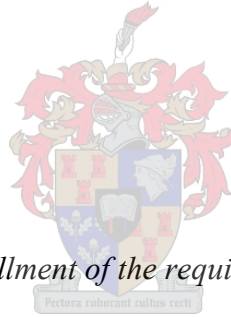


**The father's experience: A South African perspective on caring for a child with autism
spectrum disorder**

by

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Master of Science (Psychology) at Stellenbosch University

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Declaration

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

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Summary

Autism spectrum disorder (ASD) is a developmental disorder that currently affects millions of individuals and their families across the globe. This study aimed to explore the experiences of fathers of children with ASD within the South African demographic, with a focus on the challenges experienced by these fathers in their caregiving role as well as the resources they employed to cope with these challenges. The study was exploratory and qualitative in nature. Semi-structured interviews were conducted with 15 fathers of children with ASD and the responses were thematically analysed. The themes that were identified through the process of thematic analysis were conceptualised in terms of Bronfenbrenner's ecological systems theory. Thematic analysis revealed both the challenges these fathers are faced with as well as resources they utilise to cope with these challenges. The challenges experienced by the study participants included lack of respite, symptomatic challenges, health related issues in the child, the diagnosis, family dynamics, uninformed general public, financial challenges and services. Contrarily, the resources fathers utilised to cope with these challenges were giving it a name, respite, support, finances, characteristics of the child, beliefs, services and adjustment over time were all resources that some or all of the fathers employed. The results of this study suggest that even though fathers experience a multitude of challenges that impact their lives significantly, they also make use of various resources to assist them in their caregiving task. The results of this study indicate that the greatest strength these fathers have is an ability to employ problem-focused coping mechanisms to cope with the challenges they face. This study provides a point of departure for future studies to further investigate the well-being of fathers caring for children with ASD.

Key words: Autism, autism spectrum disorder, challenges, fathers, resources.

Opsomming

Outisme spektrum versteuring (OSV) is 'n ontwikkelingsgestremdheid wat tans wêreldwyd miljoene individue en hul families beïnvloed. Hierdie studie het beoog om die ervarings van pa's van kinders met OSV in die Suid-Afrikaanse milieu te bestudeer deur te fokus op die uitdagings wat hierdie pa's in hul rol as versorgers ervaar, asook die hulpbronne wat hulle inspan om hierdie uitdagings te hanteer. Die studie was verkennend en kwalitatief van aard. Semi-gestruktureerde onderhoude is met 15 pa's van kinders met OSV gevoer en die antwoorde tematies ontleed. Die tema's wat deur middel van tematiese analise na vore gekom het, is in terme van Bronfenbrenner se ekologiese sisteme teorie gekonseptualiseer. Tematiese analise het beide die uitdagings waarmee hierdie pa's te doen het asook die hulpbronne tot hul beskikking ontbloot. Die verskeie uitdagings wat die studiedeelnemers ervaar het is 'n tekort aan rus, simptomatiese uitdagings, gesondheidsverwante uitdagings in die kind, die diagnose, familiedinamiek, die oningeligde publiek, finansiële uitdagings en dienste. Daarteenoor om die versteuring 'n naam te gee, rus, ondersteuning, finansies, eienskappe van die kind, geloof, dienste en aanpassing met die verloop van tyd na vore gekom as hulpbronne waarvan die pa's gebruik maak om die uitdagings te hanteer. Die uitslae van die huidige studie dui daarop dat alhoewel pa's 'n verskeidenheid uitdagings wat hul lewens merkwaardig beïnvloed ervaar, hulle ook van verskeie hulpbronne gebruik maak om hul by te staan in hul rol as versorgers. Die uitslae van hierdie studie dui verder daarop dat pa's se vermoë om van probleem-gefokusde hanteringsvaardighede gebruik te maak 'n merkwaardige sterkpunt is en dat hul sodoende in staat is om die uitdagings waarmee hul te doen het te hanteer. Die studie dien as 'n vertrekpunt vir toekomstige studies om die welsyn van pa's van kinders met OSV verder te bestudeer.

Sleutelwoorde: hulpbronne, Outisme, outisme spektrum versteuring, pa's

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Table of Contents

Declaration.....	ii
Summary.....	iii
Opsomming.....	iv
Acknowledgements.....	v
Table of Contents.....	vi
Chapter 1: Introduction.....	1
Definition of Key Terms.....	2
Autism Spectrum Disorder.....	2
Caregiver.....	2
Challenges.....	3
Resources.....	3
Outline of the Research Project.....	3
Chapter 2: Literature Review.....	5
Definition.....	5
Prevalence.....	5
Aetiology.....	9
Nature or nurture?.....	9
The genetic component.....	9
The environmental component.....	10
Clinical Picture.....	12
Social communication and language delays.....	13
Repetitive, restricted behaviours and need for sameness.....	14

Comorbidity.....	15
Diagnosis.....	16
Treatment.....	19
Parental decisions and involvement regarding treatment.....	21
Caregiving.....	23
Raising children with ASD.....	24
Fathers of children with ASD.....	25
Distinguishing between Maternal and Paternal Challenges.....	28
Challenges faced by Fathers of Children with ASD.....	29
Lack of information and services.....	30
Difficult behaviours associated with ASD.....	31
Parental isolation.....	32
Absence of support system.....	33
Impact on a marriage.....	34
Comorbidity.....	35
Financial burden.....	35
Guilt.....	36
Thoughts about child's future.....	36
Distinguishing between Maternal and Paternal Resources.....	37
Resources and Support Available to Fathers of Children with ASD.....	39
Support.....	39
Empowering themselves.....	40
Driving interventions and working towards goals and outcomes.....	40

Acceptance of the diagnosis, focusing on the positive and hope for the future.....	41
Being involved.....	41
Religion.....	42
Adaptation over time.....	42
Theoretical Framework.....	43
Conclusion.....	44
Chapter 3: Methodology.....	46
Rationale.....	46
Research Question.....	47
Aims and Objectives.....	47
Research Design.....	47
Participants.....	47
Data Collection.....	52
Data Analysis.....	52
Trustworthiness.....	53
Ethical Considerations.....	56
Conclusion.....	58
Chapter 4: Results.....	59
Challenges.....	61
Microsystem.....	61
Lack of respite.....	61
Symptomatic challenges.....	63
Health related issues in the child.....	66

The diagnosis	67
Mesosystem.....	70
Family dynamics.....	70
Uninformed general public.....	71
Exosystem	72
Financial challenges.....	72
Macrosystem.....	74
Services.....	74
Resources.....	76
Microsystem.....	76
Giving it a name.....	76
Respite.....	78
Support.....	79
Ability to provide.....	80
Characteristics of the child.....	81
Macrosystem.....	82
Religion.....	82
Services.....	82
Chronosystem.....	84
Adjustment over time.....	84
Conclusion.....	85
Chapter 5: Discussion	86
Discussion of the Findings, Theoretical Framework and Literature.....	86

The Microsystem.....	88
The Mesosystem.....	93
The Exosystem.....	96
The Macrosystem.....	97
The Chronosystem.....	98
Limitations and Recommendations for Future Research.....	99
Conclusion.....	100
References.....	102
List of Appendices.....	120
Appendix A: Call for Research Participants.....	121
Appendix B: English Informed Consent Form	125
Appendix C: Afrikaans Informed Consent Form.....	129
Appendix D: English Biographical Questionnaire.....	133
Appendix E: Afrikaans Biographical Questionnaire.....	134
Appendix F: English Semi-Structured Interview Questions.....	135
Appendix G: Afrikaans Semi-Structured Interview Questions.....	136
Appendix H: Ethical Clearance.....	137
Appendix I: Turnitin Report.....	138
List of Tables	
Table 3.1 Participant Biographical Details.....	51
Table 4.1 The Main Challenges and Resources Experienced by Fathers Caring for Children with ASD within the ecological systems theory.....	61

Chapter 1: Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that affects people of all genders, races and socio-economic sectors across their lifespan (Centres for Disease Control and Prevention [CDC], 2014; LeBlanc, Riley, & Goldsmith, 2008).

ASD is currently estimated to affect 1 in 68 children (CDC, 2014), and thus has an impact on millions of lives worldwide. The features of ASD manifest behaviourally with deficits in social interaction and communication and repetitive and restricted behaviours being the two defining criteria of the disorder (American Psychological Association [APA], 2013).

Apart from the many individuals affected by ASD, the disorder impacts on the lives of all the people caring for these individuals (Rivard, Terroux, Parent-Bousier, & Mercier, 2014; Samadi & McConkey, 2014). Despite the fact that fathers tend to be involved in caring for their child with ASD and that the paternal caregiver's experience differs from that of the maternal caregiver, the literature pertaining to the father's role and experience in this role remains limited (Braunstein, Peniston, Perelman, & Cassano, 2013; O'Halloran, Sweeney, & Doody, 2013), particularly within the South African context.

The majority of studies that have examined parental experiences, challenges and resources relating to caring for a child with ASD examined the experiences of both mothers and fathers or the experiences of mothers in isolation (Braunstein et al., 2013). In the limited literature available, fathers have reported difficulties obtaining access to information and services. Additionally, their child's behaviour and coping with the financial burden of caring for a child with a disability were factors they found challenging (Dababnah & Parish, 2013; Martins, Walker, & Fouché, 2013; O'Halloran et al., 2013). On the other hand, familial support, gaining access to information and services and seeing improvements in their child have been

reported as resources by fathers caring for a child with ASD (Dababnah & Parish, 2013; Greeff & Nolting, 2013; O'Halloran et al., 2013).

Although limited, the available literature suggests that the experience of fathers differs in some aspects from those of mothers, particularly with regard to the coping styles of fathers and mothers differ in their coping styles. Fathers have been reported to employ a more problem-focused coping style, as opposed to mothers of children with ASD who primarily tend to employ an emotion-focused coping style (Hastings et al., 2005, Martins et al., 2013).

In light of the paucity of the available literature on this subject, the current study thus aimed to explore the experience of fathers of children with ASD in South Africa, focusing particularly on the challenges they experience as well as the resources they utilise to assist them in coping with their caregiving role.

Definition of Key Terminology

Autism spectrum disorder. ASD is a behaviourally manifested neurodevelopmental disorder that affects individuals across their lifespan (LeBlanc et al., 2008). The symptoms of ASD range across a spectrum, with features present to a greater or lesser extent in affected individuals. Characteristic features of ASD include difficulties in social communication and language, repetitive behaviours and thought patterns that are rigid and lacking in imagination (APA, 2013).

Caregiver. A caregiver can be defined as a person who looks after a sick, elderly or disabled person on a regular basis. A caregiver can be either a family member or a paid individual (Stevenson, 2010). In the present study, the interviewed fathers were caregivers.

Challenges. Stevenson (2010) defines challenges as any task or situation that is demanding or taxing on an individual. Within the context of the present study, challenges were the experiences fathers perceived as testing to deal with.

Resources. Resources are any factors that can aid or assist an individual in challenging circumstances and/or any asset that an individual has in supply or stock (Stevenson, 2010). In the present study, resources included any experience or asset that was perceived as helpful and supportive by fathers.

Outline of the Research Project

A discussion of the available literature pertaining to the experiences of fathers of children with ASD will be provided in Chapter 2. This chapter will commence with an extensive definition of ASD, a discussion of global prevalence rates of ASD, the aetiology of the disorder, the clinical picture of the disorder as well as the diagnostic features and processes of the disorder and treatment options. Thereafter, caregiving will be outlined, looking at fathers of children with ASD in particular. This is followed by a discussion of fathers' experiences when they are raising a child with ASD, with a particular focus on challenges and resources experienced and utilised by fathers. In conclusion, the theoretical framework within which the current study is situated will be considered.

In Chapter 3, the research methodology of the present study is discussed. This discussion is commenced with an outline of the rationale of the study, followed by the research question addressed by the study, the study's aims and objectives and the research design. Thereafter the participants are described, followed by a description of the data collection and data analysis techniques employed by the current study. Finally, trustworthiness and ethical considerations are discussed.

In Chapter 4, the results of the present study are presented. The main themes (including Challenges and Resources) that were identified by means of thematic analysis will be presented here.

Lastly, Chapter 5 serves as a discussion of the findings presented in chapter four. The findings of the present study will be considered and related to findings of previous literature and unique aspects of the present study will be highlighted. The findings of the study will be considered within Bronfenbrenner's Ecological systems theory (Bronfenbrenner, 1977). Finally, the limitations as well as recommendations for future studies will be discussed.

Chapter 2 : Literature Review

This chapter provides a background and point of departure for the current study by discussing the available research that has been conducted on fathers caring for children with ASD, with a focus on the challenges and resources they experience in their caregiving role.

Firstly, the definition, prevalence, aetiology, clinical picture and treatment of individuals with ASD is discussed. Thereafter, caregiving, particularly with regard to raising children with ASD is addressed, followed by a review of the role modern fathers play in child rearing. The challenges fathers are faced with when raising a child with ASD as well as the resources that assist them in coping with their caregiving task is then considered. Finally, the theoretical framework within which the study is situated is outlined.

Definition

ASD is a behaviourally manifested, neurodevelopmental disorder that affects individuals across their lifespan (LeBlanc et al., 2008). The symptoms of ASD range across a spectrum and features are present to a greater or lesser extent in all affected individuals.

The disorder is widespread, is characterised by difficulties in social communication and language across multiple contexts as well as repetitive behaviours and thought patterns that are rigid and lacking in imagination (APA, 2013). Diagnostic features emerge in early childhood and these difficulties result in impairments and challenges in social, personal, academic and occupational functioning (APA, 2013).

Prevalence

Many prevalence studies have been conducted and even though there is no conclusive prevalence rate, research has indicated that ASD occurs much more often than initially thought (CDC, 2014; Fombonne, Quirke, & Hagen, 2009).

Despite many studies that have been conducted, the occurrence of ASD in the general population has proven difficult to ascertain with prevalence studies reporting varying and inconsistent results. Prevalence results vary from as low as 0.01% (Yang, Hu, & Han, 2007) to as high as 2.6% (Elsabbagh et al., 2012). The American CDC has also reported ASD to be the second most common developmental disability, with intellectual impairment being the most common (CDC, 2014) and survey data available on prevalence studies conducted by the CDC furthermore indicates that ASD is more prevalent than childhood cancer, diabetes and acquired immune deficiency (CDC, 2014). These statistics indicate the continuing need for ASD research and interventions.

ASD affects all races, ethnicities and socio-economic sectors. Furthermore, the disorder occurs almost five times more often in males than in females and is currently reported to affect one in every 42 boys and one in every 189 girls (CDC, 2014).

A major challenge faced by researchers when determining and discussing prevalence rates of ASD, is the substantial change in diagnostic criteria since the disorder was first described in the 1940s. The earliest cases that were described in the 1940s by Leo Kanner were narrowly defined (Kanner, 1944) and encompassed only those cases that would today be classified as severe or low functioning autism (Elsabbagh et al., 2012). Diagnostic criteria systematically expanded from the 1940s to include individuals with a less severe presentation of ASD in the 1980s. Since then, the International Classification of Diseases (ICD) as well as the DSM-5 have been updated multiple times, with altered diagnostic criteria every time, thus resulting in a difficulty to determine changes in prevalence rates based on diagnoses made with so many different sets of diagnostic criteria (Elsabbagh et al., 2012).

A recent global prevalence review examined more than 600 prevalence studies that were

conducted worldwide since 2000 in an effort to gauge a global prevalence estimate (Elsabbagh et al., 2012). The results of the current study concluded that, on average, ASD is present in 0.62% of the general population.

Analysis of the prevalence based on studies that were conducted in Europe indicated an average prevalence of 0.18% (Elsabbagh et al., 2012). However, study samples and results vary greatly, with sample sizes ranging from 826 to 490 000 and results from 0.019% to 0.73%.

With regard to the prevalence of ASD in the Western Pacific, South East Asia and the Eastern Mediterranean, an average prevalence of 0.1% was reported. Here too, results varied greatly from study to study. The highest estimate to date, 2.6%, obtained in a Korean study stands in stark contrast to a Chinese study that found a prevalence of only 0.62% (Elsabbagh et al., 2012).

America and Canada have contributed the majority of prevalence studies to date (Elsabbagh et al., 2012). The latest American statistics released by the U.S. Centers for Disease Control and Prevention indicates a rapid increase in the prevalence of diagnosed individuals with ASD. They report that currently, one in every 68 children has a diagnosis of ASD in the United States of America. This number has increased dramatically when it is considered that one in every 110 children received this diagnosis in 2006 (CDC, 2014) and only one in every 150 children in the year 2000 (CDC, 2014).

With regard to the prevalence of ASD on the African continent, the literature is limited. Reports dating back to the 1970s describe the features of ASD among children in Africa, providing evidence that ASD occurs across various geographical regions (Elsabbagh et al., 2012).

In their review study examining literature pertaining to the prevalence of ASD in Africa,

Bakare and Munir (2011) found only two studies addressing this issue. Egypt and Tunisia were included in the first study that focused mainly on Arab countries. Results indicated that in the Egyptian and Tunisian population, 33.6% and 11.5% respectively of people with disabilities had been diagnosed with ASD (Seif Eldin et al., 2008). Thus, ASD accounts for a notable percentage of people with diagnosed disabilities, especially in Egypt. The second study examined children living in Sweden, who were born to Somali parents, and 0.7% of their sample had obtained a diagnosis of ASD (Barnevik-Olson, Gillberg, & Fernell, 2008).

In a comprehensive search for prevalence rates for ASD within the South African population, several academic databases including Academic Search Premier, Science Direct, Scopus, Sage Journals Online and Psych Articles were searched for studies containing keywords 'Autism', 'Autism Spectrum Disorders', 'prevalence' and 'South Africa' and various combinations thereof. No study was found to have examined prevalence within the South African demographic.

Furthermore, Bateman (2013) reported that the Red Cross Children's Hospital, Lentegour and Tygerberg Hospital collectively diagnose approximately 10 children with ASD per week, indicating that there is a substantial number of children and families whose lives are affected by this disorder in the Western Cape province of South Africa. This number still excludes children that are diagnosed by private physicians and is thus not indicative of national prevalence.

A study of the literature pertaining to the prevalence of ASD indicates that the occurrence of the disorder is much higher than initially thought (CDC, 2014). The available literature also indicates that determining local and global prevalence rates for ASD is no easy task (Elsabbagh et al., 2012) and that studies on the African continent are lacking (Bakare & Munir, 2011; Elsabbagh et al., 2012).

Gaining an understanding of the substantial increase in the prevalence of ASD is complicated by the fact that there is no apparent, clear cause for the disorder. Despite intensive research being done, and progress being made, the exact cause of ASD remains a mystery (Happé, Ronald, & Plomin, 2006).

Aetiology

Nature or nurture. To date, no single identifiable cause has been found for ASD (Happé et al., 2006).

Despite an increase in research on ASD (Dawson, 2013), researchers and clinicians alike continue to be baffled by the aetiology of ASD. Currently, researchers know that various factors contribute to the development of ASD and the understanding is that the disorder has both genetic and environmental components, rather than one single cause (Landrigan, 2010; Muhle, Trentacoste, & Rapin, 2004).

Overall, research into the aetiology of ASD indicates that the symptoms of ASD appear as a result of complex interactions between genetics (including epigenetics, where environmental factors modulate the expression of certain genes) and environmental factors (Gentile et al., 2013; Gialloreti, Benvenuto, Benassi, & Curatolo, 2014). The argument for an interaction between genetic and environmental factors is substantiated by research that found more pre- and perinatal complications in affected siblings when compared to unaffected siblings, but at the same time found that unaffected siblings displayed more complications than control subjects (Glasson et al., 2004).

The genetic component. Research clearly indicates that genetics is involved in the development of ASD. Twin studies in monozygotic or identical twins (who share 100% of their genetic material) indicate that if one twin presents with the features of ASD there is an increased

probability of the other twin also having the disorder (Hallmayer et al., 2011; Muhle et al., 2004).

Studies vary with regard to exact percentages, but numbers indicate that there is a probability of between 30% and 95% of ASD occurring in one twin if the other twin is affected (CDC, 2014).

Similarly, in nonidentical twins and non twin siblings (who do not share all of their genetic material), if one sibling has ASD, there is an increased probability of between 2% and 18% of the twin or sibling also having the disorder.

Genetic studies have linked various genetic occurrences including gene mutations, gene deletions, copy number variants (where certain genes or portions of genes have an abnormal amount of copies), single nucleotide polymorphisms/Variable Number Tandem Repeats, linkage regions and copy number variations with the development of ASD (Sutcliffe, 2008; Xu et al., 2012). The literature also indicates that in the majority of cases, the development of ASD is not linked to one particular gene (Gentile et al., 2013). A variety of genes have been implicated in the development of the disorder (Muhle et al., 2004).

These findings indicate that the genetic component involved in the aetiology of ASD is extremely complicated and not thus not easily identifiable or understandable. Cases where a the patient's ASD is attributable to one individual gene only accounts for approximately 20% of cases (Dhillon, Hellings, & Butler, 2011). In all the other cases, the ASD is, at least partially, caused by multiple genes or epigenetic factors.

The environmental component. Certain environmental factors interact with the genetic makeup of an individual in a particular way, resulting in the presence of the diagnostic features of ASD. An extensive number of environmental factors have been studied for a possible

causative role in the development of ASD. These include advanced parental age, maternal infections during pregnancy, gestational diabetes, teratogenic agents (which are factors that lead to abnormal development), pesticide exposure, thyroid function alterations, folic acid dysregulation, high levels of prenatal testosterone, prenatal ultrasound exposure, fever during pregnancy, gestational age at birth (and birthing methods, including delivery by caesarean section and induced labour), mercury exposure, autoimmune disease, latitude, the hygiene hypothesis, oxidative stress, urban versus rural living, living near a highway, vitamin D deficiency, leaky gut syndrome / intestinal disturbance, paracetamol and Lyme disease (Bilder, Pinborough-Zimmerman, Miller, & McMahon, 2009; Gentile et al., 2013; Gialloreti et al., 2014; Guinchat et al., 2012; Tanne, 2012).

Thus, if a fetus or baby with a certain genetic predisposition is exposed to certain environmental factors or undergoes certain occurrences in the womb, during birth or early life, this may lead to the child developing ASD (Glasson et al., 2004).

Research indicates that all the environmental factors have an organic, physical impact on brain development and anatomy and the basis of the disorder thus has an organic basis, rather than a psychological one. Studying the brains of individuals with ASD by use of Magnetic Resonance (MRI) studies have revealed physical changes (in some, but not all affected individuals) in the amygdala-hippocampal complex (Abell et al., 1999) as well as grey and white matter volume abnormalities in the cortex. Furthermore, post mortem studies of brains of people with ASD have revealed increased cell packing density and decreased neuronal size in the limbic system as well as changes in the cerebellum and the cerebral cortex. Lastly, there is evidence of increased activated microglial cells which suggests some involvement of the immune system in the development of ASD (Bauman & Kemper, 2005).

Viral infection has also been suggested to play a possible causal role in the development of ASD. However, the way in which this would happen remains uncertain and highly debatable (Gentile et al., 2013). It is hypothesised that viral exposure could have either a direct neurotoxic effect or an indirect neurotoxic effect that is mediated by the immune system. Thus, exposing the still developing nervous system in the womb to certain viruses, may lead to the development of the complex symptoms that make up ASD in genetically predisposed individuals (Gentile et al., 2013). Alternatively, exposure to a virus, could lead to an autoimmune response that results in neuronal damage.

The increase in occurrence of ASD over the past five decades has also led researchers to examine environmental factors, such as medical and lifestyle conditions that have changed or increased dramatically in recent years for a causative role in the development of ASD. Vitamin D deficiency (Gentile et al., 2013) and birth by cesarean Section (Gialloreti et al., 2014) are examples of some of these factors.

Upon review, the available literature indicates that even though some possible contributing factors are known, the uncertainty as to what exactly causes ASD has made effective treatment and prevention strategies difficult and continued investigation into the causes of the disorder remains a priority.

Clinical Picture

ASD is a neurodevelopmental disorder that manifests early in life with behavioural symptoms. People with ASD (without other comorbid disabilities) therefore appear physically normal (APA, 2013). It is generally only in interacting with or observing these individuals over time that their deficits become apparent.

The disorder presents differently in every affected individual and its presentation

depends greatly on factors such as the severity of the disorder and comorbid conditions (APA, 2013). Despite this varying presentation, the disorder limits or impairs everyday functioning in all affected individuals.

The two main features of ASD, according to the criteria set out in the 5th Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), are deficits in social interaction and communication as well as repetitive and restricted behaviours.

Social communication and language delays. Many individuals with ASD never develop verbal language, whereas others simply suffer delays in language development. Poor comprehension of speech as well as echolalia (a condition in which a person simply echoes speech), stilted speech and an overly literal interpretation of language may also be present (APA, 2013).

Verbal as well as nonverbal deficits in language and communication are often obvious when interacting with an individual with ASD, as they often do not pick up on social cues and body language. In children who do develop verbal language, it is often very simple, and used to label and request, rather than to converse and comment on their environment. With regards to nonverbal communication, eye contact and gesturing is often absent or atypical. Appropriate body orientation, facial expression and voice intonation are also often not learned instinctively by children with ASD. In adults who do not also suffer from intellectual impairment or language delays, this difficulty in social reciprocity becomes most apparent in having problem in responding to complex social cues. Joining and partaking in a conversation may thus be challenging for these individuals (APA, 2013).

Difficulties in social interaction and deficits in the ability to share enjoyment of experiences, thoughts and feelings are apparent in children with ASD. They do not initiate social

interactions with peers as would be expected from typically¹ developing individuals and they also often show little or no imitation skills. These deficits lead to children with ASD often not having sustained social interactions and friendships (APA, 2013).

What still stands out today with regards to the clinical presentation of ASD is what Leo Kanner, pioneer in the field, described initially in 1944 as an “autistic aloneness” that is present from early in life (Kanner, 1944). Affected children simply appear to be in their own world and far removed and nonplussed by the happenings around them.

Repetitive, restricted behaviours and need for sameness

Children with ASD also present with repetitive and restricted behaviours, including self-stimulatory behaviours, often abbreviated as “stims” or “stimming” (Grandin, 2011; Leekam, Prior, & Uljarevic, 2011). These are often the first symptoms noticed by the outside observer.

Repetitive behaviours and self-stimulatory behaviours may present in the form of motor behaviours such as hand flapping and finger flicking, using the same objects in a stereotypical manner, such as the stacking or lining up of toys. These behaviours, referred to as stimming, are repetitive in nature, seemingly unnecessary and can be verbal or nonverbal. Children with ASD may for example be seen pacing up and down, repeating the same word, sound or movement. It is important to note, that there is no obvious, observable cause for these behaviours. Dr Temple Grandin, who has ASD herself, describes these stimming behaviours as calming (Grandin, 2011).

Self-stimulatory behaviours may also present in the form of echolalia, where words, sounds or sentences are repeated without any understanding of their meaning (APA, 2013; Leekam et al., 2011). These repetitive behaviours were some of the first and most distinguishable features described by pioneers in the field of ASD, Leo Kanner and Hans Asperger (Asperger, 1944; Kanner, 1944) and are still of the most recognisable features of individuals with ASD.

¹ A child that develops normally, that does not display any developmental difficulties

Individuals with ASD often have an abnormal need for routine or sameness and react adversely if even a small detail in their lives (such as food packaging) changes (APA, 2013).

Children with ASD furthermore often present with special interests that develop into obsessions. These can include anything from a child being obsessed with watching the sprayer in a garden to an adult obsessively writing out timetables. At times, these obsessions and ritualistic behaviours may serve a sensory purpose in that they are the result of under- or over-sensitivity of the sensory systems. This sensory hyper- or hypo-sensitivity often occurs in individuals with ASD and they often respond abnormally to certain smells, sounds and textures (APA, 2013; Leekam et al., 2011). Inappropriate smelling or tasting of people and/or objects as well as fascinations with certain colours or textures are commonly seen in individuals with ASD. A child with ASD may for example smell and feel the hair or skin of everyone they encounter's or refuse to eat foods that have a certain texture (APA, 2013).

Apart from the social and language aspect and the insistence on sameness and routine, many other symptoms may be present due to comorbid disorders.

Comorbidity. Apart from the communication difficulties, social behaviour challenges, and stereotypical rituals which form the diagnostic features of the disorder, comorbid disorders or challenges are often present in individuals with ASD. Some of these include feeding difficulties, digestive and gastrointestinal complications, seizures, cerebral palsy, behaviours that are hard to manage, fine motor challenges, gross motor challenges, mental health disorders, Attention Deficit Hyperactivity Disorder (ADHD), intellectual impairment, feeding issues and self-injury (Kuhn & Matson, 2002; Matson, Cooper, Malone, & Moskow, 2008; Matson & Williams, 2015; Williams, 2010).

The two main features of ASD are thus deficits in social communication and language as

well as the presence of repetitive, restricted behaviours. Despite other disorders and conditions often co-occurring with ASD, observation and classification of a person based on these core features (not on the co-occurring symptoms) are the basis for diagnosing the disorder (APA, 2013).

Diagnosis

ASD is diagnosed by a multidisciplinary team of qualified medical professionals based on observations and reports of the two core features (deficits in social communication and language and the presence of repetitive, restricted behaviours) of the disorder.

A team including developmental paediatricians, neurologists and psychiatrists, using the diagnostic criteria set out in the DSM-5 (APA, 2013) may be involved in the diagnosis. Often, other therapists (including occupational therapists and speech therapists) and teachers may also be involved in the diagnostic process (Matson & Goldin, 2013). A diagnosis is obtained through a combination of observation of the child, who is presenting features of ASD, and questioning of parents and/or caregivers and other professionals involved in the lives of these children as well as using rating scales such as The Autism Diagnostic Observation Schedule (ADOS) (Corsello, Akshoomof, & Stahmer, 2013).

ASD can be diagnosed at any age, provided the symptoms can be traced back to early childhood. The symptoms have to impact on daily functioning or impair daily functioning to a significant extent. The available literature indicates that ASD can be diagnosed accurately by skilled and experienced medical professionals even in children below 3 years of age (Charman et al., 2005; Corsello et al., 2013; Matson, Boisjoli, Hess, & Wilkins, 2010). Children are most often diagnosed with ASD between age 3 and age 5 (Goin-Kochel, Mackintosh, & Myers, 2006; Latif & Williams, 2007).

There are two criteria set out in the DSM-5 that have to be met in order for a diagnosis of ASD to be made.

The first of these is persistent difficulties in social interaction. This difficulty has to be persistent across various times and contexts. These difficulties manifest as deficits in understanding and reciprocating social and emotional interactions. This includes an inability to conduct a normal conversation, challenges in starting a conversation or responding when they are interacted with. Affected individuals may also display a diminished need or ability to express their interests and display or discuss their emotions (APA, 2013).

Shortcomings in ability to understand and reciprocate nonverbal communication are also an example of a deficit in social communication and interaction. This can range from limited verbal and nonverbal communication skills and abnormal eye contact and some individuals may use no nonverbal communication, such as gestures or facial expressions whatsoever (APA, 2013).

Furthermore, these social difficulties have to become apparent in the abnormal development, progression and understanding of relationships. Individuals with ASD may have difficulties adjusting their behaviour depending on the social situation they find themselves in. They may also find imaginative play challenging and have trouble making friends. They may even be completely disinterested in making friends.

The second criterion that has to be met is the presence of at least two restricted or repetitive behaviours or interests. This criterion manifests as stereotypical or repetitive motor movements and/or the repetitive use of objects or speech. Examples of such stereotypical behaviours are the perfect, linear organisation of toys or objects, flapping their hands or repeating various sounds or words (APA, 2013). This is also manifested as an insistence on

sameness, an inability to handle changes in routine or the ritualistic repetition of behaviour, which may include verbal or nonverbal behaviour. This insistence on sameness manifests as for example difficulties transitioning between activities or places, rigid thinking patterns, ritualistic greetings, difficulties coping with small changes in their daily routine or the need to take a particular route or eat the same food every day (APA, 2013). This criterion is also illustrated by highly restricted and/or fixated interests that have an abnormal intensity or focus, such as an obsession with unusual objects. Sensory under- or oversensitivity also forms a part of the second diagnostic criterium. Individuals with ASD may respond inappropriately by under or overreacting to pain, temperature. They may be over- or under sensitive with regard to sounds or textures and may for example not want to touch certain surfaces or listen to certain music. They may also display a sensory undersensitivity, where they may smell or touch certain objects excessively. Visually, they may be intrigued by a certain way in which the light falls or a certain object moves and may thus become fixated on this movement.

Once the presence of these symptoms has been established, their severity has to be specified. These severity specifiers may fluctuate over time and context, as the affected individual may adapt certain coping strategies and thus present with more or less severe symptoms at different times. Furthermore, the severity of the social communication difficulties and repetitive behaviours also has to be specified separately. The three possible severity levels that have to be specified are Level 1 (Requiring support), Level 2 (Requiring substantial support) and Level 3 (Requiring very substantial support).

The diagnosis of ASD should also be accompanied by a specification regarding the presence or absence of accompanying intellectual or language impairment or whether any known medical (for example genetic) or environmental factors are associated with the symptoms (APA,

2013).

Once the diagnostic criteria have been met, there are still two checkpoints that have to be passed for a diagnosis to be confirmed.

Firstly, the symptoms must have been present from early in life. Here, it should be kept in mind that the deficits, although traceable to early childhood development may only have become apparent later on, due to growing social and academic demands. Furthermore, even if a person has acquired strategies to cope with social or academic demands, but these symptoms were present during early development, this still constitutes evidence towards a diagnosis.

Secondly, the diagnosis of ASD will only be given if the individual is disrupted in the various spheres of their daily lives (social, home, school, work) to what is deemed a clinically significant extent. Finally, these difficulties with social interaction, language and imagination may only lead to a diagnosis of ASD if an intellectual disability or Global Developmental Delay does not account for the deficits (APA, 2013).

Obtaining a diagnosis of ASD is thus not something that happens overnight. It is a process that requires many professionals and results from observations and reports of the two core features of the disorder, namely deficits in language and social communication and repetitive and restricted behaviours (APA, 2013). Diagnosing the disorder is the first step towards ensuring a positive outcome for the affected child as well as their families, followed by an effective treatment program.

Treatment

Once a diagnosis of ASD is obtained, treatment options can be considered and a treatment program can be embarked on.

At this time, there is no cure for ASD (Baron-Cohen, 2009; Matson, Adams, Williams, &

Rieske, 2013). However, there are various interventions available that target the behavioural manifestation as well as the neurology of the disorder and ASD is thus considered to be a treatable disorder (Matson et al., 2013; Matson & Williams, 2015).

Interventions can be divided broadly into five categories, namely skills-based interventions, physiological interventions, alternative approaches, medical interventions and eclectic approaches that will be discussed below (Green et al., 2006; Goin-Kochel et al., 2006; Bowker, d'Angelo, Hicks, & Wells, 2011). Some of these have been proven effective and are supported by empirical research whereas others have not (Matson & Williams, 2015). Almost all of those interventions that have been established as successful in treating the core symptoms of ASD can be categorised as interventions that are based on operant or classical conditioning and include the popular applied behaviour analysis (ABA) (Matson et al., 2013).

Skills based approaches, such as operant conditioning and social learning approaches that include ABA and behaviour modification, are the methods that have been found to have the best results (Matson et al., 2013). Applied Behaviour Analysis is a popular skills based intervention that works on a repetition and reinforcement basis to promote skills development and is also used as a behaviour management strategy. Occupational and speech therapy are also included in this category.

Physiological approaches include interventions such as sensory integration therapy, which has limited empirical support (Matson et al., 2013).

Special diets, such as the gluten free, casein free diet and vitamin supplements are examples of alternative therapies that people employ as a treatment option. These are also not supported empirically (Matson et al., 2013).

Medication such as central nervous stimulants, antipsychotics and anticonvulsants are

often prescribed for children, teenagers and adults with ASD but are generally not aimed at the core symptoms of ASD, but rather at comorbid disorders, often anxiety, ADHD and depression (Matson et al., 2013; Matson & Williams, 2015).

Eclectic approaches incorporate two or more treatments (Matson et al., 2013) and it is often the case that multiple treatment options are employed.

The available literature indicates that there are a multitude of treatment options (some that are empirically supported and others that are not) available. Parents are thus in a challenging position where they have to decide upon a course of treatment for their child.

Parental decisions and involvement regarding treatment. Due to the nature of the disorder and its lifelong impact on a child's independence, parents of children with ASD are often required to be more involved in their child's life than parents of children without developmental difficulties (Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011).

From early childhood and often into adolescence and adulthood (Krauss, Seltzer, & Jacobson, 2005; Matson & Williams, 2015), parents ultimately shoulder the responsibility of deciding on a treatment program for their child with ASD and deciding on a course of treatment is no easy task for parents to be faced with. Parents have furthermore been found to play a vital and possibly pivotal part in the outcome of interventions (Robbins, Dunlap, & Pleinis, 1991).

Research indicates that parents generally choose to use multiple intervention strategies and Goin-Kochel and colleagues (2007) reported that an average of 7 - 9 different types of treatment are used at a time. The reasons for why parents resort to using such a large number of treatments are complex.

Firstly, the complex nature and comorbidity often associated with ASD demands more than one approach aimed at targeting both the primary symptoms of ASD (social

communication, language and repetitive behaviours) as well as the associated symptoms of comorbid disorders (such as ADHD). It would be impossible for a single intervention to target the social and language aspects of the disorder as well as other physiological conditions such as ADHD or cerebral palsy that often occur comorbidly with ASD (Matson & Williams, 2014). Thus, multiple therapies (and therapists) are often necessary to treat the various aspects of the disorder.

Secondly, parents of children with ASD are often desperate when they are endeavouring to find the correct interventions for their child. Parents often opt for any and every possible treatment that may be beneficial, regardless of empirical support (or lack thereof) (Matson & Williams, 2014). Notably, there is no link between parental education level and choice of empirically substantiated treatments (Miller, Schreck, Mulick, & Butter, 2012), which may indicate that parents make emotional decisions, rather than rational decisions.

Thirdly, parents are bombarded by vast amounts of information regarding treatment options. The internet, psychologists, occupational- and speech therapists, other parents, magazines and books all present parents with countless and often conflicting suggestions regarding the effectiveness of different treatment options. Parents can be easily confused and overwhelmed by this surplus of information, making it challenging for them to decide upon a course of action regarding treatment.

In the fourth place, child age can limit the application of particular treatments. Behavioural treatments have been found to be less applicable to very young children as well as older adolescents, and psychotropic drugs have been found to be the preferred choice of treatment for adolescents (Goin-Kochel et al., 2007).

Parents' treatment choices are also motivated by where they feel their child's greatest

deficiencies lie and it is also notable that data supplied by national autism associations do not always prove beneficial and often supply limited guidance in selecting treatment options that are truly beneficial (Matson & Williams, 2015).

Not surprisingly the perception and expectation that a parent has of a treatment beforehand, also impacts on treatment decisions made by parents (Matson & Williams, 2015).

Unfortunately, parents often opt for interventions that are not empirically supported (Matson et al., 2013). This is also an attempt from the parents' side to try anything and everything that claims to treat ASD. It is estimated the 32 - 92% of parents make use of these unsubstantiated therapies for their children with ASD (Matson et al., 2013). There are also other methods that have not been studied sufficiently, but that do show promise and warrant further examination. Matson and colleagues (2013) identifies Hansen's More Than Words Program for Toddlers and the Early Start Denver model as two examples of such methods. Many of the commercially available and utilised interventions are not empirically supported at this time (Matson et al., 2013).

It is clear from the literature that while there is no shortage in treatment options, deciding on a course of treatment is no easy task for parents and many multiple factors weigh in on their decision regarding a treatment program for their child.

Caregiving

Raising children is a challenging task that comes with many responsibilities, ranging from physical care to making complicated decisions regarding a child's future.

Parents of children with ASD have to overcome many more challenges and shoulder much more responsibility than parents raising a typically developing child (Dabrowska & Pisula, 2010). Adjusting to raising a child with ASD may take longer than adjusting to raising a

typically developing child.

Raising children with ASD. Caring for a child with ASD presents many challenges to parents and other caregivers (Samadi & McConkey, 2014; Resch et al., 2010; Rivard et al., 2014).

Generally, parents are the primary caregivers and parental involvement in promoting the success of interventions for children with ASD has been highlighted (Stoner et al., 2005). Parents' lives are often thrown upside down when at first their child does not develop normally, displays behavioural difficulties and is then diagnosed with ASD.

Vacca (2013) described five phases that parents might progress through when raising children with disabilities (including ASD). Firstly, they move through what he identified as the Normative Phase, in which they are expecting a healthy baby. Secondly, they move into a Self-Study Phase. The characteristic feature of this phase is that parents blame themselves for the child's disability. Hereafter, they move into the Acceptance Phase, where they embrace the child. He identifies the fourth phase as the Determining Quality of Life Phase. During this phase, fathers examine factors that play a role in their quality of life, such as marital relations and health. Finally, they achieve a phase where they plan for their own future and start considering future possibilities such as having more children, possible job changes and moving house for example.

The challenges presented by caring for a child with a disability has been found to cause more stress for parents than caring for a typically developing child (Dabrowska & Pisula, 2010; Resch et al., 2010). Furthermore, caring for children with ASD may be more challenging and lead to higher levels of stress in parents than raising children affected by other disabilities (Dabrowska & Pisula, 2010; Baker-Ericzn, Brookman-Fraze, & Stahmer, 2005). There are

multiple reasons for this increased demand intensity, including increased uncertainty of lifespan care for children with ASD, due to the limited interventions available in comparison to other disabilities as well as the increased challenge presented by the challenging behaviours exhibited by children with ASD (Dabrowska & Pisula, 2010). In a study of fathers' experiences raising children with ASD, a father is quoted saying "I would rather have a child with cerebral palsy than Autism because at least he would talk to me and interact with me instead of just stare at the wall or move his hands in weird ways" (Vacca, 2013, p85).

Furthermore, even though many professionals are involved in programs aimed at treating children with ASD, parental support, input and commitment remain vital to increase a positive outcome for a child (Strauss et al., 2012), thus requiring a highly involved and intensive form of parenting, when compared to raising typically developing children.

Raising a child with ASD is thus more challenging for parents not only than raising a typically developing child, but also seems to be more challenging in some instances than raising a child with other disabilities.

Fathers of children with ASD. Traditional roles of parents and family structure are no longer as applicable as they were 30 to 40 years ago. Fathers traditionally fulfilled the role of provider and breadwinner and mothers the role of caregiver. In both the western world and in developing countries, this structure of families has changed drastically over the past 40 years (Lamb, 2004; Morrell, Posel, & Devey, 2003, Posel & Devey, 2006). The traditional nuclear family structure, which consists of a mother, father and two children, can no longer be assumed and as such, the traditional roles of mothers as primary caregivers and fathers only as financial providers do not necessarily apply anymore. The modern lifestyle has resulted in more households where both parents work, where children are raised by single parents or where

children are cared for by external caregivers.

The roles of modern fathers have been explored and fathers have been found to be more involved in all spheres of parenting than before (Lamb, 2004). Research acknowledges that fathers are no longer believed to fulfill an one-dimensional role (that of financial provider) and fathers are recognised to play a number of noteworthy roles, such as caregivers, role models, breadwinners and protectors (Lamb, 2004) and also that paternal involvement plays an important role in child rearing (Borke, Lamm, Eickhorst, & Keller, 2007; Lamb, 2004; Vacca, 2013). Fathers have been found to refer to themselves as caregivers, teachers and providers (Vacca, 2013).

A South African study that may shed some light on the role modern South African men play in their families examined the role of fathers who have a family member with HIV/AIDS in rural KwaZulu Natal (Montgomery, Hosegood, Busza, Timaeus, 2006). Even though the study did not focus on ASD, it still sheds some light on the involvement of South African fathers by indicating that instead of being uninvolved and distanced (as might have been expected), these South African men were actively involved, provided physical care for the AIDS patient and their children as well as financially supporting immediate and extended family.

However, the study indicated that these activities and contributions by fathers were often not acknowledged (Montgomery et al., 2006).

Developmental psychologists have been researching both maternal and paternal engagement in child rearing and have been highlighting that it is highly beneficial for both parents to be involved in raising children (Borke et al., 2007; Clarke-Stewart, 1978; Coley & Coltrane, 2007; Pancsofar & Vernon-Feagans, 2006; Pleck, 2007). However, despite the changes in family structure and the increased role fathers play, mothers are still the focus of most of the

studies on caring for disabled children (Braunstein et al., 2013; Phares, Fields, Kamboukos, & Lopez, 2005). There is a paucity of research on fathers' roles and experiences with regard to child development and psychopathology in general (Cassano, Adrian, Veits, & Zeman, 2006; Phares et al., 2005) and with regard to ASD in particular (Braunstein et al., 2013). This is the case both internationally and locally.

In 2013, Braunstein and colleagues reviewed 404 articles published on ASD between 2001 and 2010. Of the 404 articles, fathers were explicitly included in only 13.6% of the studies. Both mothers and fathers were included (and results analysed separately for gender) in 12.1% of the studies and only 1.5% investigated fathers only. This contrasts to 21.3% of the studies that focused solely on mothers. A further 65.1% of the studies reported that they studied "parents". However, these studies did not analyse results separately by gender. Many possible explanations have been offered to account for this underrepresentation of fathers, including assumptions about fathers being more difficult to access and outdated views on parental roles and responsibilities (Braunstein et al., 2013; Lamb, 2004).

However, the limited studies that did focus on fathers as caregivers for children with ASD identified certain challenges encountered by fathers in their caregiving role. These challenges may also contribute to clinically significant levels of stress (Dabrowska & Pisula, 2010). Only one study examining fathers of children with ASD in South Africa could be found (Martins et al., 2013). The results of the study by Martins and colleagues (2013) also bear testament to the strain these fathers experience.

A study of the available literature indicates that traditional family structure and roles of mothers as caregivers and fathers as breadwinners can no longer be assumed. More recent conceptualisations of family structures suggest that fathers have become more involved in all

aspects of child rearing and as such, are more susceptible to the challenges presented by caring for a child with a disability such as ASD. The ways in which they are affected has however not been studied sufficiently.

Distinguishing between Maternal and Paternal Challenges

The available literature indicates that the majority of studies that have examined parental experiences, challenges and resources related to caring for a child with ASD, have examined the combined experiences of mothers and fathers or the experiences of mothers in isolation (Braunstein et al., 2013).

However, due to the modern father's increased involvement in child rearing, it is possible that some of the challenges experienced by mothers may be applicable to fathers too. Some studies have examined fathers in their role as caregivers for children with developmental disabilities, including ASD (Barak-Levy & Atzaba-Poria, 2013; Dababnah & Parish, 2013; O'Halloran et al., 2013). These studies suggest that the experience of fathers differ in some respects from that of mothers (Hastings et al., 2005), particularly with regard to the coping mechanisms they employ to manage the challenges they face whilst raising their disabled child (Barak-Levy & Atzabia-Poria, 2013).

Thus, regardless of the level of challenge experienced, different aspects of raising a child with ASD are experienced by maternal and paternal caregivers. Mothers and fathers may also employ different coping mechanisms to cope with these challenges (Keller & Honig, 2004; Hastings et al., 2005). Mothers have been found to be more affected by difficulties in self-regulation, such as eating and sleeping difficulties, displayed by their children whereas fathers find the externalising behaviours displayed by their children as well as child characteristics (such as the need to adhere to a routine) more challenging to deal with (Davis & Carter, 2008; Barker

et al., 2011).

The nature and samples of the studies conducted to date do not allow conclusions to be drawn with regard to differences in the level and nature of challenges experienced by mothers and fathers of children with ASD.

On the one hand, comparable levels of stress and depressive symptoms in mothers and fathers of children with ASD has been reported (Davis & Carter, 2008; Hastings et al., 2005). On the other hand, there are studies that have reported higher levels of paternal stress as a result of the challenges they are faced with (Rivard et al., 2014), while others indicate that fathers experience lower levels of stress than mothers (Baker-Ericzn et al., 2005).

Thus, despite some indications that stress levels differ between mothers and fathers as well as differences in the nature of the challenges experienced due to raising a child with ASD, results of assessing and addressing these differences between mothers and fathers remain inconclusive. As such, particular challenges experienced by parents will thus be discussed jointly, while highlighting the challenges reported by fathers in particular.

Challenges faced by Fathers of Children with ASD

Due to the changes in family structure over the past decades, fathers are more involved in child-rearing than they were previously. Despite difficulties determining differences in stress levels between mothers and fathers and the nature of challenges experienced, it is clear that fathers of children with ASD experience more stress and suffer from poorer health than fathers raising typically developing children (Samadi & McConkey, 2014). It is clear that fathers of children with ASD are faced with multiple challenges with regard to caring for their child (Dababnah & Parish, 2014; Martins et al., 2013).

Research has indicated that the way in which fathers respond to and experience the

journey of raising a child with ASD varies from that of mothers. Fathers tend to focus on interventions, milestones and planning for the child's future from as early on as when a diagnosis of ASD is received (Barak-Levy & Atzaba-Poria, 2013; Donaldson, Elder, Self, & Christie, 2011).

The challenges experienced by fathers of children with ASD are also not limited to the challenges presented directly by the core features of the disorder. There is a ripple effect, whereby some challenges stem from secondary results of the symptoms of the disorder (Benson, 2006). For example, the primary challenge of dealing with a child that only wants to eat certain kinds of food, such as only macaroni or only foods that are red in colour, may result in secondary challenges such as having to manage tantrums because of this preference or an added financial burden as certain foods have to be purchased especially because of this rigidity in behaviour.

The challenges that have been identified in the available literature will be discussed in the next section. The main challenges include a lack of information and services; difficult behaviours associated with ASD; parental isolation, the impact on marriages; comorbidity; financial burden; guilt and thoughts about the child's future.

Lack of information and services. Parents of a young child displaying a developmental delay or concerning behaviour often find themselves in a very difficult position, where they feel isolated and in the dark due to the lack of awareness with regard to ASD.

Limited awareness of the signs and symptoms of ASD, poor health care services and long waiting lists to see medical professionals provide a substantial challenge for parents with a child that displays developmental difficulties. Both mothers and fathers have reported difficulties in obtaining information and gaining access to services such as specialised doctors, educational

institutions and therapists (Moh & Magiati, 2012; O'Halloran et al., 2013). Statistics South Africa report that a quarter of children aged 5 - 6 with severe communication difficulties and 16.5% with mild communication difficulties do not attend an early childhood development educational setting (Lehohla, 2014). These percentages increase throughout elementary and primary school and in children aged 14 - 19, 40% of children with severe communication difficulty as well as 25% with mild communication difficulty do not attend school.

Furthermore, the time parents have had to wait to gain access to services has been found to be a very challenging facet of caring for their child with ASD (Dababnah & Parish, 2013; Mitchell & Holdt, 2014; Moh & Magiati, 2012; O'Halloran et al., 2013; Resch et al., 2010; Rivard et al., 2014). Difficulties obtaining a diagnosis has proven especially challenging for many parents (Jones & Passey, 2005; Moh & Magiati, 2012).

Furthermore, even if a family were able to access medical or educational services, professionals have been found to be inadequately equipped in terms of training or experience to deal with the particular challenges of teaching or treating a child with ASD (Mitchell & Holdt, 2014; Woodgate, Ateah, & Secco, 2008). This often leads to prolonged efforts for parents to ensure the correct intervention for their child. In one South African study, parents indicated that they experienced professionals as having insufficient knowledge of diagnostic tools and found that professionals feared misdiagnosing or labelling a child, resulting in them not wanting to diagnose a child as having ASD (Mitchell & Holdt, 2014).

These difficulties in turn, lead to prolonged periods where children do not receive the correct intervention and the symptoms of their ASD may increase. During these periods, the language difficulties as well as social behavioural difficulties that the child presents may prove extremely challenging for parents to cope with.

Difficult behaviours associated with ASD. There are certain behaviours associated with ASD that may be extremely challenging for parents to cope with. These behaviours, referred to as externalising behaviours, are actions that direct problematic energy outwards and include actions that harm or disturb others. Severe tantrums that include kicking, screaming or biting are examples of behaviours that may prove challenging to manage in a public setting (Davis & Carter, 2008; Hastings, 2003; Lecavalier, Leone, & Wiltz, 2006; Martins et al., 2013). Self-stimulatory behaviours may also be challenging to manage, as this often includes repetitive noises or movements that are socially inappropriate or trying for parents.

Fathers in particular have been reported to find the externalising behaviours (such as tantrums and socially inappropriate actions) related to ASD and the inflexibility in routine challenging as these behaviours impact on the family functioning in social settings (O'Halloran et al., 2013). Stress, that results from these challenging behaviours may be sensed by children and may also lead to more negative child behaviour patterns, thus creating a vicious cycle where both the child's and the parent's behaviour is negatively reinforced (Meltzer, 2011; Walsh, Mulder, & Tudor, 2013).

These actions have been found to be predictive of parental stress (Lecavalier et al., 2006) and they may be challenging to manage. They may also result in unwanted scrutiny in public settings, which fathers find challenging to deal with (Davis & Carter, 2008). This in turn may result in parents avoiding public settings, and social situations which may have long term implications for their well-being and may lead to parental isolation.

Parental isolation. Parents often feel isolated and excluded from society as a result of raising their disabled child. Parents are often left feeling misunderstood, alone and often stigmatised in their daily task of caring for their child (Woodgate et al., 2008).

These feelings of isolation and stigmatisation impact severely on both mothers' and fathers' social lives, often making it challenging to attend social events, to go shopping for example and the outcome is often to avoid these situations altogether. Parents have reported that dealing with family, friends and neighbours can be very challenging (Jones & Passey, 2005). This is because certain aspects of caring for a child with ASD, such as disruptive behaviours, the absence of speech in their children and increased attention demanded by their children are often unknown to people who are not familiar with the disorder (Woodgate et al., 2008).

Despite successful ASD awareness programs in the US and the UK (Dillenburger, Jordan, McKerr, Divine, & Keenan, 2013), parents in these countries continue to experience a lack of awareness of the presentation and prevalence of ASD in the general population (Woodgate et al., 2008) Even in these countries, this leads to feelings of isolation and being misunderstood. These feelings are likely to be much more pronounced in countries where awareness as well as services are less.

Furthermore, this isolation may be present within the family structure too. Fathers have reported an inability to connect with their child as challenging for them (Vacca, 2013). Fathers and mothers have also reported feelings of isolation within their marriage, at times when they experience conflicting feelings with regard to their child and thus find themselves in different mindsets regarding their child's development and interventions (Woodgate et al., 2008).

Absence of a support system. In a world where parents feel isolated and misunderstood (Gray, 2002; Sivberg, 2002), the lack of a support system can further add to their feelings of isolation.

Parents have indicated that their quality of life was heavily dependent on the presence or absence of effective support systems for them and their child (Rivard et al., 2014; Woodgate et

al., 2008).

Apart from the educational and health needs of their child, support for parents in the form of parent support groups, involved family members and friends, and a strong marriage seem to be absent from many parents' lives, with many parents feeling that they are fighting a battle on their own (Higgins, Bailey, & Pearce, 2005; Woodgate et al., 2008).

The lack of these support structures may further add to the burden of caring for a child with ASD.

Impact on a marriage. Throughout its course, every relationship will be exposed to challenges and hurdles. Raising a typically developing child is in itself a factor that adds to the challenges experienced by parents and this is even more so for raising a child with a disability.

Naseef and Freedman (2012) report that raising a child with ASD can substantially contribute to parental stress when compared to parents of typically developing children. In particular, it can result in marital strain. The change in what is expected in terms of raising the child, financial difficulties, finding appropriate schooling, intensive therapy time-tables and the child's challenging behaviour are all factors that contribute to strain on parental relationships.

Furthermore, parenting a child with both a developmental disability and behaviour problems can prove extra challenging and place even more strain on a relationship (Benson, 2006; Brobst, Clopton & Hendrick, 2009). Marital satisfaction has also been found to be impacted negatively by caring for a child with ASD for both mothers and fathers (Gau et al., 2012; Higgins et al., 2005).

A poor marital relationship may thus become another challenge parents of children with ASD are burdened with and adds substantially to the challenges already experienced by these parents (Brobst et al., 2009).

However, despite these challenges and the common belief that the divorce rate in families with a child with ASD increased, Naseef & Freedman (2012) report that 64% of children in the US reside in two parent households. This percentage is similar to marriages with typically developing children, suggesting that, despite the undeniable challenges associated with raising a child with ASD, this does not necessarily lead to higher divorce rates.

Comorbidity. Other medical conditions, such as ADHD, digestive difficulties, cerebral palsy, gastrointestinal tract difficulties and sleep difficulties often co-occur with ASD and provide extra challenges for parents (Matson et al., 2008).

Coping with the challenges that result due to comorbid conditions have been reported by both mothers and fathers (Dababnah & Parish, 2013; Hartley et al., 2011; Resch et al., 2010). These challenges may include decisions regarding medication and side effects of medication.

Coping with these challenges may impact on parents' physical health and lead to exhaustion and sleep problems (Kuhlthau et al., 2014). Parents have also reported that they neglect their own health in order to take care of their children (Kuhlthau et al., 2014), which could likely have negative long-term effects for both parents and children.

Thus, there are many additional challenges parents have to deal with as a result of disorders or conditions that co-occur with ASD.

Financial burden. Raising children is generally expensive. Costs involved in the physical care, schooling, extracurricular activities and medical care are already a substantial factor to deal with. It is not surprising then, that having a child with ASD adds substantially to the financial burden of a household (Newacheck & Kim, 2005).

In the case of a child with ASD, all aspects of child rearing is specialised and thus more expensive. Specialised schooling is required. Specialised medical attention is required, including

consultations and testing by highly specialised (and costly) medical doctors. Often, individualised therapies, including occupational therapy and speech therapy are needed, that also come at a price.

The expenses related only to the health care of a child with a disability is on average more than three times that of caring for a child without disabilities (Newacheck & Kim, 2005). The financial implications involved in the testing, interventions and other support and supplies (such as visual aids and specialised occupational- and speech therapy equipment and resources) have been reported as challenging by fathers in particular (Dababnah & Parish, 2013).

Guilt. Raising a child with ASD requires intensive involvement by both mother and father. It is a task that requires large quantities of time and money and many parents have also reported feelings of guilt toward their child, with parents often feeling that they are not doing enough for their child (Kuhlthau et al., 2014).

Fathers reported that they felt responsible to spend all their free time tending to their child's need and that they feel guilty when they do not do so. Guilt was also often associated with feelings regarding neglect of other typically developing children, due to the high demand placed on their resources by the child with ASD (Kuhlthau et al., 2014).

Thoughts about the child's future. Vicarious futurity is defined as the hopes and despairs a parent has with regard to their child's future. These hopes and despairs have proven in recent years to more comprehensively reflect the complex feeling parents experience in relation to their child with ASD (Faso, Neal-Beevers, & Carlson, 2013).

In a study by Wong and Heriot (2007) parents of children with ASD reported high feelings of despair and low feelings of hope for their child, whereas parents of typically developing children have high feelings of hope and low feelings of despair, indicating that

parents struggle with thoughts about the future of their disabled child.

People with disabilities are often at a disadvantage where employment opportunities are concerned, often due to lack of formal education and skills. Unemployment leads to various challenges for disabled individuals, including financial dependence on family members or the social security system. According to results of the 2011 South African census, eight out of ten disabled individuals in South Africa are unemployed (Lehohahla, 2014). This prospect contributes to parental fears regarding their child's future.

Concerns about what will become of their child in future have been reported by fathers in particular (Donaldson et al., 2011; O'Halloran et al., 2013). In young children this concern is focused on shorter term prospects and aspects of life such as schooling, whether their child will be able to integrate into a mainstream school and whether their child will develop independence in terms of toileting, feeding and other self-help skills. As children age, however, fathers become concerned with factors such as who will be able to physically and financially care for their child once they are no longer alive, whether their child will be happy and whether their child will reach his or her full potential (O'Halloran et al., 2013).

It should be noted that despite all these challenges experienced by fathers caring for children with ASD, not all parents who are raising children with ASD report elevated stress levels and depressive symptoms (Davis & Carter, 2008). This indicates that some parents possess important resources and support systems that assist them in coping with challenges they experience as a result of caring for a child with ASD (Davis & Carter, 2008).

Distinguishing between Maternal and Paternal Resources

It is clear from the available research, that although caring for a child with ASD presents many challenges for fathers, the resources they have at their disposal play a major role in their well-being.

Research indicates that ultimately, the coping style utilised by a parent, or the resources they employ to cope with the challenges presented when caring for a child with the disorder proves more powerful than the challenges themselves (Dabrowska & Pisula, 2010; Hastings et al., 2005).

As with paternal challenges, the literature pertaining to paternal resources and support systems in particular is very limited. However, some studies have examined this subject, albeit in conjunction with that of maternal caregivers (Dababnah & Parish, 2013; Gray, 2003; Greeff & Nolting, 2013; Rivard et al., 2014). The resources utilised by mothers and fathers will thus be discussed alongside each other, whilst highlighting the resources reported by fathers in particular.

Research findings indicate that there is a difference in the general coping styles of mothers and fathers. Generally, mothers tend to have an emotional coping style. They often talk about the difficulties they experience and turn to friends, family and religion to gain strength to overcome the challenges they are faced with. In contrast, fathers tend to display a cognitive coping style where they try to solve the child's difficulties in a systematic way by means of reasoning and rationalisation (Barak-Levy & Atzaba-Poria, 2013; Gray, 2003).

Fathers who implemented this problem-focused type of coping, rather than an emotion-focused coping style were found to have a better quality of life. Problem focused coping includes focusing on the broader, practical implications of raising their child with ASD such as the financial implications involved, developmental milestones that have to be reached and ensuring

that the child will be provided and cared for in future (Donaldson et al., 2011). It is noteworthy here, that passive or avoidant coping styles were found to impact negatively on quality of life (Hastings et al., 2005; King et al., 2006) and a problem-focused coping style is thus desirable.

Resources and Supports Available to Fathers of Children with ASD

Certain resources and supports have been reported to help parents overcome the challenges presented by caring for a child with ASD, thus resulting in families that are well-adapted and adjusted to caring for their disabled child (Bayat, 2007; Dababnah & Parish, 2013; Greeff & Nolting, 2013; Hastings & Taunt, 2002; Rivard et al., 2014). There remains a paucity of knowledge with regard to exactly what the major sources of support are for fathers within the South African context.

It has to be kept in mind that the majority of studies that have examined the experiences of parents raising children with ASD were conducted in westernised, developed countries.

Fathers of children with ASD have been reported to utilise social and familial support; empowering themselves; driving interventions and working towards goals and outcomes; acceptance of the diagnosis; focusing on the positive and hope for the future; being involved; religion and adaptation over time. It is vital for fathers to discover and utilise these resources and supports, as ultimately, physically and mentally healthy parents are better equipped to adequately care for their child with ASD (Gray, 2003).

Support. During challenging times, people often turn towards the ones closest to them for support. This has also been found to be true for parents raising children with ASD with parents turning to their spouses and their families for support (Dababnah & Parish, 2013). Interestingly, mothers are more likely to turn to friends for support while fathers tend to turn to people inside the family (Jones & Passey, 2005). Fathers in particular have reported that support

from a spouse, other children and extended family members is a valuable resource that assists them in coping.

The support offered by family members ranges from physical supports such as offering parents respite to emotional support such as providing an ear for the parent to talk to (Dababnah & Parish, 2013; Greeff & Nolting, 2013; O'Halloran et al., 2013), which makes them feel understood and included.

Empowering themselves. Parents have reported that empowering themselves through researching the causes, treatments and possible outcomes of ASD has proven to be a valuable resource that assists them in coping with the challenges presented by raising a child with ASD.

Fathers in particular have reported that gaining knowledge on the disorder, by reading books and scouring the internet is a valuable resource that assists them in coping (Dababnah & Parish, 2013). Obtaining knowledge regarding the causes, presentation and interventions available for ASD, allows fathers to proceed to action, and this in turn leads to fathers who feel that they are taking control of the situation (Barak-Levy & Atzabio-Poria, 2013).

Driving interventions and working towards goals and outcomes. As challenging as it can be to not have access to adequate information and services, it can be extremely supportive and resourceful if a child does gain access to doctors, therapists and schools that are equipped to adequately tend to their needs (Dababnah & Parish, 2013; Greeff & Nolting, 2013; Martins et al., 2013; O'Halloran et al., 2013).

For fathers in particular, driving these interventions and working towards particular goals (for example, saying two word sentences, toilet- training or writing their name) is an extremely valuable resource (Dabrowska & Pisula, 2010).

Parents have reported that when their child's health and educational needs were

adequately tended to, their lives were much improved (Kuhlthau et al., 2014).

Acceptance of the diagnosis, focusing on the positive and hope for the future.

Furthermore, although the initial reaction to receiving a diagnosis of ASD may include denial and disappointment regarding future goals for their child, fathers who have accepted the diagnosis have a far more positive parental experience than fathers who have not accepted the diagnosis (Donaldson et al., 2011).

Acceptance of the diagnosis and its implications in turn, leads to an adjustment of goals and expectations and in the end hope for a positive outcome for their child's future was also found to be positively associated with life satisfaction. Thus, appropriately processing the diagnosis, what it means, and setting realistic goals allow fathers to be hopeful about their child's future and this impacts positively on overall life satisfaction (Faso et al., 2014). This also acts as a valuable resource for fathers of children with ASD. Interestingly, the association between this hope for their child's future and life satisfaction persists, regardless of the severity of the ASD symptoms present in the child. Thus, the way a parent feels about their child impacts more on the level of challenge they experience than the severity of the symptoms of the child with ASD (Faso et al., 2014).

Being involved. Fathers have reported that spending quality time with their children validates them in their role as a father, and thus makes it easier for them to cope with raising a child with ASD. Interacting and communicating with their children, albeit in a nonverbal way, also acts as a resource for these fathers (Donaldson et al., 2011).

Programs that focus on father-child interaction and involving fathers in the child's intervention (such as Elder's Father-Directed In-Home Training) have also been shown to be a

valuable resource. Thus, fathers who are more equipped to interact and manage their children with ASD cope better with the child-rearing task (Donaldson et al., 2011).

In interviews with parents of children with ASD, fathers have expressed positive attitudes towards their children, particularly related to positive attributes of their children, and focusing on these positive traits assist fathers in coping. These include for example that their child has mastered basic skills such as toileting (Dababnah & Parish, 2013).

Furthermore, paternal involvement in the treatment and care of their child seems to act as a resource that assists them with coping (Dababnah & Parish, 2013). Involved fathers reported increased self-confidence as well as overall competence and marital satisfaction when compared to fathers in the control group (Seung, Ashwell, Elder, & Valcante, 2006).

Religion. Religion has been reported as a source of solace and a means of coping with the diagnosis as well as the further challenges presented by caring for a child with ASD for mothers and fathers (Dababnah & Parish, 2013, Sivberg, 2002).

People turn to religion in this instance to give meaning to their situation and it contributes to their physical, psychological and emotional well-being (Tarakeshwar & Pargament, 2001). Parents who are religious and use religion as a resource have reported that their religion gives meaning to the challenges that go hand in hand with raising their child. They have also reported that religion helps them to understand ASD on a spiritual level, which does not yet have a conclusive scientific explanation (Tarakeshwar & Pargament, 2001).

Adaptation over time. Although this is not a resource parents can employ themselves, parents adapt over time and they become more confident and competent at raising their children with ASD.

Gray (2006) examined how coping changes in parents raising children with ASD over

time. The results of his study indicated that as time passed, parents employed fewer and fewer coping strategies, possibly indicating that as time goes by, parents experience less emotional distress.

An inexperienced parent of a young child who has only recently been diagnosed with ASD is thus likely to experience more challenges (and utilise more resources to assist them in coping) than an experienced parent whose child is older. Participants in this study reported that their children were significantly easier to live with once they were older (Gray, 2006).

Thus, the combination of the parental adaptive skills and the improvement in the severity of the ASD symptoms (which is likely due to the interventions received), result in better coping over time.

Theoretical Framework

In the current study, the experiences of fathers caring for children with ASD will be examined within the framework of Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1977). Bronfenbrenner's model consists of five levels, namely the microsystem, the mesosystem, the exosystem the macrosystem and the chronosystem. According to Bronfenbrenner (1977), each of these systems has an impact on individual development. Using this framework allows the exploration of both the challenges that fathers face and the supports that fathers have at their disposal on an individual level as well as within the wider social context.

The first level (or microsystem) comprises the individual's immediate environment and includes their closest relationships (Bronfenbrenner, 1977). In the proposed study, the microsystem would for example include the interaction between the father and his child with ASD as well as his relationship with his wife or life partner.

The mesosystem is the second level of ecological systems theory and refers to the interrelationships between the microsystems of which the individual forms a part (Bronfenbrenner 1977). An example pertaining to the proposed study would be how the interaction between the mother and the child with ASD or the interaction between siblings and the child with ASD impact on the father.

The informal and formal social structures that influence the individual, even though they are not themselves part of the systems make up the exosystem (Bronfenbrenner, 1977). Examples of these systems applicable to the proposed study are government interventions for ASD that are available.

The macrosystem refers to the broader social context. This includes cultural norms and standards, government policies, social beliefs and laws (Bronfenbrenner, 1977). An example of this system would be the family's medical aid, grants offered by the government for children with ASD and the country's laws regarding care and interventions for disabilities.

Lastly, the chronosystem refers to the changes that happen across the other systems over time.

In the present study, the challenges and resources, collectively referred to as experiences, faced by fathers of children with ASD will be examined and interpreted within the ecological systems theory (Bronfenbrenner, 1977).

Conclusion

A review of the available literature indicates that ASD is an increasingly prevalent neurodevelopmental disorder that is estimated to affect one in 68 individuals throughout their life. ASD is diagnosed by trained medical professionals, based on the criteria set out in the DSM-

5. The core features of the disorder are delays in social communication and language as well as repetitive and restrictive behaviours.

Treatment is aimed at managing the symptoms of the disorder and include medical, therapeutic and educational intervention

No single, identifiable cause has been found for ASD as yet, but there is an understanding that the disorder has both a genetic and an environmental component.

Raising a child with ASD provides multiple challenges for both mothers and fathers. The majority of research into this subject has examined the experiences of only mothers, or mothers and fathers together and the challenges that have emerged are lack of information and services; difficult behaviours associated with ASD; parental isolation; impact on marriage; medical challenges; financial burden; guilt and thoughts about the child's future.

However, despite these challenges, fathers also utilise valuable resources and supports to assist them in their caregiving task. These include support offered by friends and family; empowering themselves; driving interventions and working towards goals and outcomes; acceptance of the diagnosis; focusing on the positive and hope for the future; being involved; religion and the passage of time.

In conclusion, the literature review emphasises the importance of the identification of these challenges and resources reported by fathers within the South African context.

Understanding the needs of these fathers is of particular importance, as understanding their needs will allow for them to be appropriately assisted.

Chapter 3 : Methodology

This chapter provides an overview of the methodology that was applied in the present study. First, the rationale of the study is provided. Thereafter, the research question and the aims and objectives of the study are outlined. Thereafter, the research design will be discussed and a description of the study participants. A discussion on data collection methods as well as data analysis follows and the process that was utilised to maintain trustworthiness within the study is explained. The chapter concludes with a discussion of the ethical considerations applicable to the study.

Rationale

In the light of the available literature, it is apparent that ASD is a disorder that currently affects millions of lives worldwide (Elsabbagh et al., 2012). Raising a child with ASD presents many challenges not only for parents in general but for fathers in particular. These include challenges in fathers' personal and professional lives. These challenges could for example lead to financial stress, lower marital satisfaction and depressive symptoms (Dababnah & Parish, 2013; Gau et al., 2012).

However, the literature also indicates that despite these challenges, parents find ways to cope with these challenges and some factors have been reported to assist with the caregiving task. These include familial support and seeing improvements in their child (O'Halloran et al., 2013). It is evident that the literature pertaining to fathers of children with ASD is limited (Braunstein et al., 2013). The limited available literature does, however suggest that the experiences of fathers differ from those of mothers in some respects (Barak-Levy & Atzaba-Poria, 2013; Gray, 2003). The experience of fathers of children with ASD therefore seems to be

a neglected, but an important area of research to explore.

Although limited studies have been conducted on this specific topic internationally (Hastings et al., 2005), only one South African study could be found that investigated the subjective experiences of fathers of children with ASD and included only five research participants (Martins et al., 2013). The current study therefore aims to explore the experiences of fathers of children with ASD in the South African context and will hopefully contribute to our knowledge pertaining to the experiences of fathers of children with ASD.

Research question

The research question addressed by the current study can be formulated as follows:
What are the experiences of fathers caring for children with Autism Spectrum Disorder in South Africa?

Aims and objectives

The study aims to examine the experiences of fathers of children with ASD in the South African context, focusing specifically on:

1. The challenges that fathers of children with ASD face.
2. The resources and/or support that assist fathers in caring for their children with ASD.

Research design

The study implemented an exploratory, qualitative research design. A qualitative design was decided upon, to allow for rich, descriptive data to be gathered regarding the experiences of the fathers (Dey, 2005).

Participants

The inclusion criteria stipulated that the child must have obtained the diagnosis of ASD at least 12 months prior to the interview being conducted, to incorporate the traumatic effect of

having received a diagnosis recently to some extent. Fathers whose children were younger than four years were excluded, to allow for at least 12 months passing after obtaining a diagnosis, which usually occurs around 3 years of age in the majority of cases (Charman et al., 2005). Therefore, fathers of children between the ages of 4 and 19 years with a primary diagnosis of ASD were included as participants of the current study. Furthermore, only fathers who were living with their children on a permanent basis were included. This was to ensure the current active involvement of fathers in caring for their children and to contribute to the homogeneity in the sample.

Purposive sampling was used to recruit a sample for the current study. Purposive sampling is a kind of nonprobability sampling that is often employed to reach a particular population (Tongco, 2007). It involves deliberately approaching a certain informant, based on the fact that the informant possesses certain qualities (Tongco, 2007).

Firstly, potential participants were identified with the assistance of Autism Western Cape. Autism Western Cape is a nonprofit organisation that connects families in the Western Cape that are affected by ASD with services, facilities and support. They assist families throughout the process of obtaining a diagnosis to finding the correct academic and therapeutic placement for their child as well as offering support groups and training for families and caregivers who are affected. The existence of this organisation relies on donations and fundraising and thus has no minimum membership fee. As such, they do not exclude any layers of society. Furthermore, they pride themselves on working in lower income areas of the Western Cape and as such provided an opportunity for members from all socio-economic sectors to volunteer to participate in the current study. This organisation sent out a call for research participants (see Appendix A) to their database. The call for participants contained all

information pertaining to the study, the ethical clearance number awarded to the study by the Health Research Ethics Committee (HREC) at the Faculty of Health Sciences at Tygerberg Hospital as well as assurance that their participation in the study was completely voluntary and that their identities would be protected. The Projects and Support Manager of Autism Western Cape then forwarded the contact details of fathers, who had responded and agreed to be contacted for participation in the study, to me.

Participants were also recruited from an early intervention centre, which provides therapeutic intervention for children with ASD. Here, the same procedure was followed. The centre sent out a call for participants to their database and fathers who were willing and interested to participate were contacted. Another method that was utilised to identify potential participants was through the school for children with ASD where I was employed. With the permission of the director of the school, the calls for participants were sent out via e-mail to the parents in the database of the school. Crabtree and Miller (1999) suggest that five to eight participants are sufficient to provide rich information for qualitative research. Interviews in the current study were conducted up to the point of theoretical saturation, where no new themes emerged during the data collection (Lincoln & Guba, 1986). Theoretical saturation was reached after fifteen interviews and provided a rich data set.

A total of 15 fathers were interviewed for the current study. They ranged from 32 to 55 years of age, with a mean age of 42.2 years. Of the 15 participants, 11 (73%) were white, three (20%) were coloured and one was African (7%). Fourteen of the 15 participants (93%) were the child's biological father and one father (7%) was a foster parent of the child. The participants' children ranged in age from 4 to 19, with a mean age of 8.9 years and of the 15 children, nine (60%) were male and six (40%) were female. The children were diagnosed at ages ranging from

1.5 years to eight years of age (mean = 3.14 years), with one father being unsure at which age his daughter was diagnosed with ASD. Thirteen of the 15 (86%) fathers were married, one father was divorced (7%) and one father was single (7%). Fourteen (93%) of the participants were employed full time and one participant (7%) was unemployed (See Table 3.1).

Of the 15 fathers, 14 (93%) reported that they had other children. Ten of the 15 fathers (67%) had only one other child, three fathers had two other children and one father had three other children. The ages of their other children ranged from 18 months to 34 years with a mean age of 10.05 years. Five of the children with ASD (33%) were the eldest child and five (33%) were the youngest child. Two (13%) were middle children with siblings older and younger than them, one (7%) had a twin and one (7%) was an only child. Fathers reported spending an average of 4.2 hours per day with their child during the week and they reported spending more time with their children over weekends, with 11 fathers (73%) reporting that they spent all weekend with their child. One father (7%) reported spending 4 hours, another one (7%) reported spending 8 hours per day with his child over weekends. Two fathers (13%) reported that they spent an average of 2.5 hours, and one father (7%) reported spending 3 hours per day with his child over weekends.

Table 3.1.

Participant Biographical Details

Participant Code	Age of father	Race of father	Employment Status	Marital Status	Age of child	Gender of child
F1 ²	32	Coloured	Full-time	Married	6	Female
F2	37	White	Full-time	Married	7	Male
F3	48	White	Full-time	Married	6	Male
F4	37	White	Full-time	Married	4	Male
F5	55	White	Full-time	Married	17	Male
F6	42	White	Full-time	Married	13	Male
F7	38	White	Full-time	Married	4	Male
F8	38	White	Full-time	Married	4	Male
F9	39	Coloured	Full-time	Married	5	Female
F10	51	African	Full-time	Married	15	Female
F11	43	White	Full-time	Married	12	Female
F12	52	White	Unemployed	Single	19	Female
F13	43	White	Full-time	Divorced	14	Male
F14	42	Coloured	Full-time	Married	4	Male
F15	36	White	Full-time	Married	4	Male

²Note. F= Father, 1= Number of interview

Data collection

After receiving the contact details of potential participants as described in the previous section, potential participants were contacted via e-mail or telephone and invited to participate in the study. All participants were informed of the research question addressed by the study as well as the aims and objectives of the study. Once a participant agreed to take part in the study, a time and venue that suited the participant for a semi-structured interview was arranged. Each participant was required to sign an informed consent form (see Appendices B and C) before any data could be collected. Before the interview commenced, each participant was required to fill out a biographical questionnaire (see Appendices D and E). The qualitative data were collected through semi-structured interviews and each interview lasted between 30 and 75 minutes. The fathers' subjective experience of caring for their child with ASD was then explored using broad, open-ended questions. The interview commenced by a discussion of the father's life before their child with ASD was born and the major ways in which their lives had changed since their child started displaying developmental difficulties. Interview questions focused on the major challenges experienced by fathers as a result of caring for their child with ASD as well as available resources that assisted them in coping with the demands placed on them (see Appendices F and G for the full interview schedule). Permission was requested from participants to record the interviews, to allow for verbatim transcription.

Data Analysis

Thematic analysis was employed to analyse the data (Braun & Clarke, 2006). Braun and Clarke indicated that the aim of thematic analysis is to single out and analyse themes, ideas or

patterns from a data set. The process consisted of six steps.

The first step required me to immerse and familiarise myself with the data. This involved performing and transcribing the audio-recordings of the interviews myself, which gave me an initial overview of the data, followed by reading and re-reading the transcribed data, making notes and reaching a point where preliminary ideas about the experiences of participants emerged.

After this initial immersion, I coded interesting aspects of the data. I systematically went through the entire data set and collated relevant data to each code (Braun & Clarke, 2006). Thirdly, I assembled the various codes into potential themes by analysing codes and grouping various codes together to form an overarching theme. All coded data extracts were organised within these emerging themes. Hereafter, the preliminary themes identified in step three were refined. This involved revisiting all the quotes that had been collated to the various themes and ensuring that they were appropriately allocated to a particular theme.

The fifth step entailed defining the themes as well as naming them (Braun & Clarke, 2006). The final step and final opportunity for analysis was reporting the results. The final, clearly defined themes are reported in the next chapter, with appropriate extracts pertaining to the specific themes cited as examples (Braun & Clarke, 2006). Throughout the thematic analysis process, the details of each theme were revisited and refined, while keeping the aims of the research in mind at all times.

Trustworthiness

For a study's findings to be applied, they have to be open to evaluation and critique. In quantitative studies, reliability and validity serve as measures of trustworthiness of results.

The use of reliability and validity as measures of trustworthiness in qualitative studies has

been questioned and other methods are employed in order to establish rigour in qualitative research (Long & Johnson, 2000). The current study made use of four methods to address the trustworthiness of the findings.

The first measure implemented was reflection. Reflection forms a vital part of qualitative research (Long & Johnson, 2000). By reflecting on the data, I examined my own thoughts in the same way I would examine those of the study participants. I aimed to achieve reflection through journaling throughout the interview process. The interviews and notes taken were discussed with my supervisor on a regular basis. These measures ensured that I was aware of the potential influence of my own views and values on the research process. It should be noted that both my supervisor and I are female, while all the study participants were male. I am also younger than all the participants I interviewed. I also come from a different ethnical and cultural background than some of the participants. Initially, I feared that these factors may make it difficult for the participants to relate to me and to trust me with personal information. To compensate for the possible impact of these factors, I drew from my previous experience in interacting with families of children with ASD when conducting the interviews. Having interacted with parents and children who are impacted by ASD on a regular basis for the past three years, I already had an understanding of the disorder and the challenges associated with ASD. Thus, my knowledge and previous experience with families with children with ASD assisted me to confidently interview the participants. This contributed to putting the participants at ease to share their own experiences with me.

Furthermore, Davis and colleagues (2010) reviewed the available literature on the influence of gender, race and ethnicity of the researcher in qualitative interviews. They found that results on the nature of the impact of these factors on research results is inconclusive, but

report that some studies have found that female researchers received more uninhibited responses from participants of both genders than male researchers, due to participants feeling more comfortable disclosing personal information on sensitive topics to female researchers. I do not believe that my gender negatively impacted on the trustworthiness of the results. From as early as the first interview, I already experienced that fathers displayed a need to be listened to and to be understood. I did not experience that me being a white, younger woman impacted negatively on their interaction with me. In my experience, the participants responded positively to me and appeared to appreciate that someone was taking the time to listen to them.

The second measure taken to establish rigour was respondent validation or member checks. Here, it is important to verify with participants that the data gathered is a true reflection of what they intended to communicate (Long & Johnson, 2000). To implement this measure, I summarised and recapitulated prominent points with the participants. The aim of this was to ensure that the participant's point was clearly understood by me and that their intended thoughts were communicated and understood clearly.

Peer debriefing is a third measure that was implemented to ensure trustworthiness of the results. Peer debriefing requires the researcher to continuously discuss and verify data obtained with a colleague to explore additional and alternative perspectives or explanations throughout the interview stage as well as throughout the data collection and analysis phase (Long & Johnson, 2000). I continually discussed the interviews I had conducted as well as the emerging themes and my interpretation thereof with my supervisor, who has expert knowledge in conducting qualitative research with caregivers in particular. I further discussed the emergent themes throughout the data collection and analysis phase with a colleague who has more than 10 years' experience working with children and families with ASD and is currently the director at a school

that specialises in ASD. Discussions with the director and incorporating her expertise on ASD contributed to more objective data analysis, as she brought her views and interpretations (that are influenced by many years' experience) to the table. Including this expert in data analysis by no means infringed on the privacy and confidentiality of the study participants as she only gained access once participant names were removed and changed to participant codes.

It is also standard protocol for research proposals in the Department of Psychology at the Stellenbosch University to be submitted for review by at least two members of the department. The study was thus subjected to review by at least two colleagues who checked the academic merit and theoretical soundness of the research proposal as well as the ethical implication of the study.

Ethical Considerations

Ethical clearance for this research project was obtained from the Health Research Ethics Committee (HREC) at the Faculty of Health Sciences at Tygerberg Hospital before any participants were recruited for data collection. The ethical clearance number awarded to the study is S14/05/106 (see Appendix H).

Participants were notified that they participated in the study on a voluntary basis and that taking part in the study would not cost them anything. They were notified that they may (at any time) choose to withdraw from the study and that their withdrawal will hold no negative consequences. The identities of the participants were also protected by using code names rather than their names as well as omitting any information that may lead to them being recognisable based on the study's results. The study uses a number system for code names - for example 'F1', refers to the first father that was interviewed.

Only my supervisor, the director at the ASD specific school in Somerset West where I

was employed and I had access to any recorded or transcribed data. My supervisor as well as the director of the school for children with ASD, an expert with regard to ASD, was consulted throughout the process of data collection and analysis to contribute to the trustworthiness (in the form of peer debriefing) of the results of the current study. The director only gained access to data once names had been replaced by code names and was thus not able to connect any comments made in the interviews with particular persons. The involvement and roles of these three parties was explicit in the informed consent form.

Throughout the study, all hard copies of data was stored safely in a locked cabinet and all digital records were stored on my computer as password-protected documents. All raw data will be safely stored for five years, after which it will be destroyed or discarded in an appropriate manner by my supervisor.

Although the participants were required to share personal information about a sensitive topic, we did not anticipate any emotional reactions from the participants, which would necessitate referral to a health care professional. However, there was a referral system in place, should it have been necessary. In the event where a participant showed signs of distress, I would have referred them to my supervisor, who is a counselling psychologist. She would have taken responsibility to provide the participant with a referral to an appropriate healthcare professional. If such an event had occurred, the cost of an initial debriefing session would have been carried by the research team. The need for such a session would have been determined based on observations during interviews as well as self-reported emotional distress by the participants.

In the event where I was unsure, I would have consulted with my supervisor to listen to the recordings of the interviews. It was, however not necessary to implement this procedure, because none of the participants reported or showed signs of emotional distress during or as a

result of the interviews.

Conclusion

In this chapter, the research methodology of the study was discussed. Firstly, the research rationale and motivation for the research were provided. This was followed by the research question and the aims and objectives of the study. Thereafter, the study's research design was discussed. This was followed by a description of the method of data collection and data analysis. Trustworthiness within the study was then discussed after which the chapter concluded with the ethical aspects regarding the study.

Chapter 4: Results

The results of the study are reported in this chapter. Thematic analysis of the 15 semi-structured interviews conducted with fathers of children with ASD revealed that despite differences in their age as well as the ages of their children, several challenges and resources were commonly experienced by these fathers.

During the data analysis of the 15 semi-structured interviews, the themes that emerged were first grouped together based on whether they were identified as a challenge or resource. Thereafter the themes were organised according to the different levels of Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1977). The main themes as well as their ecological systems theory classification are set out in Table 4.1.

Table 4.1

The Main Challenges and Resources Experienced by Fathers Caring for Children with ASD within the ecological systems theory

	Systems Theory	Main theme
Challenges	Microsystem	Lack of respite
		Symptomatic challenges
		Health related issues in the child
		The diagnosis
	Mesosystem	Family dynamics
		Uninformed general public
	Exosystem	Financial challenges
	Macrosystem	Services
	Chronosystem	None
Resources	Microsystem	Giving it a name
		Respite
		Support
		Ability to provide
		Characteristics of the child
	Mesosystem	None
	Exosystem	None
Macrosystem	Religion	
		Services
	Chronosystem	Adjustment over time

Challenges

Eight themes emerged from the thematic analysis of the data as challenges that fathers experienced with respect to caring for their children with ASD. These are lack of respite; symptomatic challenges; health related issues in the child; the diagnosis; family dynamics; uninformed general public; financial challenges; and services. A discussion of each of these themes is provided in the next section.

Microsystem. Bronfenbrenner (1977) describes the microsystem as the innermost system in his ecological systems theory. The themes within the current study that fall into the microsystem therefore include all the challenges that impact fathers on an individual level. The themes that emerged within the microsystem were lack of respite; symptomatic challenges; health related issues in the child; and the diagnosis.

Lack of respite. This theme falls within the microsystem as it pertains to one of a father's closest relationships, his relationship with his child. Lack of respite emerged as an important theme within the microsystem, with 11 of the 15 fathers reporting a lack of respite as a major challenge they were faced with.

The majority of fathers reported that their child needed constant supervision. This required their heightened awareness and attention, even when they were at home and it furthermore made it very difficult to leave their child with other people, as illustrated by the following quotes:

...but the biggest change is where that independence starts to develop in the [other] child, this child now looks after itself a little or starts to entertain himself and starts to play with

other children, [but Arnold² doesn't]. We see it now, with our second child, what could have been (F2).

You first see to it that he is happy, then you do your own thing. Always first. It is not like another child that you can just leave and he will do his own thing (F3).

So, the biggest mission is that we cannot leave them with anyone. Because people do not understand (F4).

Furthermore, 10 of the 15 fathers reported that they found themselves homebound due to their child with ASD. According to these participants, going out with their child often led to stress and challenges and they thus resorted to staying at home. The general sentiment being that it was simply easier not to go out.

Sometimes also because you know what the potential is, you do not feel like making arrangements for it. Also to take others along, you do not want to put other people through the stress if it does not work out well (F2).

And the adjustment of not going out or going away for a weekend. It's a waste of time...So we failed quite a few of those tests, now we just don't go there (F4).

There's not much we can do, as a family, because you know, when Janice was four years old, she could go with us into a mall for example and we could tell her 'don't go there, stay close to us', we can't do that with Jimmy, so we're home bound a lot of the time, because he doesn't get the fact that he needs to stay with us to not go and run around or go and cause chaos somewhere, he just wants to do his own thing (F14).

² Note. Pseudonyms are used throughout to protect the identities of the individuals involved

As a result of the fact that their child needed permanent supervision and fathers often found themselves homebound, many fathers reported that they did not socialise often. The permanent supervision needed by their child as well as the lack of support offered by their friends led to these families leading secluded lives. Participants described their situations as follows:

What we realised is that we very seldom visit friends. Seeing that it was an effort for us to go to friends, because you could not join the conversation, because you had to look after Carl (F3).

...doing the little things like going out, visiting friends, a lot of things that need to be planned for and sometimes is just too tiring you know (F6)

Symptomatic challenges. The multiple symptoms (both primary and secondary) that are associated with the features of ASD emerged as another theme within the microsystem, as these symptoms directly influence the father, child relationship. The participants reported that they found some of their child's behaviour challenging to deal with.

Two of the fathers reported that their child's sensory processing difficulties were particularly challenging to cope with at times.

That ongoing stimming and running around and trying to get out of the house and tearing things, throwing things out of the window, wanting sweets all the time and things like that. After a while it builds up a bit (F2).

They've got this hypersensitivity issue. Jimmy was like that from a visual, a physical, my space kind of perspective and also taste....so you could not look the boy in the eye. Ya, he couldn't handle eye contact. He couldn't handle you in his space, I mean like I couldn't kiss my son, or hug him because it would freak him out. I remember once putting him on

the grass for the first time when his feet touched the grass he freaked out (F14).

In addition, nine fathers reported that their child's language difficulties ranked as one of the biggest challenges for them.

The other big challenge for us is language. She can only speak English and she understands Afrikaans very well...when we go places, because people don't know or understand her, they frown [on] her when she speaks to them in English. Some make nasty comments, not even understanding what the problem is (F10).

...there are other times when I feel exceptionally sorry for him, because I can see the frustration he has when he wants to communicate something. All he can do is throw a tantrum. Sometimes he'll put his hands and try to pull his hair out, literally you know, and the tears are streaming and he's screaming, so I feel really bad for him in that way....I feel bad that he's not able to communicate to us yet, not properly anyway (F14).

just the communication part. I think that was the biggest thing (F1).

Some of the research participants found their child's lack of social skills challenging to manage, particularly in public places. The experiences of two participants are highlighted in the following quotes:

When he pulls down his pants in public because he wants to pee. He doesn't understand. He is not embarrassed. He has no idea what that means (F3).

One thing is he obviously doesn't have a sense of shame, so I mean he will just let the toilet door open while he's in the bathroom, so at home that's kind of OK-ish, not necessarily when you have guests, so, or in the morning when he undresses, he undresses and then walks naked back to his room and the kind of thing you can't do when you have

other people around than the family (F6).

Many fathers reported that they found their child's difficulty to express his/her emotions appropriately, very challenging to manage.

When Arnold throws his worst tantrum, that is the worst. It is all a very high stress level...very high stress levels in general (F2).

Then you end up at the hairdresser...I need everything I have to hold him down. Everything. My wife cannot do it, she is small...He is incredibly strong (F4).

Everybody thinks it's easy, but it's not. It's more her behaviour. She'll scream sometimes. She is frustrated (F9).

She also used to hit people, hit her brother, hit me, hit her mother (F9).

Finally, nine of the 15 fathers revealed that they struggled to interact and spend quality time with their child, due to their child's ASD.

One interacts as much as you can with him on his level. That is not often, you know, sometimes he prefers his leaves and his little things (F2).

What I find very difficult, is that Arthur...to play with him...He doesn't play like a normal child...So it is very challenging to engage with him and to try to play with him, because I would throw the ball at him and he would throw it over the wall...You must really make a point of forcing, in a way, a relationship with your child (F15).

I look at my daughter and her friend who is exactly the same age as him (my son), down the road. The conversations that I have with him that I do not have with my own son (F7).

Health related issues in the child. This theme also impacts fathers on the microlevel as these challenges relate to the father's direct relationship with his child. Issues pertaining to their child's health were reported by eight of the fathers and included challenges pertaining to their child's medication and comorbid disorders as well as feeding issues.

Father 13 expressed the challenges he experienced in finding the correct medication for his son:

...the medication he was on suppressed his appetite quite a lot, so he was very thin for a while... Then, the medication changed and he started having a lot of appetite and he got very overweight (F13).

The following quotes highlight some of the comorbid disorders and conditions that add to the challenges presented by the core features of ASD that were reported by some of the fathers:

Then at a stage he started getting all the more anxious about things with which he had been totally comfortable with, just randomly and there is no logical reason for it, but then he totally loses it. He cannot look at it and then he runs away (F2).

...he has Agenesis of the Corpus Callosum (F5).

He is like Asperger's with very mild Tourette's. Not wildly, but he's got little tics (F13).

That is why it is so important - when you talk to him and he doesn't listen, you might as well be talking to the wall... You can talk and even while you are talking to him, you can lose his attention in 10 seconds, then you have to say his name again, tell him to listen (F3).

Several participants also highlighted feeding difficulties in their child, that presented a challenge for them to cope with:

He is a very picky eater. Since he started eating solid food, he's been a very picky eater.

He likes very bland food, and dry. So he eats pasta with no sauce for example...He won't eat spaghetti for example, even though it's the same stuff, it's a different shape (F13).

He took to bananas and for a long time that was virtually all he had. Bananas and milk.

That's it. Eventually he took to strawberry yogurt...Today as we sit here, he's nearly four years old, he eats a bit of variety, he still doesn't eat solids, you know, he'll eat Cerealac, he'll have his milk, he'll occasionally now eat banana, he'll have strawberry yogurt and muffin, but it must be vanilla flavoured muffin, no other (F14).

He battled to eat since he was born. So from the beginning it was quite a big challenge, that he would just start eating (F5).

The diagnosis. The diagnosis forms part of the microsystem as this theme involves their child that forms a part of their microsystem. The diagnosis emerged as a salient theme within the microsystem in the current study.

Fourteen of the 15 fathers revealed some challenging aspects of the diagnosis and the only interview where this theme did not crop up was the interview with the adoptive father, who had only started caring for the child after she had been diagnosed with ASD. The process of obtaining a diagnosis; lack of knowledge about what the diagnosis meant; coming to terms with the diagnosis; uncertainty about the prognosis; the unexplained cause of their child's ASD; and concerns about the future all contributed to the challenge experienced by fathers. Five of the fathers reported that they did not have any knowledge about what ASD was at the time of their child's diagnosis. The following quotes illustrate the fathers' lack of knowledge of ASD when their child was diagnosed:

...but for me it was such a foreign concept, because I'd never met anyone or I've never

been in circles with people who have Autistic kids or anything like that (F14).

...but if you don't know, you are a total layman (F2).

I did not quite know what it was, to be honest (F15).

Several fathers also expressed how challenging it was for them to come to terms with their child's diagnosis and accept that their child was going to live with ASD for the rest of his/her life.

It was hard... you know you feel like something's been taken away from you and it's this obstacle in your path and you're never going to have what other people have (F8).

It is almost as if you are going through a mourning period... things change. Your outlook on life, your dreams that you have for him, all of that changes in one moment. It's almost as if you are going through a process of mourning, I would say. It is like a pain that doesn't go away, I think you will always have it. And you find it hard when you see other people with their children. That is where it becomes really hard (F15).

It is like saying your child is deformed, or it has cancer. It is quite... it was heavy. (F7).

It took us a long time. I mean years, to realise that these interventions were not going to help, there is no cure (F2).

For many of the participants, the fact that nobody could give them a clear prognosis for their child was identified as a significant challenge, as indicated by the following quotes:

I promise you, the biggest fear is that you don't know if your child is going to be able to speak in his life (F3).

The thing that I find very hard, is that no one can give you a prognosis about where your

child is going to end up. That puts a lot of pressure on one, because you don't know, is your child going to be able to go into mainstream school or not? (F15)

I don't know if a mildly autistic kid can go to a normal school eventually. Can you give me a quick yes or no on that? (F14)

Similarly, the following quotes indicate how frustrating fathers found the fact that there was no clear cause for their child's disorder:

No one really knows what it is, and that's what makes it so difficult (F15).

But you don't know. You...and the parents have remorse, because it is our child that is like that. Why? Does it come from us? You don't know. What is the cause? I am normal, my wife is normal. Why is he like that? (F3)

Uncertainty about their child's future was raised by 10 of the 15 of fathers, indicating that it was a common challenge experienced by the participants and something that fathers struggled with from their child's early childhood through to adulthood.

You completely abandon that thought of being free ever again. So you just can't go anywhere or do anything (F3)

The future is actually always a bit of a scary prospect. Look, if you think of where you come from and where you are standing now, things don't really become easier. Things just get worse (F2).

OK, is our child going to be able to live a normal life? Is he going to have friendships? Is he going to be able to get married? Is he going to be able to hold down a job? Is he going to be a financial burden for the rest of our lives? Will he be self-sufficient? Those things

were really weighing heavily on us, as well as... from a selfish perspective, was I going to be able to do the things I would expect to do with a son? Play sports, have a conversation or go fishing, all that stuff (F8).

Mesosystem. The second system within ecological systems theory is the Mesosystem (Bronfenbrenner, 1977) and encompasses all the interactions between the various microsystems of which the individual forms a part. Family dynamics and uninformed general public emerged as themes within the Mesosystem.

Family dynamics. Family dynamics involve the relationships of a spouse or other children with the child with ASD and thus forms part of the mesosystem. Participants revealed that their spouse or partner's interaction with the child with ASD as well as the child's interaction with other siblings was often challenging for them to deal with. As expressed by the following quotes, a few of the participants disclosed that at times they disagreed with the way in which their spouse interacted with the child:

There are times when I'm highly frustrated with him...but I don't even think that's an autism thing, that's probably more because my wife is too lenient with him. She lets him get away with murder, so I think he's just plain naughty (F14).

She is guilty of that. It does bother me a bit, I suppose. We should push him way more to do things himself (F3).

These negative feelings towards his spouse's interaction with the child were most pronounced in the father who was divorced.

She keeps them out of school at the drop of a hat and it really bothers me. She does things that are to their detriment to get at me. That's seriously destructive (F13).

Nine of the 15 fathers expressed concerns for their other children as a result of living with

a sibling with ASD.

It is easy to neglect the other children with a child like that and one picks up that the other children can become a bit resentful (F2).

How can you expect her to always be the least? She is 6 years old. Now, she is wonderful, but you cannot blame her that it gets to her every now and then, because it gets to us (F4).

She [her sister] would often say to me she wishes Nancy was not autistic (F12).

The big challenge and that is why we chose to put her in aftercare, is to give our other children a breather in the afternoons and us as well (F11).

Uninformed general public. The uninformed general public relates to the relationship of the general public with the child with ASD and thus makes out a part of the mesosystem. Many fathers reported that they experienced a lack of knowledge pertaining to ASD amongst the general public, which made it challenging for them to go out with their child and also resulted in them feeling alone and unsupported in their caregiving task. Six of the fathers revealed that they found it difficult to go out with their child, because they perceived the general public as uneducated about ASD and reported that people often responded negatively towards their child.

Carl would do something funny, but then the old man wants to shout at him. “The child is naughty, keep your child under control”. And it is very difficult in that situation, to let people understand... because you and I know what it means, but those people don’t (F3).

That is one difficult thing. People who do not know autism, or who have never heard about it. When they see her doing things, they have their own interpretation (F10).

This lack of knowledge and understanding often led to fathers feeling unsupported by the general public, as is illustrated by the following quotes:

I think especially in the community and things like that it's tough for people, man, when they see a kid and they'll say like 'no, she's naughty' or 'the kid's just naughty' (F5).

If you tell people about it, you know that they don't know what it is, so their reaction always disappoints you in a way, when you talk to them about it. They think "Oh, but he will get better" (F15).

One father in particular noted that it was challenging to speak about his son to his friends, as they did not understand his situation:

What I find difficult... You cannot really talk to your male friends about it... It is not as if I go and have coffee with a friend and pour out my heart about how I feel (F15).

Exosystem. The exosystem is the third level of Bronfenbrenner's ecological systems theory and consists of all the formal and informal social settings that do not contain the individual but impact on him nonetheless (Bronfenbrenner, 1977). Financial challenges forms part of the exosystem as these challenges are the result of demands placed on fathers by both the educational system and the healthcare system in South Africa. Financial challenges was the only challenge that emerged within the exosystem in the current study.

Financial challenges. All 15 fathers who were interviewed raised the financial aspect of caring for a child with ASD in South Africa as challenging for them, thus making this theme particularly noteworthy. Many of the fathers who were interviewed were the sole breadwinners in their households, thus adding to the severity of this challenge. In the following quotes, fathers expressed the challenging nature of providing financially for a child with ASD, plus other children and often their wives too:

Firstly financially... It is one thing to think you have to cope with it, but it is another when you have to pay for all this and you don't have the money to do so. That adds a lot of stress (F2).

Yes, so financially it is a big thing. Yes, it is a financial commitment that not everybody will understand. It is one thing on top of the other (F15).

Fathers brought up special needs schooling as a major financial burden placed on them.

This is highlighted in the quotes by Father 10 and Father 12:

Then she went through that ABA [applied behaviour analysis] program and eventually we couldn't afford it so we put her in a regular crèche at one of the schools (F10).

[She's not in school anymore], I couldn't pay the tuition anymore. I fell behind and they started getting grumpy with me. She could still be there, but I just can't afford it. I was hoping the grant would come through (F12).

In addition to school fees, Father 7 and Father 10 revealed that financing therapy fees were also a challenge for them.

When she was at the regular private school, she would go for speech therapy and then OT (occupational therapy) and also then have a facilitator in class full time. So those things didn't come cheap (F10).

The costs involved are major. It is three therapists... (F7).

The fees they had to pay to get their child assessed and diagnosed were also reported as a substantial financial challenge for the fathers.

...we have to go for another two evaluations at different doctors, which cost another arm and a leg (F9).

Financially, it's been a hard hit.... The medical aid costs me nearly R9000 per month.

(F13)

Macrosystem. Finally, the macrosystem (the outermost system in the ecological systems theory) is made up of cultural values, laws and government policies. Services, including the South African healthcare and educational systems, influence the fathers, even though they are not in direct contact with them. As such, this theme forms part of the macrosystem.

Services. Thirteen of the fathers raised the challenge presented either by the availability of services, difficulty accessing services or poor quality of services. Throughout the interview process, many fathers disclosed that they found services, including specialised schools, therapists and medical professionals very hard to find.

We started doing our investigation to get her into a specific special school... they can help her with speech therapy and occupational therapy and all of that... she is on the waiting list, number two hundred and something (F9).

I think the problem with the whole autism thing, especially here, is that there isn't very much support and there is such a spectrum of children... there's this whole range in the middle... there's very little for them (F13).

...[there's a big need for education around ASD]... especially for dad's like me who work 10–12 hours a day, we don't have time to... go onto the laptop and research autism (F14).

Fathers furthermore reported that even in instances where services were available, accessing these proved to be quite an obstacle. Due to the lack of services, children often had to travel far to attend schools or to see specialists or therapists.

It is a lot of driving. From here to her school is about 20 km and then from her school to

my offices is about 40 km...we don't have any other options (F10).

It was killing me, taking her to school in town [about 80 km return trip]. I'd have to get up early, shoot through to drop her off there at 7 am. Then I'd have to come tearing back to work by 07:30 and then back at 14:30. It was costing me a fortune in petrol (F12).

Fathers also raised concerns over the quality of the services they had encountered, expressing disappointment in the medical and educational systems they had dealt with.

But I mean we went for allergy tests and I think we were hectically let down by the professionals that we did see. I mean, in hindsight, they didn't pick up on the most obvious things. So that was disappointing (F8).

The school started going more and more backwards and we realised that actually they were getting very far behind the curriculum... and it seemed like the school was getting into financial difficulty... so it was a big mess (F13).

We did not have good support, no. In the first place, to get doctors who knew what they were working with, was something that took us a very long time and we went to different paediatricians, psychiatric paediatricians and it was only 'Here is a tablet, take it'. There is no support. The doctors prescribe medication and that's it. There is nothing more (F11).

Something that irritated me about it was Dr X* (the developmental paediatrician). I don't know, it was like... I did not go with [to the feedback session], but it was so clinical. It was like plugging your child into the wall and the wall tells you OK cool, it's number 5.

There was no counselling or anything (F7).

Resources

Thematic analysis of the interview data revealed nine main themes that fathers experienced as resourceful in assisting them in their caregiving task. It was therefore evident from the data analysis that although the participants found it challenging to care for a child with ASD, these participants had several resources that helped them to cope with their caregiving task. The main themes representing the resources reported by fathers were giving it a name; respite; support; finances; the child's characteristics; informed general public; religion; services; and adjustment over time.

Microsystem. Several resources emerged at the level of the microsystem (Bronfenbrenner, 1977). These were giving it a name; respite; support; finances; and characteristics of the child, as all of these pertain to relationships in which fathers are directly involved.

Giving it a name. This theme emerged within the microsystem, as it affects fathers on an individual level. The majority of fathers highlighted that they found it helpful to give a name to the disorder and symptoms that afflicted their child, as this enabled them to act in certain ways to support their child and to cope with the challenges presented by their child's symptoms.

Four of the 15 fathers reported that they found obtaining a diagnosis for their child's condition helpful, as it gave them a starting point from which they could assist their child. This opinion is illustrated by the following quotes:

You were worried, up until that first diagnosis and then we knew something and we started doing some research (F3).

So now it is actually better. So what was bad, the time when we did not know was bad, then we knew something, then we did not know if it was good or bad and then one started

to realise, that's it now and then one started to adjust (F5).

I think it's good to have a diagnosis. I'm not worried, you know people will say 'don't label' a child', I think the label helps, it focuses you in a direction (F13).

Despite it not being an easy process, several fathers reported that things started getting easier for them once they had accepted their child's diagnosis, as this allowed them to adjust their expectations of their child and thus avoid disappointment.

One comes to a certain point... The child that you had before that time dies and you get a new child, who is different. The more I thought about it, the more that association made acceptance easier for me (F2).

Say you see his friends do something, then we no longer expect that he'll be able to do it. That in itself was a good process (F5).

Once we stopped having any expectations, that's when things got better (F8).

As illustrated by the following quotes, eight of the 15 fathers revealed that they felt empowered once they started reading up on ASD and gaining knowledge on their child's disorder:

When you equip yourself better, for me, then you automatically start adapting better, you know, because you understand autism better (F1).

I insist very strongly on that. I mean I have to know. So I read for a long time and I watched videos and all those things. So yes, knowledge is power (F7).

... and it did help, because it made us realise a lot of things that we were not aware of, like the diet (F10).

Many of the participants reported that taking action to help their child was helpful in caring for their child with ASD.

So we are busy with a bigger scheme to see how [we can help]. We want to do like a whole community development... So at this stage we are busy researching all such networks (F5).

Then we said right, here is something that's not right, let's figure it out. We are facing it. And if it doesn't work, we change it (F4).

After we found out from the occupational therapist, because she said it [that he has autism], we immediately started asking "What can we do?" ABA³, we took him to the OT, we took him to someone else who worked with him and so on and that was a major change, from two years ago to what he is now, remarkable (F7).

Respite. The second theme that was identified as a resource was respite. Nine of the fathers reported that they had trustworthy caregivers, albeit nannies, family members or tutors who they could entrust their child to. They reported that even though it did not happen often, knowing that a trustworthy, competent person was looking after their child made it possible for them to leave their child with a caregiver and have some free time.

Arthur's first therapist... was very kind, so she came to babysit for us occasionally. And that worked quite well, because he knows her and he is acquainted with her. That made sense (F15).

We're lucky to have a very good nanny working for us. She is with us every day from 8 to 4 (F7).

³ Note. ABA = Applied Behavioural Analysis

Father 6 in particular referred to the efficacy of a respite system they had experienced while living abroad that provided them with one free night per week, while their child was being looked after by trained and experienced caregivers:

That was actually very, very nice, that one night a week where you just don't have to worry about anything. It was something that felt very relieving (F6).

For some participants, socialising with people who did not have children with disabilities was perceived as a time of relaxation.

We meet all the other kids that race [go-karts] and their dads and we have a good time. (F12).

I think, getting involved in some extracurricular activities has helped. I'm involved with mountain rescue and stuff like that (F13).

Support. The third resource that came forth within the microsystem is support. Support consists of support from a spouse or partner and support from family members or friends. Support falls within the microsystem as it involves the direct, immediate relationships between a father and those that support him in his caregiving task.

Support from a spouse or partner was highlighted as a resource by nine of the 15 interview participants, indicating that it acted as an important resource. Fathers reported that they formed a team with their partner or spouse and that they supported each other. The fathers described this resource as follows:

Yes, I think my wife and I support each other. You have to, otherwise you will never be able to do it. I mean with all due respect, I cannot see how you will do it. So I can see on the days when she feels a bit down, then I do a bit more with him. Quietly, without asking or so, you just do (F3).

The tougher it gets, the closer we get to each other (F4).

You need to support each other to make things work, because there's a lot of challenges in raising an autistic child (F10).

Family members and friends also offered support to some of the fathers, as illustrated by the following quotes:

I explained to my family also and then they changed their whole perspective of Ingrid, now they understand, so now they are more accommodating (F9).

Our family supports us... but they are 1500 km from us, so you have that emotional support from them (F15).

To see how these friends react to him and how accepting they are of him (F5).

We have very cool friends and very cool people (F7).

Ability to provide. The ability to provide financially forms part of the microsystem due to the fact that it involves the father's immediate environment and is dependent on his own career and work situation. The ability to provide the financial means needed for specialised schooling, therapy and resources emerged as another theme within the microsystem. It was revealed by several fathers that despite the major challenge posed by providing financially for their child, they could at least give their child what he or she needed. The following quotes illustrate fathers' feelings around being able to provide for their child:

In some way, by hook or by crook, we are still coming by in some way to give it to him (F3).

The fact that we can still help Arthur by sending him for therapy, you know, there are a

lot of parents who cannot do that and I just wonder, if I were a parent who did not have those resources, how would I feel? (F15).

We are lucky that we can afford it, because not everybody can. We are privileged to be able to buy iPads (F4).

Characteristics of the child. The father's relationship with his child falls within the microsystem. Several fathers expressed positive feelings around their child's personality and revealed how proud they were of their child's personality, special abilities or talents.

Seven fathers revealed that they found their child's characteristics endearing and that interacting with their child eased the challenges presented by caring for them.

I think it also depends on the child there, for example, my son has a loving personality, so I promise you if he smiles at you or talks to you or looks you in the eye... (F3).

I think the main thing that makes it easier for me and that might be what the other fathers don't have. But Arthur, although he has autism, he shows affection. And I think if your child does not show affection, then it makes it very difficult, because then it is even harder to build a relationship (F15).

She takes everything in her stride and that makes things much easier. She can laugh at herself. So that makes it much easier (F11).

A few of the participants reported that their child's strengths or talents acted as a resource for them. They applauded their child's talents, expressing their admiration for these.

There are stuff that she would do that would totally [amaze us]. She would mention stuff or see stuff on TV and a day later, she would do it, mimic it. We bought her a 100 piece puzzle. At her age, people would say a standard 20 piece puzzle would be wonderful. She

did the 100 piece, she took about 45 minutes the first time (F9).

Her eye for symmetry is unbelievable. Jenga blocks. She builds them on end at a perfect 45 degree angle, tall structures. I once took a protractor and cited the angle, it was a perfect 45 degree angle (F12).

In many other ways he can do things that other children can't. He builds puzzles like you cannot believe it. He operates an iPad better than me (F7).

Macrosystem. Religion and services were the two themes that came to the fore within the macrosystem. Religion pertains to the greater norms and cultural beliefs within society and therefore falls within the macrosystem. Services are also part of the macrosystem because it involves government and the educational system within South Africa.

Religion. Religion was only mentioned as a resource by two of the interview participants. However for these two fathers it was a very prominent theme, in particular in the case of Father 4's interview. As such, it is included as a theme. The following quotes describe Father 3 and 4's feelings regarding religion as a resource:

You know what, through and through. You cannot, other people might do it, but we couldn't have done it without religion. No ways (F3).

You cannot tackle it without God. You cannot. I believe God gives you enough grace to cope with every day (F4).

Services. Services is the second theme that forms a part of the macrosystem. Six of the interview participants reported that gaining access to services assisted them in coping. Getting their child into the correct school, in particular, emerged as an important resource, as expressed by Father 11:

What helps a lot, are the schools. The school where she is now has made an incredible difference. We moved home for the school's sake. We put our house on the market, the [other] children in new schools, for the school's sake (F11).

Furthermore, seven fathers noted that they had at some stage dealt with helpful medical and educational professionals who assisted their child and in turn made it easier for them to cope.

I don't know if we were just very lucky or what, but we came into contact with the most knowledgeable people that you could get. By hook or by crook. I don't think other people are that lucky (F3).

I think they also do reflexology at the ABA centre... On a number of occasions, they would tell us that they are picking up that his ear is not well. Then we take him to the doctor, then he has an ear infection... If they don't tell us, we won't know. So that also sort of helps (F15).

We were very lucky to come into contact with people like them. I mean, the lady at the school and the girl who does the ABA. The OT was also very good. Everyone was simply phenomenal (F7).

Furthermore, two of the 15 fathers revealed that they had sought psychotherapy for themselves to assist them to cope. Both these fathers disclosed that they had found the psychotherapy very helpful, as highlighted by Father 10:

The psychologist helped us in terms of what we should avoid or how we should deal with things in terms of not encouraging her with things (F10).

Chronosystem. The Chronosystem consist of the changes that take place within all the systems within the ecological systems theory over time. Paternal adjustment over time falls

within the chronosystem as it refers to how fathers and their children adapt to their circumstances over time.

Adjustment over time. A number of participants reported that their own way of managing their child's symptoms and interacting with their child had improved over time. This led to them feeling more equipped to manage the challenges presented by the disorder.

We got used to it. I then eventually found ways to deal with certain things and to manage her so to say you know (F1).

His condition is improving a bit and the fact that we're just more used to it (F8).

You have to set the boundary and you've got to assert dominance, otherwise she would run all over you. She's as clever as a cartload of monkeys (F12).

He doesn't play like a normal child...but we have gotten around it now in ways. Like he loves a trampoline, so we will literally jump on the trampoline with him for an hour every day, because that is what he loves and then we do it together. It is a way in which he and I interact and he loves it. He laughs and he loves it (F15).

Seven of the fathers reported that they were encouraged by the progress their child made over time. They thus found it rewarding to look at where their child is now, as compared to where they were at a previous point in time.

...and within the first day they got speech out of him... and for me and my wife it was like a miracle had taken place (F3).

But he's progressed really nicely. Once his language started and he could express himself a little bit, he really started to fly (F8).

It is better [his compliance]. We can half way go somewhere and he won't just run away (F8).

He's becoming easier (F14)

Conclusion

Fathers caring for children with ASD were faced with multiple challenges on a daily basis. Thematic analysis of the 15 semi-structured interviews conducted with fathers of children with ASD revealed that despite differences in their age as well as the ages of their children, several challenges and resources were commonly experienced by these fathers. Analysing interview data for themes revealed eight main challenges reported by these fathers: including lack of respite; symptomatic challenges; health related issues in the child; the diagnosis; family dynamics; uninformed general public; financial challenges; and services. However, despite these challenges, nine themes, including: giving it a name; respite; support; finances; the child's characteristics; informed general public; religion; services; and adjustment over time were identified as resources that assisted fathers in managing their caregiving task.

In the following and final chapter, the results will be critically discussed in relation to the existing literature on this topic.

Chapter 5: Discussion

The themes that were identified within the results were categorised according to the five levels within the ecological systems theory (Bronfenbrenner, 1977) in Chapter 4. These levels are the microsystem, the mesosystem, the exosystem, the macrosystem and the chronosystem. This theoretical framework is used to discuss the findings of the present study and to link these findings to the existing literature.

The limitations of the present study as well as recommendations for future research are also presented, after which concluding remarks are made.

Discussion of the Findings, Theoretical Framework and Literature

The present study aimed to explore the experiences of fathers caring for children with ASD within the South African context by exploring some of the most difficult challenges they faced, as well as some of the most helpful resources at their disposal.

The available literature indicates that raising a child with ASD presents many challenges for parents (Resch et al., 2010; Rivard et al., 2014; Samadi & McConkey, 2014). Some researchers argue that caring for a child with ASD is not only more challenging than raising a typically developing child, but may even be more challenging and lead to higher levels of stress than raising children affected by other disabilities (Dabrowska & Pisula, 2010; Baker-Ericzen et al., 2005).

Furthermore, the roles of modern fathers have been explored and fathers have been found to be more involved in all spheres of parenting than before (Lamb, 2004). Previous research acknowledges that fathers are no longer believed to fulfill a one-dimensional role (that of breadwinner). Fathers are now recognised to play a number of noteworthy roles, such as caregivers, role models, breadwinners and protectors (Lamb, 2004). Paternal involvement also

seems to play an important role in child rearing (Borke et al., 2007; Vacca, 2013) and in the outcome of interventions for ASD (Seung et al., 2006).

Despite these findings, there is a paucity of research with regards to the role and experiences of fathers relating to child development and psychopathology in general (Cassano et al., 2006; Phares et al., 2005) and with regard to ASD in particular (Braunstein et al., 2013). This is the case both nationally and internationally. There are some studies that have examined fathers in their role as caregivers for children with developmental disabilities, including ASD (Barak-Levy & Atzaba-Poria, 2013; Dababnah & Parish, 2013; O'Halloran et al., 2013) and these studies suggest that the experience of fathers differs in some respects from those of mothers (Hastings et al., 2005). These differences are most apparent in differences in the coping styles mothers and fathers employ, indicating a need for research that focuses on paternal experiences, including the ways in which they cope with the challenges they experience (Barak-Levy & Atzaba-Poria, 2013).

Of the few studies examining paternal caregiving experiences, the majority was conducted in developed, westernised settings and as such experiences within the South African, developing context may be different.

Prior studies have indicated that on the one hand, fathers raising children with ASD are faced with multiple challenges (Dababnah & Parish, 2013; Davis & Carter, 2008; Higgins et al., 2005; Mitchell & Holdt, 2014; Woodgate et al., 2008). On the other hand, fathers utilise numerous resources to aid them in overcoming the challenges presented by caring for their child (Bayat, 2007; Dababnah & Parish, 2013; Greeff & Nolting, 2013; Hastings & Taunt, 2002; Rivard et al., 2014).

The present study obtained similar results. Fathers reported that they faced various challenges and had several resources that assisted them in their caregiving task. Often, where the lack of a certain factor presented a challenge, the presence of that same factor could act as a resource, indicating that raising a child with ASD may lead to conflicting emotions and experiences in fathers. For example, a difficulty accessing services could present a challenge to fathers, whereas gaining access to services could act as a resource that assisted them in coping.

It is noteworthy, however that even though both challenges and resources were identified in the present study, the bulk of the interview data pertained to the challenges that fathers experienced. Of the 512 quotes that were identified from the interviews as relevant to be included in data analysis, 334 quotes (65%) referred to the challenges fathers experienced, and only 178 (35%) pertained to resources.

In the following sections, the themes that were identified during the process of data analysis are discussed, according to the five levels of Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1977). Each level is examined individually. Firstly, the challenges that were identified within each level are discussed, followed by a discussion of the themes that emerged as resources within that level.

The Microsystem. The first level within which the individual is situated is the microsystem and it is made up of the individual's immediate environment, including their closest relationships (Bronfenbrenner, 1977).

As the present study aimed to examine the experiences of individuals, the majority of the challenges that emerged were identified as forming part of the microsystem. In line with findings of previous studies, several themes emerged as challenges or resources with regard to caring for a child with ASD in South Africa. Findings of the present study support previous research

findings that suggest that paternal involvement in their child's life is currently much higher than in the past (Lamb, 2004), with fathers reporting that they were very involved in various aspects of child rearing. Results of the current study also indicated that fathers were affected substantially by their child's ASD.

The first themes that were identified within the microsystem relate to the diagnosis of ASD. In previous studies, fathers reported that on the one hand, receiving a diagnosis of ASD as well as the difficulties involved with obtaining this diagnosis are substantial challenges they are faced with (Jones & Passey, 2005; Moh & Magiati, 2010). The results of the present study support these findings with 14 of the 15 participants reporting that they had found the diagnostic process extremely challenging. The interviews generally commenced with participants spontaneously providing some background on their child's early development and the process to get to a diagnosis of ASD.

However, obtaining a diagnosis often acted as a resource to fathers, with fathers reporting that obtaining a diagnosis allowed them to get a grip on what was happening to their child and provided them with a starting point from which they could take action to help their child. Thus, even though obtaining a diagnosis did not offset all of the challenges these fathers faced, it at least gave them a point of departure. This outcome agrees with previous findings indicating that the diagnosis acts as a starting point from which fathers can empower themselves with knowledge regarding ASD (Dababnah & Parish, 2013) as well as starting on working towards goals and desired outcomes for their child (Dabrowska & Pisula, 2010; Donaldson et al., 2011).

The current findings furthermore support the notion that males use a problem-focused coping style (rather than an emotional coping style) to manage the challenges presented by caring for their disabled child (Hastings et al., 2005). Thus, for these fathers, receiving a diagnosis was

part of the solution to the problem (i.e. not knowing what was wrong with their child) that they faced. Obtaining a diagnosis motivated them to take action to treat and manage their child's ASD and this made them feel more competent in their caregiving task.

These findings also suggested that fathers would benefit greatly from receiving a diagnosis while their child was still young. In the time before their child was diagnosed, they felt incapacitated due to not knowing why their child was struggling and they could therefore not act to help them. Thus, the quicker the formal diagnosis could be made, the sooner this problem-solving coping of the fathers could commence. Fathers would therefore also benefit from a seamless diagnostic process, where professionals were available, affordable and competent.

Concerns about the future were a salient theme that was identified as part of the microsystem in the present study. Previous studies also highlighted this as a major challenge fathers are faced with (Donaldson et al., 2011; O'Halloran et al., 2013) The uncertainty about whether their child would be able to provide for themselves and live independently was raised, often repeatedly, throughout the interview process by all the participants.

Despite the wide age range of the children of the participants, all fifteen of them reported some or other concern about their child's future, most often whether their child would be able to provide and care for themselves once they, as parents, had passed away. These anxieties and worries did not subside as the children grew older, and is indicative of the nature of the disorder, which affects people across their lifespan.

These findings support Eaves & Ho (2008) and suggested that the current interventions were not succeeding in adequately equipping children with the skills they needed to fend for themselves after they left school. This furthermore relates to the innate need of a father to equip his child to survive without him (Eaves & Ho, 2008), which, for many of the fathers participating

in the current study, was not a likely outcome. Effective intervention programs for both children and adults with ASD thus have a long way to go before giving fathers peace of mind and assuring them that their child is making progress and gaining independence.

Another theme that was identified as part of the microsystem centred around respite. Many of the fathers reported that their child needed constant care and attention. They particularly drew attention to the fact that their child had very unique needs that not everyone understood these needs and knew how to manage them, thus resulting in challenges around leaving their child with just anybody. They also reported that this constant need for supervision as well as the challenges associated with finding appropriate alternative caregivers resulted in them often being homebound. These difficulties finding appropriate caregivers and the challenges presented by going out, resulting in a lack of respite for fathers, was reported in various other studies, indicating that parents often feel alone, frustrated and isolated in their caregiving task (Higgins et al., 2005; Woodgate et al., 2008). Notably, this parental isolation was still found to be present in the United States and the United Kingdom, despite successful ASD awareness programs being implemented there (Dillenburger et al., 2013), indicating that awareness alone is not enough, but that time away from the challenges associated with caring for their child, is needed. The efficacy of respite as a resource was articulated by one of the interview participants who had resided in Germany at one stage, where their family had had access to a respite service that looked after their child with ASD one evening every week. The participant reported that this 'time-out' had been of great value for their family at the time and that a system like that would make a big difference to them in South Africa.

On the other hand, the presence of social and familial support may act as a strong resource for fathers (Dababnah & Parish, 2013), most notably, the support offered by their

spouse or partner. The majority of the participants in the present study reported that they experienced support primarily from their spouse, rather than from other family members and friends. However, this was not the case for all the fathers. Where previous research findings indicate that mothers are more prone to turn to friends for support than fathers (Jones & Passey, 2005), some of the participants in the current study were involved in social groups, including bicycling groups, 4 x 4 groups, go-kart groups and fire search and rescue groups. These fathers practiced their hobbies and these assisted them in coping for their disabled child. For these fathers the relaxation offered by these groups acted as a strong resource, indicating that even though this was not a resource that was utilised by all the participants, it did provide those fathers with much needed time-out when they utilised it.

Furthermore, other medical conditions, such as ADHD, digestive difficulties, cerebral palsy and sleep difficulties often co-occur with ASD and may provide additional challenges for parents (Matson et al., 2008). Findings from the present study also indicated that the health challenges their child faced, such as issues surrounding their child's medication, comorbid disorders and feeding issues posed a challenge for them to deal with.

Awareness surrounding these comorbid conditions were mentioned as resource in the current study, as was the proficiency of the healthcare professionals who were involved in these aspects of their child's health.

Another challenging aspect of raising a child with ASD, is the challenging behaviour that children with ASD often display. This can include socially inappropriate behaviour and inflexibility in routine (O'Halloran et al., 2013). This theme was also identified as part of the microsystem, because it has a direct impact on the father of the child with ASD. In line with the results by O'Halloran and colleagues (2013), these symptomatic challenges emerged as a salient

theme within the present study, with fathers revealing that they found some of their child's symptoms difficult to manage. Symptomatic challenges reported in the present study included sensory processing difficulties; language difficulties; stimming; and lack of social skills. These findings may suggest that fathers do not necessarily possess the skills to allow them to manage their child's behaviour appropriately. However, because these behavioural traits are so difficult to manage and often do not respond to the actions fathers take to address them, fathers are often left feeling helpless. As these fathers prefer to cope by taking action and solving problems, this is quite a compromised position for the fathers to be in because their children with ASD do not respond to their attempts to rectify and manage their behaviour, thus rendering their efforts futile.

A final resource within the microsystem relates to the interaction between the father and his disabled child. The findings of the current study suggest that although fathers generally found it difficult to cope with and to manage their child with ASD's difficult behaviour, these participants viewed their interaction with their child with ASD as rewarding and voiced pride in their children's achievements and skills. Dababnah and Parish (2013) suggest that paternal involvement in their child's treatment and care can act as an important resource for the fathers. Furthermore, as previous research indicates that paternal involvement in their child's upbringing and interventions may lead to positive outcomes in the child (Seung et al., 2006), it stands to reason that the interactions with their children may have a positive influence on their children which in turn leads to the positive feelings reported by these fathers.

The Mesosystem. The mesosystem refers to the interrelationships between the microsystems in which the individual participates (Bronfenbrenner 1977).

The first theme within the mesosystem pertains to family dynamics, which includes marriage and other children in the household. The strain placed on a family with a child with

ASD is substantial. Financial challenges, intensive therapy schedules and difficult behaviour all contribute to strain on marital relationships (Benson, 2006; Brobst et al., 2009; Naseef & Freedman, 2012).

Results of the present study with regard to marriage appeared to be ambiguous. On the one hand, fathers clearly expressed that the marital difficulties they had experienced in the past or were experiencing at the time of the interviews were in part due to the strain of raising their disabled child. One father also reported that his son's ASD played a major role in the divorce from his wife. On the other hand, the majority of fathers, including some of the same fathers that had reported marital difficulties, reported that their spouse or partner offered them invaluable support and that they acted as a team.

Several fathers voiced concerns over how their spouse interacted with their disabled child, expressing views that their opinions regarding how to interact with the child in certain settings differed from the way in which their spouse interacted with their child and that this led to conflict between them. They reported that they felt that their spouse did not encourage independence enough in the child, resulting in increased dependence by their child, and that their spouse or partner was too lenient with their boundaries. These conflicts seem to suggest a difference in parenting styles between the mothers and fathers of these children. The way in which most of the participating fathers interacted with their child involved setting clear boundaries for them and encouraging independence. This interaction style seemed to be preferable to the maternal interaction style employed by their spouses or partners. Osborne and colleagues (2007), reported that behaviour in children with ASD is directly influenced by parent behaviour and particularly that setting clear limits for children with ASD results in better behavioural outcomes in these children.

It thus appears that even though some of the fathers experienced some marital difficulties, spouses or partners still acted as a strong support system for them.

A second aspect within the family dynamics theme pertains to other children in a household, apart from the child with ASD. The present study supports previous findings that fathers are worried about the impact their child with ASD has on their other children (Kuhlthau et al., 2014). All the participants who had other children apart from their child with ASD expressed concerns over the impact that growing up with a sibling with ASD might have on their other children, as the disabled child received more attention and more resources were allocated towards their development.

Secondly, within the mesosystem, the perception of ASD and the general lack of knowledge pertaining to ASD in the general population, as reported by Hu (2008) and Sivberg (2002) came to the fore as themes in the present study. A lack of awareness regarding the symptoms and behaviour of children with ASD among the general population means that due to the way in which the general population interacts with their child with ASD, parents of these children often find themselves in situations where their child is stared at, pointed at, or they are perceived as incompetent parents (Woodgate et al., 2008). Due to this lack of awareness, people interact in a certain way with the child and this leads to fathers feeling isolated, misunderstood and unsupported (Woodgate et al., 2008).

The general sentiment of the participants was 'People just don't understand'. Fathers resorted to avoiding public places due to this general lack of understanding and support.

However, in the instances where individuals, including strangers and family or friends displayed a sense of understanding and support towards their child, fathers expressed a great gratitude towards these people, voicing how much easier it made things for them when people

displayed a sense of understanding and patience. These results indicate that educating the general population regarding the symptoms of children with ASD would greatly benefit fathers of children with ASD as they would feel more understood and have more alacrity to take their child out with them, which might result in them not being homebound as much.

The Exosystem. The informal and formal social structures that influence the individual, even though they are not themselves part of the systems make up the exosystem (Bronfenbrenner, 1977).

The financial aspect of caring for their child is a double-edged sword, acting as a challenge on the one end and as a resource on the other end.

The financial impact of caring for a child with ASD is immense (Dababnah & Parish, 2013; Newacheck & Kim, 2005). This financial burden emerged as a major challenge both in the available literature (Newacheck & Kim, 2005) and in the present study, with all 15 participants voicing their financial concerns repeatedly during the interviews.

Many of the participants of the present study were solely responsible for providing financially for their families, and thus shouldered the cost not only for specialised schooling, therapy and medical professionals for their child with ASD, but also for all other family expenses.

On the contrary, some of the fathers reported feelings of acknowledgement and reward that at least they possessed the financial resources to provide their child the interventions they needed and they could at least find some solace in the fact that they were managing to care for their child by providing for them financially. This drive expressed by fathers once again attests to their problem-focused coping style (Barak-Levy & Atzaba-Poria, 2013), where they cope through actively doing things to help their child, in this instance, making enough money to pay

for their child's educational needs. Financial support in the form of social grants and more affordable schooling and therapies were some factors reported in the present study that would substantially assist these fathers with one of the most challenging aspects of caring for their child.

The Macrosystem. The macrosystem refers to the broader social context. This includes cultural norms and standards, government policies, social beliefs and laws (Bronfenbrenner, 1977).

Firstly, poor health care services and long waiting lists to see medical professionals have been reported to provide a substantial challenge for parents of children with ASD (Dababnah & Parish, 2013; Mitchell & Holdt, 2014). Fathers specifically reported difficulties in obtaining information and gaining access to services such as specialised doctors, educational institutions and therapists (Hu, 2008; Sivberg, 2002). Furthermore, it has been reported that even if medical or educational professionals in the field are consulted, they are often experienced as inadequate in terms of training or expertise and perceived as lacking the particular skills needed to tend to a child with ASD (Mitchell & Holdt, 2014; Woodgate et al., 2008).

These sentiments regarding the availability, accessibility and quality of services were strongly supported by the findings of the current study. In the first place, many fathers reported difficulties in finding the appropriate medical professional, school or therapeutic setting for their child. Secondly, these settings were often far from where they lived and very expensive. In the third place, they raised concerns over the quality of the services they encountered. They specifically raised concerns over medical professionals not picking up on symptoms or behaviour in their child that they felt these specialists in the field of ASD ought to have picked up. Something that emerged in the current study that did not come to the fore in previous studies was

insensitivity on the part of the doctors who had diagnosed their child with ASD. A number of the participants reported that they felt dejected with the way in which they had been treated by medical professionals. They reported that the interaction style of the health care providers were impersonal and often insensitive. It is possible that this type of interaction may be more pronounced in the South African context due to the high workload experienced by doctors. Professional and compassionate specialists and other health care professionals that act with understanding throughout the diagnostic process and who guide parents in the right direction after providing them with a diagnosis of ASD could therefore assist these fathers and support them during a challenging time.

Secondly, making use of religion as a coping strategy contributes to people's physical, psychological and emotional well-being (Tarakeshwar & Pargament, 2001) and many parents have reported that their religion helped them to cope with the challenges presented by caring for their child with ASD (Hastings et al., 2005). Religion has been reported as a source of solace and a means of coping with the diagnosis of ASD as well as the further challenges presented by caring for a child with ASD for mothers and fathers (Dababnah & Parish, 2013, Sivberg, 2002).

Religion was mentioned as a resource by only two of the fathers in the present study. However, religion was a major resource for one father in particular, providing him with hope and courage. This indicates that where religion is utilised as a resource, it can be valuable.

The Chronosystem

Finally, the chronosystem refers to changes in the individual's environment that occur over time.

Gray (2006) reported that parents employ fewer coping strategies as time passes, indicating that parents adjust and are less distressed as their child grows and they become more adept at caring for their child.

Similar attitudes were observed in the present study. The majority of fathers reported that their way of managing their child's symptoms and interacting with their child improved over time. Several fathers also reported that their child displayed improvement over time, revealing that they found hope in looking to where their child came from compared to where they were now. However, one of the father's experience differed from the majority of the participants. He did not observe the same improvement in his child and consequently he reported that his burden became heavier as his child aged. This could possibly be related to the severity of his child's symptoms, because his child was affected by severe social and language difficulties that were not improving over time, despite multiple therapeutic, medicinal and educational interventions.

Limitations and Recommendations for Future Research

The first limitation of the present study is the nature of the sample. Despite variation in the age and race of the participants as well as the age and gender of their children, all the participants live in an urban setting in the greater Cape Town region of the Western Cape province of South Africa and are thus not representative of the South African population. Therefore, in order to confirm and generalise the findings of the current study, it is recommended that future research includes a larger sample that is more representative of the South African population. This can be achieved by including participants from a wider range of socio-economic statuses and residential settings across South Africa.

Secondly, the data were not verified. The themes that emerged from thematic analysis could have been sent to the participants to ensure that their experiences were accurately reflected

by the interviews. Focus groups could also have been implemented to present and discuss the themes with the participants. These measures could, however, not be implemented due to time constraints. It is therefore recommended that future studies implement these methods of data verification to contribute to the trustworthiness of the results obtained.

Finally, before starting the data collection process, I expected fathers to be reserved and unwilling to share their experiences openly with me. From the first interview, however, I was astounded by their openness and desire to be listened to and understood. It is thus clear that these individuals have a need for support. An additional recommendation is therefore that future studies expand on the findings of the current study in order to develop and implement support structures for fathers of children with ASD. These findings could then also contribute to the improvement of services available to families who are affected by ASD.

Conclusion

The present study aimed to examine the experiences of fathers of children with ASD in the South African context, with a particular focus on the most important challenges that these individuals face and the resources that are available to them. The study was qualitative and exploratory in nature. Results of the study indicated that fathers experienced various challenges and resources in caring for their child with ASD.

The study revealed that fathers faced multiple challenges as caregivers of children with ASD. These were lack of respite; symptomatic challenges; health related issues in the child; the process of getting to a diagnosis of ASD; difficult family dynamics; uninformed general public; financial challenges; and a lack of services. On the other hand, several resources that assisted fathers in coping were also revealed. Resources included arriving at a diagnosis of ASD; respite; support; ability to provide; the child's characteristics; informed general public; religion; access to

services; and adjustment over time. In many respects, the challenges faced by the fathers and the resources utilised by them could be regarded as the two sides of the same coin.

The results were discussed within Bronfenbrenner's ecological systems theory and were examined in relation to the available literature on paternal experiences of caring for a child with ASD. The results of the present study were similar to experiences of fathers caring for children with ASD as well as other disabilities, reported in previous studies.

A central, unifying theme was identified in the current study related to the ability of fathers to make use of a problem-focused coping style to deal with their situation. This ability was revealed as a resource at these fathers' disposal that could be employed regardless of the particular challenge they were faced with regarding their child with ASD. Furthermore, the results of the present study indicated that some of the fathers displayed a preferable parenting style in which they encouraged independence in their child and set clear boundaries for their child. Previous studies found such a parenting style to lead to improved behavioural outcomes in the child and in turn to lower levels of stress in fathers.

The present study was one of the first studies to examine the experiences of fathers raising children with ASD in South Africa. I hope that the findings will contribute to the understanding of the perceived experiences of fathers with a child with ASD and that the knowledge that was generated could assist in providing improved assistance to these individuals. In outlining the challenges that they faced and the resources utilised by these fathers. I hope that the current study contributed towards paving the way for future research into the well-being of fathers of children with ASD.

References

- Abell, F., Krams, M., Ashburner, J., Passingham, R., Friston, K., Frackowiak, R., . . . Frith, U. (1999). The neuroanatomy of autism: A voxel- based whole brain analysis of structural scans. *Neuroreport*, *10*(8), 1647-1651. doi: 10.1097/00001756-199906030-00005
- American Psychological Association. (2013). *Diagnostic and Statistical Manual for Mental Disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Asperger, H. (1944). Die “Autistischen Psychopathen” im Kindesalter. *European Archives of Psychiatry and Clinical Neuroscience*, *117*(1), 76-136.
- Bakare, M., & Munir, K. (2011). Autism spectrum disorders (ASD) in Africa: A perspective. *African Journal of Psychiatry*, *14*(3), 208-210. doi: 10.4314/ajpsy.v14i3.3
- Baker-Ericzn, M. J., Brookman-Fraze, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, *30*(4), 194-204. doi: 10.2511/rpsd.30.4.194
- Barak-Levy, Y., & Atzaba-Poria, N. (2013). Paternal versus maternal coping styles with child diagnosis of developmental delay. *Research in Developmental Disabilities*, *34*(6), 2040-2046. doi: 10.1016/j.ridd.2013.02.026
- Barker, E. T., Hartley, S. L., Seltzer, M. M., Floyd, F. J., Greenberg, J. S., & Orsmond, G. I. (2011). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology*, *47*(2), 551. doi: 10.1037/a0021268

- Barnevik– Olsson, M., Gillberg, C., & Fernell, E. (2008). Prevalence of autism in children born to Somali parents living in Sweden: A brief report. *Developmental Medicine & Child Neurology*, 50(8), 598-601. doi: 10.1111/j.1469-8749.2008.03036.x
- Baron-Cohen, S. (2009). Does autism need a cure? *The Lancet*, 373(9675), 1595-1596. doi: 10.1016/S0140-6736(09)60891-6
- Bateman, C. (2013). Autism – mitigating a global epidemic. *South African Medical Journal*, 103(5), 276-278. doi: 10.7196/samj.6915.
- Bauman, M. L., & Kemper, T. L. (2005). Neuroanatomic observations of the brain in autism: A review and future directions. *International Journal of Developmental Neuroscience*, 23(2), 183-187. doi: 10.1016/j.ijdevneu.2004.09.006
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9), 702-714. doi: 10.1111/j.1365-2788.2007.00960.x
- Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of Autism and Developmental Disorders*, 36(5), 685-695. doi: 10.1007/s10803-006-0112-3
- Bilder, D., Pinborough-Zimmerman, J., Miller, J., & McMahon, W. (2009). Prenatal, perinatal, and neonatal factors associated with autism spectrum disorders. *Pediatrics*, 123(5), 1293-1300. doi:10.1542/peds.2008-0927
- Borke, J., Lamm, B., Eickhorst, A., & Keller, H. (2007). Father-infant interaction, paternal ideas about early child care, and their consequences for the development of children's self-

recognition. *The Journal of Genetic Psychology*, 168(4), 365-379. doi: 10.3200/GNTP.168.4.365-380

Bowker, A., D'Angelo, N. M., Hicks, R., & Wells, K. (2011). Treatments for autism: Parental choices and perceptions of change. *Journal of Autism and Developmental Disorders*, 41(10), 1373-1382. doi: 10.1007/s10803-010-1164-y

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

Braunstein, V. L., Peniston, N., Perelman, A., & Cassano, M. C. (2013). The inclusion of fathers in investigations of autistic spectrum disorders. *Research in Autism Spectrum Disorders*, 7(7), 858-865. doi: 10.1016/j.rasd.2013.03.005

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. doi: 10.1177/1088357608323699

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513. doi: 10.1037/0003-066X.32.7.513

Cassano, M., Adrian, M., Veits, G., & Zeman, J. (2006). The inclusion of fathers in the empirical investigation of child psychopathology: An update. *Journal of Clinical Child and Adolescent Psychology*, 35(4), 583-589. doi: 10.1207/s15374424jccp3504_10

Centers for Disease Control and Prevention. (2014). *Prevalence of autism spectrum disorder among children aged 8 Years—Autism and developmental disabilities monitoring network*,

- 11 sites, United States, 2010*. Retrieved March 2015 from <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm>.
- Charman, T., Taylor, E., Drew, A., Cockerill, H., Brown, J., & Baird, G. (2005). Outcome at 7 years of children diagnosed with autism at age 2: Predictive validity of assessments conducted at 2 and 3 years of age and pattern of symptom change over time. *Journal of Child Psychology and Psychiatry, 46*(5), 500-513. doi: 10.1111/j.1469-7610.2004.00377.x
- Clarke-Stewart, K. A. (1978). And daddy makes three: The father's impact on mother and young child. *Child Development, 29*(2), 466-478. doi: 10.2307/1128712
- Coley, R. L., & Coltrane, S. (2007). Commentary: Impact of father involvement on children's developmental trajectories: New findings panel for the national fatherhood forum. *Applied Development Science, 11*(4), 226-228. 10.1080/10888690701762134
- Corsello, C. M., Akshoomoff, N., & Stahmer, A. C. (2013). Diagnosis of autism spectrum disorders in 2-year-olds: A study of community practice. *Journal of Child Psychology and Psychiatry, 54*(2), 178-185. doi: 10.1111/j.1469-7610.2012.02607.x
- Crabtree, B. F., & Miller, W. L. (1999). *Doing qualitative research*. United States of America: Sage Publications.
- Dababnah, S., & Parish, S. L. (2013). "At a moment, you could collapse": Raising children with autism in the west bank. *Children and Youth Services Review, 35*(10), 1670-1678. doi: 10.1016/j.childyouth.2013.07.007

- Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and down syndrome. *Journal of Intellectual Disability Research, 54*(3), 266-280. doi: 10.1111/j.1365-2788.2010.01258.x
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38*(7), 1278-1291. doi: 10.1007/s10803-007-0512-z
- Davis, R.E., Couper, M.P., Janz, N.K., Caldwell, C.H., & Resnicow, K. (2010). Interviewer effects in public health surveys. *Health Education Research, 25*(1), 14-26. doi: 10.1093/her/cyp046
- Dawson, G. (2013). Dramatic increase in autism prevalence parallels explosion of research into its biology and causes. *JAMA Psychiatry, 70*(1), 9-10. doi: 10.1001/jamapsychiatry.2013.488
- Dey, I. (2005) *Qualitative Data Analysis, A User-Friendly Guide for Social Scientist*. New York: Routledge
- Dhillon, S., Hellings, J. A., & Butler, M. G. (2011). Genetics and mitochondrial abnormalities in autism spectrum disorders: A review. *Current Genomics, 12*(5), 322-332. doi:10.2174/138920211796429745
- Dillenburger, K., Jordan, J. A., McKerr, L., Devine, P., & Keenan, M. (2013). Awareness and knowledge of autism and autism interventions: A general population survey. *Research in Autism Spectrum Disorders, 7*(12), 1558-1567. doi: 10.1016/j.rasd.2013.09.004

- Donaldson, S. O., Elder, J. H., Self, E. H., & Christie, M. B. (2011). Fathers' perceptions of their roles during in-home training for children with autism. *Journal of Child and Adolescent Psychiatric Nursing, 24*(4), 200-207. doi: 10.1111/j.1744-6171.2011.00300.x
- Eaves, L. C., & Ho, H.H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(4), 739-747. doi: 10.1007/s10803-007-0441-x
- Elsabbagh, M., Divan, G., Koh, Y., Kim, Y. S., Kauchali, S., Marcín, C., . . . Wang, C. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research, 5*(3), 160-179. doi: 10.1002/aur.239
- Faso, D. J., Neal-Beevers, A. R., & Carlson, C. L. (2013). Vicarious futurity, hope, and well-being in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 7*(2), 288-297. doi: 10.1016/j.rasd.2012.08.014
- Fombonne, E., Quirke, S., & Hagen, A. (2009). Prevalence and interpretation of recent trends in rates of pervasive developmental disorders. *McGill Journal of Medicine, 12*(2), 99-107.
- Gau, S. S., Chou, M., Chiang, H., Lee, J., Wong, C., Chou, W., & Wu, Y. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders, 6*(1), 263-270. doi: 10.1016/j.rasd.2011.05.007
- Gentile, I., Zappulo, E., Militerni, R., Pascotto, A., Borgia, G., & Bravaccio, C. (2013). Etiopathogenesis of autism spectrum disorders: Fitting the pieces of the puzzle together. *Medical Hypotheses, 81*(1), 26-35. doi: 10.1016/j.mehy.2013.04.002

- Gialloreti, L. E., Benvenuto, A., Benassi, F., & Curatolo, P. (2014). Are caesarean sections, induced labor and oxytocin regulation linked to autism spectrum disorders? *Medical Hypotheses*, *82*(6), 713-718. doi: 10.1016/j.mehy.2014.03.011
- Glasson, E. J., Bower, C., Petterson, B., de Klerk, N., Chaney, G., & Hallmayer, J. F. (2004). Perinatal factors and the development of autism: A population study. *Archives of General Psychiatry*, *61*(6), 618-627. doi: 10.1001/archpsyc.61.6.618
- Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism : The International Journal of Research and Practice*, *10*(5), 439-451. doi:10.1177/1362361306066601
- Grandin, T. (2011). *The way I see it: A personal look at autism & Asperger's*. Arlington: Future Horizons.
- Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, *24*(6), 734-749. doi: 10.1111/1467-9566.00316
- Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine*, *56*(3), 631-642. doi: 10.1016/s0277-9536(02)00059-X
- Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, *50*(12), 970-976. doi: 10.1111/j.1365-2788.2006.00933.x
- Greeff, A. P., & Nolting, C. (2013). Resilience in families of children with developmental disabilities. *Families, Systems, & Health*, *31*(4), 396. doi: 10.1037/a0035059

- Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities, 27*(1), 70-84. doi: 10.1016/j.ridd.2004.12.002
- Guinchat, V., Thorsen, P., Laurent, C., Cans, C., Bodeau, N., & Cohen, D. (2012). Pre-, peri- and neonatal risk factors for autism. *Acta Obstetrica Et Gynecologica Scandinavica, 91*(3), 287-300. doi: 10.1111/j.1600-0412.2011.01325.x
- Hallmayer, J., Cleveland, S., Torres, A., Phillips, J., Cohen, B., Torigoe, T., . . . Smith, K. (2011). Genetic heritability and shared environmental factors among twin pairs with autism. *Archives of General Psychiatry, 68*(11), 1095-1102. doi: 10.1001/archgenpsychiatry.2011.76
- Happé, F., Ronald, A., & Plomin, R. (2006). Time to give up on a single explanation for autism. *Nature Neuroscience, 9*(10), 1218-1220. doi: 10.1038/nn1770
- Hartley, S. L., Barker, E. T., Seltzer, M. M., Greenberg, J. S., & Floyd, F. J. (2011). Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *American Journal of Intellectual and Developmental Disabilities, 116*(1), 81-95. doi: 10.1352/1944-7558-116.1.81
- Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*(4-5), 231-237. doi: 10.1046/j.1365-2788.2003.00485.x

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005).

Coping strategies in mothers and fathers of preschool and school-age children with autism.

Autism : The International Journal of Research and Practice, 9(4), 377-391.

doi:10.1177/1362361305056078

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with

developmental disabilities. *American Journal of Mental Retardation*, 107(2), 116-127. doi:

10.1352/0895-8017(2002)107%3C0116:PPIFOC%3E2.0.CO;2

Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style

and coping strategies of families with a child with an autism spectrum disorder. *Autism :*

The International Journal of Research and Practice, 9(2), 125-137. doi:

10.1177/1362361305051403

Jones, J., & Passey, J. (2005). Family adaptation, coping and resources: Parents of children with

developmental disabilities and behaviour problems. *Journal on Developmental Disabilities*,

11(1), 31-46.

Kanner, L. (1944). Early infantile autism. *The Journal of Pediatrics*, 25(3), 211-217. doi:

10.1016/S0022-3476(44)80156-1

Keller, D., & Honig, A. S. (2004). Maternal and paternal stress in families with school-aged

children with disabilities. *American Journal of Orthopsychiatry*, 74(3), 337. doi:

10.1037/0002-9432.74.3.337

- King, G., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P., & Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or down syndrome. *Child: Care, Health and Development*, 32(3), 353-369. doi: 10.1111/j.1365-2214.2006.00571.x
- Krauss, M. W., Seltzer, M., & Jacobson, H. (2005). Adults with autism living at home or in non-family settings: Positive and negative aspects of residential status. *Journal of Intellectual Disability Research*, 49(2), 111-124. doi: 10.1111/j.1365-2788.2004.00599.x
- Kuhlthau, K., Payakachat, N., Delahaye, J., Hurson, J., Pyne, J. M., Kovacs, E., & Tilford, J. M. (2014). Quality of life for parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 8(10), 1339-1350. doi:10.1016/j.rasd.2014.07.002
- Kuhn, D. E., & Matson, J. L. (2002). A validity study of the screening tool of feeding problems (STEP). *Journal of Intellectual and Developmental Disability*, 27(3), 161-167. doi: 10.1080/1366825021000008594
- Lamb, M. E. (2004). *The role of the father in child development*. Hoboken, New Jersey: John Wiley & Sons.
- Landrigan, P. J. (2010). What causes autism? exploring the environmental contribution. *Current Opinion in Pediatrics*, 22(2), 219-225. doi:10.1097/MOP.0b013e328336eb9a
- Latif, A. H., & Williams, W. R. (2007). Diagnostic trends in autistic spectrum disorders in the South Wales valleys. *Autism : The International Journal of Research and Practice*, 11(6), 479-487. doi:10.1177/1362361307083256

- LeBlanc, L.A., Riley, A.R., & Goldsmith, T.R. (2008). Autism Spectrum Disorders: A lifespan perspective in J. Matson (Ed), *Clinical Assessment and Intervention for Autism Spectrum Disorders*. 65-90. Burlington: Elsevier.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50(3), 172-183. doi: 10.1111/j.1365-2788.2005.00732.x
- Leekam, S. R., Prior, M. R., & Uljarevic, M. (2011). Restricted and repetitive behaviors in autism spectrum disorders: A review of research in the last decade. *Psychological Bulletin*, 137(4), 562. doi: 10.1037/a0023341
- Lehohla, P. (2014). *Profile of persons with disabilities in South Africa* (Report No. 03-01-59). Pretoria: Statistics South Africa.
- Lincoln, Y. S., & Guba, E. G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Program Evaluation*, 1986(30), 73-84. doi: 10.1002/ev.1427
- Long, T., & Johnson, M. (2000). Rigour, reliability and validity in qualitative research. *Clinical Effectiveness in Nursing*, 4(1), 30-37. doi: <http://dx.doi.org/10.1054/cein.2000.0106>
- Martins, C. D., Walker, S. P., & Fouché, P. (2013). Fathering a child with autism spectrum disorder: An interpretative phenomenological analysis. *Indo-Pacific Journal of Phenomenology*, 13(1), 1-19. doi: 10.2989/IPJP.2013.13.1.5.1171

- Matson, J. L., Adams, H. L., Williams, L. W., & Rieske, R. D. (2013). Why are there so many unsubstantiated treatments in autism? *Research in Autism Spectrum Disorders*, 7(3), 466-474. doi: 10.1016/j.rasd.2012.11.006
- Matson, J. L., Boisjoli, J. A., Hess, J. A., & Wilkins, J. (2010). Factor structure and diagnostic fidelity of the baby and infant screen for children with autism traits-part 1 (BISCUIT-part 1). *Developmental Neurorehabilitation*, 13(2), 72-79. doi: 10.3109/17518420903213576
- Matson, J. L., Cooper, C., Malone, C. J., & Moskow, S. L. (2008). The relationship of self-injurious behavior and other maladaptive behaviors among individuals with severe and profound intellectual disability. *Research in Developmental Disabilities*, 29(2), 141-148. doi: 10.1016/j.ridd.2007.02.001
- Matson, J. L., & Goldin, R. L. (2013). What is the future of assessment for autism spectrum disorders: Short and long term. *Research in Autism Spectrum Disorders*, 8(3), 209-213. doi: 10.1016/j.rasd.2013.01.007. doi: 10.1016/j.rasd.2013.01.007
- Matson, J. L., & Williams, L. W. (2014). Depression and mood disorders among persons with autism spectrum disorders. *Research in Developmental Disabilities*, 35(9), 2003-2007. doi: 10.1016/j.ridd.2014.04.020
- Matson, J. L., & Williams, L. W. (2015). The curious selection process of treatments for autism spectrum disorders. *Research in Autism Spectrum Disorders*, 9, 21-25. doi: 10.1016/j.rasd.2014.10.004

- Meltzer, L. J. (2011). Factors associated with depressive symptoms in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 361-367. doi: 10.1016/j.rasd.2010.05.001
- Miller, V. A., Schreck, K. A., Mulick, J. A., & Butter, E. (2012). Factors related to parents' choices of treatments for their children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6(1), 87-95. doi: 10.1016/j.rasd.2011.03.008
- Mitchell, C., & Holdt, N. (2014). The search for a timely diagnosis: Parents' experiences of their child being diagnosed with an autistic spectrum disorder. *Journal of Child & Adolescent Mental Health*, 26(1), 49-62. doi: 10.2989/17280585.2013.849606
- Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6(1), 293-303. doi: 10.1016/j.rasd.2011.05.011
- Montgomery, C. M., Hosegood, V., Busza, J., & Timaeus, I. M. (2006). Men's involvement in the South African family: Engendering change in the AIDS era. *Social Science & Medicine*, 62(10), 2411-2419. doi: 10.1016/j.socscimed.2005.10.026
- Morrell, R., Posel, D., & Devey, R. (2003). Counting fathers in South Africa: Issues of definition, methodology and policy. *Social Dynamics*, 29(2), 73-94. doi: 10.1080/02533950308628676
- Muhle, R., Trentacoste, S. V., & Rapin, I. (2004). The genetics of autism. *Pediatrics*, 113(5), e472-e486. doi: 10.1542/peds.113.5.e472

- Naseef, R., & Freedman, B. (2012). A diagnosis of autism is not a prognosis of divorce. *Autism Advocate*. Fall, 9-12.
- Newacheck, P. W., & Kim, S. E. (2005). A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, *159*(1), 10-17. doi: 10.1001/archpedi.159.1.10
- O'Halloran, M., Sweeney, J., & Doody, O. (2013). Exploring fathers' perceptions of parenting a child with Asperger syndrome. *Journal of Intellectual Disabilities : JOID*, *17*(3), 198-213. doi:10.1177/1744629513494928
- Osborne, L.A., McHugh, L., Saunders, J., & Reed, P. (2007) The effect of parenting behaviors on subsequent child behavior problems in autistic spectrum disorders. *Research in Autism Spectrum Disorders*, *2*(2), 249-263. doi: 10.1016/j.rasd.2007.06.004
- Pancsofar, N., & Vernon-Feagans, L. (2006). Mother and father language input to young children: Contributions to later language development. *Journal of Applied Developmental Psychology*, *27*(6), 571-587. doi: 10.1016/j.appdev.2006.08.003
- Phares, V., Fields, S., Kamboukos, D., & Lopez, E. (2005). Still looking for poppa. *American Psychologist*, *60*(7), 735. doi: 10.1037/0003-066X.60.7.735
- Pleck, J. H. (2007). Why could father involvement benefit children? Theoretical perspectives. *Applied Development Science*, *11*(4), 196-202. doi: 10.1080/10888690701762068
- Posel, D., & Devey, R. (2006). *The demographics of fathers in South Africa: An analysis of*

survey data, 1993–2002 in Baba: Men and Fatherhood in South Africa. 38-52. Cape Town: Human Sciences Research Council Press.

Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology, 55*(2), 139-150. doi: 10.1037/a0019473

Robbins, F. R., Dunlap, G., & Pleinis, A. J. (1991). Family characteristics, family training, and the progress of young children with autism. *Journal of Early Intervention, 15*(2), 173–184. doi: 10.1177/105381519101500206

Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(7), 1609-1620. doi: 10.1007/s10803-013-2028-z

Samadi, S. A., & McConkey, R. (2014). The impact on Iranian mothers and fathers who have children with an autism spectrum disorder. *Journal of Intellectual Disability Research, 58*(3), 243-254. doi:10.1111/jir.12005

Seif- Eldin, A., Habib, D., Noufal, A., Farrag, S., Bazaid, K., Al-Sharbati, M., . . . Gaddour, N. (2008). Use of M-CHAT for a multinational screening of young children with autism in the Arab countries. *International Review of Psychiatry, 20*(3), 281-289. doi: 10.1080/09540260801990324

- Seung, H., Ashwell, S., Elder, J., & Valcante, G. (2006). Verbal communication outcomes in children with autism after in-home father training. *Journal of Intellectual Disability Research, 50*(2), 139-150. doi: 10.1111/j.1365-2788.2005.00767.x
- Sivberg, B. (2002). Family system and coping behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism : The International Journal of Research and Practice, 6*(4), 397-409. doi: 10.1177/1362361302006004006
- Stevenson, A. (Ed.). (2010). *Oxford dictionary of English*. New York: Oxford University Press.
- Stephenson, J., Carter, M., & Kemp, C. (2012). Quality of the information on educational and therapy interventions provided on the web sites of national autism associations. *Research in Autism Spectrum Disorders, 6*(1), 11-18. doi: 10.1016/j.rasd.2011.08.002
- Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world parent perceptions of interactions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities, 20*(1), 39-51. doi: 10.1177/10883576050200010401
- Strauss, K., Vicari, S., Valeri, G., D'Elia, L., Arima, S., & Fava, L. (2012). Parent inclusion in early intensive behavioral intervention: The influence of parental stress, parent treatment fidelity and parent-mediated generalization of behavior targets on child outcomes. *Research in Developmental Disabilities, 33*(2), 688-703. doi: 10.1016/j.ridd.2011.11.008
- Sutcliffe, J. S. (2008). Genetics. insights into the pathogenesis of autism. *Science (New York, N.Y.), 321*(5886), 208-209. doi:10.1126/science.1160555

- Tanne, J. H. (2012). Maternal obesity and diabetes are linked to children's autism and similar disorders. *BMJ (Clinical Research Ed.)*, *344*(apr171), e2768-. doi:10.1136/bmj.e2768
- Tarakeshwar, N., & Pargament, K. I. (2001). Religious coping in families of children with autism. *Focus on Autism and Other Developmental Disabilities*, *16*(4), 247-260. doi: 10.1177/108835760101600408
- Tongco, M. D. C. (2007). Purposive sampling as a tool for informant selection. *Ethnobotany Research & Applications*, *5*, 147-158.
- Vacca, J. J. (2013). The parenting process from the father's perspective. Analysis of perceptions of fathers raising their child with autism spectrum disorder. *Best Practices in Mental Health*, *9*(2), 79-93.
- Walsh, C. E., Mulder, E., & Tudor, M. E. (2013). Predictors of parent stress in a sample of children with ASD: Pain, problem behavior, and parental coping. *Research in Autism Spectrum Disorders*, *7*(2), 256-264. doi: 10.1016/j.rasd.2012.08.010
- Williams, D. (2010). Theory of own mind in autism: Evidence of a specific deficit in self-awareness? *Autism : The International Journal of Research and Practice*, *14*(5), 474-494. doi:10.1177/1362361310366314
- Wong, M. G., & Heriot, S. A. (2007). Vicarious futurity in autism and childhood dementia. *Journal of Autism and Developmental Disorders*, *37*(10), 1833-1841. doi: 10.1007/s10803-006-0317-5

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research, 18*(8), 1075-1083.

doi:10.1177/1049732308320112

Xu, L. M., Li, J. R., Huang, Y., Zhao, M., Tang, X., & Wei, L. (2012). AutismKB: An evidence-based knowledgebase of autism genetics. *Nucleic Acids Research, 40*(Database issue),

D1016-22. doi:10.1093/nar/gkr1145

Yang, S., Hu, Y., & Han, Y. (2007). Prevalence investigation of autism in children. *Journal of Applied Clinical Pediatrics, 24*, 1872-1873.

List of Appendices

The following attached documentation is included in support of this research project:

A. Call for Research Participants

B. English Informed Consent Form

C. Afrikaans Informed Consent Form

D. English Biographical Questionnaire

E. Afrikaans Biographical Questionnaire

F. English Semi-Structured Interview Questions

G. Afrikaans Semi-Structured Interview Questions

H. Ethical Clearance

I. Participant Profiles

J: Turnitin Report

Appendix A: Call for Research Participants

Dear Sir,

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

TITLE OF THE RESEARCH PROJECT: The father's experience: A South African perspective on caring for a child with Autism Spectrum Disorder.

REFERENCE NUMBER: S14/05/106

PRINCIPAL INVESTIGATOR: Mrs Marilet van Rooyen

ADDRESS: 301 Danrust, 8 Handel Street, Somerset West, 7130

CONTACT NUMBER: 082 791 0982

What is this research project all about?

- This study aims to explore the experiences of fathers of children with Autism Spectrum Disorder (ASD) in South Africa.
- Although many studies have examined Autism Spectrum Disorder on national and international level, very little research has been done on the fathers' experiences in particular. It is possible that themes that emerge in this study could identify not only the challenges that fathers of children with ASD face, but also the factors that assist them in coping with their caregiving role.
- The study will take place at a time and place that suits you best. More or less 10-15 individuals who are all fathers of children with ASD will participate in this study. The first step in the interview process will be the filling out of a biographical questionnaire. I will then ask you a number of open-ended questions about your experiences of having a child with ASD. The interview will be conducted one-on-one and should last between 60 and 90 minutes. Your permission will be required to record the interview. This will allow me to transcribe the data accurately and this will allow me to analyse the data accurately.

Who can participate?

- Fathers of children between the ages of 4 and 18 years with a primary diagnosis of Autism Spectrum Disorder.
- The diagnosis had to be obtained at least 12 months ago.
- Fathers need to live with their children.
- Fathers need to be either married or in a cohabitation relationship.

What will your responsibilities be?

- You will only be expected to take part in one semi-structured interview that should last more or less 60–90 minutes. During the interview, we will discuss some of the challenges you face, as well as some of the factors that assist you in coping with your child with ASD.

Will you benefit from taking part in this research?

- There is no direct benefit to be gained from participating in this study. This research will however contribute to the existing knowledge in the field of ASD. The study addresses a gap in the literature and as such the findings could be published in a peer-reviewed journal. This in turn could lead to a greater understanding of the experiences of fathers of children with ASD in the South African demographic and the development of interventions aimed at assisting individuals in your position.

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

- Participating in the study holds no anticipated risks. However, due to the emotional and personal nature of the study, it is possible that the questions discussed in the interview may lead to emotional distress. If this does happen, and counseling services are required, my supervisor, Dr Chrisma Pretorius (a counseling psychologist), will refer you to a suitable healthcare practitioner. She can be contacted on (021) 808 3453 or chrismapretorius@sun.ac.za. The research team will carry the cost of such a counseling session.

Who will have access to your medical records?

- Any information that is obtained in this study will be treated as confidential and any information that can be connected to a participant will not be disclosed without your permission. Your identity will be protected by assigning a code instead of using your

name. Only myself (the researcher) and my supervisor will have access to the information obtained during the study. All the data collected during the interviews will be locked in my supervisor's office where it will be stored for five years after my study has been completed. It will then be appropriately destroyed and discarded.

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

- You will not receive any money for taking part in this study, however, the study will not cost you anything and you will be reimbursed for any traveling expenses you incur to conduct the interview.

Is there anything else that you should know or do?

- If you are eligible and wish to participate in the study, please contact me on 082-791- 0982 or marilet.vanrooyen@gmail.com.
- Further enquiries may be directed to Dr Chrisma Pretorius at 021-808- 3453.
- The Health Research Ethics Committee can be contacted on 021-938 9207 with further questions that have not been answered by me or Dr Pretorius.

Kind Regards,



Marilet van Rooyen

Appendix B: English Informed Consent Form**PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

TITLE OF THE RESEARCH PROJECT: The father's experience: A South African perspective on caring for a child with Autism Spectrum Disorder.

REFERENCE NUMBER: S14/05/106

PRINCIPAL INVESTIGATOR: Marilet van Rooyen

ADDRESS: 301 Danrust, 8 Handel Street, Somerset West, 7130

CONTACT NUMBER: 082 791 0982

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

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- This study will explore the experiences of fathers of children with Autism Spectrum Disorder in South Africa.
- Although many studies have examined Autism Spectrum Disorder in South Africa and overseas, very little research has been done on the fathers' experiences in particular. No such study has been done in South Africa. It is possible that themes that emerge in this study could identify not only the challenges that fathers of children with autism face but also the factors that assist them in coping with their caregiving role.
- The study will take place at a time and place that suits you, best. You will participate in this study with 10-15 individuals who are all fathers of children with autism. First, you will be asked to fill out a questionnaire with all your biographical details. I will then ask

you questions about your experiences of having a child with autism. The interview will take place one-on-one and should last between 60 and 90 minutes. Your permission will be asked to record the interview. This will allow me to later rewrite (transcribe) the information exactly as it is, which will allow me to analyse the data accurately

- **Why have you been invited to participate?**
- You have been invited to participate in this study because you have been identified as a father of a child with ASD in South Africa.

What will your responsibilities be?

- You will only be expected to participate in one semi-structured interview that should last more or less 60–90 minutes. During the interview, we will discuss some of the challenges you face, as well as some of the factors that assist you in coping with your child with autism. If you do not want to answer a question, you do not have to. You may also stop the interview at any time if you do not want to complete it. This will not impact you negatively at all.

Will you benefit from taking part in this research?

- Taking part in the study will not benefit you directly. The study addresses a topic that hasn't been studied before and the findings could be published in a peer-reviewed journal. This in turn could lead to a greater understanding of the experiences of fathers of children with ASD in South Africa and the development of interventions aimed at helping other people in your position.

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

- Participating in the study holds no anticipated risks for you. However, the topic is personal and emotional and it is possible that the questions discussed in the interview can leave you feeling emotionally distressed. If this does happen, and you require counselling, my supervisor, Dr Chrisma Pretorius (a counselling psychologist), will refer you to a suitable healthcare practitioner. She can be contacted on (021) 808 3453 or chrismapretorius@sun.ac.za. The costs of an initial counselling session will be carried by the research team.

Who will have access to your medical records?

- Any information that you share in this study will be confidential and any information that can be connected to you will not be given out without your permission. Your identity will be protected by assigning a code instead of using your name. Only myself (the researcher), my supervisor and one of my colleagues, who has expert knowledge and is experienced in the field of ASD will have access to the information obtained from you during the study. Furthermore, all the data collected during the interviews will be locked in my supervisor's office where it will be stored for five years after the study has been completed. It will then be appropriately destroyed and discarded.

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

- You will not be paid for taking part in this study. However, the study will not cost you anything and you will be reimbursed for any travelling expenses involved in attending the interview.

Is there anything else that you should know or do?

- Dr Chrisma Pretorius may be contacted at 021-808- 3453 with any further questions.
- The Health Research Ethics Committee can be contacted on 021-938 9207 with further questions that have not been answered by me or Dr Pretorius.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled: The father’s experience: A South African perspective on caring for a child with Autism Spectrum Disorder.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2014.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him to ask questions and took adequate time to answer them.
- I am satisfied that he adequately understands all aspects of the research, as discussed above.
- I did/did not use an interpreter. *(If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) on (*date*) 2014.

.....
Signature of investigator

.....
Signature of witness

Appendix C: Afrikaans Informed Consent Form**DEELNEMERINLIGTINGSBLAD EN -TOESTEMMINGSVORM**

TITEL VAN DIE NAVORSINGSPROJEK: Die pa se ervaring: Versorging van 'n kind met Outisme Spektrum Versteuring in Suid-Afrika.

VERWYSINGSNOMMER: S14/05/106

HOOFNAVORSER: Marilet van Rooyen

ADRES: 301 Danrust, Handelstraat 8, Somerset Wes, 7130

KONTAKNOMMER: 082 791 0982

U word genooi om aan 'n navorsingsprojek deel te neem. Lees asseblief hierdie inligtingsblad op u tyd deur. Die besonderhede van die navorsingsprojek word hierin verduidelik. As daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorsingspersoneel daarvoor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan waarvoor die navorsingsprojek gaan en hoe u daarby betrokke kan wees. U deelname is ook heeltemal **vrywillig** en u mag weier om deel te neem aan die studie. U sal op geen wyse hoegenaamd negatief beïnvloed word, indien u sou weier om deel te neem nie. U mag ook enige tyd van die navorsingsprojek onttrek, selfs al het u aanvanklik ingestem om daaraan deel te neem.

Hierdie navorsingsprojek is deur die **Gesondheidsnavorsingsetiekkomitee (GNEK) van die Universiteit van Stellenbosch** goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Wat behels hierdie navorsingsprojek?

- Die studie beplan om die ervarings van pa's van kinders met Outisme Spektrum Versteuring (OSV) te verken binne die Suid-Afrikaanse konteks.
- Alhoewel daar reeds baie navorsing oor Outisme Spektrum Versteuring gedoen is, is daar nog baie min navorsing gedoen oor pa's se ervaring rondom die versteuring. Geen Suid-Afrikaanse studie het al die onderwerp ondersoek nie. Dit is moontlik dat uitdagings waarvoor pa's te staan kom deur die studie geïdentifiseer kan word. Dit kan ook lei tot die identifisering van hulpbronne om pa's by te staan en hulle taak meer hanteerbaar te maak.

- Die datainsamelingsonderhoud sal plaasvind op 'n tyd en plek wat u pas. Ek (die navorser) gaan die onderhoud individueel met u voer. Min of meer 10 tot 15 deelnemers gaan aan die projek deelneem. Die onderhoud gaan begin met die invul van 'n biografiese vraelys. Nadat die vraelys ingevul is, gaan ek u vrae vra oor u ervaringe as 'n pa met 'n kind met OSV. Die onderhoud behoort min of meer 60 tot 90 minute te duur. U toestemming gaan gevra word om die onderhoud op te neem. Dit sal my in staat stel om u antwoorde presies soos u dit beantwoord het, oor te skryf en sal akkurate data-analise verseker.

Waarom is u genooi om deel te neem?

- U is as 'n pa van 'n kind met Outisme Spektrum Versteyring geïdentifiseer en as gevolg hiervan genooi om aan hierdie navorsingsprojek deel te neem.

Wat sal u verantwoordelikhede wees?

- Die enigste vereiste is dat u aan 'n enkele onderhoud van ongeveer 60–90 minute deelneem. Gedurende die onderhoud gaan ons die uitdagings wat u ervaar, asook die hulpbronne wat tot u beskikking is in verband met u kind met outisme bespreek. As u nie 'n spesifieke vraag wil beantwoord nie, hoef u nie. U mag ook enige tyd die onderhoud stop as u nie verder wil aangaan nie. Dit sal geen negatiewe invloed op u hê nie.

Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?

- Alhoewel daar geen direkte voordeel getrek kan word deur aan die studie deel te neem nie, gaan die bevindinge van die studie bydra tot die uitbou van kennis van OSV. Aangesien dit 'n unieke studie in die Suid-Afrikaanse konteks is, mag die bevindinge in 'n portuurbeoordeelde joernaal gepubliseer word. Dit sal lei tot verhoogde begrip en kennis in verband met hoe pa's die uitdagings wat hulle in die gesig staar, ervaar en hanteer wat kan lei tot die ontwikkeling van programme om ander individue in u posisie by te staan.

Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?

- Alhoewel daar geen risiko voorsien word nie, mag die emosionele en persoonlike aard van die studie lei tot emosionele ongemak. As dit sou gebeur en u berading benodig, sal my studieleier, Dr. Chrisma Pretorius ('n voorligtingsielkundige) u na die geskikte professionele gesondheidsorgwerker verwys. Haar kontakbesonderhede is: (021) 808 3453 of chrismapretorius@sun.ac.za.

Wie sal toegang hê tot u mediese rekords?

- Enige inligting wat u in die onderhoud deel en wat met u geassosieer kan word, sal vertroulik bly en geen inligting sal bekend gemaak word sonder u toestemming nie. U identiteit sal beskerm word deur van 'n kode gebruik te maak, en u naam sal nie gebruik word nie. Slegs ek (die navorser), my studieleier en een van my kollegas (wat 'n deskundige is op die gebied van OSV) sal toegang hê tot u inligting. Alle data word toegesluit in 'n kabinet in my studieleier se kantoor en sal vyf jaar na die einde van die studie op 'n gepaste manier vernietig word.

Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?

- Daar is geen betaling vir deelname aan hierdie studie nie. Dit kos u egter ook niks om aan die studie deel te neem nie en u sal vergoed word vir enige vervoerkostes wat u mag aangaan om aan die onderhoud mee te doen.

Is daar enigiets anders wat u moet weet of doen?

- U kan Dr. Chrisma Pretorius kontak by tel. 021-808-3453. Sy is beskikbaar om enige vrae wat u mag hê, te beantwoord.
- U kan die **Gesondheidsnavorsingsetiek administrasie** kontak by 021-938 9207 indien u enige verdere vrae het wat nie deur my of Dr. Pretorius beantwoord kan word nie.
- U sal ook 'n afskrif van hierdie inligtings- en toestemmingsvorm ontvang.

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek,, om deel te neem aan 'n navorsingsprojek getiteld Die pa se ervaring: Versorging van 'n kind met Outisme Spektrum Verstearing in Suid-Afrika.

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm geles het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig is en gemaklik omgaan.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek enige tyd aan die navorsingsprojek mag onttrek en dat ek geensins daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te (*plek*) op (*datum*) 2014.

.....
Handtekening van deelnemer

.....
Handtekening van getuie

Verklaring deur navorser

Ek (*naam*) verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek 'n tolk gebruik het/nie 'n tolk gebruik het nie. (*Indien 'n tolk gebruik is, moet die tolk die onderstaande verklaring teken.*)

Geteken te (*plek*) op (*datum*)2014

.....
Handtekening van navorser

.....
Handtekening van getuie

Appendix D: English Biographical Questionnaire

Biographical information

Name and Surname:

Age:

Ethnicity: White/Coloured/African/Other*

*If other, please specify:

Marital Status:.....

Home language:

Email address:

Contact number:

Child's gender: Male/Female

Child's age:

Age at which child was diagnosed with ASD:

Number of other children:.....

Ages of other children:.....

Number of hours spent with child with ASD every day:.....

Occupation: Part-time/Full-time/Unemployed

***Race is included to determine how representative the study sample is of the South African demographic**

Appendix E: Afrikaans Biographical Questionnaire

Biografiese Inligting

Naam en van:

Ouderdom:

Ras: Wit/Kleurling/Swart/Ander*

*Indien ander, dui asseblief aan

Huwelikstatus:

Huistaal:

E-pos adres:

Kontaknommer:

Kind se geslag: Manlik/Vroulik

Kind se ouderdom:.....

Ouderdom waarop kind gediagnoseer is met OSV:

Getal ander kinders:.....

Ander kinders se ouderdom:.....

Getal ure wat u daaglik met u kind met OSV spandeer :

Beroep: Deeltyds/Voltyd/Werkloos

***Ras word ingesluit om te bepaal hoe verteenwoordigend die studie steekproef is van die**

Suid-Afrikaanse bevolking.

Appendix F: English Semi-Structured Interview Questions

Questions for Participants

1. Can you tell me about your life and your experiences before your child was diagnosed with ASD?
2. What was your child like as a baby and toddler?
3. What interventions are in place for your child?
 - Who looks after him/her during the week?
 - Who looks after him/her over weekends?
4. What role do you play in terms of caring for your child?
5. How was the term ASD explained to you when your child was diagnosed?
6. Do you feel that the diagnostic procedure could have been handled differently?
 - If so, how?
7. In which ways has your life changed since your child received the diagnosis of ASD?
8. What feelings did you experience when your child was diagnosed with ASD?
9. How do you feel about the diagnosis of ASD now?
10. What resources or supports do you have that assist you in coping with your child with ASD?
 - What factors make caring for your child easier?
11. What are the main challenges that you have experienced as a father of a child with ASD?
 - Which factors complicate caring for your child? (e.g. financial, physical or emotional difficulties).
 - What is the impact of caring for a child with ASD on your role as father and/or husband?
12. How do you think about the future regarding your child with ASD?

Appendix G: Afrikaans Semi-Structured Interview Questions**Vrae vir deelnemers**

1. Vertel my asseblief van u lewe voor u kind met Outisme Spektrum Versteuring (OSV) gediagnoseer is.
2. Hoe was u kind as 'n baba en 'n kleuter?
3. Van watter intervensies maak u gebruik vir u kind?
 - Wie sorg gedurende die week vir hom/haar?
 - Wie sien oor naweke na u kind om?
4. Wat is u rol in terme van die versorging van u kind?
5. Hoe is die term OSV aan u verduidelik toe u kind gediagnoseer is?
6. Voel u dat die diagnostiese prosedure anders hanteer kon word?
 - Indien ja, hoe so?
7. In watter opsigte het u lewe verander vandat u kind met OSV gediagnoseer is?
8. Beskryf asseblief aan my u gevoelens toe u kind met OSV gediagnoseer is?
9. Hoe voel u nou oor die diagnose?
10. Oor watter hulpbronne en ondersteuningstelsels beskik u?
 - Watter faktore vergemaklik u taak as versorger?
11. Wat ervaar u as die grootste uitdagings in die versorging van u kind met OSV?
 - Watter faktore kompliseer die versorging van u kind? (bv. finansiële, fisiese of emosionele uitdagings)
 - Watter implikasie het die versorging van u kind met OSV op u rol as vader en eggenoot?
12. Hoe dink u oor die toekoms met betrekking tot u kind met OSV?

Appendix H: Ethical Clearance



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jou kennisvennoot • your knowledge partner

Approval Notice

Response to Modifications- (New Application)

23-Oct-2014
van Rooyen, Marilet M

Ethics Reference #: S14/05/106

Title: The father's experience: A South African Perspective on caring for a child with Autism Spectrum Disorder.

Dear Mrs Marilet van Rooyen,

The **Response to Modifications - (New Application)** received on **06-Aug-2014**, was reviewed by members of **Health Research Ethics Committee 2** via Expedited review procedures on **25-Sep-2014** and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **23-Oct-2014 - 23-Oct-2015**

Please remember to use your **protocol number (S14/05/106)** on any documents or correspondence with the HREC concerning your research protocol.

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

After Ethical Review:

Please note a template of the progress report is obtainable on www.sun.ac.za/hrs and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.
For standard HREC forms and documents please visit: www.sun.ac.za/hrs

If you have any questions or need further assistance, please contact the HREC office at 0219389207.

Included Documents:

Investigator CV (van Rooyen)
MOD_Budget
MOD_Call for research participants
MOD_Investigator declaration (Pretorius)

Appendix I: Turnitin Report

The father's Experience: A
South African perspective on
caring for a child with autism
spectrum disorder

by Marilet Van_Rooyen

FILE	70009_MARILET_VAN_ROOYEN_THE_FATHER_S_EXPERIENCE_A_SOUTH_AFRICAN_PERSPECTIVE_ON_CARING_FOR_A_CHILD_WITH_AUTISM_SPECTRUM_DISORDER_160342_582897305.DOC (579.5K)		
TIME SUBMITTED	02-DEC-2015 04:08PM	WORD COUNT	29819
SUBMISSION ID	608575971	CHARACTER COUNT	172853

Running head: **CARING FOR A CHILD WITH AUTISM SPECTRUM DISORDER**

i

The father's experience: A South African perspective on caring for a child with autism spectrum disorder

by

Marilet van Rooyen

*Thesis presented in fulfillment of the requirements for the degree of
Master of Science (Psychology) at Stellenbosch University*

Supervisor: Dr Chrisma Pretorius

The father's Experience: A South African perspective on caring for a child with autism spectrum disorder

ORIGINALITY REPORT



PRIMARY SOURCES

1	Submitted to University of Stellenbosch, South Africa Student Paper	13%
2	www.news-line.org Internet Source	1%
3	Comprehensive Guide to Autism, 2014. Publication	1%
4	Encyclopedia of Autism Spectrum Disorders, 2013. Publication	<1%
5	Martins, Claudia D.; Walker, Stephen P. and Fouché, Paul. "Fathering a Child with Autism Spectrum Disorder: An Interpretative Phenomenological Analysis", Indo-Pacific Journal of Phenomenology, 2013. Publication	<1%
6	Pretorius, Chrisma, and Ninon Joubert. "The experiences of individuals with Multiple Sclerosis in the Western Cape, South Africa", Health SA Gesondheid, 2014. Publication	<1%