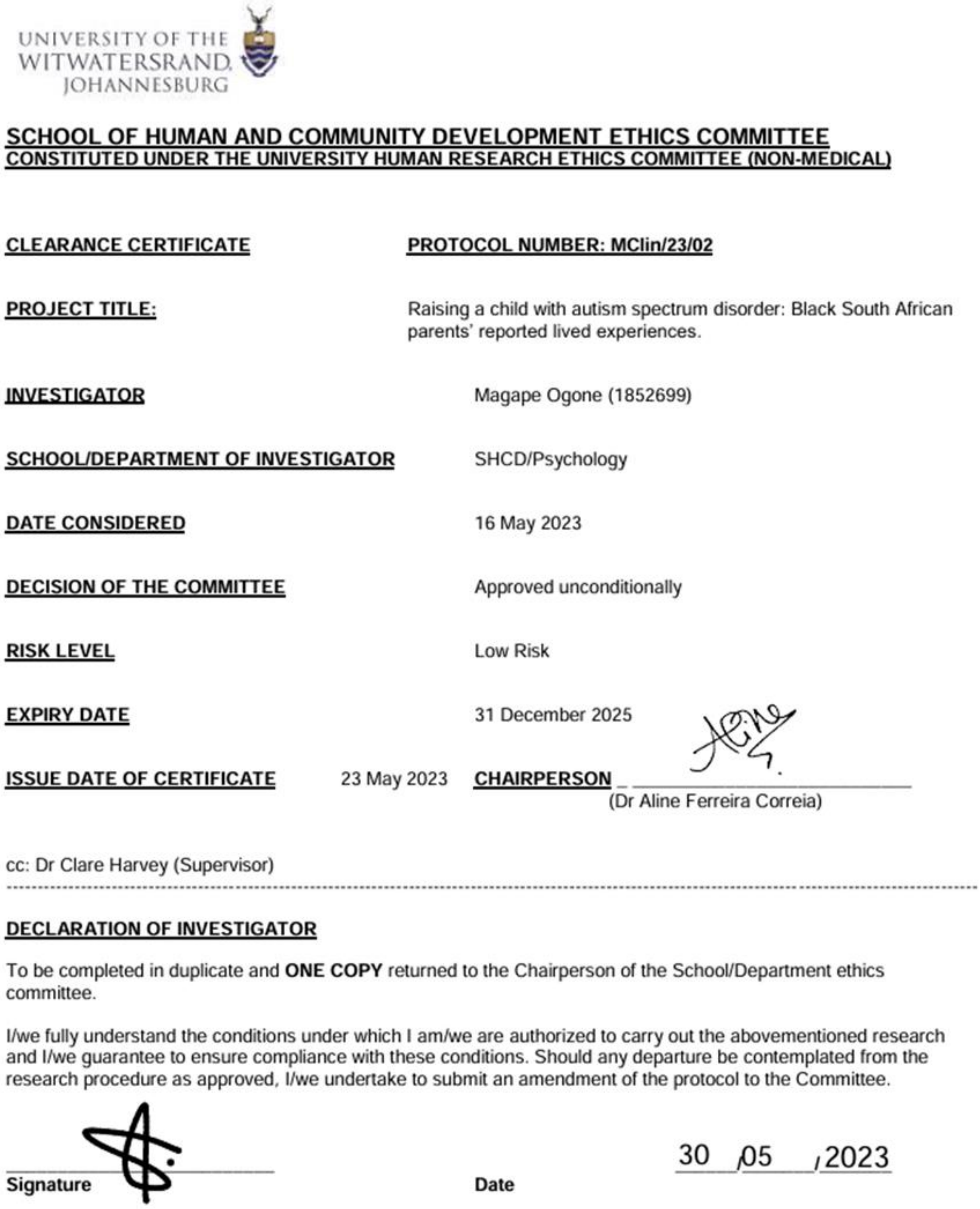
Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B., & Rempel, G. (2015). Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. *BioMed Central pediatrics*, *15*,1-15. https://doi.org/10.1186/s12887-015-0514-5

World Health Organization. (2021). *WHO Policy on disability* [policy brief]. https://www.who.int/about/policies/disability

World Health Organization (19 -24 May 2014). *Sixty-seven world health assembly* [Paper presentation]. Geneva.

Yoon, S. H., Choi, J., Lee, W. J., & Do, J. T. (2020). Genetic and epigenetic etiology underlying autism spectrum disorder. *Journal of clinical medicine, 9* (4),966-992. https://doi.org/10.3390/jcm9040966

Appendix A: Ethics Certificate



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT ETHICS COMMITTEE
CONSTITUTED UNDER THE UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)

CLEARANCE CERTIFICATE **PROTOCOL NUMBER: MClin/23/02**

PROJECT TITLE: Raising a child with autism spectrum disorder: Black South African parents' reported lived experiences.

INVESTIGATOR Magape Ogone (1852699)

SCHOOL/DEPARTMENT OF INVESTIGATOR SHCD/Psychology

DATE CONSIDERED 16 May 2023

DECISION OF THE COMMITTEE Approved unconditionally

RISK LEVEL Low Risk

EXPIRY DATE 31 December 2025

ISSUE DATE OF CERTIFICATE 23 May 2023 **CHAIRPERSON** _ __________________________
(Dr Aline Ferreira Correia)

cc: Dr Clare Harvey (Supervisor)

DECLARATION OF INVESTIGATOR

To be completed in duplicate and **ONE COPY** returned to the Chairperson of the School/Department ethics committee.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved, I/we undertake to submit an amendment of the protocol to the Committee.

____
Signature

Date 30 /05 /2023

Appendix B: Interview schedule

Demographic questions

1. How old is your child with autism spectrum disorder?

2. What is the gender of your child with autism spectrum disorder?

3. How would you describe the level of severity of your child's autism spectrum disorder?

4. Who diagnosed your child with autism spectrum disorder?

5. Do you have other children? If so, how many?

6. What is your current employment status?

7. Do you have access to public or private intervention facilities for your child with autism spectrum disorder?

8. What is your current relationship status?

9. what is your ethnicity?

Possible interview questions

1. What are some behaviours that you noticed that prompted you to have your chid screened/assessed for autism spectrum disorder?

2. How old was your child when he/she was diagnosed with autism spectrum disorder?

   a. What was your response/reaction to his/her diagnosis?

   b. What thoughts/feelings did you experience after the diagnosis of your child?

3. When your child was diagnosed with autism spectrum disorder, what did you understand about this diagnosis?

   a. Did you know about autism spectrum disorder before the diagnosis?

   b. How did you learn more about autism spectrum disorder?

4. What has been some challenges in raising your child with autism spectrum disorder?

   a. Please elaborate.

5. How has parenting your other children (if any) while still providing additional support for your child with autism spectrum disorder been?

6. Is there already diagnosis of autism spectrum disorder or another psychological or psychiatric disorder within the family? How has this been in comparison to your own experience?

   a. When family members learnt that your child has autism spectrum disorder what were their reactions? How was that experience for you?
   b. And when community members learnt that your child has autism spectrum disorder what were their reactions (comments/opinions)? How was that experience for you?

7. Were there any specific autism spectrum disorder programs or support systems that you use/d to help you in raising your child?

   a. How did you experience having/not having support programs or systems?

8. Has raising a child with autism spectrum disorder affected your relationship with your spouse/partner (if applicable)?

   a. Please elaborate.
   b. What about your social relations?

9. Did you experience any financial difficulties in raising your child with autism spectrum disorder?

   a. Can you elaborate on some of those difficulties if you feel comfortable?
   b. What would have helped you in this regard?

10. Is your child currently in school/preschool?

   a. How has this experience been for your child?
   b. How has this been for you?

11. How would you describe autism spectrum disorder to someone who does not know or understand the disorder?

12. What advice would you give to other parents who are raising a child with autism spectrum disorder?

13. Has raising a child with autism spectrum disorder taught you anything about yourself that you were not aware of?

  a. Please elaborate.

14. What has been some of the rewarding experiences in raising your child with autism spectrum disorder?

15. What role do you feel your black African race and culture plays in raising your child with autism spectrum disorder?

a. How do you think black parents experience autism spectrum disorder treatment services in South Africa?

16. Is there anything else that I did not ask, and you would like to add/discuss?

Debrief questions

1. How did you experience this interview?

2. Did the interview bring up any emotions that you would like to talk about?

    a. Would you like to talk more about these feelings in a counselling setting? (if difficult emotions seems to have been triggered by the interview)

    b. Would you like for me to help you in arranging counselling for yourself?

3. Is there anything else that you would like to discuss?

4. Are you okay for us to end the interview now?

Appendix C: Letter of invitation

A CLINICAL PSYCHOLOGY
MASTES STUDY

RESEARCH PARTICIPATION
NEEDED

AUTISM SPECTRUM DISORDER

BLACK SOUTH AFRICAN PARENTS' EXPERIENCES

Are you a black South African parent raising a child with autism spectrum disoder?

Share your experience of raising a child with autism spectrum disorder, in a 60-90 minutes in-person (preferably)/ online interview

What is autism spectrum disorder:
Autism spectrum disorder is a lifelong neurodevelopmental disorder which is characterised by impairments in social settings, non-verbal and verbal communication deficits, and stereotypical repetitive behaviours

for more information, contact Ogone Magape (the researcher) at
ogonemagape@gmail.com
067 902 7372

Appendix D: The participant information sheet

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
PSYCHOLOGY

Participant Information Sheet

Raising a child with autism spectrum disorder: Black South African parents' reported lived experiences

Dear Sir/Madam,

My name is Ogone Magape, and I am a masters student in Clinical Psychology at the University of the Witwatersrand, Johannesburg. As part of my degree, I am conducting a research project under the supervision of Dr Clare Harvey, exploring black South African parents' experiences of raising a child with autism spectrum disorder.

I want to find out about your experiences raising a child with autism spectrum disorder, how you have understood and made sense of these experiences. Autism spectrum disorder is a lifelong neurodevelopmental disorder which is characterised by impairments in social settings, non-verbal and verbal communication deficits, and stereotypical repetitive behaviours (American Psychiatric Association (APA), 2013). This research is being conducted so that the experiences of black South African parents raising a child with autism spectrum disorder can be better understood as parents form part of the holistic management of the child.

I would like to invite you to be a part in my research study. Participation in the study is completely voluntary and there are no foreseen benefits or incentives that will be received for participating in the study. Participating in the study may however contribute to literature and help clinicians better understand parents' lived experiences and hopefully help in developing effective interventions aimed at improving the mental health and overall wellbeing of the parents. Participation involves an individual in person (preferably), or online interview that will approximately last 60-90 minutes. Interviews will be arranged at a time and place that is convenient for participants. For online interviews, these will be conducted via Microsoft Teams or Zoom. The interview involves answering questions about your experience raising a child with autism spectrum disorder. During the process of the interview, if there are any questions that you find difficult or uncomfortable to answer you will be allowed to refrain from answering them, without any negative consequences. Furthermore, if you want to withdraw from the study any time before data collection ends you are free and allowed to do so, without facing any negative consequences. You are also welcome to not answer any questions you wish to.

Before participating in the study, a consent form will be sent to you which I require you to sign. Furthermore, the interviews will be audio recorded for data analysis purposes, therefore your consent to audio record the interview is also required. A consent form is a form which provides your agreement and understanding that participating is fully voluntary, and you give me permission to interview you and record the interview, as well as use information provided for data analysis and final write up of the study. Only myself and the specific participant will have access to the meeting link to ensure confidentiality. During the interview I will be alone in a private place to ensure and protect your confidentiality. For in person interviews, these will be conducted in a secluded place and only myself and the specific participant will be in the room. The recordings will be password protected and only I will have access to them. The recordings will be transcribed verbatim for data analysis purposes, the transcribed scripts will not have any identifying information such as your name or child's name to ensure your final anonymity and will also be password protected.

The transcribed scripts with identifying data removed will only be shared with my research supervisor who is also bound by confidentiality principles. The anonymised transcripts will be stored in a password protected device. It is possible that direct quotes from your interview will be used in the final research report, however, no identifying information will be included, and I will use pseudonyms instead of your real name, e.g., participant 1. This is to ensure full anonymity in the final write up of my study. With your permission, other researchers may use the data collected from this research study, but your name and any personal information will not be used or passed on, they will only be given the anonymised transcripts and will also need to ensure they apply appropriate measures such as not sharing the data with anyone who is not authorised to and keep the data in a password protected device to protect confidentiality of the data.

The interview will involve reflecting on, and recalling your lived experiences of raising a child with autism spectrum disorder which may potentially be distressing and trigger complex emotions. Before ending the interview, we will have a debrief session which will include talking about your experience of the interview and triggered emotions, if any, to ensure you feel fine to end the interview. If you feel unduly stressed and would like to discuss your emotions further, please use the free counselling services at the Emthonjeni Centre at the University of the Witwatersrand:

- Emthonjeni Centre: Tel: 011 717 4513 (contact person: Ms Paballo Lepota)

Additionally, if you need further specialised autism spectrum disorder-related services, you can contact the following service providers:

- Autism SA: 011 484 9909
- TARA- The H Moross centre: 011 535 3110
- Chris Hani Baragwanath Child Psychiatry Department: 011 933 8951
- Charlotte Maxeke Johannesburg Academic Hospital Child and Family Unit: 011 481 5103

Before participating in the study please read and sign the consent form.

If you have further questions about the study, please contact me at ogonemagape@gmail.com and I will be happy to assist. Alternatively, you can contact my supervisor at clare.harvey@wits.ac.za

If you have any concerns or complaints about the ethical procedures of this study, you are free to contact the University of the Witwatersrand Human Research Ethics Committee (Non-Medical), telephone +27 (0) 11 717 1408, email hrecnon-medical@wits.ac.za.

Kind regards

Ogone Magape (Researcher)	Clare Harvey
067 902 7372	011 717 9999
ogonemagape@gmail.com	clare.harvey@wits.ac.za