Experiences of South African fathers raising a child with autism

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Abstract

This study emphasises the experiences, challenges and the significance thereof that fathers encounter when raising a child with autism. It explores how this journey influences their interactions with their culture, religion, and language. Additionally, it explores how fathers' relationships with society change as they manage the complexities of fatherhood. These dynamics impact how men perceive their masculinity concerning societal expectations of their *identities* and roles as fathers. The children involved in this study have been diagnosed by a licensed psychologist, psychiatrist, or neurologist recognised by the Health Professions Council of South Africa (HPCSA). A minimum age of 3 years was set for the children to provide meaningful insights into the fathers' experiences, with a maximum age of 18 years at the time data was collected. This inquiry helps us understand how these experiences shape a father's *identity.* The sample includes seven fathers aged 32 to 50 years from various cultural and ethnic backgrounds: four African fathers, one Indian father, one Coloured father, and one White father. Data were gathered through face-to-face semi-structured interviews at times and locations chosen by the fathers. Recruitment occurred through outreach to private therapy practices to identify appropriate candidates, with additional participants found through snowball sampling. For those unable to participate in person, online interviews were conducted using the Zoom platform. Following data collection, thematic analysis was used to classify the experiences into common and significant themes. These themes include; the loss of an ideal, experiences/challenges within familial, social and or healthcare institutions and finding a new perspective on fathering a child with autism.

Glossary of terms

Caregiver: Someone who offers support and assistance to those who cannot fully care for themselves, such as children or individuals with illnesses, disabilities, or disorders (American Psychological Association, 2023).

Disability: This research paper employs first-person disability language, where the child in question is viewed as a person first and foremost, and their disability is only one facet of their overall *identity* (American Psychiatric Association (APA), 2013). In the case of this study, children with a diagnosis of autism spectrum disorder (ASD) will be referred to as a 'child with autism' (APA, 2013).

Social model of disability: This model perceives disability as a result of societal barriers rather than individual impairments. It contends that disability stems from inaccessible environments, discrimination, and systemic challenges, instead of solely from physical or cognitive conditions. In contrast, the medical model of disability treats disability primarily as a personal issue that requires medical intervention (Oliver, 2013).

Social constructivism: A theory proposing that social interactions and cultural influences shape human development and understanding. It highlights the idea that knowledge is created through interactions with others and the environment (Vygotsky & Cole, 2018).

Interpretivism: Highlights the importance of understanding human experiences and social interactions through a subjective lens. This theoretical paradigm argues that reality is a social construct, shaped by individual perceptions and interactions (American Psychological Association, 2018).

Autism Spectrum Disorder (ASD): ASD is a neurodevelopmental condition characterised by persistent deficits in social communication and social interaction across various contexts. The severity of the condition is based on impairments in social interaction/communication and restricted, repetitive patterns of behaviour (American Psychological Association, 2013).

Identity: In this thesis, *identity* is defined through a social constructivist framework. Therefore, *identity* is not static; instead, it is constantly influenced by culture, interactions, institutions, and societal expectations (Michael, 1996). Thus, *identity* in this work is described as one's understanding of oneself in relation to how this understanding may shift through engagement with other people, institutions, and environments (Michael, 1996). *Identity* has been italicised throughout this thesis to improve clarity and emphasise what is meant when this word is used.

Gender ideology: refers to the ideas that shape society's perception of gender *identity*, roles, and expressions. These ideas impact cultural norms, policies, and individual *identities* (Davis & Greenstein, 2009).

Chapter 1

Rationale and research aim

The aim of this study was to provide insight into the experiences of fathers of children with autism in South Africa. It is surmised that as many as 95 percent of the world's individuals living with autism live in developing countries, such as South Africa, highlighting the relevance of such a study in this context (Adams, 2024).

The study encompasses financial, mental, and social aspects of parental experience with regard to raising a child with autism. Autism can encompass a wide range of symptoms and is also often accompanied by an intellectual disability (Rafferty et al., 2020). Children with autism exhibit behaviour that can be difficult to manage, such as frequent disruptive tendencies and difficulties communicating verbally and non-verbally (Ludlow et al., 2012). Considering the behavioural difficulties associated with autism, fathers' experiences of raising are reportedly shaped by the influences of societal barriers to disability and gender ideologies. Thus, fathers must navigate their unique caregiving experiences while addressing how these experiences are shaped by societal expectations, institutional support, and local attitudes.

The role of the primary caregiver has traditionally been the responsibility of the mother; however, the rise in dual-income households has shifted more caregiving responsibilities to the father (Seymour et al., 2017). Due to the relative novelty of these changes in familial roles, there is still much to learn about the experiences of fathers raising children with autism. Hence, there is limited evidence as to how levels of stress differ between maternal and paternal parenting roles, but those differences that have been to the typical roles assumed by mothers or fathers (Kourkoutas et al., 2012). Ludlow et al. (2012) postulate that carer duties

between mothers and fathers differ in scope, which begs the question as to how the scope is shifted in fathers, if at all, in parenting a child with autism.

The fathers in this study all have *identities* that are uniquely shaped by their culture, their religion, relationships, and their interactions with institutions, particularly healthcare and mental healthcare institutions. Furthermore, their *identities*, outside of their roles as fathers, may be at odds with their unique experiences as fathers raising a child with autism. Cultural expectations and beliefs may create conflicts with how they, as fathers, accept their child's autism diagnosis, where gender ideologies in South Africa are largely determined by culture and religion (Kehinde et al., 2023). Fathers, socially and culturally conditioned to play the role of protector and provider, may find this at odds with what is required of a father raising a child with autism. Typical caregiving duties such as hands-on nurturance, emotional support, and household management, traditionally a maternal role, may be expected of fathers raising a child with autism. Thus, a father may be required to play a role which was previously considered culturally and/or religiously inappropriate for a man (Kehinde et al., 2023).

The current study considered how these experiences shape fathers' overall *identities* as both parents and individuals. By gathering different accounts from fathers reported lived experiences, a thematic analysis was conducted to better understand similarities and/or differences faced by the fathers forming the cohort of this study. Thus, gaining a greater understanding of the positive and negative experiences faced by fathers of children with autism.

Research questions

1) What are fathers' experiences of raising a child/children with autism?
    a. What factors influence a father's positive/negative experiences of raising a child/children with autism?

b. How does this experience shape fathers' overall *identities*?

2) How do fathers manage mental and physical health when raising a child/children with autism?
3) What support systems are available to fathers raising a child/ren with autism in South Africa?

Theoretical Framework

This research was conducted using a lens focusing on gender-role theory and a social model of disability to conceptualise fathers' experiences of raising a child with autism.

Firstly, Concha et al. (2016) illustrate how the gender ideology held by a father will influence their experiences of fatherhood and their level of involvement in all aspects of their child's life. Gender stereotypes concern the roles played by men and women in a given society and these can influence the gender ideology of a father (Kehinde et al., 2023). The beliefs surrounding how a man is 'supposed' to behave and the tasks he is 'supposed' to perform influence his view of what fatherhood requires of him and, subsequently, his experience of fatherhood (Concha et al., 2016).

In South Africa, gender norms are very much shaped by culture (Kehinde et al., 2023). Cultural norms in South Africa mean that men are seen to play the role of primary breadwinner and the leader of the family, while child-rearing duties are reserved for the mother (Kehinde et al., 2023). The traditionally conservative gender norms in South Africa provide an interesting lens through which to view fatherhood, particularly the experiences of fathers raising a child with autism.

Secondly, for the purposes of this study, a social model of disability is considered in which the participants were viewed through the entirety of their experiences, primarily as individuals, then as fathers, and finally as fathers of a child or children with autism. The

fathers' reported experiences of raising a child with autism are considered, recognising that their ability to engage with the world, their community, and their child's diagnosis is affected by societal barriers and stigma surrounding disability (Moodley & Graham, 2015). Disability is not viewed from an individualistic perspective but rather from a collectivist lens, where one's disability is shaped by the society in which they live, including the limitations in institutional support, infrastructure, and attitudes (Gamez-Calvo et al., 2025). Through research, one can begin to promote understanding and foster more accepting and inclusive environments (Gámez-Calvo et al., 2025), while the intersection of disability with race, class, gender, etc., can be better understood (Moodley & Graham, 2015). Furthermore, exploring the experiences of fathers of children with autism can inform relevant support structures, educational institutions, and healthcare professionals. By emphasising the physical and social barriers to inclusivity, there can be a shift away from a narrow focus on disability as an issue of individual impairment.

This brings Chapter One to a close, which focused on the aims of the research and the theoretical lens used to discuss the findings discovered in the study. Chapter Two will examine the literature reviewed in this research.

Chapter 2

Literature review

The literature consulted was gathered through a comprehensive search of primary journal articles, books, and case studies. These resources concentrated on the social model of disability, gender identity theory, and parental experiences related to raising a child with autism. The researcher prioritised works focused on the African context while also broadening the search to include international publications to enrich the literature base. The purpose of this literature review is to emphasise key factors to consider when exploring a father's journey of raising a child with autism. It addresses diagnostic components and societal influences that shape fathers' experiences, including the impact of gender ideologies and social attitudes toward autism. Furthermore, it identifies common challenges and typical parental experiences to compare with those reported by participants in this study.

Diagnostic factors of autism

Autism is a neurodevelopmental disorder that is characterised by social deficits in communication, limited understanding of verbal and non-verbal cues, and a focus on repetitive behaviours (Hirota & King, 2023). Children can be diagnosed as early as 18 months as this is when the associated characteristics of autism can be differentiated from other developmental disorders (Adams, 2024). It is surmised that as many as 95 percent of the world's individuals living with autism live in developing countries, such as South Africa (Adams, 2024). Research and intervention programs that are well established in high-income countries are not transferable to low-income countries where resources are scarce, and with a limited number of trained healthcare professionals, implementation is difficult (Adams, 2024). The first prevalence study of autism conducted in Africa was done by Lotter in 1978 and it was found that 1 in 145 children in sub-Saharan would meet the criteria for autism

(Adams, 2024). Pillay et al. (2021) attempted to contribute to this knowledge with their study on the Western Cape school-going population, where they found a 0,08% prevalence of autism. It is surmised from these findings that cases of autism are significantly under-reported in the Western Cape, and it stands to reason that it may also be the case nationally (Pillay et al., 2021).

Given the characteristic social deficits in autism, it may be difficult for a father to be aware of their child's needs if they are unable to communicate them (Hirota & King, 2023). A child with autism will often fail to react to their name being called, along with limited or no use of gestures of communication, and limited-to-no capacity for imaginative play (Hirota & King, 2023). Hence a child diagnosed with autism may struggle to develop and maintain relationships which can have a significant impact in all areas of their life (APA, 2013). People with autism exhibit extreme sensitivity to their environment, including sounds, tastes, and textures (APA, 2013). The severity of an autism diagnosis is determined by the level of impairment or restriction in social communication (APA, 2013). Hence, autism is described by the biomedical model as existing on a spectrum under the umbrella of autism spectrum disorder/s (ASD) (APA, 2013). The severity of a child's autism in this study will be discussed using the following diagnostic factors drawn from the DSM-5 (APA, 2013):

Severity Level	Social Communication	Restricted, repetitive behaviours
Level 3 (Very substantial support required)	• Severe deficits in verbal and non-verbal communication (APA, 2013) • Very limited social interaction, intelligible speech and minimal response to social engagement from others (APA, 2013).	• Inflexibility in behaviour, extreme difficulty coping with change and marked interference with functioning in all spheres (APA, 2013).
Level 2 (Substantial support required	• Marked deficits in verbal and non-verbal communication (APA, 2013). • Reduced social interaction and reduced or abnormal responses to social engagement from others (APA, 2013).	• Inflexibility in behaviour, difficulty coping with change and repetitive behaviours that are clear to a casual observer (APA, 2013).
Level 1 (Support required)	• Without support, deficits in social communication (APA, 2013). • Difficulties in social interaction and examples of atypical responses to social engagement from others (APA, 2013).	• Inflexibility in behaviour interferes in one or more contexts. • Difficulty organising or planning, which impacts independence (APA, 2013).

Social Model of disability

The social model of disability was first introduced in 1976 by the Union of Physically Impaired Against Segregation (UPIAS), a group of disabled activists in the United Kingdom. Their goal was to shift the focus from individual hardships to societal factors (Adam & Koutsoklenis, 2023). In this framework, impairment refers to physical, mental, or sensory characteristics, whereas disability signifies limitations imposed by society's political, economic, and cultural characteristics (Adam & Koutsoklenis, 2023). This thesis considers disability as a form of social oppression that restricts the participation and integration of

individuals with impairments within South African society (Adam & Koutsoklenis, 2023). The current study explored fathers' experiences regarding their child's autism, particularly in relation to social activity participation, access to healthcare for their child, and whether these experiences are unique to fathers or typical among parents of children with autism. Their experiences may be shaped by how society accommodates both them and their child's impairment (Thacher, 2024).

The available evidence on autism in Sub-Saharan Africa is scarce (Adams, 2024). Most research has been conducted in Nigeria and South Africa (Adams, 2024). This lack of knowledge and awareness contributes to significant stigma surrounding autism and disability (Adams, 2024). Many caregivers initially go through denial following their child's autism diagnosis (Sumbane, 2024). This raises the question of whether parental experiences could be less challenging if societal views on autism were more informed and supportive. In South Africa, caregivers of children with autism often worry about leaving their children with others, concerned that those individuals may struggle to manage their child's behaviour (Sumbane, 2024). This concern highlights not only the difficulties linked to autism but also reflects a society that lacks comprehension and acceptance. As a result, numerous individuals and families refrain from seeking treatment or community assistance due to fears of discrimination and ostracism (Adams, 2024). In this scenario, self-isolation is partially due to the demanding caregiving required for raising a child with autism but primarily arises from concerns about how their children will be treated (Sumbane, 2024). Consequently, parents do not distance themselves from friends and family because of their child's impairment, but rather because any atypical behaviour is often stigmatised (Sumbane, 2024).

Caregivers of children with autism in Sub-Saharan Africa face significant barriers regarding access to healthcare services, educational opportunities, and support (Adams, 2024). This leads parents to experience considerable emotional and financial stress while seeking

appropriate services for their child's needs (Adams, 2024). Moreover, several contextual factors significantly impact caregivers' experiences raising a child with autism (Adams, 2024). Aspects like culture, language, treatment location, and the type and cost of treatment heavily influence how parents navigate their caregiving roles (Adams, 2024). Frequently, these factors force parents to choose at-home treatments, allowing them to retain control and circumvent rigid societal perceptions of autism (Adams, 2024). While organisations in South Africa, such as Mothers of Children with Autism (MOCWA) and Fathers of Children with Autism (FOCWA), have made progress in addressing misconceptions about autism, additional actions at the state level are essential to foster a more inclusive society. This includes recognising difficulties, but not to ostracise or exclude, but to find ways to cater for such difficulties, thereby removing hurdles to equal societal participation (Adams, 2024).

Exploring fatherhood through the lens of gender ideology

Parental roles and responsibilities within a household are influenced by both societal and cultural norms regarding gender roles (Ozgun et al., 2011). Consequently, experiences of fatherhood can significantly vary across and within societies, shaped by these norms (Ozgun et al., 2011). The connection between a father and child, along with emotional support and nurturing, is closely tied to how parenthood is perceived within the household. A father's involvement in his child's life ultimately defines his fatherhood experience, which is particularly true for fathers of children facing the unique challenges associated with autism. These fathers may be required to adopt various roles linked to nurturing and hands-on caregiving (Lien et al., 2021). This unfolds against the idealised expectations of masculinity, which typically cast men as providers, problem solvers, and protectors within the family (Lien et al., 2021). Increased father involvement correlates with better socio-emotional, behavioural, and cognitive outcomes for children with developmental challenges like autism (Goldberg, 2014). However, if stepping into such roles conflicts with how fathers

conceptualise their own *identity* as men, a layer of complexity may be added to their experience. Increased paternal involvement can reduce stress within the family, especially alleviating emotional stress for mothers and enhancing partnerships (Goldberg, 2014). However, does this involvement come at the cost of fathers feeling conflicted about their self-*identity*? Bitalo et al. (2024) discuss how parenthood is a crucial aspect of being human. This experience is influenced by a parent's cultural, religious, and gender *identities* (Bitalo et al., 2024). The authors conducted a qualitative study with eight black South African fathers, who discussed their experiences of masculinity and fatherhood shaped by cultural expectations. These fathers underscored their responsibility to provide materially, viewing their caregiving involvement as secondary to their role as providers (Bitalo et al., 2024). While they acknowledged the importance of nurturing and emotional support, these roles are traditionally assigned to mothers (Bitalo et al., 2024). Given this, fathers raising a child with autism may find it necessary to rethink their *identity* as men if they are expected to take on more maternal roles, which may not conform to their cultural norms.

Parenting and autism

It is natural for parents to experience a wide array of emotional responses upon hearing their child's diagnosis of autism. Feelings of shock, denial, and anger are often followed by feelings of guilt and shame (Marcinechová et al., 2023). Parents may feel guilty because of a belief that they were in some way responsible for their child's autism, which can be a very painful experience to overcome (Marcinechová et al., 2023).

It is commonly reported that parents of children with autism suffer significant stress because of the unique challenges associated with the disorder (García-López et al., 2016). Parents are frequently confronted with a wide array of emotional and behavioural problems, ranging from their child's sleep difficulties, aggressiveness, self-injury, and attention problems (Marcinechová et al., 2023). These behaviours from the child may occur publicly which can

lead to hostile responses from others and judgements around the parenting practices of caregivers (Marcinechová et al., 2023). Since societally ‘different behaviour’ is not always accepted, parents may experience feelings of guilt and shame around how their child is perceived and how their abilities as parents are perceived (Marcinechová et al., 2023). In these instances, it has been shown to be useful to implement coping mechanisms and have self-compassion (Marcinechová et al., 2023).

Added stress on parents can negatively affect their relationship with one another, which adds further difficulties in adapting to their child’s challenges. The ability of the parents to adapt to their child’s autism diagnosis is an important factor in the child’s long-term prognosis. Hence, managing stress and offering support to one another as parents is crucial in the overall care of a child with autism (García-López et al., 2016).

The added care required for a child with autism can place a financial burden on parents for a longer period compared to a typically developing child (Brobst et al., 2009). The experiences of parents largely correlate with the family’s socioeconomic circumstance and the parent’s adaptability to the child’s diagnosis (Jones et al., 2013). Furthermore, within the familial structure, siblings of children with autism are shown to be more susceptible to depression and anxiety (Garrido et al., 2020). These authors note that emotional difficulties for siblings of children with autism are not getting enough social support, which can be the result of the additional attention and responsibility focused on the child with autism. Families with children with autism also receive less social support from extended families than families with typically developing children (Garrido et al., 2020). This could mean that fathers may feel isolated and alone with their experience.

The literature discussed above explores how raising a child with autism affects fathers' experiences. It specifically explores the influence of social, cultural, and institutional factors

on their ability to connect with their child, themselves, and their world. Social and cultural norms often shape how fathers approach parenting, especially when certain roles fall outside their traditional expectations. Moreover, fathers may face mental and physical health challenges while raising a child with autism (Garrido, 2020). Yet, they might opt for self-isolation rather than seek support due to fears of misunderstanding. These norms can also limit how fathers engage with their communities, underscoring how societal barriers directly impact the experiences of individuals with autism and their parents. The next chapter discusses the methodology used in this study.

Chapter 3

Methodology

Research design

This research study employed a qualitative research design that emphasises human experiences, particularly focusing on the context and the meanings participants associate with those experiences (Maxwell, 2012). The choice of a qualitative design aimed to highlight the intricate experiences of fathers raising children with autism, enhancing the understanding of how these experiences have influenced and continue to influence their overall *identity*. An interpretivist paradigm was utilised to explore the subjective experiences of individuals and the meanings they attribute to those experiences, constituting their 'reality' (Flick, 2022). In this approach, interpretivism aims at understanding rather than merely explaining an individual's reality (Flick, 2022). Additionally, social constructivism was incorporated, based on the idea that knowledge is shaped through interactions with others and one's environment. In this research, social constructivism specifically aimed to focus on the cultural context of fathers in shaping their understanding of reality (Flick, 2022).

A thematic analysis was performed to categorise participant data based on themes derived from their lived experiences (Braun & Clarke, 2006; add more recent issues throughout). The analysed data is discussed through the perspectives of gender-identity theory and a social model of disability.

Sample and sampling

In this study seven research participants were gathered to participate in the research. All the participants are fathers to at least one child with an autism diagnosis in South Africa. The child in question is at least three years of age, and this was done to allow enough time for a

father to have experiences to relay. For the sake of specificity of scope in the study, the child with autism must have had a formal diagnosis from a registered clinician, such as a Psychiatrist, Psychologist or Neurologist registered with the Health Professionals Council of South Africa (HPCSA) who was authorised to conduct such an assessment. It is important to note that for this study, all neurodevelopmental disorders falling under the umbrella of autism spectrum disorder (ASD) in the DSM-5 have been applied (APA, 2013). These include Asperger's disorder, pervasive developmental disorder, and childhood disintegrative disorder (APA, 2013). The inclusion criteria for this study required fathers between 25 and 65 years of age; however, the actual participants who were interviewed ranged between 32 and 50 years of age. The participants are all biological fathers of the child with autism in question. Furthermore, the child had to live with the father and could not be younger than the age of three or older than the age of 18. This provided a data set that is rich in terms of the experiences of the fathers involved.

Purposive sampling was used to find participants for the study. Campbell et al. (2020) illustrate the relevance of purposive sampling in finding a specific sample in qualitative research as it has the "aim of increasing the depth (as opposed to breadth) of understanding" (p. 653). The reason purposive sampling was chosen is to find a particular kind of participant, i.e., 'a father to a child with autism who has been formally diagnosed', with the view that each individual may hold different and important views on what this experience of fatherhood entails. This method of sampling was particularly useful to find suitable participants within the researcher's budget constraints (Campbell et al., 2020). Participants were acquired through invitation and through the clinical practices of speech and occupational therapists in the greater Johannesburg region specialising in childcare. These professionals were approached with information on the proposed study and asked if they would be willing to source participants, being fathers utilising the practice's services. Fathers

raising children with autism were approached and asked if they would be interested in participating in the study, and if this was the case consent was given to share their contact details with the researcher. Fathers were contacted via email with information outlining the purpose of the study, the requirements of them as participants, and consent forms should they decide to participate. Once consent was obtained, interviews were scheduled at the participants' convenience. Snowball sampling was also used to complete the sample, to enable the meeting of a minimum of six participants. Snowball sampling is a method whereby samples are collected at random by using already gathered participants to refer further participants who are related to the study (Kirchherr & Charles, 2018). In the case of this research, snowball sampling was only used because purposive sampling was incapable of gathering a complete sample. It is important to note the severity of autism for the children in question. The fathers in this study all have children who are on the milder part of the autism spectrum. When considering the functional levels of autism, the children in question here would range between level one (in need of support) and level two (in need of substantial support) (APA, 2013). The table below outlines the demographics of the participants.

Demographical information					
Participant	**Income range**	**Age**	**Race**	**Child's age**	**Diagnosed at**
Bob	Middle	34 years	Indian	6 years	3 years
Joe	Upper-middle	40 years	African	6 years	4 years
Sihle	Middle	32 years	African	3 years	3 years
Tembi	Middle	40 years	White	7 years	4 years
Ted	Middle	38 years	African	4 years	3 years

John	Middle	50 years	Coloured	18 years	5 years
Tinus	Middle	33 years	African	4 years	3 years

Data collection

After obtaining ethical clearance from the University of the Witwatersrand, data collection involved one-on-one semi-structured interviews (see Appendix C for the interview schedule) with seven fathers aged 32 to 50 years (Fouché et al., 2021). This data collection approach used a predetermined set of questions to gather varied perspectives on the same topic, while also allowing the researcher to adjust questions based on the study's objectives (Adeoye-Olatunde & Olenik, 2021). The interview questions aimed to explore the experience of fatherhood, its impact on overall *identity*, and the factors affecting both positive and negative experiences of fatherhood. During the interviews, fathers were prompted with specific questions, and the researcher guided the discussion when additional elaboration was needed. All interviews were conducted in English, and each session was audio recorded to facilitate a detailed analysis of language usage and nuance, particularly for participants whose first language was not English.

To ensure the data was trustworthy, the interview questions encouraged participants to provide comprehensive descriptions of their experiences. Although the interviews had a semi-structured format, the themes remained consistent to elicit diverse perspectives on similar subjects. The similarities and differences in the participants' economic and social backgrounds offer an intriguing starting point for interpreting their experiences in raising a child with autism. Furthermore, for trustworthiness, the study was limited to South African fathers residing in South Africa, aged between 25 and 65 years. The interview schedule (see appendix C) was meticulously developed by the researcher, drawing on relevant literature

pertinent to the study's scope. All collected data was securely stored on a computer with access restricted to the researcher and supervisor, protected by a password. While it was intended to conduct all interviews in person, logistical constraints limited this; three interviews occurred in person, while the remaining four were held online via video conferencing platforms like Zoom and Microsoft Teams. Although online interviews offered greater scheduling flexibility, the rapport established through in-person interactions was significantly more effective than that fostered through online means.

Ethical considerations

The researcher obtained ethical approval from the Human Research Ethics Committee (non-medical) at the University of the Witwatersrand, and the study commenced once this clearance was granted (refer to Appendix D for the ethics approval certificate). The researcher then began recruiting participants. Participants received clear and concise information about the research in a document (see Appendix A for the participant information sheet), which outlined the study's purpose, data collection methods, and ethical considerations. After being fully informed, participants consented to the study by signing a consent form (see Appendix B). This form indicated their willingness to partake in the research, and they were made aware of their right to withdraw from the study at any stage, for any reason, until the data analysis began. Additionally, during the interview, participants could choose not to answer any uncomfortable questions they encountered.

To maintain confidentiality within the study, all recordings are securely stored in a password-protected folder accessible only to the researcher and their supervisor.

The researcher chose to use English during the interview process because of language limitations, which may have caused some communication issues. While all participants could communicate in English, it is not all the participants primary language, potentially restricting

their expression of nuance and depth that might have been conveyed in their native tongues. The intention was to use a common language for effective communication, fostering mutual expression and understanding between the researcher and participants; however, this choice appeared to impose constraints. Keeping this in mind, throughout the interview process, the researcher recognised these limitations and sought clarification when needed to draw out richer responses.

All interviews were conducted in private settings to prevent the disclosure of sensitive information, and participants were informed that the interview could be paused if they felt uncomfortable at any time. Moreover, participants were encouraged to access free counselling services available at the University of the Witwatersrand's Emthonjeni Centre clinic if needed. Given that interviews were conducted both face-to-face and through a video conferencing platform, complete anonymity could not be guaranteed. Nevertheless, pseudonyms have been applied in the final report, and none of the participants' identifying details have been disclosed, including information about their families and children. This approach ensures that definitive anonymity is upheld in the research report.

Data analysis

The data gathered has been thoroughly examined with the support of various academic perspectives to ensure its confirmability (Adeoye-Olatunde & Olenik, 2021). As previously stated, the interviews employed a semi-structured approach that allowed for adjustments to questions based on insights gained from earlier interviews. After each interview, transcripts were created verbatim from the recordings, and any themes that emerged were noted (Fouché et al., 2021). In this study, thematic analysis was performed to construct a meaningful interpretation of the significance participants attribute to their lived experiences (Flick, 2022). One benefit of thematic analysis is its capability to reveal both similarities and differences in participants' perspectives, as well as to uncover any unexpected findings (Nowell et al.,

2017). The researcher derived interpretations from the fathers' shared stories throughout the research process, once all data had been gathered (Flick, 2022).

The data was categorised based on topics of interest from participants' accounts and then organised into themes reflecting content commonalities, significant discussion points, and differences among the fathers in the study (Byrne, 2022). Consequently, the researcher reviewed the data, familiarising himself with its breadth and depth. Collecting the data in an immersive and interactive manner allowed for detailed analysis (Byrne, 2022). The extracted data was further coded based on the content and context of each shared account (Braun & Clarke, 2006). Once codes were established for each participant's data extracts, they were organised into themes. The primary themes were subdivided into subthemes or notable discussion points within those main themes (Braun & Clarke, 2006). After categorising all data into themes and subthemes, the researcher assessed whether sufficient data existed to support each theme or if data diversity precluded strong thematic support (Braun & Clarke, 2006). The fifth step in the thematic analysis was to define and refine the themes, providing explanations for each theme based on the encompassing data (Byrne, 2022). After thoroughly defining and reviewing the themes and corresponding data, the researcher reported findings centred on shared themes, definitions related to the collected data, and additional significant talking points (Braun & Clarke, 2006). Themes have been subsequently named, defined, and systematically organised in the final report to clarify the collected data (Braun & Clarke, 2006). Participants in this study are regarded as 'experts' on the topic, and the themes emerging from their perspectives aim to address the research questions. The research sought to explore the meaning fathers attribute to their lived experiences as individuals and as fathers, including the influence, if any, of their child/ren's autism on their *identity* construction. Theoretical saturation was reached when no new themes or concepts emerged from the interview process (Fouché et al., 2021). The themes, concepts, and categories

identified from the data were elaborated on using relevant academic literature to deepen the understanding of the significance fathers assign to their experiences (Johnsson, 2021).

Reflexivity

Acknowledging my personal biases and subjective perspectives was essential, as they might have affected data collection in this study. I am a white English-speaking man who has a strong interest in fatherhood experiences, despite not being a father myself. My understanding of fatherhood and masculinity stems from my own experiences and cultural background, which may potentially misrepresent the realities faced by men and fathers from different cultures. Although I chose this topic due to an interest in cross-cultural fatherhood, my perspectives are shaped by personal and cultural biases, risking a distorted interpretation of the studied fathers' experiences. Serving as both a psychologist in training and the interviewer, I held a position of structural power in the interviews, controlling the questions asked and guiding the conversation. This power dynamic could have potentially pressurised interviewees, influencing their responses and engagement during the interviews.

I as the researcher understand that my own biases and authoritative role as the interviewer could influence participants in various ways. Therefore, I carefully considered the interview technique, and the questions posed to create an atmosphere where participants would feel comfortable sharing candidly. Despite my positionality, I needed to maintain a demeanour of openness and curiosity.

Acknowledging that complete objectivity is unattainable, I, as the researcher, along with my supervisor's guidance, sought to recognise any personal biases and discuss ways to address them, aiming for a research study that was as trustworthy as possible. Additionally, my supervisor acted as a mediator to eliminate barriers to acquiring trustworthy data. This was done specifically by reviewing the questions posed in the semi-structured interview schedule

and identifying questions that were limiting the richness of the data or shutting down open and honest conversation.

Trustworthiness of qualitative research

Qualitative research focuses on understanding meaning in participants' experiences instead of seeking absolute truth (McSweeney, 2021). As a result, it has often been criticised as unreliable due to this emphasis on experience over truth (Cope, 2014). However, qualitative research can achieve credibility if researchers implement necessary safeguards (Cope, 2014). McSweeney (2021) highlights that modern theories support this approach by stating, "it relieves me of the obligation to be right and demands only that I be interesting" (p. 1063). Given the inherent subjectivity in qualitative research, characterised by both the researcher and participant perspectives, establishing checks and balances is crucial to gaining the trust of the scientific community.

Lincoln and Guba (1985) proposed four essential checks and balances, and a fifth was added later (1994), which pertain to the perceived reliability of a qualitative study: credibility, dependability, confirmability, transferability, and authenticity. This research utilised this framework for assessing trustworthiness. Initially, credibility was established through the researcher's design of the interview schedule, which aimed to extract honest feedback from participants (Cope, 2014). Additionally, the data was meticulously transcribed and reported to mitigate any potential bias from the researcher, as illustrated by McSweeney (2021).

Dependability was largely ensured by conducting the interviews under uniform conditions (Lincoln & Guba, 1985). The sample was consistent, as all participants were fathers of children with autism. Efforts were made to conduct interviews in person whenever possible, at times and locations convenient for the participants, to create a comfortable and accessible environment. When in-person interviews were not feasible, platforms such as Zoom and

Microsoft Teams were utilised, ensuring a secure and consistent data collection process via password-protected meetings solely accessible to the researcher and participant. To further ensure dependability, the researcher's supervisor collaborated closely with the researcher to verify that all conditions were satisfied.

Following dependability, confirmability was addressed by acknowledging the researcher's potential biases, enabling the final report to faithfully represent the collected data. As Cope (2014) noted, this was achieved by incorporating participant quotes throughout the report to demonstrate that emerging themes were derived from the data, not merely from the researcher's viewpoints or biases (McSweeney, 2021).

Transferability pertains to the generalisability of the research findings (Cope, 2014). In this study, transferability has been ensured through adherence to all the aforementioned checks and balances. The underlying assumption is that if the research is credible, dependable, and confirmable, it is also likely to be transferable (Cope, 2014). If the fathers' experiences captured in this study are accurately depicted in the final report, it follows that other fathers outside the study may relate to these experiences to some extent. The researcher has achieved this by authentically reflecting participants' experiences with rich quotations and precise summaries (Cope, 2014).

This chapter described the methodology employed in this research study, the process used to collect and analyse data, and how and why reflexivity was thoroughly considered. The next chapter presents the research findings through rich quotations taken from interviews with the participants.

Chapter 4

Findings

The following chapter reports what the fathers' experiences have been in raising a child with autism. The use of rich quotations and explanations has been used to link the quotes to the themes and subthemes that emerged in the data. Furthermore, the rich use of quotations underpins the authenticity of the data to demonstrate these themes (McSweeney, 2021). The themes that were discovered in this research can be found in the table below and have then been discussed in detail through the lens of the social model of disability and gender ideology.

Breakdown of themes	
Theme	Sub-theme/s
Loss of an ideal	• The loss of an imagined relationship • The path to acceptance • Feelings of guilt, shame and disappointment • Feelings of stress, fear, frustration and inadequacy
Social, familial, and institutional support and challenges	• Social support and challenges faced • Communication and Language • Lifestyle • Familial support and challenges faced • The impact on fathers' romantic partnerships • Institutional support, challenges and financial impact
A new perspective	

The loss of an ideal

The loss of an imagined relationship

One of the common themes found is fathers having to come to terms with a relational dynamic that their child with autism does not align with their fantasies of what their connection with their child would have been like had they not had autism. For many of the fathers interviewed, they describe a lack of emotional intimacy and connection with their child, which is something they had not expected. For some of the fathers, the unique, different connection they have developed with their child is something they have come to terms with, but for others, there is still a yearning that the relational dynamic becomes a 'normal' father/son or father/daughter relationship.

For example, Tembi's son struggles to understand his own emotions, especially love, and the emotions of others, impacting the ideal of the relationship Tembi envisaged:

"So, if you had to show him a picture that would represent love, he would get to love, maybe one or two tries, but he'll get to it, if you need to explain to him what love is, like explain to me what love is, he's not gonna get there."

For Sihle, when his daughter T was first diagnosed, he did not know how to respond to her. She would become highly emotionally dysregulated, and he would not know what to do, which was very difficult:

"Sometimes she melts down and at some point, we didn't understand, why is she crying? What is she crying for? Because she hadn't been sick, but we are told that sometimes it's a matter of meltdowns."

Initially after Y was diagnosed, Tembi describes how concerning it was for himself and his wife when his son would not come to them for support or help when he was upset. This was

something Tembi would do as a child, he would seek out help and support from his parents, so it felt unnatural for him that his son would not come to him for support:

"He would not come into our room if it wasn't that we said, oh, you can go and watch a movie. When he had nightmares, he would not come to our room until we kind of helped him with it and then said to him, alright but if this happens, come to our room."

Likewise, Ted has found it difficult at times to connect to his son in the way he would like. His son is easily distracted, which makes it difficult to have a conversation:

"Sometimes it's not really about him being distracted, but it's about that conversation being a distraction to him, for an example, if he's fixed on whatever he's thinking, and you come now and introduce a new topic, you find that he's still fixed on the previous one that he was thinking about. So, when he talks to you and still go back to what he was busy with or to what he was thinking about before."

Joe describes his struggle to accept his son's autism, acknowledging that his child is different from many others. This reflects Joe's upbringing in a context where atypical behaviour was often derided. Although his son benefits from a special education environment tailored to his needs, the situation underscores the societal barriers that influence exclusion and inclusion for individuals with autism. Nonetheless, it's essential for Joe to try and recognise that his son has his own unique way of being and his *"own normal"*:

"At times I get upset. I don't know to myself to think, you know what's wrong. Why can't he be like normal kids? I believe like that's his own normal I don't know, but yeah, it's been a battle to be honest with you. So now he's going to a special school, like with kids with similar characters."

Bob reflects on how his relationship with X differs from the one he envisioned for his child. Due to X's autism, he struggles to comprehend others' emotions and social cues. Bob's

difficulty in recognising and embracing an alternative way to connect with his son showcases a broader societal inflexibility, where social norms heavily influence relationship dynamics. Bob has a more 'ideal' relationship with his other son who does not have autism, but with X, this has been hard to achieve. This elusiveness brings him sadness and may also challenge him to reconsider his *identity,* as both a father and an individual, as he strives to achieve the connection with X that he craves:

"There is a connection there. Yes, yes. There's not a connection that you want to have with your child. So obviously you want to connect. You want to teach them about all the wonderful things in life. You want to show them how to do certain things. And with X, I don't have that opportunity, but with the brother I had the opportunity, at least."

Ted shared his experience of getting used to the fact that his son's milestones will differ to other children:

"It was hard for an example, you know, whenever a child, one of the milestones that you look up to is when the child starts to call you Mama, Baba, something like that. But for him, not able to identify us as his parents."

Ted describes the severe limitations to his son's social skills, highlighting a relationship that Ted did not envisage having with his child; though he does believe there is hope:

"Progress academically as well that give us hope. It's OK that means this thing is possible"

Joe struggles to accept his reality. He feels sorrow for his son and genuinely wants the best for him; however, reconciling with the diagnosis proves challenging, leading him to doubt his circumstances and experience deep sadness and anger. His feelings of sadness for his son underscore how autism constrains his opportunities, not because his autism hinders him from

functioning, but due to a societal framework that limits the integration and involvement of individuals with disabilities:

"I was sad for him, but not myself, umm because I wanted him to be like, normal kids, like, yeah, like, normal kids. Umm, yeah, I was sad, like I was always, I wouldn't say, like, at times like I was sad, and wonder, like I would be like, in a depression mode to think. Why? Why?"

Tembi needs to convey to his son what love feels like and what a father-son connection entails. This has made it challenging for him to cope with his son's autism and the unique way he communicates, which is different from Tembi's expectations. He mentions the difficulty for *"dads to admit it"*, hinting at a sense of shame that he may carry. He might find it hard to share his son's autism journey with others, anxious about facing judgement and misunderstanding. This can lead to a feeling of isolation:

"It is definitely a shock. I think not many dads want to admit it. There's also a sense of, teleurstelling [disappointment], I think that disappointment is there, is a there, is a point. But again, you don't, as a father, want to say, Oh, I'm disappointed in my son. It's not about the son. It's disappointment in your own dreams that you have to realise that it's not your dream anymore."

Tembi's words are a poignant example of how his social and cultural expectations of fatherhood have begun to shift through the lived experiences of raising a child with autism. Tembi describes how it's difficult because he wants to show his son love and affection, but Y does not receive it in the way Tembi would like:

"I would randomly phone him, let's say I go away from work and I phone him, and then the first thing he'll take the phone is, why do you phone me? Oh, because I miss you. Oh, but he doesn't engage that, like, okay, why would you do that?"

Tembi is an individual who deeply appreciates sports and competition, making it challenging for him to grasp that his son Y may not share the same viewpoint or enthusiasm. He refers to this realisation as a *"bitter pill to swallow."* His sense of his masculinity has been closely linked to sports, a passion he hopes to pass on to his son. Nevertheless, his son's differing interests have prompted Tembi to reassess his approach to fatherhood and his own *identity* as a man:

"*It is and he doesn't get the fact that there's competition, so even in the hockey and all of that, and which is good for them at their age, is not to compete, but he doesn't get the competition part where he'll even be excited if the other team scores, because there was a goal scored. And I'm like, yah, it's a bit of a tough one to swallow but okay."*

Bob has faced considerable challenges in coming to terms with his unique experience of fatherhood. He describes how there is a blueprint and expectation for what parenting should be, but his journey with his son, has been vastly different. Though Bob had a grasp of what fatherhood entailed, drawing insights from his parents and grandparents, his understanding appears limited. This likely stems from insufficient research and inadequate institutional support on parenting a child with autism. As a result, he feels unprepared and is now reconsidering his views on parenting:

"I think for me it's the most difficult thing I've basically been processing in my entire life. So, everything else has been quite easy, like, in terms of life. But for X, it's like been difficult because, you know, as a young parent, no one teaches you to be a parent, you basically learning on the spot when the child come and so at the beginning, it's like, okay, no, this child is here, but you're trying to learn how to be a parent. But to be a parent, you have some recollection from maybe watching shows and seeing how other people treat their children and parent children, but with X, you're doing those things and you're not getting the

response that you wanted. So now it becomes, like, very difficult. Like, are you doing the right thing? What are you doing? You don't know. Like, up until now, the smaller one, I know exactly what to do with him. With X, till now, I don't know. You are just trying different things and seeing what works the best."

The path to acceptance

Bob talks about this change in perspective and how, as a father, one faces the choice of either accepting or denying the loss of an 'ideal' relationship. This shift relates not only to Bob's expectations for his relationship with his child but also signifies a personal transformation in his approach to parenting. He has opted to adopt a flexible demeanour as a father instead of expecting his child to adapt and behave in a predetermined way:

"So you can't be a parent where he has to fit into your personality and your schedule and your understanding."

Joe discusses the challenges he faces when his son expresses his frustrations through actions instead of words. In the past, he reacted by shouting at his son, K, for this behaviour. However, he now believes it is more beneficial to accept it and give his son the opportunity to find other ways to communicate. Joe's frustration may stem from his recognition of social norms that dictate acceptable and unacceptable behaviours. As a father, he worries that his child's acting out could be seen as ignoring these societal expectations, making this aspect of fatherhood particularly difficult to manage:

"Yes, yeah. Yeah, it is different because also, like, I wouldn't want to, like, really shout at him. I want to, like, allow him to be a kid, because at times I see, like, when I would shout at him, like, he, he kind of, like overreacts because he cannot like really say, so he would, like, bang the door, like, throw things. Maybe it's normal for other kids, but with him, it's because he cannot express it with words, so he just umm yeah, uses action. So yeah…"

Bob embodies the acceptance of the loss of his previous ideals, while embracing a new perspective and experiences that arise from parenting a child with autism. He starts from a place of limited understanding about autism, which reflects the general scarcity of information for fathers available in South Africa on raising children with the condition, as well as the insufficient integration between neurotypical individuals and those with autism. Bob strives to come to terms with his child's identity, recognising that his child's happiness is what truly matters:

"Then there this autism thing. It's a hell of a thing, because no one can prepare you. And even, like growing up, I wouldn't have said that I've met someone with autism, so like this is the first person that you know that has autism, and now you have to parent this person. You don't know how to parent. You're trying to parent here and there, but obviously there are certain things that he'll do, and you're like, okay, no, you're happy the child is here, that he is the way he is."

Sihle sees his child's diagnosis from a new perspective. Although it has been challenging to accept, he believes it has largely brought positive changes to his life. As a father and a man in South Africa, Sihle may not have expected to take on such a nurturing role in his daughter's life. However, because of her autism and the need for hands-on care, he is now engaging with her in ways he never anticipated:

"It was a positive change because I love her more, I don't know whether it was changed because of that or because she's growing and I'm experiencing, I'm getting more of her. So, I don't know. I think if there's a change, it's a positive one."

The love Sihle describes for his daughter is noticeable:

"For me, it's too, it's too difficult to spend just a day without her. It's very difficult. I find it hard to spend a day without her."

Sihle's language reveals that the medical model of disability still shapes perceptions. He describes autism as a disease that needs treatment (APA, 2013). This perspective underscores a broader problem: atypical development in an individual is seen as a personal deficit, instead of a unique personality that deserves accommodation and inclusiveness in society. Sihle is trying to adjust his perception and challenge this notion. He is working to accept the diagnosis in order to learn how to adapt, and care for his daughter:

> *"But then I was like, okay, let me accept the situation. This is how my daughter is, lets focus on treating the disease, and see if you will."*

Autism is a lifelong condition, not one that can be eradicated (APA, 2013). However, Sihle is still searching for acceptance of his daughter's diagnosis, believing that it is something that will pass; he is somewhat positive about the future, but whether the reality has truly sunk in is another question:

> *"Knowing that, it's something that will pass. The only thing that is my concern is the speech only if my daughter can be able to speak, then, because the autism is not extreme. The only challenge is her not speaking."*

He believes that viewing her at face value presents a highly beneficial perspective. Sihle endeavours to embrace his daughter for who she is, regardless of her autism, illustrating a change in his mindset as he learns to accept her as an individual, rather than expecting her to conform to his needs:

> *"Yes, yes. It has been a positive point, like when, even when I see her, I don't see her... sometimes I forget that she's autistic because, like, it's not something that is in my mind. Except when she has to go for therapy, that's when I'm reminded that, oh, my daughter is autistic. When she has to go to doctors and stuff. But yeah, I even forget that she's autistic, I'm that person who accepts things the way they are."*

John on the other hand has had time to come to terms with his son's diagnosis. V is 18 years old and was diagnosed at the age of 5 years, which has given John time to adjust to his and V's reality. He accepts that the autism is something that is a part of V's identity and not something that can be outgrown:

> *"And yeah, going forward, whatever. Obviously, it's common sense, but you can't grow out of it like she explained, and we understand that."*

For John, autism is a part of his son's identity and embracing this has been tremendously beneficial in reconciling with his reality. V is perceived primarily as a person, and his father recognises him in this way. Consequently, John has reached a stage where his experience of fatherhood is as fulfilling as he had anticipated, where his role and his expectations have been shaped to cater for his son's needs:

> *"But hey, why is this kid talking differently or speaking with sort of an accent. He doesn't speak like his brother standing next time, you know, that type of thing. But eventually you just shrug it off and you know, it's V and that's how he is, and, yeah, that's how he's going to be going forward, you know?"*

Bob finds comfort in recognising the positive moments in raising X, which aids him in accepting X's diagnosis. He expresses the profound joy he experiences whenever X utters a new word or successfully completes a task. These moments enrich Bob's journey as a father. This perspective suggests that these experiences are not exclusive to parenting a child with autism, pointing to similarities between the experiences of neurotypical and atypical parents:

> *"So he'll say words, but when X wants something, he doesn't communicate in sentences, he'll say one word, and you'll just know this word means, yeah. So that's where he is now. So he is getting to a point. So even, like, when we see those things happening, it actually brings so much joy to myself and my wife, because, like, okay, I*

haven't heard him say this before. It's a good thing. He's starting to say this more. It's a good thing."

Ted has discovered that his research and reading on autism have fostered a renewed belief and optimism regarding his son's potential. He recounted a story about a video he viewed featuring a man with autism who learnt to socialise and work in the broadcasting industry. It shows that autism itself is not necessarily a barrier to achievement or typical functioning; instead, societal barriers, restricted opportunities, and a lack of institutional support create the obstacles. Through this new understanding Ted has challenged his traditional norms and aims to provide his son with the support he needs to pursue his goals, freely and optimistically:

"So, when I look at him, his career, how he started his career, for him to be even in TV and have that celebrity status, someone who's autistic, battling with all these social things, there was a time whereby he was talking about his first time on set, how he battled there. But when we hear people talking, how he managed to survive, how managed to become the veteran there, to be the best."

Although he acknowledges the unique challenges that his son may face throughout his life, Ted believes he has found hope that his son can live a certain quality of life:

"So, okay, if you want to go this route, there is a way, as much as it will be hard for him, like anyone else, but there is a way. The one I just saw, think was last year as well, when they're talking about that Silicon Valley where companies are. They've already accepted or realised that these people, most especially, that are high functioning, they do need them. In fact, most of these new, latest innovations, they come from autistic people."

Speaking about a University of Pretoria Masters graduate with autism, Ted shared his hope that his son could have the same academic opportunities, despite his diagnosis:

"Progress in academically as well that give us hope. It's OK that means this thing is possible."

For Joe, accepting his son's diagnosis was a contentious issue due to cultural beliefs that offer alternative explanations for his child's symptoms. Embracing his son's autism diagnosis also put him at odds with his parents. In his experience, Joe faced scepticism from them, leading them to refer his son to a traditional healer in search of answers. Although Joe initially supported this idea, he ultimately felt relieved when his parents accepted the medical explanation for his son's condition. Personally, this meant Joe had to accept a change in how he perceives his culture and traditions:

"So, so we did that whole ceremony, you know, umm you know, like naming him. So their healer said, no, we don't need to write it on a birth certificate or whatever. So it's just to, at times, I call him by S you know, so, so we did that. So for them, okay, we did that. So, yeah, like, they're fine with, like, now what we're doing so they're not, like, encouraging, okay, maybe this didn't work. Let's go to another healer. So they kind of like accepted, and they understand, okay, he's going through therapy."

This experience underscores the journey of seeking answers and reaching acceptance, emphasising the vital role that family support plays in a father's acceptance of their child's autism. Conversely, without this support from family and the broader community, a parent may feel significantly isolated.

For Tembi, he shares how getting past a denial of his son's diagnosis was important in achieving acceptance. He is now at a point where he is well read on autism and open to this unique experience of fatherhood:

"Yah, it's a lot of self-reflection, then the research helps, and then being open about it, not hiding it, like it is, what it is, and we're not going to change, and he cannot change. So I

think it's that attitude, kind of, to me, is that it was the key factors to accept what it is. Like I said disappointment yah, to some extent denial but not for long because you can see it's not going to work. But then once you've accepted it and you live, not by his terms, but in his capabilities, then it was easy."

Tembi finds it easier to accept Y's autism because he believes that he can function fully and independently, even when him and his wife are not around, he feels as if Y will be okay:

"Oh definitely yah, yah, no, there's, there's always been, he's always progressed in the right direction. And then, even though it's slower to others, myself and the wife, we've realised that, you know, the best part of this is he, we know that he'll be fine. He will. And yes, he's fully functional, but he's on the spectrum, but we know he's going to be fine, even if we're not there one day. And I think in the beginning stages, that could have been a concern that that we as a couple never spoke about."

John holds the perspective that his son V is an independent individual. Although he does not always agree with V's decisions, John finds comfort in knowing his son will be fine. This example illustrates how crucial institutional and familial support is for a child with autism to succeed. Initially, John struggled to create a supportive environment but through experience and adapting to his son's needs he was able to adjust his approach to engage with and support V, allowing his son to thrive:

"He's V He's always going to be V He has his own identity. He likes doing things a certain way. He will dress the way he wants to dress, cut his hair the way he wants to do it. We might not always agree on his dress code or haircut, or whatever he is, what it is. He's his own person, and hopefully going forward, he will, he will grow even more and become even more self-sufficient."

Feelings of shame, guilt and disappointment

Bob discusses the challenges he faces in raising X, revealing deep pain and discomfort, including feelings of resentment towards his child. He expresses how this experience has altered his desire for more children. Although things are getting better, it remains a considerable struggle for him. He is apprehensive about having a third child, fearing they might also have autism. It raises the question of whether his fear is intensified by a sense of isolation among parents and the lack of support for individuals with autism:

> *"We don't want a third child, because there's that fear there, what if the third child is like X, and that was extremely difficult. It's actually gotten a lot easier as time is going on, but at the beginning it was difficult. It's like, even sometimes going as far, like, personally speaking, resenting the child, like, just obviously not wanting him. And like, obviously, as a parent, you don't want that. You want always the best for your, your child."*

A poignant example of losing an ideal occurred when Tembi purchased a motorbike for his son, as he, his wife, and daughters all ride together. Unfortunately, his son's response to the gift deeply saddened Tembi. Initially, Tembi saw this as an individual limitation related to his son's autism, which he felt prevented him from integrating into the family system. This reflects the typical societal construction of disability in South Africa. Tembi viewed his son's autism as an individual problem or limitation that would prevent him from participating equally in the family's dynamic, rather than viewing the system as the issue, which doesn't cater to his son's needs and desires. However, Tembi is now working to adapt and better accommodate his son's needs:

> *"I bought Y his first motorbike when he was I think five, a Peewee 50. The first time I started it, he said, just switch it off, it's making a noise, then we tried earplugs, we tried the*

helmet with the ear plugs. I've tried everything. He would never go anywhere close to that motorbike."

This is an activity Tembi would have liked to share with his son, but early on it is something Y would not entertain. Tembi believes that it is coming to the realisation that the relationship a father dreamt of, will not be, but it will be something new, different:

"As soon as that mindset changes, it kind of then self-aligns itself again."

Ted describes a similar experience, whereby he has little in common with his son:

"There are few that there's not much that we like to do together."

For Ted, it is about adapting to his son's rapidly changing interests and taking an interest in them as well:

"I can be able to assist him and show him how to do it so it's things like that that he's really forced at some point. It's just his stuff is also seasonally interested in this thing for like 3 months after that. Something else, it turns out at some point he was interested."

Joe expresses his frustration about being unable to share certain aspects of his life with K, particularly his passion for soccer. Although he can play with K, he sometimes feels that his son is either disinterested or not as involved as he had hoped. In this case, the coach's lack of flexibility adds to Joe's distress. K does not engage with the activity as a neurotypical child might, but that does not mean he cannot participate at all. If the coach had a better understanding of K's autism, it might be possible to create an environment that better integrates him:

"Yeah, we, we are like, you know, he can kick a ball, although, like, I feel like he can do better. Because when I see kids his age, like they do listen, like there was a time where I

enrolled him for soccer like, for kids. And the coach will be like K no! This is what we're doing, and he would wonder around do his own thing."

Bob expresses his desire to avoid sounding ungrateful for the blessings of his children. Yet, he sometimes grapples with dark thoughts that he wishes to avoid. These feelings can clash with his understanding of himself, presenting a significant challenge as he recognises these new aspects of his *identity*:

"I don't want to sound ungrateful towards myself or to God. It was obviously children are from God. But I, if I knew this, what children would bring I wouldn't ever have children. I think my life would be a lot better off not having children to obviously having kids. And then also, another thing is that you find that people are saying, your children such a blessing. Obviously, you tell yourself that, but you really believe it. I don't really like I haven't seen that part of parenting it. I haven't seen the joys and the positivity and all those sides of parenting. I just see there's a lot of work, and obviously not unnecessary. But if I never had children, I don't have to go through all of this nonetheless."

A recurring theme in the fathers' stories is a deep sense of responsibility, shame, and guilt regarding their child's diagnosis. For instance, Bob reflects on his genetics and questions if they contributed to his son's autism. This situation underscores the shock parents experience upon discovering their child's autism and may stem from how Bob's views have been influenced by societal norms because society emphasises individual impairments as obstacles to achieving a successful and fulfilling life. Bob's reaction to his child's diagnosis certainly suggests a belief that autism equates to impairment and limitation:

"There's actually a lot of guilt in it. So, at the beginning, you thinking, What did I do as a parent to obviously bring this about? Is it something I've done, did something happen throughout the pregnancy, is it something that you did while before it got to that point."

Joe feels shame in situations where his son interacts with others who do not understand him. Unaccepting environments can cause fathers like Joe to bear emotional burdens that could be alleviated through increased awareness and acceptance from society at large:

"When people want to interact with him, he doesn't know how to respond. And yeah, I just feel like it's difficult, shameful."

Tembi describes how he and his wife have felt guilty at times because Y does not come to them when he is struggling or when he is hurt. It has made him question his abilities as a father:

"Normal kids will cry a lot when they get hurt. He does not cry, when he does get hurt, he will not come to myself or to mom. You would hear him cry, and he will be hiding. And if we find him it's like, what's going on? No, I got hurt or fell off the bicycle. Well, why don't you come to us? And he cannot answer it, he doesn't answer it, he just ignores that part. And in the beginning, we're like really, like we're kind of shit parents, like he doesn't want to come to us."

Joe also explained how his son's diagnosis would lead to blame being assigned to try and find answers to his son's autism:

"You know, because at times, like, I would tell my wife, I'm like, No one, no one in my family is like this. Maybe, it's you know like your family, that finger-pointing."

Bob speaks about the guilt he feels for behaving in a way that is not in line with the person he is when X is difficult to manage due to his autism. He explains that when he is trying to help, but is not getting the intended reaction from his son, it leads to intense frustration:

"And then in the morning, after the crying, you feel guilty, like, why did I do that, I didn't want to hit the child, but you also couldn't control your anger and your aggression as

well. In the moment, it was so intense, it was so intense because, like even myself, I'm not an aggressive person, and you get the guilt of feeling that in the world you treat everyone with respect and kindness. You're a good person to people, but your own child you're treating like this, yeah. So that becomes a bit difficult."

Bob does however explain how he as a father to X has developed and how he has become more patient, learning ways to manage X's behaviour and his own emotional reaction:

"So, I mean, as time goes on and then you started to realise that, you know, this child has autism, then you go to the internet, you read about autism, what is it? Then you tell yourself, as a parent, okay, no, I need to change my approach and my behaviour. And as time goes on, you obviously adopt this approach where you're trying to be more understanding and more patient towards him."

Bob discusses the challenges related to public perception, as well as the shame and embarrassment he sometimes experiences when in public with X. These situations can influence how Bob perceives himself as a father. Culturally, Bob is expected to occupy the role of provider and head of the household, and these experiences may cause him to doubt his ability to fulfil this role as he envisioned it:

"So sometimes you might find that if you go to Checkers and your child is screaming, you can't control your child, you get the stares like, to say, okay, now why can't you control your child, what type of parent are you?"

Feelings of stress, fear, frustration and inadequacy

Tembi describes how difficult it is at times to manage his own emotions when Y is dysregulated. Tembi tries to hold his son, soothe him, and calm him down, but the reaction he receives is difficult to accept:

"Yah it is difficult. It almost, your own rage then also starts taking an effect, you know you got, you can also just take so much of it. And then you need to mentally prepare yourself if we're going into this rage, you know it's coming so you isolate yourself. I would take Y into my bedroom and just sit there with a fan on and nobody else must come in, because anything that kind of distracts it again goes kind of it can just flare up again. So yeah, not easy but I think once you kind of figured out what works, that was the go-to."

Bob is still coming to terms with the amount of emotional and physical energy that is exerted in showing up as a father for X. He speaks about how the challenges he faces at home have started impacting his ability to be productive at work:

"Never in my life have I been burnt out. So I used to be someone who could work for maybe one year straight, one and a half years straight, two years straight, without taking leave. I've never been burnt out. And all of a sudden, I'm burnt out."

This stress and tiredness are compounded by X's sleeping needs related to his autism, which disrupt Bob's ability to get proper rest. He is at times forced to move to another room to get the rest he needs:

"It's still frustrating that you want to hold my neck. And I know I don't want to shove him, but I'm shoving you one side, and you're still coming, and they lay like right on you. So now you wake up. You wake the brother up. Both of you want me. I'm laying on my pillow, and now I have two heads breathing on me, and I'm trying to sleep here at night, and it becomes very frustrating. Eventually, you like, sometimes you brush it off, most of the time, I just brush it off. We are just, okay, okay. And I'm gonna, I'm going to sleep now, but now when you want to turn, and I'm someone that I always need to turn when I do sleep here, then I'll just take this position afterwards I can't turn because then it becomes so frustrating. And then you eventually like, I would rather go sleep in another room on my own."

At times, the frustration Bob feels as a father to X makes him contemplate escaping in search of refuge and peace. While Bob likely envisioned his role as a father, the hands-on care and nurturing his son X requires may clash with that expectation. It appears Bob is grappling with the loss of the independence and freedom he once had before becoming a parent:

"Sometimes you get to a point where it comes, it becomes so frustrating, where the wife is frustrated, the children frustrated. I feel like, let me just jump in my car and just drive. I've never done it before, but you always get those thoughts, yeah, you get very weird, dark thoughts sometimes, and obviously you dismiss it, but they do come through, like, I just want to drive away, or I don't want the children anymore. I want to be on my own. But it's, it's something where you realise, where it's you just want some time to recollect yourself. You just need to basically recentre yourself, then I can continue there."

Bob feels sad that a large part of his relating to his son is reprimanding him for dysregulated behaviour. He wishes he could share more positive interactions with X:

"He always wants to do something that he's not supposed to do. And you and your wife, you're obviously shouting at him. So it's feeling like all the time. You're always having negativity towards him. You're always shouting at him. You're not really having any good moments with him because of that."

Tinus has found his son's behaviour at times to be particularly challenging to manage and he is concerned that his hyperactivity will get in the way of him being able to function at school:

"He's very hyper. Like his day-to-day when he wakes up in the morning, he only has like a 30-minute buffer just to reboot the system and then after that it's just hyper. He's talking non-stop, he's singing. He's what they call it, those kid songs. The wheels goes round and round… Nursery rhymes and he sings but he doesn't sing them in the right tempo. He is fast forwarding them in his mind, and he goes through them in the loop. He's jumping around.

He's just having a lot of adrenaline in him. So, I was like, OK, this is not really the way to go to school."

Social, familial, institutional support and challenges

Social support and challenges faced

Over time, Bob has stopped worrying about how others perceive his abilities as a father. However, his wife still struggles with this. While Bob has found it beneficial to change his views on public perception, it can still impact his ability to connect with the community. His main priority is his child's needs, but in a society that can be intolerant of certain behaviours, some fathers might opt for isolation to avoid negative reactions, even if this conflicts with their true selves:

"I just brush it off for me. For me, it's nothing. For my wife, she'll say that she doesn't really care what other people think, but she really does actually care. Okay, you can tell she cares. But for myself, I don't really care what other people think, though. So, like, I'm that type of person where you can actually think what you think. It's actually your right. I can't tell you how to think and how to behave, but I can do what I have control over, so in this situation, I have control over myself and my child, so I don't have to feel bad because you're looking at me in a certain way. I just need to make sure that child is okay, is he hurt? Is he sick? Does he have whatever he needs? But obviously, in that regard, I'm not really too phased about other people."

For him, it does not matter if his child is neurotypical or autistic; his responsibilities as a father remain unchanged. Although it was difficult initially, Bob's *identity* as both a father and a man is no longer affected by this. He appears to have accepted his circumstances and finds similarities between his experiences as a parent to a child with autism and those of

parents with neurotypical children. He believes that judgement of one's parenting abilities is inevitable:

"I think, as a person, also as a father, you can't really have this perception where people are going. People will judge you anyway. So even if you never had a neurotypical child, people will judge anyone, anyone, anytime, anyplace. So if I'm going to worry what everyone thinks about me… there's other more important things that I have to take care of as a father, as a, obviously a caregiver of a household and so forth. I need to make sure that other things are being taken care of, besides worrying what you think and what you what you feel."

Joe shares how a friend enduring a similar situation has aided him in processing his son's diagnosis, making him feel less isolated. Conversely, fathers without such relatable experiences may perceive their journey into parenthood quite differently. This emphasises the need for initiatives undertaken at both the institutional and state levels to address stigma and misinformation about autism and disabilities, thus leading to more empathetic and supportive interactions for parents of children with autism:

"My close friend is also; their kid is going through the same process. So I can now, I've got, like, someone who, you know, I can share the experience, and I don't feel alone, or I'm the only dad, yeah, you know."

For Joe, witnessing his son bond with another child was uplifting. He describes how both his friend's son and K share common interests and interact without reservation. As highlighted in the experience below, young children are not socialised to see differences. It raises the question of whether greater integration of disabled individuals into mainstream society could address this challenge, fostering more accepting environments:

"They were playing, took out all his cars, which normally he doesn't do that with. Say, if some of our friends come with kids, he would lock himself in the room. Doesn't wanna, want them to touch his cars. But with him, because they go to the same school, they know each other, yeah? Like he was so free, you know?"

Sihle emphasises the importance of treating his daughter equally to her sibling and involving her in activities. He values spending time with both his son and daughter, as well as encouraging them to bond as siblings, highlighting the need to integrate his daughter into the world just like any other child. Seemingly aiming to 'normalise' her experience and his role as a father:

"I try to involve her as much as possible, you know, like say when I go for soccer. Like, she would say, "Oh, you're going with U?" I'm like, no, let's go like, you know, we go together and we kick a ball, like, before we play with the big, with the guys, so just to socialise with them, and also, like taking them to like movies and stuff. So, we, I try to do like a lot together with them."

Bob speaks about how his extended family reacted to the news of X's diagnosis and how originally there was surprise and confusion, but the support has always been forthcoming:

"So, both my parents, as well as my wife's parents, very understanding, very supportive. So, my mom, at the time, she couldn't understand, what is this autism? Why would the child have autism? She would be like, she would say that she's very good at picking up certain things from people, but this here, slipped under the radar. She never suspected it at all. But the support is always there."

It was important for Bob, for his family and friends to treat X as they would any other child and this has been the case for the most part:

"So, you know how sometimes people would treat a disabled child, we didn't want them to treat him any differently than they would treat any other children."

John seconds this sentiment, he has always wanted others to treat his son V as they would treat others. He sees V's autism as just one of the many factors that make him who he is:

"So even the people that he interacts with like, four times a week, six years straight, they didn't really recognise anything. So that was something good to me. And I enjoyed that, you know, and then they treat him like any normal kid you know."

Tembi speaks about how accepting his friends have been towards his child's autism and how it has helped connect him to Y and allowed his friends to get to know Y:

"Where now it's, with my mates and that, it's never, remember he is different, no, it's Y, include him. Well, even if you guys have to kick the ball lower or high, just you know, accommodate him. But I think it's more also the era is more accommodating to everybody."

Familial support holds significant importance for Tembi. While it is a blessing to receive help from family, it's crucial to inform everyone about Y's situation and to explain to Y who will be visiting and the reasons behind it. This highlights that transparency and inclusion can create a nurturing environment for the child with autism and enhance the parenting experience for the father. Tembi discusses this in the context of his father's visit, for instance:

"Let's say grandpa's coming to visit, all right Monday we say to him, listen here, Grandpa might come and visit, and then step for step, building it up. So by the time he gets there, he's acclimated to the idea that, okay, Grandpa's here, where, if Grandpa just shows up, you can see it, it's unbalanced now in the house."

Communication and language

Bob describes the difficulties in relating to his son and also the challenges that come with his son, X's, limited ability to communicate what he needs and wants:

"So he will communicate with you when he wants to communicate with you, but if you want to commit. Want to speak to him. You can't really chat to him and speak to him and those sorts of things true. It's very tough. Yeah, very tough. So obviously, because you frustrated, but you understand where he is at this point in time, but because no communication it's very difficult to find out what's wrong."

Joe describes how painful it is to see his son struggling. His son's difficulties also impact the relationship he is able to have with him:

"Shame, like it is difficult for him, like, to get his point across, like, and he would be upset, and he would be emotional, and, yeah, it kills me, like, when I'm like, watching like that, Yah, it just kills me."

He shares how his son's difficulties in communicating what he wants and needs impact the connection Joe is able to have with him, which is very difficult to accept:

"I guess, like not being able to, to, you know, not have that conversation. And you know at times like, he would say one or two words to me and yeah, I find it difficult to understand him at times. And yeah, it just makes, makes it difficult for me not being able to understand what he's saying at times. And also, like, you know, when he wants something, or, like, trying to talk, I just say yes, but it's like, just to, like, you would think, like, I heard what he's saying but at times, I wouldn't understand. And I would just say yes, just for the sake of, of it, you know? And yeah, that's like, very difficult."

Sihle describes how his daughter, T, can make sounds, but is unable to sing or talk without imitating what she has heard. He wishes she could begin to communicate more naturally and authentically:

"She makes noise, she can sing your Happy Birthday, but even the Happy Birthday is not clearly like, say Happy Birthday, it's because of what she sees at creche. So, she's now, it's only now that she's trying to imitate some of the things."

Sihle describes how when T needs something, she gestures and vocalises to express her wants, and Sihle interprets these cues and knows how to react. However, he worries that others may not understand this. This underscores how fathers' experiences are influenced by their interactions with the environment. Sihle appears to worry that the outside world will not be as supportive and accommodating of his daughter's needs as he and his wife are:

"Hmm, because even when she wants to drink water, she will grab my hand, take me to the sink, and I'll know she wants water, then I can go, and I don't know whether other people will understand her that now she needs food, now she needs water. That's how she communicates with us."

It is a matter of physically communicating with her, which is something that took Sihle some time to adapt to. For him, it has been about being adaptable to the new normal:

"So, so it's a matter of the only change I'm saying is a change, or it's something that I have to change that's different. Because when I say, I say no to her, I must demonstrate what I'm saying. When I talk to her, I must actually demonstrate what I'm saying."

Tinus has similar worries about his son. He mentions that while he has accepted his son's autism, he is struggling to adjust his expectations for his son's future, which he finds challenging. For example, he talks about his son's delayed speech, and his concerns about whether his son will be able to interact socially, at school, and in other areas of life. Tinus in

fact alludes to social exclusion, where he has seen how his son is outcast from his peers because of his differences:

"So I am concerned about the speech, the speech and the social part. My most worry is the social part of it, because I don't want him to grow up as introverted and really closed out on his own to a point where he doesn't really allow people to make, not to make friends or to be able to be quite socialised in, in, in every environment because I've seen that."

Tinus believes that resolving the speech issue will enable his son to live a quality of life where he can interact and connect with others. This illustrates how society emphasises "treating impairments" to conform to social norms, rather than creating an accepting and accommodating environment for individuals that are differently abled:

"I think with every interaction, wherever you go, whether it's at friend or family, that speech is actually one of the number one things that you that's where you start from. You have to talk to the person, find out what's wrong with them. So, if the speech is not taken care of, that is one of the biggest challenges with me."

Tinus is hopeful however that one day, he will be able to have a conversation with his son that is authentic and natural. Yet, at this point he may still be struggling to accept his son's diagnosis and the developmental speech delay that is characteristic of a child with autism:

The isn't the expectation of. I'm supposed to be having a conversation. I'm really not that, that happy about it, but I'm still trying to say, OK, maybe one day we'll have a good morning, then get, then build from there."

Tembi shares the unique bond he has with his son, which sharply contrasts with the relationship he maintains with his two older daughters. For instance, he communicates in Afrikaans with his daughters and wife, but speaks English with his son, as it is the only language his son understands. This situation causes Tembi shame, as he feels he has forfeited

the ideal masculine father-son dynamic. As an Afrikaans man, Tembi finds it difficult to accept that he must silence part of his *identity* for his son's benefit, particularly when it goes against what is socially and culturally accepted:

> *"You're an Afrikaans father with, with the whole rugby scene, and all of your mates, their kids, been playing this since they were, like, three, four years old. Now, everybody, we get asked a question everywhere, but why is he English?"*

In the beginning, this was a difficult experience for Tembi, having to explain his son's difference and the fact that he chose a language that is not his, English. However, Tembi says he is slowly coming to terms with the reality.

Ted faces a similar challenge in wanting his son to learn his native language, IsiZulu, while his son currently speaks only English. In a way, Ted must set aside a part of himself to communicate with his son, which might create a cultural disconnect between him and his child due to this language barrier:

> *"That's it. The challenge we're having now was that the main focus was to help him to learn to speak, but now he also needs to learn our language, because right now it's all English, because all his material was all in English, so now that's when we are starting to teach him isiZulu. So that the part now, I wouldn't say he's battling, but like any other person you're teaching them the language. But when it comes to English, that's what we, that's what he's good at."*

Lifestyle

Sihle speaks about how much his daughter's autism dictates the lifestyle he and his partner can live:

"That's our biggest issue. You see now we can't, we can't even, like, maybe travel and leave her behind, because we don't know whether the next person that we will be leaving her with will be able to understand her."

Ted shares this sentiment, coming to the realisation that his son's autism will greatly impact the life he and his wife are able to lead:

"Is this how life going to be now? Are we going to be really limited in going out to places? That's the kind of feeling we're having other than. So it was more just incredibly difficult to come to terms with maybe the life you'd be able to lead and how it would affect your relationship with him as a father and with his mother. It was more just worries about that."

Joe shares the same sentiment, whereby his lifestyle has had to be adjusted to cater to K's needs:

"Yeah, he doesn't like loud noises. So, if maybe there would, like, there would be something that's loud, or radio at home, or music playing, he'd be like, what's that about? Noise? Turn it off."

One of Ted's biggest concerns in coming to terms with his son's autism, and what it means for their lives as parents, is the lifestyle they are able to lead and whether his son will be able to live a certain quality of life:

"The only thing that with the feeling we were having was like, is this how life going to be now? Are we going to be really limited in going out to places? That is the kind of feeling we're having, other than the shame, the blame, the whatever you may think, no, we didn't really have that. In fact, sometimes you really felt sorry for him, because we, we now knew that it's not him, that he does this thing on purpose, he is battling with this thing."

Familial support and challenges faced

Ted discusses the significance of his family's understanding regarding his son's autism and the positive support this has provided. A father's experience in raising a child with autism can be profoundly influenced by how well their family support systems embrace the child's diagnosis and delivers essential accommodations and inclusion:

"We making the point that we need to make sure that he gets that plaything so that he can learn how to socialise, learn, to with other kids. So they were more than open for that. In fact, they're the one who bring that kid over so that he can play. And also those kind of supports, and also other than us, they became the first people then that can be able to stay with him, even that one hour cause stress, it's a mission. So it was easy for our family, we knew that okay, if he's there with them, maybe we need to go somewhere, at least we know that they will take care of him, because some of the things with him where the child is being naughty, or all those things. So we know that, okay, when he is here now, he's safe, he can be himself, they know him. They would take care of him, he would get whatever he, he needs."

Tinus' experience growing up and the perspective of his family meant that he did not have much of a blueprint or point of comparison when he heard of his son's diagnosis. He speaks about how he has had to adapt and open his mind to new information about something like autism:

"I'm like from my background and from where we had kids that had had difficulties at school even just concentrating and just following simple instructions, and I remember nobody really cared much about them saying OK, maybe they are, they are on the spectrum or they are just somewhat challenged. It was always like crazy kid, normal kid. There was nothing in between. There was nothing."

Tinus feels that his family members, particularly his mother and sister, are very supportive, which has greatly assisted him and his partner:

"She's [Tinus' mother] very much into trying to help him out because even right now she goes to the pharmacy and tried to get some over the counter medicine just to calm him down and all that. So she is very. She doesn't really have any judgement whatsoever, because this is the first grand kid as well, so she's very much invested. I have my sister as well just the same box as me."

He does however worry that his mother does not fully understand the severity of his son's autism or the nature of autism, and how it is a permanent part of who he is:

"What I've noticed, is my mom, she tries to play it down and I don't think she really sees it of what it is to say, OK, maybe he's in the spectrum. She always just says no my grandson will be fine, let's just get him this particular syrup, it says that he's going to make him less hyper, so I'm not quite sure whether she's really taking it in."

Ted shared how his son's autism impacts his son's ability to understand the meaning of relationships. This has been particularly challenging with sibling relationships, where Ted's son is the elder brother, but does not necessarily know what this means:

"But still he, like I said, he battles to, to understand what relationships mean. So every now and then you keep on reminding him but you are the big brother, she's your little sister, this is what big brothers do."

One of the challenges Joe faces is in offering both his children the same attentions and affections. He describes how his daughter feels as if he favours K more and this can impact the family system, creating upset and upsetting a potential support system:

"She would think, no, I don't like her, love her. I love my, my son, or K, more than, more than her. And I keep on, like I need to reiterate to her that it's not like that. You know, understand, like your brother has a condition, and we, you know, need to treat him in a bit of a different way. But, you know, I love you guys both. So it's just, so she understands, but at times like she becomes a kid and just says, nah, you love him more than me. You know, so, yeah, those are, like the battles…"

Tembi describes how his son Y often creates conflict in the household because he will rile up his two sisters, which for Tembi, does not make sense and provides many challenges:

"And he cannot read a room like, I've got two teenage girls. So, let's say that the girls are in a dispute, or anything to that extent. Any normal kid at six, seven can say, you know what, if I say something now, this thing is going to explode, and he would say it. And you would like, Dude, you need to read the room, he just doesn't get that."

For John, it has been a blessing how his two sons get on with one another. He has found that his older son has always been caring and inclusive of V, which is what John hopes will continue as they grow older:

"They still operate together, he buys him things, whatever. So it's, it's not that they, I mean, now Seth's obviously old and also studying psychology, so he also understands more of what's happening. So they operate together all the time. It's not that he will kick his brother to the curb, you know, and even back then, he didn't do it. So I'm hoping, going forward, I mean, he's much older, they will still be together."

The impact on fathers' romantic partnerships

A shared experience as told by a few of the fathers in the study is how their child's autism has impacted their relationship with their romantic partner. It has presented new challenges, but as Tembi emphasises, it has also brought him and his wife closer together in some ways:

"So, we as parents, needs to be set fast in our routine. We cannot just make upright changes, because, again, that doesn't suit him. So it opens up our communication with one another a lot about him".

Joe has noticed the impact his son's diagnosis has had on his and his wife's relationship. In the beginning, they would blame each other for not fulfilling their responsibilities equally. He does however believe that it is something that they have both come to terms with and they are beginning to get to a place of acceptance:

"Oh, you're not pulling your weight, you know, in helping the boy to, you know, like, like, make him read and just, like, engage with him. So yeah, it has had an impact. And yeah, but I think now we kind of, like, have accepted and moved on, yeah, trying to find what's best for him."

Bob has found that X's diagnosis has brought about similar challenges for him and his wife. He and his wife will argue about the responsibilities they both hold and the roles they should be fulfilling. However, he believes that it is natural and does not feel as if it is a real concern as he has absolute faith in their relationship:

"Why aren't you doing it? You should be doing it. We obviously argue with each other, and we fight with each other, but I'm not someone that, I don't like to argue with people. I'll say my bit. She will rant and shout and do her thing and do whatever she does. But I know after she's gotten it out of her system, after the next few hours, the next morning, she'll be okay again, then we'll be back to lovey-dovey."

Bob feels that these challenges are not unique to parents of children with autism, but rather they are parenting challenges in general. He does, however, acknowledge that X's behaviour does contribute to said challenges:

"So it's obviously parenting things, normal relationship things that happen everywhere, obviously what you watch, what you might find is that because of with one's behaviour, it heightens that a bit more sometimes. So whereas if he didn't do that, we wouldn't be lashing out with each other because of that there. So obviously, if he was a lot more calmer and relaxed, then that fight could have actually been avoided, but because obviously, X is crying, you're trying to get done in the morning. You're trying to go and sleep and get done for the evening. With X crying now your tensions is raised. And when the mother's tensions is raised in the house, everyone's tensions is raised."

John got a divorce from V's mother, but he insists that V was not the cause of the separation. In fact, he shared that V's diagnosis brought them closer together:

"No, if anything, it made us closer. Because now you have to figure out things together. You have to, not that you shouldn't be figuring out things together, but now you really have to figure out things together"

However, John did share how his ex-wife and him often will not see eye-to-eye on how they should treat and raise V:

"His mother will not send him to school, stupid things like that. And I told her, treat him the way he should be treated, take the gloves off. He is old enough now."

Bob shares how he finds it difficult to reach his wife at times. She feels as if he is unable to understand her experience and this is difficult for Bob to accept, particularly when his wife is struggling with regards to their child's autism:

"Lonely, the word I want to mention was lonely, but when you said lonely, my wife always tells me, you don't know what I'm going through, but she is going through so that when you said lonely actually speaks to this. I do think now when you said lonely, she might

feel lonely sometimes, although she might be speaking to me about certain things, I can't I always tell, I can't understand certain things."

Bob describes the news of his son's autism as impactful on his relationship with his wife but not straining. There have been added frustrations and conflicts, but he believes that he and his wife are slowly coming to terms with the changes in their dynamic as partners and as parents. He feels that while the impact has been difficult to adjust to, open communication and understanding between himself and his wife has allowed for a smoother transition:

"So there is an impact on the relationship, but it doesn't put a strain in the relationship. So I feel that my wife and I, we have a very good relationship. We both have a very good understanding of each other, but we, obviously, we, we do fight when there's certain frustrations. When it comes to X there are frustrations between the two of us, so we'll lash out at each other and obviously, but it's not something that I would say puts a strain on our relationship, on our marriage. So we've been fortunate enough where we don't have any strains on our relationship, on our marriage. We understand each other, we understand what it is our roles and our responsibilities in terms of parents, husband and wife."

What is particularly difficult for Bob, however, is feeling villainised by his wife when challenges linked to their son's autism come about:

"So I understand, I understand. Okay, no, you're lashing out on me based on the children, because the children are frustrating you and upsetting you, but now you're coming on to me to basically get rid of your frustration. Looking for something to blame. She wants someone to blame. So she won't blame the children, she won't blame herself, but she'll blame me."

For Sihle, the impact of his daughter's diagnosis on his relationship with his partner has been noticeable. His biggest concern with this is how it effects his daughter's well-being, because he feels that when him and his partner fight or argue, it negatively impacts T:

"You know, sometimes I see even when the situation is not good at home, between me and the mother, she will pick it up, and then she will just get sick. So, yeah, so that's why I must not worry too much about her, her condition. I must try to accept the situation, the condition, so that she doesn't feel it. I don't take it out on her actually."

Institutional support, challenges and financial impact

A shared narrative as told by a few fathers in the study is their positive experiences of educational and healthcare support systems in South Africa. Both John and Bob speak of the ease of access to support for their sons' autism. John's son V has been in a special educational institution since he was seven years old, and the experience has allowed V to get the extra attention and specific care he needs:

"We got him in at school called G special needs out in … in Cape Town. And he spent, V spent, I think it was five years there and there what they had is they had the year that he actually started, the year that he started, the day is when they started having classes specific for kids with ASD. So, he was in a small class. There were three classes, like five, six kids in a class, and they'd have a psychologist, they have an OT, obviously the class teacher had training to handle kids with ASD. There's an assistant teacher, and there was another lady also there, yeah, yes, they had quite a team. So that was nice."

Bob talked about his experience of looking for a school who could cater to his son X's needs. While the schools he has been looking into are expensive, he has been surprised by the availability of such institutions and the extent of the care they offer:

"In terms of the support that there is in the country, I feel, I feel that South Africa has a lot more support compared to any other country. So, we're even contemplating immigrating to, like, New Zealand, Australia, Dubai, obviously, wherever there is. But when we notice that the support that the other countries offer, based on like TikTok videos from other parents that are in those countries, there isn't as much support in those countries compared to South Africa, so in terms of like but even if there is support there, it's very costly compared to here. So here it's very affordable, readily available. There's a lot of speech therapists, audiologists, occupational therapists, the developmental paeds [paediatricians] are there. So, all the support that we need for with X is in South Africa."

Joe shares how his son's mood has significantly improved since he began attending a special needs school. For Joe, this was a huge relief and something that brought him joy to see this improvement in K:

"Yeah, it's been for him, like it's been exciting because he's looking forward to go there, because they do like activities different from the creche. So, with the creche, at times, he would cry to get out of bed. With this school, like he wakes us up, you know, like he's always looking forward, and he packs his own lunch, crazy stuff. And, yeah, he wants to go. He's the first one in the car."

While he is happy to see his son doing well, Joe does still wish that K could attend a *"normal school"*. However, he is beginning to accept that this may not be possible:

"For me, I feel like I can't just, I can't wait for him to speak, and I want him to go to a normal school. But yeah, daily, I'm kind of like accepting maybe he might be here forever."

Bob likewise expressed how he has limited spaces in which he can share his experiences, but an eye-opening experience for him was the support he received from the company he works

for. They offered him counselling services, as he was unable to work to the best of his abilities. The experience helped him to talk through a lot of what he was thinking and feeling:

"So I phone, I guess. So they, on the other line, they'll have, like, a psychologist or whatever available. So I start speaking to this lady. She'll ask, like, a few questions. So I start speaking to her. And as I'm speaking to her, obviously now I'm speaking about work, the things you have to do at, at home, started speaking about X as well. Then on the phone, I started crying, whereas I don't usually, I'm not really someone that cries. So I started crying on the call, I didn't expect to cry."

Joe shares how the institutional support he has received for K has also given him access to a community of people with similar challenges, leading to sources of information, support, and guidance. This has made him feel less lonely with his experience:

"Yeah definitely, they are helpful. So also like it you know, it exposes me in that whole community. And you know, there's like some learnings or experiments that you know, OT or speech therapy would share with us to you know, to try with him to help him. And I've seen it that works. Like, his speech definitely has improved a lot, but it's not there yet. But like, there is an improvement."

The guidance Joe and his wife have received from healthcare professionals has greatly improved K's functioning, but also Joe's experience of fatherhood:

"They give us, (what's this man), you know, like activities to do at home, like to help him. Yeah, I've seen, like, it does help, to be honest with you, like it does help, and, yeah, like, since he's been going there, like, we've been seeing a huge improvement."

Sihle was initially very concerned about his daughter's behaviour and wellbeing. He and his partner were unable to find a school that could cater to her needs, and this was particularly

challenging and all-consuming for him, however, he and his partner were eventually able to find a solution:

"It was very bad. It was very bad at first, because we even changed her, we were assisted by the therapist to get a school that can accommodate, because the first school, they couldn't accommodate her. They couldn't understand, they couldn't understand, they couldn't understand her in terms of the situation."

He does however share how he is beginning to become more hopeful that his daughter's behaviour is improving since they were able to find her a new school:

"She wants her own space, and the other kids would be coming to her, wanting to interact with her. But ever since we changed her, I can see the improvement. Now, she no longer cries when she goes to school."

While the healthcare and educational support that is available to fathers has been reported to be readily available, it comes with the added stress of increased financial pressure. Bob compares the added financial strain to that of having to pay another bond:

"They're very high. They're very high compared to your normal schools. So obviously you have government schools, which obviously is going to be a lot lower. But if, if I compare the price compared to with X, or in terms of where they need to go, with X it is a lot. It's almost like you're paying another bond."

Tinus finds the added cost a significant stressor as well, particularly the educational requirements for his son:

"Also, the financial side of which say OK, now we need to find him a special school."

Bob also describes the challenges and concerns associated with sending X to a special needs school. He is worried that in some ways the behaviour of other children in these institutions may rub off on X, hampering his development:

"You don't want him to be around other children that is worse off than him, because you don't want him to pick up on that behaviour and exposing him to those type of things."

He shares how it can be particularly challenging when he is out with his son because other people do not know or understand why his son behaves in the ways that he does. Joe is fearful that he and his son are viewed as rude:

"Like some people wouldn't understand, like maybe, we would maybe go to the shop and the cashier, the cashier would try to make a conversation with him, you know? And yeah, he would not react, or he would just talk about gibberish. And yeah, it's some people don't, like, really understand, like, these conditions. And yeah, it makes it difficult. And so…"

A new perspective

The data indicates that the experience of fatherhood when raising a child with autism presents many challenges. The participants shared how their child's emotional regulation difficulties, speech challenges, and limited awareness of social cues impact their relationship with their child. However, a noticeable theme that has emerged from the fathers' shared narratives is how their perspective has been shifted through raising a child with autism; and while the ideal may not have been realised, such a perspective shift would not have been possible without their unique experiences of fatherhood. Bob speaks to how he has become more accepting of difference:

"Now you understand the world a lot differently. Now you actually have a better understanding and a better empathy towards those children and those parents and their

background and what they're going through and what they being exposed to, and so forth. So even as as a person, you're developing a lot more empathy towards every type of person."

Bob describes his steps into fatherhood as being life changing. Particularly so because of X's autism diagnosis:

"It completely changes your life. And not only children. Having your first child. It's not only your second child, your first child being an autistic child. So because of that, that obviously that first child being an autistic child, it changes your entire understanding of being a parent, because you never had the past, past experience of being a parent. And now the first child is an autistic child, autistic child."

For Tembi, he finds that he has learned a new way of seeing the world, through the perspective of his son Y:

"Yes, it's almost an, it's a breath of fresh air into life, because to start seeing it the way that he sees it."

Ted likewise speaks about how his son challenges him to read and educate himself in order to connect with his son and his interests. He shared how his son is intellectually strong and at times it is difficult to understand the way in which his son sees things, but Ted sees it as an opportunity to learn and engage with things he would not normally engage with:

"Well, that is not much that we like to do together, because he's on his own league but...ahhh he just, he does challenge us a lot, because he's high functioning things that even us as adults, we battle to understand, he understands them way quickly. So that forces us that now we need to always catch up with him and be ahead of him so that we can be able to assist him where he gets that. For an example, he's into solving the Rubik's Cubes..."

Joe believes he has become more patient, calmer, and has developed a greater appreciation for people and their differences as a result of having his son:

"But like, it's now, like, it's a full appreciation, like, okay, you know, let's work together, help you know each other and yeah, like it is, it has changed, like, I've become more calmer, like calm and more understanding and patient."

Bob describes a different kind of support, but a factor nonetheless that has been hugely helpful in him coming to terms with his experience of fatherhood and X's autism. He describes the role religion has played and how this sense of community, understanding, and acceptance has given him a sense of inner peace:

"So for me, personally, speaking, I just make another point, is that if it wasn't for my religion, I don't know where would I be, or what would I do, or how to be able to cope with everything, not only in terms of X but just in terms of life. Because the older you get, the more things seem to be like starting to get more difficult. Life, like as a teenager. Life is easy. And then when you in your 20s, early 20s, you don't have a wife, you don't have responsibilities. Life is easy. Then you get married, becomes a bit more difficult. You get children, it becomes a lot more difficult. And the older you get, the more difficult it becomes. And then I'm just thinking obviously, because obviously your faith teaches certain things and certain ways to be. Because of that knowledge that I have and that understanding I have, it helps me a lot in terms of my relationships and my understanding and my life and all those sort of things. So that's spirituality for me. It's number one. It's number one."

Shortly after X was diagnosed, Bob sought out answers for why his son had been diagnosed with autism, seeking the guidance of a religious scholar. While he does accept the diagnosis and the challenges that come with it, like many of the fathers in this study, he was searching for answers:

"What's wrong? So I explained to him, No, the autism, the behaviour, whatever. And then indirectly, I asked him about, like, you know, the witchcraft and those type of thing, but not directly. So I asked him in an indirect way as well."

The 'Molana' or religious scholar provided Bob with several herbal remedies and dietary suggestions to aid in helping X maintain stability when he becomes emotionally dysregulated. Bob is a Muslim man and has found a lot of peace and guidance from his faith. He was able to find a better way of managing the challenges associated with raising X, particularly his own stress levels and managing his own emotions:

"You have to do what you're supposed to do as a Muslim man as well, make sure your religious responsibility is taken care of, and when all of that is taken care of, your household basically runs a lot more smoothly than if I wasn't. So from then, because of all of those things, I was actually able to regulate my relationship with X, so even like the aggression and the frustration that we have with him isn't really there that much because of obviously, having other avenues."

Joe has had a similar experience whereby since his son's diagnosis, he has become more in touch with his spirituality. He, like Bob, was in search of answers:

"Yeah, yeah and also like, umm I would say like, I've been more like, also like, spiritual, in a way where, like, I would talk to God, if there's such? Or I believe there is a God, like, I've been more like, more like, more in touch with that aspect, you know, because of this whole change, I don't know why, but it's because I need answers. Like, you know, why my son is like this? And you know that has, yeah, like, opened...opened, opened my eyes."

Bob describes the importance of self-care in his ability to fulfil his roles as a father and husband. He believes that the challenges that come with raising children and raising X have

made him realise how important it is to take care of yourself, to give yourself the best possible chance of fulfilling your responsibilities:

"So I think also, like obviously, your study based on being a father, all men have a sense of understanding of that you need to provide. You need to do. You need to make sure things are done. And because of that load, sometimes you also need time for yourself. You have to make time for yourself no matter what it is. And also, I've always been someone that I've always been physically active, like running, soccer, boxing, kickboxing, all those things. So only from that, I realised you always need to take care of your physical health also. So your physical health will have a direct impact on your mental health. It will have a direct impact on your family as well. So even though men have all this responsibility, they have to take care of themselves."

Sihle was originally concerned about T's diagnosis, but he now has a more positive view on what this could mean for his daughter. He describes how people perceive people with autism, and how people with autism seem to have a unique and complex outlook on things:

"There are advantages of autism, and because autistic people are perceived to be clever people you see. They can, I don't know how to explain it, but they can see things even before they happen, their anticipation is just on another level."

For John, he believes he has become more observant, and his son offers him a fresh perspective, leading him to view the world in a way that is novel:

"Yeah, I mean, he'll point out that I don't take note of, their minds work differently, he'll point out things that you may be overlooked, or whatever the case is, we didn't think about it, and he will see it, or he will remember about something you told him five years ago and bring it up in a conversation, prove you wrong or whatever. He will go out of his way to sometimes do stupid things like that. He's always cheerful. He's never freaking miserable, and

that's what I like about him, he's always, he gets up in the morning, he's got a smile on his face."

The next chapter will discuss these findings in relation to theory, critically engaging with the narratives through a lens of the social model of disability and gender ideology. The fathers' experiences will be dissected to reveal how their child's/children's autism has shaped them as fathers, as men, and as people. Furthermore, the quality of their experience will be discussed in relation to factors that may impact on this, to ultimately answer the research questions posed.

Chapter 5

Discussion

The path to acceptance and redefining fatherhood

This research primarily aimed to investigate the factors that affect fathers' experiences in raising a child with autism and how these experiences influence their *identities* and the way in which they relate to themselves and others. Accepting the loss of the "ideal" father/child relationship while parenting a child with autism poses significant challenges for the fathers involved in this study. Moreover, their ability to engage with and embrace their new roles within the framework of social, cultural, and religious norms has played a crucial role in shaping the quality of their experiences as fathers. Marcinechová et al. (2024) emphasise the struggle fathers face when they cannot grasp the underlying reasons for their child's autism. Tembi describes the initial period after his son's diagnosis as one of *"disappointment,"* referring to the realisation that the relationship he envisioned with his son would be altered. Whereas Sihle continues to seek answers regarding his daughter's autism and contemplates whether he or his partner are partially to blame for her condition.

For all fathers in this study adjusting to the disparity between ideal and actual experiences has required a gradual transition into a new form of fatherhood. The data demonstrates that the duration of time passed since the child's diagnosis significantly affects a father's capacity to understand their child's reality, the nature of their relationship with the child, and influences how their experience of fatherhood shapes their self-perception, cultural *identity*, and masculinity (Dardas et al., 2014). Connected to the time since diagnosis is the child's age, which also affects parental experiences (Marcinechová et al., 2024). For instance, Sihle's journey contrasts sharply with John's. Sihle's daughter is currently three years old and has recently received her diagnosis, while John has spent over a decade coming to terms with his

son’s autism. Initially, John faced similar challenges to Sihle, experiencing emotions such as guilt, anger, shame, and loss after his son’s diagnosis; however, he has had time to adjust to both his son’s autism and their father/son relationship. In general, feelings of guilt, anger, shame, and even depression are typical responses for parents learning about their child’s autism, as noted by Marcinechová et al. (2024). In particular, the fathers in this study have been asked to examine how they reconciled the imagined loss of an ideal relationship with their child and adjusted to the transformative process of redefining and perceiving their roles as fathers and individuals. Fathers may face the realisation that their *identities* are changing as they embrace the roles necessary for raising a child with autism. Concha et al. (2016) discuss how gender-role *identities* can significantly influence how parents perceive their domestic responsibilities. Furthermore, as Kehinde et al. (2023) observe, gender stereotypes dictate fathers' behaviours and the roles deemed acceptable for their masculinity. In South Africa, traditional conservative values regarding family gender roles prevail (Petersen & Lesch, 2022). Traditionally, fathers have been seen as protectors and providers, while nurturing responsibilities were assigned to mothers (Petersen & Lesch, 2022). In their study, Bitalo et al. (2024) emphasises that while black South African fathers may recognise the importance of emotional support and participation in their children’s lives, this duty is often seen as secondary to their primary role as men and fathers, which is to provide materially for their families. However, as the data in this study suggests, when raising a child with autism fathers in South Africa may have to challenge their own understanding of how they are to show up as men and as caregivers. This means challenging their own understanding of their masculinity which is inherently linked to their culture (Bitalo et al., 2024). Furthermore, by taking up a role that is typically not accepted as a part of cultural practice, they may fear upsetting others in their community or even their family.

This argument extends beyond gender roles, into how societal norms may greatly influence a father's experience raising a child with autism. For instance, Joe demonstrates how his cultural background has led to his family questioning the spiritual implications or authenticity of his son's autism diagnosis. Culturally, such situations may be viewed as atypical, whereby communities cast negative spiritual or cultural judgments (Lentoor et al., 2023). Hence, fathers like Joe may experience rejection or ostracization because of a lack of acceptance of his child's autism. Such stigma around autism speaks to how societal and cultural barriers may negatively influence fathers' experiences. Instead of acceptance and support, fathers may experience inflexible social and cultural beliefs that limit their child's integration into society and by consequence, their own integration (Lentoor et al., 2023). Fathers who prior to their child's diagnosis may have been heavily involved in their communities, may choose to self-isolate out of fear that their child and themselves will be mistreated (Sumbane, 2024). Thus, the parenting responsibility falls on the individual or their immediate family in making the necessary adjustments to care for a child with autism. Adam and Koutsoklenis, (2023) argue that the responsibility should not only fall with the individual and their family, but with the community and social institutions who can create more inclusive environments for individuals with disabilities. However, as Tembi can attest, his social group has found it difficult to accept his child's autism and the behaviours that accompany it. Tembi is a proud Afrikaans man whose *identity* is linked to his love for his culture and by virtue of this, a love for sport, particularly rugby. However, his son does not engage in sport as he would wish, which has been a difficult thing for him to accept. Part of Tembi's difficulty in coming to terms with his son's autism is having to let go of his dream to share his love of sport with his son. Instead, he has had to be flexible and adopt new interests that align with his son's, thereby enabling a point of connection. Tembi's experience highlights how conflicting it can

be for fathers to shift aspects of their *identity* to cater for their child's needs when they do not have absolute support and acceptance from their communities (Adam & Koutsoklenis, 2023).

Fathers in this study expressed how overwhelming they initially found the demands of hands-on caregiving. A gentler, more nurturing form of masculinity and fatherhood is often essential in raising a child with a disability (Adam & Koutsoklenis, 2023. However, embracing this as a father may be difficult as they may not have been expecting to take up such caregiving roles. Furthermore, fathers may not seek out support from their communities, fearing that others will not understand how to care for a child with autism (Sumbane, 2024). Hence fathers in this study, and others in similar situations, may need to challenge traditional beliefs about gender roles, showing a willingness to fully engage in all aspects of their child's care, moving beyond responsibilities typically associated with men or father figures. This process underscores their need to acknowledge and embrace a new *identity* as fathers and men.

A prevalent social model of disability and associated challenges

Behavioural acceptance

Lentoor et al. (2023) elaborate on the psychological impact of raising a child with a neurodevelopmental disorder such as autism. The daily challenges of caregiving are very different to those faced in parenting neurotypical children, which can lead to great despair for a caregiver (Lentoor et al., 2023). Tinus speaks about the difficulty in even the most basic tasks relating to his son because of his hyperactivity, i.e., getting his son ready for school or getting him to eat a meal. All these tasks can be challenging to navigate because of his son's behavioural issues related to his autism. Lentoor et al. (2023) attribute the experienced psychological distress of parents to their inability to fully understand their child's needs and struggles in managing behavioural difficulties. Fathers like Joe, Sihle, and Bob have all highlighted how difficult it has been to adjust to some of the behavioural challenges

associated with their child's autism. This is particularly challenging because of the stigmatisation of such behaviours and 'difference' (Alareeki et al., 2019). This may be due to the biomedical model and the stigmatisation that comes with a diagnosis such as autism (Alareek et al., 2019). A stigmatisation that reinforces the social model of disability whereby the prevailing norms and social perceptions are a barrier to acceptance and inclusion. It highlights the unaccommodating nature of a society that views difference as an individual medical problem, but it is in fact a social one (Hogan, 2019). Bob describes the shame one may feel when others judge one's parenting ability because of one's child's disruptive behaviour that is linked to their autism. Alareeki et al. (2019) speak about how parents may find themselves on the receiving end of judgement because they cannot keep their child 'in order'. Adam and Koutsoklenis (2023) discuss how the social model of disability focuses on the sociological aspects of disability, ignoring the medical or inherent characteristics. However, as fathers in this study have made clear, their child's autism does come with behavioural characteristics that not only create individual challenges but rather they are perpetuated by an unaccepting society that is unwilling to make the necessary accommodations to cater for such individual challenges.

In South Africa, mainstream schools are required to cater to the needs of individuals with learning disabilities as outlined in the Education White Paper 6 (Hove et al., 2024). However, the reality is that many mainstream schools in South Africa have not fulfilled this obligation, meaning a significant burden is placed on special needs schools, of which there is a shortage (Chirowamhangu, 2024). Bob highlights the issue with this from a socialisation perspective; autism is associated with difficulties in relation to understanding social cues, so integration with neurotypical children in a learning environment could assist in this regard. Thus, although he is happy that he was able to find a special needs school for his son, he is concerned that it means his son will not engage with neurotypical individuals. Hence, as the

social model of disability highlights, individuals with autism may be separated from mainstream society and by virtue of that, fathers may also be separated from parents of neurotypical children, further embedding a lack of inclusivity (Thacher, 2024).

Consequently, children with autism are then required to attend Special Learning institutions, which are specifically for children with similar challenges, meaning that opportunities to develop an understanding of social cues by integrating with neurotypical individuals are limited. This is a double-edged sword as this is not only isolating for individuals with autism and their families, but it also limits mainstream society's interactions with individuals with autism, perpetuating a lack of understanding and by virtue of this, a lack of acceptance (Adam & Koutsoklenis, 2023). For example, Bob acknowledges that his son is the first person he has ever known to have autism, which emphasises a lack of inclusivity for individuals with disabilities that the social model of disability highlights (Adam & Koutsoklenis, 2023). Conversely Tembi's experience has been more positive because of his son's integration into a mainstream schooling environment that is able to cater to his needs. While he still faces challenges regarding his cultural *identity* and difficulties with his community in accepting his son's behaviours, he is far less isolated from members of his community and other parents. He is able to engage with parents and teachers about his son's autism, which fosters an understanding of the disability, and lessens his feelings of shame around his son's diagnosis and his experience as a father (Hove et al., 2024).

Communication challenges

Generally, fathers in this study report that their child with autism struggles with social skills and cues, emotional regulation, and attention and hyperactivity (APA, 2013). These are common symptoms of autism, and the severity of behavioural difficulties greatly determine how a father experiences the day-to-day fathering of a child with autism (Reed et al., 2017).

For example, Bob and Joe have experienced more day-to-day frustrations associated with the hyperactivity and communication difficulties of their sons, in comparison to fathers such as Tembi and John who had more difficulties with their children's lack of social skills and understanding social cues. These nuances in how autism presents itself in a particular child can greatly shape how a father experiences fatherhood in these instances (Reed et al., 2017).

The managing of these behavioural differences is made particularly challenging because of the severity of communication difficulties and/or repetitive behaviours which are often associated with autism (APA, 2013). Hirota and King (2023) emphasise how communication difficulties in children with autism can lead to troubled relationships with parents. For Tembi and Joe, this is something they can relate to, whereby it is difficult to build an emotional connection with their sons, as Dawson (2023) surmises may often be the case. Tembi's experience in the early stages following his son's diagnosis was difficult and more negative because of a possible reluctance to shift parts of his *identity*. The social model of disability speaks to this lack of flexibility and how a disabled individual's experience is shaped by the way in which their environment is able to accommodate and accept them (Thacher, 2024). Tembi's negative experience may have been linked to his inflexibility to meet his son where he was, thereby making it more challenging to connect to his son in the way he desired. For example, Tembi's immediate family speak to one another in Afrikaans, the language makes up a large part of his cultural *identity*, but his son is unable to communicate in Afrikaans and will only communicate in English. This is something that may be very difficult for a father to accept, whereby he is unable to share this part of his culture with his son (Alareeki et al., 2019). Furthermore, this difficulty for Tembi was enhanced by his community's tendency to question his son's inability to communicate in their language, leaving him feeling ashamed and excluded as a father (Alareeki et al., 2019). However, his experience of fathering his son improved greatly once he was able to accept the shift in what was required from him as a

father, namely, to communicate in English with his son. By virtue of this, his son was able to connect to him on a level that was not previously possible, which made Tembi's experience of fatherhood more pleasurable and meaningful.

What has been difficult for fathers in this study is providing for their children when they are not able to communicate verbally exactly what it is they need. Joe speaks to the frustration of his son acting out when his needs are not being met, but he does not vocalise, which makes it frustrating for Joe because he is left feeling stuck, not knowing how he can ease his child's discomfort or dissatisfaction. This is a finding that Hirota and King (2023) also identify in their study on parents' experiences of raising a child with autism. However, the behavioural tendencies and communication styles are idiosyncrasies that all contribute to what makes each child unique and this is no different in a child with autism (Jones et al., 2013). John emphasises this in describing how his son's autistic traits are simply one aspect of his *identity,* and they are what makes him special in his own way.

The fathers in this study report the difficulties of their children to be more in line with a level 1 autism severity. However, when analysing the reported difficulties closely, such as those experienced by Bob's son, a level 2 severity may be more accurate. One wonders whether this is an attempt to under-report the severity of their child's autism as an attempt to avoid judgement and ostracization (Lentoor et al., 2023). In Bob's case he may be struggling to acknowledge where his child is in terms of his communication needs. This may stem from a difficulty in accepting a more hands-on, day-to-day nurturing role that he is not entirely comfortable to accept as a Muslim man (Glas, 2023). Bob may be accustomed to the typical roles of a father, being that of provider and head of the family and to adapt to his child's needs, communicating with him in a more nurturing way may be shaming for him as a man (Glas, 2023). Hence, the downplaying of the severity of his son's autism may also speak to a difficulty in accepting that his role is religiously and culturally atypical and one he is

reluctant to play (Glas, 2023). However, by denying this role, he may not be able to connect to his son in the way he would like, thereby directly influencing the quality of his experience as a father. Bob's experience emphasises how rigid South Africa's social, cultural, and religious norms may be and how this rigidity can consequently impact the levels of accommodation and acceptance of a child's autism (Adams & Koutsoklenis, 2023). Fathers in South Africa may struggle to communicate and connect with their child with autism, preventing a relationship with their child that they desire, and this may be down to a difficulty in accepting an atypical cultural, religious, or gender role (Bitalo et al., 2024).

The impact on the psychological and mental well-being of fathers

Koltai et al. (2024) note that having a child with autism can affect not only the father's mental health but also disrupt the entire family, thereby increasing stress for parents as stated by John who discusses experiencing episodes of depression in the years following his son's autism diagnosis. However, the emotional and physical effects of raising a child with autism can be mediated by focused practices to maintain personal health as attested to by several of the fathers. Dein (2018) argues that religion and spirituality can positively impact one's mental health. Namely by; promoting a greater sense of hope, improving self-esteem, and increasing life satisfaction (Dein, 2018). Bob, Joe, and Tembi share the positive impact their spirituality has had on them being able to manage their physical and psychological health. For example, Bob highlights how being a Muslim man enables him to find structure, guidance, and peace in an otherwise fraught experience of raising a son with autism. Monteiro-Junior et al. (2013) also highlight how physical exercise is linked with better mental health, which is particularly important when under increased stress, as is the case for fathers in this study. It was commonly shared how physical exercise and sport has contributed to them being able to manage the increased stress they feel in their day-to-day roles as fathers. The extent to which fathers have positive or negative experiences when raising a child with autism is considerably

shaped by their acceptance of the reality (Weiss et al., 2012). Parent empowerment refers to a concerted effort by parents to eliminate stressful events by educating themselves with skills and knowledge to prevent such stressful events taking place in the future (Weiss et al., 2012). Fathers such as Bob, Joe, and Ted stressed the importance of open communication with their partners and continuously seeking out new information or knowledge. Parental empowerment links directly to parental acceptance, whereby parents can acknowledge that their reality, i.e., the challenging behaviours of their child with autism cannot be immediately resolved or ignored (Weiss et al., 2012). Weiss et al. (2012) describe a negative correlation between levels of acceptance and psychological difficulties such as anxiety, stress, and depression, meaning the more accepting a father is of his child's autism and the reality of his experience of fatherhood, the less he is likely to struggle with significant mental health challenges. Acceptance in this context refers to a father's willingness and ability to embrace the idea that typical coping mechanisms such as avoidant or problem-focused strategies are not effective with their child because of the frequency and persistent nature of behavioural difficulties associated with autism (Burell et al., 2017). However, this means that fathers need to embrace their emotional struggles and seek out support, which is something that men traditionally struggle to do (Ward et al., 2013).

Zondi (2022) notes how in South Africa, many mental health struggles go undiagnosed for men due to a stigma around what is expected of a man. Men may often feel afraid to seek out support because societal and cultural beliefs dictate that men are strong providers, who stoically carry their personal challenges on their own shoulders (Zondi, 2022). One may infer that the perceived stigma surrounding male mental health issues and disability and autism in South Africa may limit the ability of fathers to engage openly within their communities about their experiences. However, if they are unable to do this out of a fear that their child will be misunderstood, or out of fear that their own challenges will not be understood, they may

choose to isolate, leading to an overall negative experience of fatherhood. Fathers raising a child with autism may need to confront their own *identities* as men and what this means in this unique context of fatherhood, but they also must navigate this experience in the context of a society that perpetuates the very masculine ideals that they are needing to confront. Hence, fathers may desire emotional support, but social and cultural barriers may prevent them from seeking out such support (Zondi, 2022). Fathers in this study speak to how challenging it can be to communicate openly about their emotional experience. Fathers are asked to adopt a new role as caregivers, where they are required to offer their child hands-on nurturing and emotional support, which is outside their primary traditional role as providers and protectors (Bitalo et al., 2024). Then to compound this conflict between their masculine ideals and their reality, they may be required to take up self-care behaviours and seek out emotional support in a way that is socially and culturally outside of the South African norm for a man (Zondi, 2022).

However, if they are able to prioritise their self-care and emotional health by seeking out support, it can leave them feeling substantially less isolated, as Bob attests to. He shares an experience where he broke down into tears and shared his struggles with a call-centre support worker. While he found this out of character and out of the norm for a man from his culture or religious background, this experience was freeing emotionally where he felt as if a burden had been lifted.

Institutional support and the financial burden

The nurturance and added care required in providing for a child with autism likewise comes with a great financial burden (Brobst et al., 2009). Bob and Ted emphasise the significant expense of enrolling their sons in special needs schools. Coupled with the need for therapies such as speech therapy, parents face a heavier financial strain, which increases stress and

complicates their experiences of fatherhood compared to fathers of neurotypical children (Brobst et al., 2009). These financial and institutional factors reiterate the social model of disability's contention that it is societal barriers that limit an individual from full inclusion and acceptance in society. Furthermore, in the context of the masculine ideal in South Africa, where fathers may be culturally and socially expected to play the role of material provider, fathers raising a child with autism may feel an even greater pressure (Bitalo et al., 2024). This may lead to experiences whereby fathers are not able to provide a certain material standard for their child and family, which may significantly shift how they view themselves and may possibly even lead to feelings of shame.

Although the added care required for a child with autism can place a financial burden on parents for a longer period compared to a typically developing child (Brobst et al., 2009), Bob speaks positively to how readily available institutional support is in South Africa. He believes that South Africa holds a position of strength when it comes to offering institutional services that cater for the needs of a child with autism. Ted agrees with this perspective, however, he believes that South Africa lacks culturally appropriate educational resources for children with autism, where most of the resources he has been able to find are from the United States of America or Europe, where the themes and language may not be culturally appropriate in a South African context.

Impact on the family system

The financial burden aside, within the familial structure, a child with autism may cause turbulence in the overall dynamic (Garrido et al., 2020). Siblings of children with autism are shown to be more susceptible to depression and anxiety (Garrido et al., 2020). These authors note that emotional difficulties for siblings of children with autism are not getting enough social support, which can be the result of the additional attention and responsibility focused

on the child with autism. Sihle speaks about how important it is to involve his other children as much as possible to prevent a disruption to the family system, where one child may feel sidelined because of the added care his son with autism requires. This experience of Sihle's speaks to a cultural pressure, whereby he is expected not only to provide materially, but to be the head of the familial unit and protect all family members involved (Lien et al., 2021). Sihle's cultural and masculine identity are an intrinsic part of who he knows himself to be and raising a child with autism may lead to him having to be more flexible with these aspects of his identity, which is something that may be challenging to accept.

Furthermore, raising a child with autism can lead to fathers facing new dynamics or challenges with their partners (Koltai et al., 2024). The hands-on care required of parents to a child with autism means that stress can put pressure on a couple's relationship (Koltai et al., 2024). Bob speaks to the challenges he and his wife have faced following his son's autism diagnosis. He shares how arguments may ensue between him and his wife over household responsibilities and care for their son. As Kehinde et al. (2023) describe, gender ideologies may influence how a father views his role in the household and this envisaged role may be at odds with what is required of him in raising a child with autism, where hands-on care is needed. However, Bob also shares how he believes his relationship with his wife has benefitted from the increased communication raising their child has necessitated. John and Tembi share this sentiment. García-López et al. (2016) highlight how important it is for parents to offer each other emotional support when raising a child with autism, and if this is the case as with John, Tembi, and Bob, stress on the family system can be better managed thus facilitating a better experience of fatherhood.

Families of children with autism typically also receive less social support from extended families than families with typically developing children (Garrido et al., 2020). However, in the case of the data collected in this study, the opposite is true. Fathers shared what, for the

most part, have been positive interactions and supportive experiences from their extended families, highlighting how the social and cultural environment can influence whether a father raising a child with autism has a positive or negative experience of fatherhood (Sumbane, 2024). This illustrates how societal accommodations shape the experience of disability and by extension, the experiences of those raising individuals with a disability. Over time the fathers in this study have adopted an accommodating and accepting attitude towards their child's diagnosis and the disclosing of it to their families. If fathers are forthcoming with information about their child's autism diagnosis to their families, their overall experience may be enhanced because of the accompanied support (Garrido et al., 2020). This is something that both Joe and Tinus share about their experience, whereby they believe they have a fresh appreciation, acknowledgement, and understanding of difference. This change in perspective and empathic point of departure has been associated with an increase in familial closeness (Kayfitz et al., 2010). Kayfitz et al. (2010) say that families containing members with disabilities or neurodevelopmental disorders have a renewed understanding and empathy for difference. This includes friendships as Joe attests to, whereby a close friend of his also has a child with autism and this shared experience adds to his sense of community and support. The added family closeness and support contributes to how fathers experience raising a child with autism (Kayfitz et al., 2010). Additionally, this highlights how the social integration of South Africans with disabilities, not only within families but in mainstream educational and social environments as a whole, can foster a greater acceptance and understanding of disability in general, as well as improve accommodation practices.

Chapter 6

Conclusion

The data in this study illustrates the nuances of fathers' experiences when raising a child with autism. Although the fathers interviewed describe many similar experiences, they also recount the different experiences in their parenting journeys thus far. These experiences are very much shaped by the presentation of their child's autism. The severity of the autism diagnosis, the communication abilities of the child, and the severity of the behavioural difficulties all impact how a father may experience his child and fatherhood. Furthermore, the data indicates that the age at which the child was diagnosed and the period of time that has elapsed since the diagnosis, also plays a role in the fathers' outlook on their situation. The financial implications involved in raising a child with autism can be burdensome on fathers and their families, which can be stressful and overwhelming. Spousal support or support from a partner can significantly improve this experience as the fathers in this study have illustrated, although raising a child with autism does test a couple's ability to communicate and work as a team. Familial support has been shown to play a big role in shaping the quality of a father's experience. As the majority of fathers in this study can attest, familial acceptance of their child's diagnosis is not only important for their own health but also for their own acceptance of their experience.

The acceptance of the reality of this unique fatherhood experience seems to positively correlate with fathers' overall contentment with their child's diagnosis and what that means. Coming to terms with the loss of an ideal is particularly difficult and this may often be accompanied by melancholia and depression (Burell et al., 2017). The relationship a father envisaged, whereby he and his son/daughter would connect in a particular way, share an emotional bond, and partake in shared activities and interests is difficult to forget when

confronted with the alternative reality of a child with autism. That being said, it seems that if this reality can be accepted as a new 'normal', the experiences of fathers can be greatly enriched (Burell et al., 2017). The new 'normal' may mean adopting child-rearing roles that are conflicting to fathers cultural and religious masculine *identities* (Lien et al., 2021). Furthermore, fathers may have to sacrifice parts of their *identity*, such as language or their affiliations to social or sporting codes in order to connect to their children in a way that is meaningful to them. The child's autism can be accepted as just another part of their *identity*; John was adamant about this being integral in enhancing his experience of fathering a child with autism. He accepts his son for who he is, the autism is simply one of his many parts (Van Beveren et al., 2023). This process can be facilitated by self-care such as religious practices, exercise, and open communication with partners (Monteiro-Junior et al., 2013). Furthermore, familial and institutional support can play an integral role in a father's experience. However, by embracing such support and sharing emotional challenges, fathers need to again confront stigmatisation around male mental health struggles and what is accepted as typical masculine self-care practices (Zondi, 2022). This study not only highlights how a father's *identity* is shaped by simply becoming a parent, but also how their unique experience of fatherhood is shaped by their child's requirements for care because of their autism. The fathers have all had to confront and redefine their traditional views of fatherhood and assume a specialised parental role where hands-on care and nurturance is paramount for the development of their child and their own overall experience of fatherhood. If they are able to challenge these ideals within themselves by showing a flexibility, acceptance, and openness to difference, then it is conceivable that greater South African society can do the same in embracing autism and disability, as it strives to achieve a more integrated society. Autism should not be viewed as an individual problem but as a societal one that is sustained by all of us. The stereotypes and prejudices we hold regarding the

abilities of individuals with disabilities may contribute to their exclusion. Therefore, this paper and the social model of disability aim to emphasise society's role in perpetuating prejudicial views on disability and aid in changing these views at a social and institutional level.

Limitations of the study, recommendations for future research and clinical implications

Limitations

In this study, all participating fathers are raising children with level 1 or level 2 autism (APA, 2013). While the findings may shed light on the experiences of fathers in these situations, they do not accurately reflect the experiences of fathers raising children with more severe autism diagnoses. Furthermore, ambiguity between the reported severity of the autism diagnosis and the actual severity of the diagnosis may have hampered the interpretation of the data. While this provides an interesting point of discussion, namely how or why fathers may misreport the severity of their child's autism, it created a difficulty in comparing the fathers' experiences accurately and definitively.

Additionally, since all fathers in this study belong to the same social class and middle-income range, the results are interpretable only in relation to others with similar socio-economic backgrounds. This sample homogeneity may have limited insights into cross-cultural and cross-class fatherhood experiences related to raising a child with autism. Regarding the theoretical frameworks employed, namely gender identity theory and the social model of disability, this homogeneity may have diminished the richness of the data and obscured points of comparison. For instance, fathers of children with autism from low-income backgrounds may encounter different societal barriers to care and support compared to their middle or high-income counterparts. However, with no such fathers included in this study, comparisons

across income classes were impossible. This shortcoming also speaks to a limitation in using the social model of disability as a framework, when the construction of disability is directly influenced by class and access to services that are dictated by socio-economic status.

Interviews for this study were conducted both in person and online via a video calling platform to accommodate participant availability; however, this presents certain limitations. In-person interviews can foster opportunities for non-verbal communication and rapport building, which are harder to achieve through video calls. This limitation might have affected the quality of the data collection process since non-verbal cues are restricted, making it more challenging to establish rapport. A lack of rapport may lead participants to be less open about sharing vulnerable, in-depth information. Furthermore, the power dynamics between the interviewer and interviewee could have influenced the openness and depth of participants' responses. Using semi-structured interviews, where the researcher prepared the questions, may have directed the conversations in particular ways, in contrast to a less structured interview approach that might have encouraged greater depth and nuance in discussions.

In the sampling process, the researcher was initially worried that fathers might be reluctant to come forward and participate in the study due to traditional gender roles and the vulnerability this could reveal. However, this was not the case. Fathers were keen to get involved and contribute to research on autism, which reflects a movement towards greater openness and engagement with disability, particularly autism. It may also indicate the fathers' desire to be heard and understood, especially in environments where they may lack spaces to discuss their experiences or those of their children.

Recommendations

For future studies, it is advisable to include fathers from diverse socio-economic backgrounds and those raising children with a level 3 autism diagnosis (APA, 2013). This could facilitate

comparisons of experiences among fathers across cultures and classes, creating a richer and more comprehensive dataset using theoretical frameworks like gender identity theory and the social model of disability. Additionally, expanding research to other regions in South Africa could provide a clearer understanding of South African fathers' experiences raising children with autism. Ideally, future studies should aim to conduct all interviews in person.

Clinical Implications

Clinically, this research contributes to the literature on parental experiences in raising a child with autism and specifically how institutional and therapeutic support can be tailored to address the unique challenges facing fathers in the South African context. By delving into fathers' experiences, the study highlights the distinct difficulties they may face. This insight can inform parental counselling and support by promoting approaches that help parents manage their physical and mental health while developing effective and adaptive strategies for coping with stress. When parents can better handle their stress related to childcare, they are more equipped to provide attentive and engaged caregiving.

The aim of this research was to explore the experiences of fathers raising children with autism in South Africa. By doing so the researcher hopes to have added to the knowledge base of parenting a child with autism, specifically from a father's perspective. A repeated refrain by fathers in this study was the comfort they derived from increasing their knowledge about their child's autism. John emphasised just how much social context can impact one's experience of disability and raising a child with disability,

"So even the people that he interacts with, like, four times a week, six years straight, they didn't really recognise anything. So that was something good to me. And I enjoyed that, you know, and then they treat him like any normal kid, you know."

The hope is that this research, and research of its kind, will provide meaningful support and insight in a South African context, to improve experiences of disability, specifically autism, and those raising children with autism.

References

Abubakar, A., Ssewanyana, D., & Newton, C. R. (2016). A systematic review of research on autism spectrum disorders in sub-Saharan Africa. *Behavioural Neurology, 2016*, 3501910-14.

Adam, S., & Koutsoklenis, A. (2023). Who needs the social model of disability? *Frontiers in Sociology, 8*, 1305301-1305301. https://doi.org/10.3389/fsoc.2023.1305301

Adams, S. N. (2024). The unmasking of autism in South Africa and Nigeria. *Neuropsychiatric Disease and Treatment, 20*, 947-955.

Adeoye-Olatunde, O. A., & Olenik, N. L. (2021). Research and scholarly methods: Semi-structured interviews. *JAACP: Journal of the American College of Clinical Pharmacy, 4*(10), 1358-1367.

Alareeki, A., Lashewicz, B., & Shipton, L. (2019). "Get your child in order:" illustrations of courtesy stigma from fathers raising both autistic and non-autistic children. *Disability Studies Quarterly, 39*(4)

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.).

American Psychological Association. (2018). *Interpretivism*. APA Dictionary of Psychology. Retrieved from APA Dictionary.

American Psychological Association. (2023). *Caregiver*. APA Dictionary of Psychology. Retrieved from APA Dictionary.

Bitalo, D. W., Piotrowski, K., & Naudé, L. (2024). Fatherhood, manhood, and personhood: South African fathers' experiences of parental identity development. *Journal of Family Studies, 30*(6), 1106-1129. https://doi.org/10.1080/13229400.2024.2398579

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

Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities, 24*(1), 38-49.

Burck, C. (2005). Comparing qualitative research methodologies for systemic research: The use of grounded theory, discourse analysis and narrative analysis. *Journal of Family Therapy, 27*(3), 237-262.

Burrell, A., Ives, J., & Unwin, G. (2017). The experiences of fathers who have offspring with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(4), 1135-1147.

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

Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., Bywaters, D., & Walker, K. (2020). Purposive sampling: Complex or simple? research case examples. *Journal of Research in Nursing, 25*(8), 652-661.

Chirowamhangu, R. (2024). Inclusive education pandemic: Learning barriers for children with disabilities in South Africa. *African Journal of Disability, 13*, 1-10. https://doi.org/10.4102/ajod.v13i0.1462

Concha, M., Villar, M. E., Tafur-Salgado, R., Ibanez, S., & Azevedo, L. (2016). Fatherhood education from a cultural perspective: Evolving roles and identities after a fatherhood intervention for Latinos in south Florida. *Journal of Latinos and Education, 15*(3), 170-179.

Cope, D. G. (2014). Methods and meanings: Credibility and trustworthiness of qualitative research. *Oncology Nursing Forum, 41*(1), 89-91.

Dardas, L. A., & Ahmad, M. M. (2014). Psychosocial correlates of parenting a child with autistic disorder. *The Journal of Nursing Research, 22*(3), 183-191.

Davis, S. N., & Greenstein, T. N. (2009). Gender ideology: Components, predictors, and consequences. *Annual Review of Sociology, 35*, 87–105. https://doi.org/10.1146/annurev-soc-070308-115920

Dawson, H. J. (2023). Father-child (dis)connections: Expectations and practices of young un(der)employed fathers in Johannesburg. *Men and Masculinities, 26*(2), 270-287.

Dein, S. (2018). Against the stream: Religion and mental health – the case for the inclusion of religion and spirituality into psychiatric care. *BJPsych Bulletin, 42*(3), 127-129.

Flick, U. (2022). The SAGE Handbook of Qualitative Research Design. In *SAGE* Publications Ltd eBooks. https://doi.org/10.4135/9781529770278

Fouché, C.B., Strydom, H. & Roestenburg, W.J.H. (2021) *Research at Grass Roots (5th ed.).* Pretoria: Van Schaik Publishers.

Fryer, T. (2022). A critical realist approach to thematic analysis: Producing causal explanations. *Journal of Critical Realism, 21*(4), 365-384.

Gámez-Calvo, L., Muñoz-Jiménez, J., & Gozalo, M. (2025). The importance of positive attitudes toward disability among future health and education professionals: A comparative study. *Education Sciences, 15*(1), 61.

García-López, C., Sarriá, E., Pozo, P., & Recio, P. (2016). Supportive dyadic coping and psychological adaptation in couples parenting children with autism spectrum disorder: The role of relationship satisfaction. *Journal of Autism and Developmental Disorders, 46*(11), 3434-3447.

Garrido, D., Carballo, G., & Garcia-Retamero, R. (2020). Siblings of children with autism spectrum disorders: Social support and family quality of life. *Quality of Life Research, 29*(5), 1193-1202.

Glas, S. (2023). What gender values do Muslims resist? how religiosity and acculturation over time shape Muslims' public-sphere equality, family role divisions, and sexual liberalization values differently. *Social Forces, 101*(3), 1199-1229. https://doi.org/10.1093/sf/soac004

Goldberg, W. A. (2014). New measure for fathers of children with developmental challenges. *Journal of Intellectual Disability Research, 58*(5), 471-484.

Hirota, T., & King, B. H. (2023). Autism spectrum disorder: A review. *JAMA: The Journal of the American Medical Association, 329*(2), 157-168.

Hogan, A. J. (2019). Moving away from the "medical model": The development and revision of the world health organization's classification of disability. *Bulletin of the History of Medicine, 93*(2), 241-269.

Hove, N., & Phasha, N. T. (2024). Support services for learners with learning disabilities in mainstream classrooms using capability theory. *South African Journal of Childhood Education, 14*(1), 1-10. https://doi.org/10.4102/sajce.v14i1.1418

Johnsson, L. (2021). Multidimensional property supplementation: A method for discovering and describing emergent qualities of concepts in grounded theory research. *Qualitative Health Research, 31*(1), 184-200.

Jones, L., Totsika, V., Hastings, R. P., & Petalas, M. A. (2013). Gender differences when parenting children with autism spectrum disorders: A multilevel modelling approach. *Journal of Autism and Developmental Disorders, 43*(9), 2090-2098.

Kayfitz, A. D., Gragg, M. N., & Robert Orr, R. (2010). Positive experiences of mothers and fathers of children with autism. *Journal of Applied Research in Intellectual Disabilities, 23*(4), 337-343.

Kehinde, O. A., Lindly, O. J., Ntombela, B., & Hermann, C. (2023). Brief report: Gender-based stereotypical roles of parents caring for autistic children in Nigeria and south Africa. *Journal of Autism and Developmental Disorders, 53*(12), 4917-4928. https://doi.org/10.1007/s10803-022-05582-3

Kirchherr, J., & Charles, K. (2018). Enhancing the sample diversity of snowball samples: Recommendations from a research project on anti-dam movements in southeast Asia. *PloS One, 13*(8), e0201710-e0201710.

Koltai, B. G., Pados, E., & Rácz, J. (2024). Unveiling missing voices - lifelong experiences of fathers parenting autistic sons: An interpretative phenomenological analysis. *Autism: The International Journal of Research and Practice,* 13623613241290096.

Kourkoutas, E., Langher, V., Caldin, R., & Fountoulaki, M. (2012). *Experiences of parents of children with autism: Parenting, schooling, and social inclusion of autistic children.* International Journal of Special Education, 27(3), 1–13.

Lentoor, A. G., Mdluli, T., & Maepa, M. P. (2023). 'I asked myself why I was having this difficult child': Care burden experiences of black African mothers raising A child with autistic spectrum disorder. *The Open Public Health Journal, 16*(1)

Lien, K., Lashewicz, B., Mitchell, J., & Boettcher, N. (2021). Blending traditional and nurturing fathering: Fathers of children with autism managing work and family. *Family Relations, 70*(1), 264-281.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications.

Lord, C., Brugha, T. S., Charman, T., Cusack, J., Dumas, G., Frazier, T., Jones, E. J. H., Jones, R. M., Pickles, A., State, M. W., Taylor, J. L., & Veenstra-VanderWeele, J. (2020). Autism spectrum disorder. *Nature Reviews. Disease Primers, 6*(1), 5-5.

Lord, C., & Bishop, S. L. (2021). Let's be clear that "autism spectrum disorder symptoms" are not always related to autism spectrum disorder. *The American Journal of Psychiatry, 178*(8), 680-682.

Ludlow, A., Skelly, C., & Rohleder, P. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology, 17*(5), 702-711.

Marcinechová, D., Záhorcová, L., & Lohazerová, K. (2024). Self-forgiveness, guilt, shame, and parental stress among parents of children with autism spectrum disorder. *Current Psychology (New Brunswick, N.J.), 43*(3), 2277-2292. https://doi.org/10.1007/s12144-023-04476-6

Maxwell, J. A. (2012). The importance of qualitative research for causal explanation in education. *Qualitative Inquiry, 18*(8), 655-661.

McSweeney, B. (2021). Fooling ourselves and others: Confirmation bias and the trustworthiness of qualitative research – part 1 (the threats). *Journal of Organizational Change Management, 34*(5), 1063-1075.

Matta Mello Portugal, E., Cevada, T., Sobral Monteiro-Junior, R., Teixeira Guimarães, T., da Cruz Rubini, E., Lattari, E., Blois, C., & Camaz Deslandes, A. (2013). Neuroscience of exercise: From neurobiology mechanisms to mental health. *Neuropsychobiology, 68*(1), 1-14.

Michael, M. (1996). *Constructing identities: The social, the nonhuman and change*. In A. Irwin & B. Wynne (Eds.), *Misunderstanding science? The public reconstruction of science and technology* (pp. 199–211). Cambridge University Press.

Moodley, J., & Graham, L. (2015). The importance of intersectionality in disability and gender studies. *Agenda (Durban), 29*(2), 24-33.

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

Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society, 28*(7), 1024–1026. https://doi.org/10.1080/09687599.2013.818773

Ozgun, O., Erden, S., & Ciftci, M. A. (2011). Examining different perspectives on fatherhood: A socio-cultural approach. *Procedia - Social and Behavioral Sciences, 15*, 364-368.

Papadopoulos, D. (2021). Mothers' experiences and challenges raising a child with autism spectrum disorder: A qualitative study. *Brain Sciences, 11*(3), 309.

Peck, B., & Mummery, J. (2018). Hermeneutic constructivism: An ontology for qualitative research. *Qualitative Health Research, 28*(3), 389-407.

Petersen, J. M., & Lesch, E. (2022). A child needs both a mother and a father: The parenting constructions of a new generation of tertiary-educated South African prospective parents. *Journal of Comparative Family Studies, 52*(4), 715-742.

Pillay, S., Duncan, M., & de Vries, P. J. (2021). Autism in the Western Cape province of South Africa: Rates, socio-demographics, disability and educational characteristics in one million school children. *Autism: The International Journal of Research and Practice, 25*(4), 1076-1089.

Rafferty, D., Tidman, L., & Ekas, N. V. (2020). Parenting experiences of fathers of children with autism spectrum disorder with or without intellectual disability. *Journal of Intellectual Disability Research, 64*(6), 463-474.

Reed, P., Howse, J., Ho, B., & Osborne, L. A. (2017). Relationship between perceived limit-setting abilities, autism spectrum disorder severity, behaviour problems and parenting stress in mothers of children with autism spectrum disorder. *Autism: The International Journal of Research and Practice, 21*(8), 952-959.

Ruparelia, K., Abubakar, A., Badoe, E., Bakare, M., Visser, K., Chugani, D. C., Chugani, H. T., Donald, K. A., Wilmshurst, J. M., Shih, A., Skuse, D., & Newton, C. R. (2016). Autism spectrum disorders in Africa: Current challenges in identification, assessment, and treatment: A report on the international Child Neurology Association meeting on ASD in Africa, Ghana, April 3-5, 2014. *Journal of Child Neurology, 31*(8), 1018-1026.

Seymour, M., Giallo, R., & Wood, C. E. (2017). The psychological and physical health of fathers of children with autism spectrum disorder compared to fathers of children with long-term disabilities and fathers of children without disabilities. *Research in Developmental Disabilities, 69*, 8-17.

Sumbane, G. O. (2024). Coping strategies adopted by caregivers of children with autism in the Limpopo province, South Africa. *African Journal of Disability, 13*, 1-11. https://doi.org/10.4102/ajod.v13i0.1384

Van Beveren, L., Rutten, K., Roets, G., & Buysse, A. (2023). Critical cultural disability studies and mental health: A rhetorical perspective. Disability & Society, 38(2), 342-361.

van der Weele, S. (2022). 'doing' normativity in disability studies: Soft suggestions towards an empirical ethics of disability. *Disability & Society, ahead-of-print* (ahead-of-print), 1-23.

Vergunst, R., Swartz, L., Hem, K., Eide, A. H., Mannan, H., MacLachlan, M., Mji, G., Braathen, S. H., & Schneider, M. (2017). Access to health care for persons with disabilities in rural South Africa. *BMC Health Services Research, 17*(1), 741-741.

Vygotsky, L., & Cole, M. (2018). Lev Vygotsky: Learning and social constructivism. *Learning Theories for Early Years Practice*, 58. Retrieved from Scientific Research Publishing.

Ward, E. C., Wiltshire, J. C., Detry, M. A., & Brown, R. L. (2013). African American men and Women's attitude toward mental illness, perceptions of stigma, and preferred coping behaviors. *Nursing Research (New York), 62*(3), 185-194. https://doi.org/10.1097/NNR.0b013e31827bf533

Weiss, J. A., Cappadocia, M. C., MacMullin, J. A., Viecili, M., & Lunsky, Y. (2012). The impact of child problem behaviors of children with ASD on parent mental health: The

mediating role of acceptance and empowerment. *Autism : The International Journal of Research and Practice, 16*(3), 261-274.

World Health Organization. (2023). Autism Spectrum Disorders. Retrieved from: https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

Zondi, N. (2022). stigma mental health often goes undiagnosed in men. *Daily News (Durban, South Africa)*

Appendices

Appendix A

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
PSYCHOLOGY

School of Human and Community Development

Private Bag 3, Wits 2050,

Johannesburg,

South Africa

TEL: 011 717 4500 **FAX:** 011 717 4559

Participant Information Sheet

Fathers' perspectives on their experience of raising a child with autism spectrum disorder

Dear Sir,

My name is Patrick Mercer, and I am a master's student in Clinical Psychology at the University of the Witwatersrand, Johannesburg. As part of my degree requirements, I am conducting a research project under the Supervision of Dr Clare Harvey, exploring fathers' perspectives on raising a child with autism spectrum disorder (ASD).

I would like to formally invite you to take part in my research study. Participation will involve an in-person interview or alternatively if this is not possible, an online individual interview via Zoom will be conducted. The interviews will be conducted at your availability and will last between 45 minutes to an hour. The interview questions will be surrounding your experiences of raising a child with ASD and how this experience shapes your personal identity both as a father and as a person. Participation in the study is completely voluntary and thus you are free to withdraw from the study at any time prior to the data analysis. Participating in the interview process is simply a means to better understand your experiences of being a father to a child with ASD and if there should be any questions that you are uncomfortable in answering, you may refuse to do so.

For the purposes of analysing the interview and with your consent, all audio will be recorded (using the Zoom platforms' recording functionality). Confidentiality will be ensured by storing all recordings and transcripts on a password-protected computer folder that will only be accessed by myself and my supervisor. Furthermore, interviews will be conducted in a private and quiet setting or alternatively if a Zoom meeting is necessary, the meeting will be secured by a specific meeting ID and password, only to be accessed by myself and you as the participant. Additionally, I will conduct the interviews in a private room to ensure no interruptions and no overhearing of sensitive information that may be shared during the interview. Although, complete anonymity will not be guaranteed as interviews will be conducted face-to-face, in the research report participants will be given pseudonyms and no identifying information will be disclosed. Thus, final anonymity will be achieved.

Due to this study requiring participants to share their lived experiences, the process may potentially elicit sensitive emotional responses. Consequently, if you at any point feel distressed and require any support, please make use of the free counselling services at the Emthonjeni Community Centre at the University of the Witwatersrand:

- Emthonjeni Community Centre: Tel: 011 717 4513, ask for Paballo Lepota

Lastly, before you take part in the interview, please may you read through and sign a consent form. The document contains all pertinent information regarding the study and will grant you the position to make an informed decision.

Should you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University's Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za. Additionally, should you have any questions or concerns regarding any aspect of this study, please free to contact myself or my supervisor.

Kind Regards

Patrick Mercer (Researcher)

0711130317

Patmerc785@gmail.com

Dr Clare Harvey (Supervisor)

0117179999

clare.harvey@wits.ac.za

Appendix B

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
PSYCHOLOGY

Consent Form

Fathers' perspectives on their experience of raising a child with autism spectrum disorder

I..... consent to participate in the interview process conducted by Patrick Mercer, for his master's degree in clinical psychology study, that will be exploring fathers' perspectives on raising a child with autism spectrum disorder (ASD). The research study has been explained to me and I understand what my participation will entail.

As a participant in his study, I understand that:

- My participation is voluntary.
- I may withdraw from the study at any time prior to data analysis.
- I do not have to answer question(s) I do not wish to.
- All my personal details and information will remain confidential and if I am quoted in the final report, it will be done so under a Pseudonym.
- Audio and video of the interview will be recorded for analysis purposes.
- The recordings and transcripts from the interview will remain confidential and will only be accessible to Patrick Mercer (researcher) and his supervisor.
- The results of the study will be used in the research report that is required for the completion of the master's in clinical psychology degree.

- The use of direct quotes may be used in the research report.
- The findings of the study may be used in publications and conference proceedings.

Signed.....

Date.....

Appendix C

Ethical clearance 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-24-01**
PROJECT TITLE:	Fathers' perspectives on their experiences of raising a child with autism in South Africa
INVESTIGATOR	Patrick Mercer
SCHOOL/DEPARTMENT OF INVESTIGATOR	SHCD/Psychology
DATE CONSIDERED	08 May 2024
DECISION OF THE COMMITTEE	Approved unconditionally
RISK LEVEL	Low Risk
EXPIRY DATE	31 December 2026

ISSUE DATE OF CERTIFICATE 04 June 2024 **CHAIRPERSON** Aline Ferreira Correia
(Prof. 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** 10 / 06 / 2024

Appendix D

Interview schedule

Demographical Questions

1) How old are you?
2) How old is your ASD child?
3) How old was your child when he/she was diagnosed with ASD?
4) Do you have any other children, if so, how many?
5) Do you have a partner?
6) Are you the primary caregiver or do you share caregiving responsibilities with someone else?
7) What level of severity is your child's ASD?

Interview Questions

1) How did you initially react when your child was diagnosed with ASD?
2) When you think about your child's ASD diagnosis now, what feelings does this elicit?
3) What have you found difficult about raising a child with ASD?
4) What about raising a child with ASD have you found to be more manageable than expected, if at all?
5) Can you recall any specific moments that you found particularly challenging/pleasurable in relation to you and your ASD child?
    a) Why were these moments particularly challenging/pleasurable for you?
    b) If particular moments were challenging, have you been able to overcome them since?

6) Prior to your child's diagnosis, how would you describe your experience of fatherhood up until that point?
    a) How is your experience of fatherhood now similar/different in comparison to your experience prior to the diagnosis of your child?
7) How would you describe your relationship with your child?
8) How has your child's diagnosis impacted your life on a day-to-day basis?
    a) How has your life changed, if it all, since your child's ASD diagnosis?
9) How would you describe your support system, how has it helped, hampered your ability to care for your ASD child?
    a) How open are you about your child's diagnosis?
    b) How would you say society views your child's diagnosis and how does this make you feel?

Demographic specific questions (siblings)

    a) How has your child's ASD diagnosis impacted your relationship with your other children?

Demographic specific questions (Partner/shared caregiving responsibility)

1) How would you describe your relationship with the ASD child's other caregiver?
    a) How has your child's ASD diagnosis impacted your relationship with one another?