Men's Narratives of Parenting a Child with Autism

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Abstract

Literature has placed particular emphasis on mothers' experiences of raising children with autism and has neglected fathers' experiences. The aim of this study was to examine how fathers construct their subjective experiences of parenting a child with autism through the process of narration. Unstructured, face-to-face interviews were conducted with ten fathers from diverse South African backgrounds in order to obtain narratives about their experiences of parenting a child with autism. A thematic narrative analysis was employed to analyse the narratives constructed by participants. Themes that emerged from the analysis include (1) diagnostic narratives, (2) narratives about the child's characteristics and (3) narratives of the child's future. Lack of knowledge about autism, uncertainty of the aetiology of the disorder, children's behavioural and communication impairments, and the future prospects for the child are all dominant features in these fathers' narratives. The process of parenting a child with autism impacts upon these fathers' paternal identities in that they report feeling unacknowledged by their children, and that their paternal control in the father-child relationship is compromised. Traditional masculine gender roles and their association to ideas about parenting practices shape fathers' narratives about raising a child diagnosed with autism. Issues of race and socio-economic status are central to participants' narratives and influence the way in which they talk about parenting. This study advocates that policy and intervention strategy consider these societal issues and their impact on fathers' experiences of raising a child diagnosed with autism.

Keywords: Autism Spectrum Disorders (ASD); fatherhood; masculinity; thematic narrative; South Africa

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Introduction

There has been a growing interest in the psychological literature with regards to the experiences of parents raising children with Autism Spectrum Disorders (ASD; Johnson et al., 2011). Autism has been described as one of most challenging childhood pathologies as the associated symptoms and behaviours may be extremely severe (Johnson et al., 2011), impacting greatly on caregivers. Parents of children with autism experience distinct demands that negatively affect their psychological wellbeing (Hastings et al., 2005; Dumas et al., 1991).

Previous autism research has tended to emphasise mothers' experiences of raising children with autism and in the process has understated men's experience (Dabrowska & Pisula, 2010). Moreover, most studies that include fathers are comparative studies between mothers and fathers and these include only a small sample of men. No studies were found in the existing literature that solely focuses on fathers raising children with autism. One can attribute this to the historical constructions of gender roles in child rearing that accentuate women's experiences over men's (Dabrowska & Pisula, 2010).

This study seeks to expand on the autism literature by providing insights into the subjective experiences of fathers who have children diagnosed with autism. An analysis of narratives by these fathers will be undertaken to determine the factors that shape their experiences and influence their paternal identities. It is hoped that the findings may inform future intervention and policies that attend to the needs of these fathers.

Relevance of the Study

It is important to establish a comprehensive picture of men's experiences of raising children with autism in order to develop an understanding of paternal-specific challenges that these men construct. More comprehensive perspectives of the nature of father-child relationships are particularly important in child-rearing of children on the autistic spectrum, given the reported differences between maternal and paternal experiences in many studies (Bitsika & Sharpley, 2004; Johnson et al., 2011).

The majority of studies investigating parental experiences and the psychological effects of raising children with ASD on parents use mothers as participants or have a particular focus on maternal experiences or challenges. It is thus evident that there is a particular emphasis on maternal parenting experiences in the ASD literature, neglecting those of fathers of autistic children (Flippin & Crais, 2011).

Research and clinical interest about the extent to which fathers influence and contribute to the development of children with ASD emerged about thirty years ago (Flippin & Crais, 2011), however there remains a gap in the literature with regards to fathers' experiences of the process of parenting a child with autism. The aim of this study is to provide insights into how fathers talk about their experiences of being a caregiver to an autism-affected child and to illustrate the meanings they draw from these experiences through the process of storytelling.

In sum, the lack of literature directed towards understanding fathers subjective experiences of parenting a child with ASD needs to be addressed. There is thus a clear gap in the literature around men's experiences of raising children with ASD.

Aims

This study seeks to explore how fathers construct narratives of raising a child with autism. These narratives will be analysed to gain insight into fathers' subjective experiences of raising children with autism. Fathers' narratives will be analysed and interpreted with the aim of determining the factors that shape men's discourse about parenting an ASD-affected child.

Research Question

What subjective meanings of parenting do men construct in their narratives about raising a child diagnosed with autism?

Secondary questions:

How do fathers talk about the process of parenting a child with autism over time?

What factors shape fathers' narratives about raising a child with autism?

Framing and Defining Autism

Autism has been identified as one of the most difficult and prevalent childhood disorders, with gradually increasing incidences globally. 1 in every 150 children are diagnosed with the disorder, with 80% of those affected being boys (Tanguay, 2006). In the publication of the latest edition of the Diagnostic and Statistical Manual (DSM) for mental disorders, autism spectrum disorders have been grouped as one of the neuro-developmental disorders. According to the DSM V, 'autism spectrum disorders is characterised by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviours used for social interactions, skills in developing, maintaining, and understanding relationships' (American Psychiatric Association, 2013, p. 31). Children with symptoms of ASD have a range of characteristics that make them distinct from children without developmental disorders, and these characteristics include communication difficulties and restricted social interaction (American Psychiatric Association, 2013; Richler et al., 2007). Furthermore, children with autism are reported to show extreme lack of empathy towards others, deficits in communication skills, and rigid forms of behaviour (Passer et al., 2009). These children also present with challenging behaviours such as tantrums, isolation and avoidance of involvement in social relationships (Matson & Nebel-Schwalm, 2007). Furthermore, the disorder is a predictor for aggressive behaviours and self-injury (McClintock, Hall, & Oliver, 2003). Most children affected by ASD find it difficult to attach to their parents and this has been partly attributed to them struggling to acquire appropriate language skills (Matson & Nebel-Schwalm, 2007).

For the purposes of this paper, the terms autism and ASD will be used interchangeably as the new diagnostic criteria for ASD do not differentiate between these two terms to describe the disorder.

The Impact of the Severity of the Disorder

Parents raising children with autism face a range of challenges in different areas in their lives. This includes anxiety, stress, depression and other negative emotions (Gray, 2003; Wachtel & Carter, 2008). The magnitude of problems experienced by parents is highly correlated with the severity of the child's symptoms (Dabrowska & Pisula, 2010). Thus, the more severe the symptoms of the children, the more difficult it is for parents to adjust to the diagnosis. The more severe the child's symptoms, the more time parents have to invest into intervention and treatment plans and they experience financial burdens related to seeking medical assistance and therapeutic strategies (Moes et al., 1992). Moreover, severe impairment in the child's communication abilities, social functioning and behaviours results in parents reporting great disconnect between themselves and their autistic children (Wachtel & Carter, 2008).

The Impact of Children's Symptoms on Parents' Wellbeing

It is important to ascertain the ways in which raising a child with ASD can negatively affect the psychological functioning of parents. Parents raising children with ASD are particularly at risk of experiencing high levels of stress, and mothers are said to experience greater stress-levels compared to fathers (Johnson et al., 2011; Bitsika & Sharpley, 2004). Johnson et al. (2011) evaluated parenting stress of families with an affected child and found that several features impacted parents' wellbeing. Abnormally high levels of stress were common between both parents, but mothers and fathers reported different stress-related experiences and sources of stress. Mothers experienced stress associated with problems with their children's behavioural impairments, physical development and attending to the emotional needs of the child. Mothers further reported experiencing stress linked to low levels of parenting competence. In contrast, fathers were more stressed by problems related to financial burdens and problems associated with the child's language and communication impairments (Johnson et al., 2011). Children's incapacity to talk and interact contributes to excessive anxiety on the part of the primary caregivers, especially for fathers (Billington, McNally, & McNally, 2000). Other findings suggest that certain fathers report more stressful experiences compared to mothers, especially in the areas of behavioural impairments and communication deficits of the child (Davis & Carter, 2008). Concerns about the future prospects of the child are also stressors that influence the psychological well-being of fathers (Gray, 2003). It is thus important that factors that influence parenting stress are determined in order to assist fathers in adapting to stressful situations associated to parenting a child diagnosed with autism.

Depression has also impact parents' well-being when raising children diagnosed with autism. Hastings et al. (2005) conducted an analysis of the extent to which parents raising children with ASD are psychologically affected. Their results showed that parents of children with autism were significantly more depressed compared to those who were raising children with other intellectual and developmental disorders. Differing levels of depression are also found between mothers and fathers in the autism literature (e.g., Bitsika & Sharpley, 2004; Hastings et al., 2005). Mothers report being significantly more depressed than fathers. Fathers' depression outcomes are influenced by the degree of depression of their spouses or partners (Hastings et al., 2005). The degree of the severity of the autism symptoms and the extent of the demands on the parent are reported to be predictors of parental depression outcomes (Hastings et al., 2005; Davis & Carter, 2008). It is apparent that parents who are raising children with ASD are at a greater risk of experiencing psychological distress, such as depression and high stress levels, when compared to parents raising children without ASD. High levels of stress and depression may affect the adjustment by parents to the child's diagnosis (Bitsika & Sharpley, 2004). Gray (2002) reported that parents' degree of psychological distress lowers when the child has been enrolled in suitable treatment and schooling programmes that accommodate for the autistic symptoms.

The reported gender differences in parental responses to raising children with autism suggest that there are paternal-specific challenges of raising an autistic child. It thus seems that a key issue that needs to be engaged with is how men experience parenting of a child with autism. This will inform the coping strategies of fathers in adjusting to the diagnosis. Parents go through various processes in trying to cope with and adapt to the child's symptoms. Parental coping outcomes are further influenced by the psychological well-being of the parents and how they respond to the child's diagnosis (Wachtel & Carter, 2008).

Dealing with a Child with Autism

How parents deal with the difficulties of raising a child with autism has important consequences for their psychological wellbeing, and research shows that ineffective coping strategies by parents can result in them experiencing a range of psychological problems (Marvin & Pianta, 1996; Johnson et al., 2011). Marvin and Pianta (1996) found that mothers who had effective coping strategies and techniques could facilitate a positive parent-child relationship. The ways in which parents perceive their parent-child relationship plays a role in enhancing positive outcomes of the ASD-affected child's development (Wachtel & Carter, 2008). According to Gray (2003), fathers report that they suppress how they feel in order to deal with the impact of the diagnosis on their emotional well-being. Men are said to deal with situations through an emotionally reserved style of coping (Gray, 2002; 2003). Gray (2003) further found that fathers express frustration through anger, whereas mothers show despondency through crying as methods of coping emotionally with their child's disorder. Literature therefore illustrates that men deal differently with the process of parenting a child with autism compared to women.

Parenting Gender Roles and Implications for Raising a Child with Autism

Traditional patriarchal perspectives view characteristics of parenting to be limited to the female gender and perceive maternity as fundamental to womanhood (Connell, 2002; McHale & Huston, 1984). These patriarchal worldviews portray fatherhood as secondary to male identity (Gerstel & Gallagher, 2001). Masculinity has been constructed in occupational terms and these traditional patriarchal notions of masculine identity are expressed in professional rather than domestic spheres (Connell, 2005). In contrast, femininity in traditional terms is associated with intimate relationships assigned to secluded, domestic domains (McHale & Huston, 1984).

Patriarchal ideologies have influenced contemporary parenting practices and child-rearing behaviour (Connell, 2002). Masculinity is thought to be driven by the pursuit for individual rights and privileges which are detached from the understanding and identification of the psychological and emotional needs of others (Connell, 2005). For traditional patriarchal systems, power, authority, and supremacy are associated with fatherhood, particularly with the father as patriarch (Seidler, 1988). In a hetero-normative familial context, fatherhood is defined as being a good provider, which is associated with masculine honour (Seidler, 1988). Hence, ‘real men’ are good fathers based on their professional work and their standard of income, which means engaging in activities away from home (Seidler, 1988). The man as patriarch is also required to be the disciplinarian through demonstrating a stern and aggressive masculinity that is different from a caring and nurturing nature (Seidler, 1988). The emotional and psychological significance of fathers’ experiences in raising children are usually overlooked because of society’s inclination to regard nurturing attributes and aspects of caring behaviours in men as emasculating (Gerstel & Gallagher, 2001). It is thus important to consider the extent to which men’s socially constructed masculine identities influence the way in which they talk about parenting a child with autism.

The theoretical background for this study is situated within a paradigm that considers traditional perspectives of masculinity and manhood. It draws on the critical studies of masculinity to analyse the findings that emerged from the fathers’ narrative accounts of parenting experience. Men’s socially constructed roles are aligned to fatherhood identities and practices, which are socio-historically constructed by patriarchal systems, ideologies and practices.

Methods

Research Design

A qualitative approach was employed in this research. Qualitative research aims to obtain in-depth understandings of peoples’ experiences with regards to particular events or circumstances (Parker, 2005. In contrast to positivist approaches, qualitative research does not make use of methods of quantification and measurement, but rather takes an open-ended approach in gathering, analysing and immersing oneself as the researcher within the data presented (Langdridge & Hagger-Johnson, 2009). The aim of a qualitative study is not to generalize findings; and the data collection and analyses techniques for qualitative inquiry are flexible in that they allow for the investigator to adapt to findings that may provide new and unanticipated insights (Langdridge & Hagger-Johnson, 2009).

This research is aligned with a critical realist position in qualitative research paradigms. This is because the narratives that fathers construct allow the researcher to gain access to their subjective experiences through language; but this language is constructed by and within broader social systems (Emerson & Frosh, 2004). Thus, the micro and macro contexts that shape fathers’ narratives will also be considered. A narrative approach was therefore best suited for the present study. The narrative method of inquiry can be described as an approach to research that makes inferences from narratives constructed by participants about their own lived experiences (Langdridge & Hagger-Johnson, 2009). This approach is most appropriate for the nature of this investigation because, through giving a narrative account, participants are able to construct their subjective experiences in a way that provides them with the agency to give their own explanations and interpretations of their experiences (Langdridge & Hagger-Johnson, 2009; Emerson & Frosh, 2004). Furthermore, this approach allows the researcher to consider how participants’ identities are constructed in the stories they tell (Riessman, 2008). Personal stories are therefore useful in the context of this study as story units will allow the researcher to explore meanings men make of parenting children with autism.

Sampling

Selecting informants who are representative of the population under study is not central to narrative research (Langdridge & Hagger-Johnson, 2009), thus a purposive sampling technique was used. Consequently, participants were selected in accordance with the aims and objectives of the research. A sample of ten (n=10) fathers between the ages of 27 and 43 were invited to take part as participants in this study. The fathers were accessed through the UCT Child Guidance Clinic (CGC). The children of these fathers have received therapy at the CGC. Only biological fathers who were on some level involved in their children's caregiving participated in this study. Only fathers with sons participated in this study, because there are a limited number of girls with autism who received therapy from the CGC and it was difficult to access their parents. This speaks to findings in the literature reporting that there is a higher incidence of boys being diagnosed with autism (Johnson et al., 2011). Children of the participants had a mean age of 6 years (range: 4 to 8).

Participation in the study was entirely voluntary. Participants represented diverse South African racial and socio-economic status (SES) groups. Race and SES are highly correlated in South Africa because of historical racial discrimination policies that created hierarchies between different racial groups, privileging white people over black people (Ferree, 2006). Consequently, black and coloured[1] people make up the majority of the country's poorer groups, having less access to resources and facing financial challenges due to unemployment and lower education levels (Ferree, 2006). Of the ten participants, two were white, three were coloured and five were black. Three fathers were from high income brackets as reflected by the fact that they had professional careers. Six fathers were from working class backgrounds and one father was unemployed. At the time of the interviews all of them were married to their child's mother and lived with their families, with the exception of one who did not live with the child or the child's mother. All participants resided in Cape Town; limiting the research context to the Western Cape, South Africa.

Data Collection Procedure

Data was gathered by means of unstructured face-to-face interviews. The unstructured interview is a data collection technique commonly used in approaches to narrative investigation (Connelly & Clandinin, 1990). An unstructured interview permitted new ideas and thoughts to be expressed during the discourse and allowed for probing of information that sparked interest for the researcher (Connelly & Clandinin, 1990; Corbin, 2003). This method of data collection

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[1] In South Africa, the term coloured is used to refer to individuals who are mixed race

allowed for both the investigator and the participant to have key roles in the interview process, where the participant and the researcher co-constructed meaning (Corbin, 2003). The participants constructed meaning by accounting for their experiences and sharing their narratives. The researcher participated through attentive and active listening, and responded to and engaged with participants’ accounts (Corbin, 2003). In the beginning of all the interviews, I asked the participants the following question: “Can you please tell me a story about being a father of a child with autism – start with hearing that your partner or the child’s mother was pregnant, and tell me how you have experienced it up until now?” In cases where participants were hesitant in speaking about their experiences, I asked open-ended questions, such as “tell me about your relationship with your child with autism”, “what do you do when you and your child spend time together?” and I asked about their emotional and psychological position about the process of having a child with autism.

Data Analysis

These personal narratives, or story units, constructed within the unstructured interviews, were analysed through a thematic narrative approach. Thematic narrative analysis is used to offer rich accounts and thorough descriptions of the thematic strands of which narratives are constructed (Babbie & Mouton, 2007; Riessman, 2008). This approach utilizes thematic interpretation of narratives told by the participant as the main agent of meaning-making in the interview process (Emerson & Frosh, 2004). The method of analysis explores the content or the ‘what’ of the participants’ narratives (Riessman, 2002).

The first step in the analysis process was to identify and code themes from the content of fathers’ discourse of raising a child with autism by establishing patterns across whole sets of cases (Braun & Clarke, 2006; Riessman, 2008). Themes developing from narratives are layers embedded in the content of the stories with the function of directing and informing meanings (Emerson & Frosh, 2004; Riessman, 2008). Although I approached my research with expectations of the challenges parents have with raising a child with autism, the analysis permitted for themes to emerge primarily from the content of fathers’ discourse. Narrative components were grouped into overarching findings that consist of subthemes.

To augment analysis of fathers’ narratives, I pulled from the core theoretical assumptions within narrative research theory. This includes assumptions of narrative structure, implications, and contexts. This composed of the second step of the analysis where I analysed these 'technical’ elements of the narratives of fathers. The analysis of narrative structure elevates the analytical process and contributes to the significance of the inferences drawn from the narrative data. Furthermore, I analysed the way in which identities are constructed, and the meanings that emerged from participants' narratives. The analysis also considered the micro and macro contexts and broader societal systems that shape fathers' discourse of raising a child with autism. Thus, the combination of the content-driven and structural analytical approaches was most appropriate for this study.

Ethical Considerations

Ethics is an important aspect of research as it directs appropriate methods that limit harm to the participants and the researcher (Willig, 2007). In order for this study to have been conducted, ethical approval was obtained from the UCT Department of Psychology Research Ethics Committee.

Informed consent. Participants received a document informing them explicitly about the nature and purpose of the study before requesting their consent to partake in the study. This functioned as the informed consent form (see Appendix A), where the aims, benefits, risks, costs and other details were outlined. Informed consent suggests that the researcher has provided the participants with all the information related to the aims and methods that the research will address (Willig, 2001). Participants were informed that they have the right to withdraw at any time during the study. They were further informed that the interview would be recorded and were told that they could terminate recording at any time of the interview. The researcher gave verbal confirmation of the information on the consent form before the interview proceeded. The signed consent forms were requested from the participants before the interview took place.

Harm to subjects. It is the researcher's responsibility to make sure that the study does not inflict physical, emotional or psychological harm on the participant (Willig, 2001). Participants were interviewed in a safe and secure environment. Most interviews took place at the participants' homes, the CGC or at a local coffee shop. The nature of the interview may have caused emotional and psychological distress for the participants, however, the unstructured nature of the interviews allowed the participants to regulate the content and expressive tenor of the interview. It was important for the researcher to assess and respond appropriately to the participants' feelings and emotions (Corbin, 2003). In the event that any participant experienced psychological or emotional distress, or if they wanted to find out more information about what was discussed, a counselling and information services referral list (see Appendix B) was provided to all participants.

Privacy and confidentiality. Participants' personal identities were not disclosed in this report and only the researcher and the supervisors have access to the recordings of the interviews. Participants were assured that they will remain anonymous in the research report and that their privacy and confidentiality will be strictly maintained. Hence, pseudonyms are used to maintain the participants' anonymity. This information was included in the informed consent form and a verbal confirmation was given to the participants before the interview commenced. Limitations to confidentiality were also mentioned, regarding the research being written up in the form of an honours research project and that it may be published in an academic journal.

Limitations of the Research

This study was limited by the fact that the researcher could not communicate in or understand an African language. English was not the first language of most fathers and a large proportion of them spoke Xhosa. This may have resulted in participants' meanings from their talk having been misplaced or lost during the interview. This may further have impacted on interpretations of the participants' discourse.

Reflexivity

Reflexivity is intricately connected to the limitations of a qualitative research study as it refers to the researcher's reflective accounts of how his or her positionality influenced the meanings that emerged from the research process (Crang, 2002). Positionality refers to the important aspects of our identity that are fluid characteristics that guide interpersonal relations (Crang, 2002). It is thus important for me as the investigator to reflect on my positionality and recognize how this might have influenced the results. I was an active agent in the construction of meaning in the process of collecting and analysing the results. I approached the analysis through a framework where I had preconceived ideas about the challenges that fathers might construct and about factors that may influence men's narratives about parenting. These preconceived ideas may have limited my interpretation of the findings.

Through the construction of narratives, participants portray specific identities and choose to include and omit information on the basis of what they prefer to reveal to the researcher. Some fathers were forthcoming in sharing their stories whereas others required me to ask more probing questions. Fathers not being comfortable with sharing their narratives may have been influenced by the lack of shared experience between them and the interviewer. Fathers were married, most were employed and came from backgrounds that were different to that of the interviewer. This lack of shared experience between the participants and I may have performed as a hindrance in establishing rapport and in determining true interpretations of the participants' experiences (DiCicco-Bloom & Crabtree, 2006). This lack of shared experience came through in the interview when one of the participants said that '(the interviewer) will never be able to understand these children if they are not yours and if you don't live with them' (Piet).

Dynamics of diversity may further influence the data that emerge from the interviews and the process of analysing the data (DiCicco-Bloom & Crabtree, 2006). My position as a UCT student working toward a postgraduate qualification may have influenced the way in which fathers constructed their narratives. Reference was made in the discussion section to how some fathers perceived me as 'an expert' who is able to provide them with more information about autism and who is able to grant a place for the child in a school. This was especially the case for fathers who were interviewed at the CGC. How the themes and meanings are generated and conceptualised from research process and context were therefore taken into account through the process of reflexivity.

Results and Discussion

Diagnostic Narratives

Narrative themes identified were as follows: 1) diagnostic narratives, 2) narratives about the child’s characteristics, and 3) narratives of the child's future. Themes and subthemes were organised to illustrate how fathers talk about their journey of raising a child with autism.

The mystery of autism: lack of knowledge about the disorder. All ten fathers reported that they did not know what autism was at the time that their child was diagnosed. When talking about the diagnosis of their child, many fathers told stories that had the element of mystery at their core. 'Mystery narratives' contain an event or incident that transpires due to an unidentified origin or aetiology (Hunt, 2000). The extracts below from Kevin’s narrative show how fathers construct the mystery of autism as a barrier to dealing with the diagnosis.

> *I didn’t know that here was something called autism. I didn’t know what to do with a child that got autism.*

Similarly, an extract from Azole’s narrative shows the intensity of the impact of not knowing about autism had on his emotional well-being.

> *I was crying because I did not know what autism is. I was crying because I was not expecting that I’ll be getting a child like this… that got this thing that I don’t even know about. I was cross and I was crying. If only I knew earlier what this autism is.*

Kevin and Azole were from lower SES groups and reported not having access to resources. Nevertheless, constructing the narrative of an ‘autism mystery’ was not unique to fathers who were from lower SES groups. Although from privileged circumstances, Zee, Ken and Piet also reported not knowing about autism at the time of the diagnosis. Zee said that it was ‘very difficult’ for him and his wife, largely because they ‘didn’t even know about this concept about autistic child’. Similarly, Ken reported that the lack of knowledge about the disorder was a great challenge for him especially at the beginning of his journey. The following quote from Ken’s narrative reflects this.

> *I had fundamentally no moral understanding of what autism or autism spectrum disorder is or implies in any way, which was challenging.*

It was evident in these fathers' stories that at time of the diagnosis they did not know what the disorder meant and they said that this lack of knowledge made it especially hard for them to adjust to the new circumstances. Usually in the pre-diagnostic and diagnostic phase, caregivers are perplexed by the problems their children start exhibiting (Billington et al., 2000). Fear and panic usually overwhelm parents from not knowing about the diagnosis they receive (Billington et al., 2000).

Fathers had different reactions to the mystery of autism. For example some black participants said that when they were confronted with the biomedical diagnosis, it contradicted their cultural knowledge systems resulting in them becoming suspicious of the diagnosis and the health professionals who diagnosed their children. These fathers reported in order for them to deal with the diagnosis, they had to start learning about autism, which was challenging as they had to start seeking information which was difficult to access. Nevertheless, fathers tended to draw on previous experiences or their own knowledge to make sense of the aetiology of autism. Fathers constructed their children's autism by blaming events that could have resulted in the child's autistic outcome; in order to 'solve the mystery of the diagnosis' (Piet). They were able to use these reasons to make sense of the aetiology of autism.

Making sense of the aetiology of autism. Different fathers attributed different circumstances to their children being autistic. A majority of fathers said that they did not understand where 'this autism came from' (Zama) considering that the pregnancy and birth of their children were normal and unproblematic. Some fathers drew on western biomedical discourses to construct their understanding of what caused the child to be affected. Kevin and Brian ascribed their wives' spotting during pregnancy to have resulted in the child being affected. Similarly, Piet and Zee explained that their children only developed these symptoms after they went for the six months vaccination injection.

In contrast, two fathers explained their children's diagnoses in terms of witchcraft. The narrative of witchcraft is a popular way in which people from African cultures explain their misfortune. One of the black fathers, Kido, stated that the reason why his son was 'behaving so strangely and was unable to talk' was because people who he considered his enemies were 'using witchcraft as a weapon' against him. In trying to make sense of the causes of his child's symptoms, Kido connected his challenges with his own HIV diagnosis and his son's unusual behaviour to 'people who were trying to get to (him)'. Their practices of witchcraft are the reason why he was infected with HIV/AIDS and why his son was demonstrating these symptoms. He believes his enemies are jealous of his success in getting a male child because in his culture 'male children are destined for greatness'.

Another black father, Loyiso, spoke about witchcraft as the cause for the child being affected,

> *I believe that someone toor [bewitch] my child. It is a belief for us as a black person that there's somebody maybe he attacked you with your child.*

Unlike Kido, Loyiso's narrative was 'restorative'. This means that the father was hopeful and positive that the child will progress towards normality and eventually lose his autistic symptoms. These views illustrate how black fathers from lower socioeconomic groups construct the aetiology of their children's diagnosis. Mandell and Novak (2005) argue that culture shapes the meanings parents attach to their children's autistic symptoms and the aetiology of the diagnosis. They assert that the way in which parents understand the aetiology may have a critical impact on their reception of the diagnosis and how they respond to and adapt to it. Parents whose cultural beliefs do not correspond with a western framework may find it particularly difficult to adjust to the diagnosis. This study's findings concur with Mandell and Novak's (2005) argument that fathers who appeared to have understood autism from their cultural framework found the diagnosis more difficult to understand in comparison to fathers who made reference to western biomedical discourses.

When caregivers eventually accept that their child's autistic condition is permanent, they begin to become hopeful. Ultimately, caregivers become hopeful when they realize that the child's autistic symptoms can be moderated with intervention strategies (Boushey, 2001). Hence, some fathers who previously used the narrative of witchcraft to make sense of their symptoms but who came to accept the biomedical diagnosis of autism at the time of the interviews, talked about their children's diagnosis as curative.

Narratives About the Child's Characteristics

Narratives about children's behaviours. Participants explained that one of the most extreme challenges was associated with autistic behaviours. Earlier research by Bebko et al. (1987) found that affected children's behaviours were particularly challenging for caregivers, increasingly so when children reach school age.

Participants described the children's behaviour as 'strange and odd relative to how a child should behave' (Zee). From their narratives, a great challenge is their children's habitual and stereotyped behaviours. They talk about being fearful of disrupting their children's routines because of the associated consequences including resistance and throwing tantrums. Children with autism present with challenging behaviours such as tantrums, isolation and avoidance of involvement, and parents report not being in control of these behavioural characteristics (Davis & Carter, 2008). Fathers in this study said that they were 'fearful in initiating physical contact' (Kevin) with their child because of the way in which the child reacted when they spontaneously played or tickled the child. 'It is hard as sometimes he (the child) will respond positively to the contact and other times the child will be upset' (Piet). The unpredictable nature of the child's responses results in a sense of ambivalence and anxiety in them to initiate contact with their children. Zee's narrative illustrates fathers' description of raising a child with autism consisting of them battling with understanding and engaging with their children's behaviours.

> *The school will give the routine. If you don't follow it, it becomes problematic. (The child's) behaviour is difficult… once you diverge or you move out of that routine you'll find a great deal of resistance from him… he will be throwing a lot of tantrums. You'll find yourself not knowing what to do. He will dominate you. (Zee)*

Brian similarly expressed these challenges, included in his description an event where he became emotionally distressed when his child threw a tantrum.

> *…you can't stop him crying or throwing a tantrum and it last for like 10, 20, 30 minutes. So it is hard, but for me it is not so bad, but my wife… she sometimes just breaks down and cries… sometimes tears will also run down my face.*

Behaviour impacts on fathers' parenting roles and identity. A study by Gray (2003) found that fathers downplay the effect of their child's autism behaviours on their personal well-being, tending to claim that the child’s behavioural characteristics did not significantly impact them but that their wives were more vulnerable to these effects. Similar findings were evident for the fathers in this study, with the majority describing the mothers as being more vulnerable. It is obvious however from Brian's narrative that fathers are significantly impacted by the child’s behaviours and that micro and macro contexts shape their narratives. Socially constructed gender expectations for men in parenting and how traditional patriarchal systems have constructed fathers’ roles in relation to mothers’ may have influenced fathers’ descriptions. The interviewer being male may also have shaped fathers’ discussion according to their normative beliefs about male communication. Gender norms impose an expectation on men to portray themselves as emotionally stable and in control of their circumstances (Addis & Mahalik, 2003). Gender norms were fundamentally challenged by fathers’ personal experience of parenting a child with autism, as fathers said that their identities as fathers in their households were redefined to adjust to the child’s behavioural symptoms. Instead of being the disciplinarian, the dominant figure and the one to have control over the child’s behaviour, they disclosed that they have to compromise in their paternal roles in order to deal with the process of raising their affected children.

Fathers described not having a sense of control over their children’s symptoms and behaviours. The participants recounted events where they were unable to exercise paternal control in order to manage the child’s behaviours, constructed as ‘stressful and difficult’, as their traditional parenting styles reinforced the child’s resistance and problematic behaviours. Many fathers said they feel unable to discipline their autistic children and that their capacity to exert control has been compromised, creating tensions, frustrations and anxieties. Usually the father has to adapt to the child’s temperament, negative reactions and atypical behaviours. The narratives of Zee, Kido and Dylan below capture fathers’ experiences of compromising on their paternal control over the child and how this has implications for their paternal identities. Zee reported,

> *It is difficult to be good father because this child is doing everything according to his own terms. If the child does not feel like talking to you, he will just ignore you. Sometimes he will want to play but other times he will be in this extremely difficult mood and then you can’t control him.*

To illustrate that he has lost his paternal position in the father-child relationship Kido explained that the child has the power,

> *He was up like a man… like the father… he will push you.*

Kido said that he feels that he has no control over his child and this makes him 'frustrated and sad'. Participants felt that if they try and control their children through an authoritative style, like they understand their fatherly role, their children ignore them; making fathers feel disempowered. Fathers construct having to adjust and redefine their parenting style for the well-being of the child. As Dylan describes,

> *You can't reprimand him in any way or scold him a bit... it doesn't work. You have to become soft. Everything is about not upsetting him. Shouting will upset him.*

And as Kido explained,

> *If I skell (shout at) him, he would just go and not take note of me and it would make me mad. But now I have to be like the mother.*

What is further significant in fathers' narratives is the reporting of how their child's temperament and behaviours make them feel disconnected from their children. Participants spoke about their child's attributes impacting their father-child relationship and their identities as fathers. Their affected children fail to acknowledge them as their fathers. Eight out the ten fathers brought up feeling that their paternal identities and roles were not acknowledged by their children. Fathers who had other children who were not affected by autism said that they do not feel acknowledged by the affected children when compared to the other children. The attributes of the autistic child contribute to estrangement. Fathers' reported that this was especially trying when their child was younger. As Zee stated,

> *…now that he is older, he knows that I am the father. Initially he didn't know and this was so hard for me.*

Many fathers' report that the level of distance between the father and the child impacts them emotionally and psychologically as Kevin further described,

> *…not being able to adjust to my wife's role, not working to provide for my family, not being able to make the child happy made me feel useless and [powerless].*

Some fathers constructed specific attachments to being acknowledged by their children as their primary caregiver. They also said that they want their children to recognize their parent role and reported feeling fulfilled when the child responded appropriately to parenting efforts. All the fathers reported that their children did not know them as a father when they were younger and ignored them to a large extent. Furthermore, they expressed that their affected children are more attached to their mothers than to them and they attribute this to them being the breadwinners for the family and so often not present, whereas their mothers are fulltime caregivers. Gray (2003) asserts that because of fathers' high obligation to be employed to provide financial security, fathers remain partially involved in child rearing activities. Fathers perceive 'the daily routine of child-raising as one that involved their wives much more extensively than it did them' (Gray, 2003, p. 635). Although this is true for the participants of this study they still long to have a more intimate bond with their children. Dylan's narrative expounds on this,

> *He is very estranged from me at times because he is at home with his mother most of the time. I go and work and so on. So there are times when he would want to play with me and there are times when he won't notice me. When I come home from work… he doesn't notice me coming in. He doesn't show when he's happy to see me or if he wants to see me for that matter.*

Fathers' stated that they and their wives try their best to balance out parenting roles, where mothers are fulltime caregivers and fathers are financial and material providers. This is in line with Gray's (2003) findings. Fathers' attach particular value to their roles as men to be the resource providers for their families. This does not mean that fathers do not engage in household and child-rearing activities, but they report being largely dedicated to the 'breadwinner' role. This aspect of the parenting gender roles is in fact reinforced by the situation of having a child diagnosed with autism, as the financial burdens, and therefore need for the father to engage in employment, is usually significant. There was a time when Kevin was unemployed and looked after the child at home while his wife was working and said that it was a challenge to make the autistic child accustomed.

This combination of factors impact on fathers' paternal identities, significantly making them feel incompetent as fathers, especially when they were unable to fulfil a particular aspect of their identity, such as being the financial provider for the family. In collaboration with the complexities of the behavioural symptoms, the child’s communication difficulties are central to how fathers’ talk about raising a child with autism.

Narratives about communication impairment. Bitsika and Sharpley (2004) found that as much as parental stress, depression and anxiety are elevated by children’s behavioural impairments, speech and communication deficits also impact parents. Parents report that communication impairment and social impairment are symptoms of autism that are the most stressful (Bebko et al., 1987; Gray, 2003). Fathers in this study reported that the speech deficit is a severe problem when raising a child with autism. Fathers talked about the inability to communicate with their child as a main barrier in the father-child relationship. They said that they felt unable to know and attend to the needs of the child because of the child’s inability to articulate these needs. Engaging in conversational dialogue is an important aspect for sustaining a relationship with children. Yet, some fathers said that they ‘just need the communication gap to be bridged even if this meant using the Packs system or sign language’ (Azole). Many of the fathers’ narratives highlighted the frustration of not knowing what the child needed at particular times making them feel incompetent in their caregiving role. This frustration and feelings of incompetence as a parent is evident in Brian’s narrative,

> *...he’ll be talking but we couldn’t understand. We couldn’t tell… sometimes he’ll be crying and then we ask him what it is… but then he can’t explain to us what is wrong…it was difficult for him to communicate and for us to communicate with him to ask him…*

Longing to be able to have a meaningful conversation with their child was fundamental to fathers’ narratives. This is deduced from their emphasis that they ‘needed their children to be able to talk’ (Kido). They want to be able to connect with their children and try and understand what they need to do to be better caregivers. The distress caused by fathers not being able to connect with their children through dialogue is evident in Zee’s narrative when he states:

> *He can’t speak, the way that you sit down with your child and he tell you something,... it makes me sad because I need my child to talk to me to tell me what I must do.*

Fathers’ expression of their child’s inability to communicate impacting on their psychological and emotional well-being is further reinforced by Kido’s narrative,

> *I need my son to talk! I don’t like him to not talk; it’s like its beating me inside. Why? Just cause it's my son and I can’t even talk to my son!*

This supports the assertion that affected children’s incapacity to talk and relate socially contribute to excessive anxiety on the part of the primary caregivers (Billington et al., 2000). This further opposes the idea that fathers are less emotionally affected by their children’s symptoms and behaviours.

In contrast to the narratives that most fathers told about the challenges in communicating with their autistic children, Ken told a 'pursuit narrative', explaining how he reinforces the child to better his communication skills through ‘accommodating (his) child’s talk’. Pursuit narratives are explained as narratives where the subjective experience is constructed as a positive challenge, and a point of view through which the narrator has been transformed (Levy, 2005). Ken's perspective was that, instead of trying to get the child to talk on their level, fathers should consider and assist their children on their level,

> *I get gobble as a response but I generously look at him and say ‘slow it down’ rather than ‘hold on, I don’t understand you’. I don’t want to be negative or him to be negative. I try and engage him in dialogue… and it’s just a way that he tries and communicate..*

Parental social class effects on narratives of fatherhood. Ken is of the most privileged amongst the sample of participants in this study. This is evident when he talks about ‘having financial resources and a supportive network of friends and family’ (Ken). In comparison to the working class fathers, the sons of Ken, Zee and Piet received their diagnosis at an early stage of the child’s development. They also reported to have more access to resources, schools, health professionals’ assistance, supportive social networks, and had more time to engage in different programmes in order to address their children’s wellbeing. These fathers were most active and involved in their children’s diagnosis and took more initiative in trying to overcome the stressors and challenges of raising their children. This confirms that socio-economic status influences fathers’ narrated meanings and experiences of parenting of a child with autism.

Fathers who are from lower SES groups provided chaotic narratives of their experience of parenting a child with autism where the disorder was constructed as something added to their already existing hardships. Kevin reported that ‘it was not enough that (his) mother died, but his child just had to be disabled’. Similarly, Kido said that ‘everything was so much for (him)’. Not only was Kido diagnosed with HIV/AIDS and spoke about his near death experience with his own diagnosis, but he had to further find out that ‘this child was taken by the evil draft’. These and similar fathers constructed their experiences in a fragmented way, jumping from narratives of negative events from one point in the narrative to another.

This was different from the narratives of Zee, Ken and Piet that followed a coherent sequence overtime. In comparison to their working class counterparts, these fathers spoke of their children's communication and behavioural challenges as events of the past and constructed their children’s future in a restorative way. Furthermore, fathers who were more privileged expressed less anxiety towards present circumstances and about their child’s future compared to fathers with low SES. The final overarching theme encapsulates fathers’ narratives of concerns about the prospects of their children’s future.

Narratives of the Child's Future

Concerns about the child’s future were constructed as one of the foremost challenges in the narratives of the participants. Literature reports that concerns about the future of the child are stressors that influence the psychological well-being of fathers (Gray, 2003). Fathers in this study stated that they feel uncertain about how their children will function effectively in society as they grow up. Concerns about of finding appropriate schooling and children’s future independence are subthemes that emerged when fathers’ talked about their autistic children’s future.

Finding a school. Difficulties associated in finding suitable schools that cater to autistic children were a dominant feature in the fathers’ narratives. This was more significant in fathers that are still on school waiting lists and those who do not possess the financial means to approach specialised schools. Zee, Ken and Piet who are from higher income groups talked about stress related to finding a school for their children, but this was not a dominant aspect in their narratives in comparison to working class fathers. This is primarily because their children were already enrolled in specialised schools that attended to their children’s needs. Although they explained the process of overcoming the barrier of being on a waiting list, after their child started schooling, great improvements in the child’s symptoms have been demonstrated. This contributed positively to their process of adjustment and coping.

In comparison, the other seven fathers from lower income groups situated the process of finding a school for autistic children as ‘one of the greatest challenges’ (Zama). These fathers, in comparison to the three participants mentioned above, reported that financial constraints and limited access to resources compromised the developmental outcomes for their children. Fathers construct themselves as the parent responsible for providing financial and material resources and the pressure of not being able to meet the development needs of the child makes them feel as if they have failed their child (Gray, 2003). Furthermore, many said that they do not foresee a positive future for their children if they do not receive specialised education. Fathers expressed fears that their child’s symptoms will not improve if they do not enrol into a specialised school at an early age. Zama’s narrative below exemplifies how the challenge of finding a school is a major problem for fathers,

> *I can’t see any future because with autism he didn’t get a school. I don’t have the money. He is supposed to start already maybe school now. But now, he is still going to crèche. He is like a child of two years but he is eight years now. It is scary to think that he’s gonna stay like a child because of that autism. He is gonna stay like that because* ***I*** *(emphasis) don’t have the money.*

Zama described his emotions as ‘feeling helpless’ because he is unable to do anything to overcome the difficulties of enrolling his child in a specialised school. This was common in fathers’ narratives. Azole’s story illustrates fathers’ aspiration to get their children into adequate schooling and how overcoming this challenge is viewed as a solution to their problems. Azole expressed that ‘all (he) needs is school for their child and everything will be better. I will feel better. I will not feel shit anymore’. In constructing narratives about the challenge of getting their children into an adequate school, Zama and two other fathers’ desperation in the narrative process culminated in an appeal for help from the interviewer to overcome this barrier. Zama’s story is an example of a 'regressive narrative', where the participants’ discourse shifted from hopefulness to hopelessness. In relation to this, Loyiso spoke of finding a school as a major challenge and wanted the interviewer’s expert advice and assistance with getting their child enrolled into a school for autism,

> *…but the problem, I can’t find the school for autism. Maybe you can tell me more about this autism, because that is what I know it is. It’s just that we are desperate to get him into school. You can help.*

When I told fathers that I am not skilled or equipped to assist them and provided them with the participants’ referral list, they proceeded to construct narratives that demonstrated a sense of hopelessness about their child’s prospects for progression and wellbeing. This demonstrate that fathers who were battling to enrol their child in a specialised school, and who did not possess significant resources, felt that they have not fulfilled their paternal role efficiently and view their child's prospects in a resigned and fatalistic manner. This is because they are unable to provide the resources to facilitate a positive trajectory in their child’s development.

Independence narratives. The majority of the fathers developed narratives around the child’s current dependence on them as parents. Fathers reported that they have fears of children not being able to become independent as they grow older. They further expressed anxiety of this challenge being an on-going process and that there will never be a time when their children are able to sustain themselves. Fathers’ feel that if children become more independent, their wellbeing will improve. Future independence is constructed by the majority of fathers as their sons being able to work in a profession, getting married to women and having children. Here fathers’ discourse is shaped by hetero-normativity. An excerpt from Kevin’s story exemplifies this,

> *He must have a wife and kids like me. He must be able to stand on his own two feet… I just want him to be independent!*

Kevin's narrative, illustrates the future security for their children is how fathers define normality, where fathers employ the heterosexual model for a successful future of their sons.

Similar to Gray’s (2003) findings, participants considered financial and material responsibility as the key role to their manhood; and they want their sons to replicate this model.

Nine out of the ten fathers spoke about their wives as caregivers and nurturers of their child and themselves as financial providers. Differing parental roles and responsibilities impact the way in which fathers define stressors that are central to them (Moes et al., 1992). Participants' narratives suggest that fathers talk about anxieties associated with independence of the child and the child's future as their primary concern. This supports the argument that men are more emotionally affected by stressful circumstances associated with employment and financial provision for the family (Gray, 2003). Similar to Moes et al. (1992), these findings suggest that stress levels may be associated with traditionally constructed parenting roles and responsibilities. Fathers express fear that their children will not improve to be able to meet the demand to be productive in society, and that no one will be there to look after the child when they die. More privileged fathers are taking active steps to address this concern and appear to feel more secure in their children's future in comparison to working class fathers. Coping strategies and resources addressing paternal stress should consider the difference in fathers' sources of stress in relation to that of mothers.

Summary and Conclusion

The following narratives emerged in fathers' talk of parenting a child with autism: 1) diagnostic narratives, 2) narratives about the child's characteristics, and 3) narratives of the child's future. Narratives provided a window through which to interpret their experience. Analysis of fathers' discourse demonstrates an overlap with existing literature offering new-found insights in the area.

Findings suggest that fathers are affected differently by parenting a child with autism. Issues of race, gender, SES and culture intersect in shaping fathers' subjective experiences. Black and coloured fathers are particularly vulnerable groups who express more challenges, anxieties and negative experiences in comparison to white fathers. Black and coloured racial groups are associated with lower socio-economic status in South Africa. However, race is not necessarily a factor that contributes to the challenge of raising a child with autism as reflected by the prominent influence of SES on fathers talk about their experience. Privileged fathers constructed having more resources and support in comparison to fathers from low SES groups. Fathers who were not from privileged circumstances spoke about more negative experiences and difficulties during the diagnostic process. They also construct more concerns about the future prospects of their child with autism because of lack of financial resources and support to ensure the well-being of their child. Challenges of finding appropriate schooling and fears for children's future independence are also significant challenges and concerns for fathers.

Participants report that lack of knowledge about autism and understanding what might have caused the disorder were great challenges, especially for those fathers who had limited access to resources and who had a particular cultural perspective of the child's symptoms that was different from biomedical perspectives. Hence, socio-economic status plays a fundamental role in shaping fathers' experiences with poorer fathers constructing more difficulties, challenges and negative experiences in adjusting to the child's diagnosis.

Findings demonstrate that fathers struggle to form bonds of attachment with their children with autism. Fathers further report not feeling acknowledged by their child with autism. This has been attributed to children's behaviour and communication impairments. Fathers talk about their children's behavioural and communicative symptoms implicating their roles and identities. Traditional perspectives of masculinity shaped fathers' experiences in that how they construct their paternal identities are challenged by their child's symptoms. Participants made explicit distinctions between their parenting roles and the roles of their wives or the mothers of their children. This male-specific parental role informed the way in which they deal with parenting a child with autism and this influences the anxieties, fears and difficulties that are central to their experiences. The fact that their children were sons shaped their challenges but this was not explored in the discussion of this paper. It is suggested that future research explore how the gender of fathers' affected child shape their subjective experiences.

Findings in this paper demonstrate that how fathers talk about their experience of the journey of parenting a child with autism are influenced by broader societal contexts in which these narratives are situated. On a macro-level, fathers' narratives of their experience are influenced by traditionally constructed gender roles, socioeconomic status and its relationship with race in a South African context, and cultural factors associated with African underpinnings of the symptoms that are different to biomedical discourses. This study advocates for policy implementation strategy and intervention techniques to take into account these broad societal systems that shape fathers' subjective experiences of raising a child with autism.

Policy implementation should identify fathers in disadvantaged and marginalised communities in order to address their particular needs. Resources and programmes addressing autism should operate in these communities in order to assist fathers with their challenges, anxieties and concerns, as demonstrated in the findings in this paper. Health policies and professionals should also be mindful of cultural factors that might contest biomedical perspectives, making fathers' experiences of the child's autism diagnosis more difficult.

In conclusion, this research sought to address the gap in the literature around men's experiences of raising children with ASD and its findings will add value to academic literature, policy implementation, intervention and further clinical practices. The findings contribute to existing theories in the literature about gender-specific experiences and challenges of raising children with autism. It further contributes to the literature in that conclusions were drawn about how fathers construct their own experiences of raising a child with autism and what factors and contexts shape their subjective experiences. Traditional masculine gender roles and their associations with parenting, as considered in this work, should continue to be at the forefront of future research aiming to address parenting for men. Issues of socioeconomic status, race and culture and how they intersect should further be considered in future research aiming to address parents' experiences of raising children with autism. A thematic narrative approach allowed for exploring participants' identities and the contexts that shape their experiences constructed through language. As executed in this study, employing a content and structural analysis of narratives is useful when analysing participants' stories and may be useful in future research aiming to investigate participants' stories. The research findings and interpretations of this study will complement the wealth of findings that focus on mothers' experiences of raising children with ASD. Majority of the studies investigating caregivers raising children with autism employ quantitative methodological approaches. This study contributed to the limited amount of qualitative research in the field of autism and caregivers experiences. This study may further inform quantitative research approaches investigating caregivers with autism-affected children.

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Appendix A

INFORMED CONSENT FORM
University of Cape Town
Department of Psychology

Men's narratives of parenting a child with Autism Spectrum Disorder (ASD)

Dear Parent,

1. **Invitation and Purpose**

You are invited to take part in this study which explores fathers' experiences of raising children with Autism Spectrum Disorders (ASD). I am a student researcher from the Psychology department at the University of Cape Town.

2. **Procedures**

- If you decide to take part in this study I will interview you about your experiences raising a child with ASD, asking you to share your experiences from when your child was first diagnosed until your most recent experiences. By interviewing you I hope to find out what it is like to raise a child with ASD and talk about any aspects of fathering that you wish to add to the discussion.
- The interview should take about an hour; however, you are free to speak to me for a shorter or longer period.
- Participating in this study is voluntary. You are free to end the interview at any time with no penalty or any other consequences.

3. **Risks, Discomforts & Inconveniences**

- This study poses a low risk of harm to you.
- Speaking about your experiences of fathering a child with ASD could bring up sensitive issues and could potentially be emotionally distressing. However, you will decide what you would like to discuss in the interview and you will not be obligated to speak about anything you do not feel comfortable speaking about.
- If you would like to contact a counsellor to further discuss your experiences, you can contact the organizations listen on the referral list.
- You might be inconvenienced by having to give up an hour of your time.

4. **Privacy and Confidentiality**

- Interviews will take place in a private space.

- Any information you share is strictly confidential. You will remain anonymous throughout the research process. You have the right to request that any information you have shared be removed from the study.
- A tape recorder will be used to record the interview. If you would like the tape recorder to be switched off at any time you have the right to request this.
- No one but myself and my university supervisors will listen to or have access to the tape recordings.
- You can choose at any time during the interview when the recording device should be switched off.
- The findings of this research paper may be published in an academic journal.

7. **Contact details**
If you have questions, concerns, or complaints about the study please contact Lance Louskieter on 0837390528, Dr. Nokuthula Tshabalala at the Child Guidance Clinic, University of Cape Town (UCT) 021 650 3901 or Dr. Floretta Boonzaier at the Department of Psychology, University of Cape Town (UCT) 021 650 3429.

8. **Signatures**

{Subject's name}________________ has been informed of the nature and purpose of the procedures described above including any risks involved in its performance. He or she has been given time to ask any questions and these questions have been answered to the best of the investigator's ability. A signed copy of this consent form will be made available to the subject.

_______________________	_______________
Investigator's Signature	Date

I have been informed about this research study and understand its purpose, possible benefits, risks, and discomforts. I agree to take part in this research as a subject. I know that I am free to withdraw this consent and quit this project at any time, and that doing so will not cause me any penalty or loss of benefits that I would otherwise be entitled to enjoy. I am aware that the interview will be audio recorded and that I can ask for the audio recording device to be switched off at any given time of the duration of the interview. I am further aware that the research will be written up in the form of an honours research project and may be published in an academic journal.

_______________________	_______________
Subject's Signature	Date

Appendix B

Referral List

Should you feel that you require counselling or support, below is a list of organizations which could be contacted:

Autism Western Cape
Services:
They provide counselling and advisory services to support the needs of children and adults with Autism Spectrum Disorders, along with their parents and caregivers.

Support line: (+27 21) 6859581
Support email: support@autismwesterncape.org.za

Life Line
Services:
24 hour telephone counselling service
Rape counselling
Trauma counselling
Face to Face counselling
HIV/Aids counselling
Payment
Services free of charge
Contact:
Office: (+27 21) 461-1113
Crisis: (+27 21) 461-1111
Email: info@lifelinewc.org.za