

Experiences of single parents of children diagnosed with Autism

By

Swadhi Sharma Purmasir

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Supervisor: Dr M. Makhubela

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Declaration

I, **Swadhi Purmasir** declare that the mini-dissertation, unless otherwise indicated is my own work. This dissertation contains no material previously published or written by another person, except where due reference is given.

Signature

Date

Swadhi Purmasir

Dedication

To those incredible single parents of children diagnosed with autism who have shown strength and resilience.

Acknowledgements

I wish to express my sincerest gratitude to:

God for the countless blessings and guidance.

My entire family for their love, patience and support throughout the entire research project. I would like to express my deepest gratitude to Shivaan the light of my life, for being the greatest inspiration in my life.

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Abstract

Autistic spectrum disorder (ASD) is a group of developmental disorders characterized by significant challenges in socialization, communication, and behaviour. Unlike many other chronic illnesses, ASD proves to be a difficult disorder for parents to cope with. Nonetheless not many studies have been conducted in the area, particularly focusing on single parents. This study aimed to add to this limited literature by extending the exploration to include experiences of all types of single parents in raising children diagnosed with autism in a South African context, specifically in Pretoria. A semi-structured interview schedule was used to collect data from six purposefully sampled mothers, and thematic analysis was used to analyse the data. The results revealed that participants were unaware of what the diagnosis of ASD meant for their children, and thus took it upon themselves to research and understand. Some of the challenges that single parents have had to face are the financial implications, behavioural problems as well as stigma. The single parents in this study showed resilience, as they were able to use resources that are available to them. Being a single parent to a child diagnosed with ASD has caused parents to adjust their lives to ensure that their child is given the biggest priority.

Key Terms: autism, single parents, experiences, children, challenges, coping

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CHAPTER 1 – OVERVIEW OF THE STUDY

1.1 Introduction

Autistic spectrum disorder (ASD) is a group of developmental disorders characterized by significant challenges in socialization, communication, and behaviour (American Psychiatric Association, 2013). The classification of ASD includes Autistic disorder, Asperger's syndrome and Pervasive developmental disorder not otherwise specified (American Psychiatric Association, 2013). ASD has a profound effect on the child and on the family. Unlike many other chronic illnesses, ASD proves to be a difficult disorder for parents to cope with. Having a diagnosis of ASD is viewed as threatening and unacceptable in social situations (Dzubay, 2011). Mak and Kwok (2010) state that parents may receive disapproval from strangers for not being able to control their child, who may not have physical characteristics of ASD and further many assume that the child is merely misbehaving.

Storms (2012) established that parents of children diagnosed with autism develop individual coping strategies that are unique to their family and themselves. Social support is one form of a coping strategy that Storms found parents make use of. Social support can be defined as the aspects of an individual's social context that may enhance psychological and physical well-being (Pottie, Cohen, & Ingram, 2009).

A study by Ali, Abdoola and Mupawose (2015) found that parents make use of communicative coping strategies, which can be defined as learning new modes of communication as a coping mechanism to communicate with their child (Ali et al., 2015). Such communicative coping strategies include adjusting and adapting to the communication of their child with ASD.

Mthimunye (2014) investigating the knowledge and experiences of single mothers raising an autistic child in a low-income community in the Western Cape, revealed that single mothers experience social support as a great tool for survival. The participants indicated that the two main types of support they used were community and family support, which refers to the integrated network of community-based resources and services that empowers parenting practices and the healthy development of children (BC Association of family resource programs, n.d).

1.2 **Problem Statement**

While there are studies (e.g., Ali, Abdoola, & Mupawose, 2015; Dzubay, 2011; Storm, 2012) that have examined stress and coping among parents of children diagnosed with autism. Limited studies have been done focusing on single parents; one study has explored the experiences of single fathers in Trinidad (Seepersad, 2016) and one study in South Africa has been done solely on single mothers

(Mthimunye, 2014). The proposed study seeks to add to this limited literature by extending the exploration to include experiences of all types of single parents (single mothers, fathers, grandmothers, etc.) in raising children diagnosed with autism in a South African context, specifically in Pretoria.

1.3 Research questions

The study seeks to explore the experiences of single parents raising children diagnosed with autism. Specifically identifying how single parents understand the disorder and the meanings they attach to their experiences.

1.4 Aim of the study

The study aims to identify and describe how single parents experience raising a child diagnosed with autism.

1.5 Objectives

1.5.1 To describe what single parents of children diagnosed with autism understand about the disorder.

1.5.2 To explore and describe the experiences of single parents of children diagnosed with autism.

1.6 **Significance of the study**

Mthimunye (2014) reports that South African communities and caregivers have misconceptions around ASD and that this is caused by a lack of knowledge and understanding of the condition. Woodgate, Ateah and Secco (2008) found that parents felt isolated due to society's lack of understanding of the apparent challenges of raising a child with ASD and that their suffering was not being recognized.

In South Africa, the majority of children are raised by single parents. A survey by the South African Institute of Race Relations (SAIRR; 2013), reported that only 33% of South African children live with both their parents. The survey also showed that just over 39% of children live with their mothers only and 4% with their fathers only. Thus single parenthood in South Africa is highly prevalent. Single parenthood, in general, has been shown to have many challenges for both the child and parent (Kavas & Gündüz-Hoşgör, 2013). As such it can be assumed that being a single parent of a child diagnosed with a mental disorder could be more challenging (Mthimunye, 2014).

Likewise, being a single parent of a child diagnosed with ASD can be quite overwhelming (Mthimunye, 2014). According to Gupta (2007), the circumstances of having a child with ASD can only worsen the management of the disorder and result in great difficulty in caring for the child, from a single parent's perspective. Thus, it is important to

understand and explore the experience of raising an autistic child from being a single parent.

1.7 **Scope of the study**

The study will be limited to single parents of children that are diagnosed with autism who attend UNICA School for Autism, in Pretoria.

1.8 **Study Plan**

The current research will include the following chapters. The literature review chapter (chapter 2) will focus on previous research done on ASD and the effects on parents and specifically single parents. The literature review will also include the theoretical paradigm that has been used in this research. The methodology chapter (chapter 3) will provide a description of how the research was conducted focusing on the research design, sampling approach, the data collection process, the data analysis process and ethical considerations. The results chapter (chapter 4) will provide a summary of the data collected. The discussion chapter (chapter 5) will provide an interpretation and evaluation of the present study's results, citing relevant literature as support. This final chapter also concludes with a summary of the important points in the research process, limitations of the present

study will be discussed and lastly areas for future research and the recommendations will be presented.

CHAPTER 2 – LITERATURE REVIEW

2.1 Introduction

The literature review chapter will focus on ASD, the effects that the disorder has on parents, the challenges that single parents face when raising children diagnosed with autism and the theoretical paradigm.

2.2 Autistic Spectrum Disorder

ASD is a neurodevelopmental disorder and can be identified by three core characteristics: the child's lack of social understanding, the child's decreased capacity to have reciprocal conversations, and the child's strong attachment and interest in a specific object or subject (Attwood, 2007). The cognitive abilities of people with autism can range from gifted to severely impaired (United Nations, 2015). The prognosis for children diagnosed with autism is quite poor; between 61 to 73% are unable to live independently and only 5 to 17% attain a stage where they can adequately live a normal social and vocational life (Gillberg & Coleman, 2000).

2.2.1 Diagnostic criteria for ASD

The diagnostic criteria for ASD as per the DSM- 5 consist of the following:

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

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

2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures: to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties

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

1. Stereotyped or repetitive motor movements, use of objects, or

speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

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

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

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

Specify current severity:

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

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited

capacities, or may be masked by learned strategies in later life).

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

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

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

Specify if;

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

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

Associated with another neurodevelopmental, mental, or behavioural disorder

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

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

2.2.2 Co-morbidity

Children diagnosed with ASD are also likely to be diagnosed with intellectual disability and structural language disorder (APA, 2013).

ASD can also be co-morbid with ADHD, and when both criteria are met, both diagnoses should be given accordingly (2013). This principle also applies to concurrent diagnoses of ASD and anxiety disorders, depressive disorders, developmental coordination disorder and other co-morbid disorders (APA, 2013).

2.2.3 Age of onset

Symptoms of ASD are usually recognized during the second year of life, which is between 12 and 24 months of age (APA, 2013), but could be recognized before 12 months if developmental delays are severe, or

could be noted later than 24 months if symptoms are more subtle (APA, 2013).

2.2.4 Prevalence of ASD

There are currently no reliable studies on the prevalence of autism in South Africa, largely due to stigma, a lack of access to medical resources, and under- and over-diagnosis of the disorder (United Nations, 2015). However, Bozalek (2014) estimates that one out of every hundred people may have ASD in South Africa.

2.2.5 Treatments for ASD

Dzubay (2011) states that parents of children diagnosed with ASD find it difficult to decide which treatment will be most beneficial to their child. To date, there is no cure for ASD, even though many treatment options (such as amantadine, clomipramine, fenfluramine and naltrexone) have been tested, none have proven to be effective. As the cause of ASD remains unknown, parents are thus vulnerable to treatments that supposedly have high success rates (Dzubay, 2011). Parents have also decided on which treatment to pursue based on what they believed caused their child's symptoms, what their child preferred or resisted and the best fit of the child and parent with the therapist (Mann, 2013).

Goals of treatment for children with ASD target core behaviors to improve social interaction, communication and to increase long-term skills in independent living (Sadock, Sadock, & Ruiz, 2015). There are also psychosocial treatment interventions that are available, which include intense behavioral and developmental interventions and cognitive behavioral therapy (Sadock et al., 2015).

Psychopharmacological interventions in ASD are mainly directed at ameliorating impairing behavioral symptoms rather than core features of ASD (Sadock et al., 2015). They target symptoms such as irritability, aggression, temper tantrums, self-injurious behaviors, hyperactivity, impulsivity and inattention (Sadock et al., 2015). Selective serotonin reuptake inhibitors (SSRIs) and antipsychotic medicines are also used to treat ASD behavioral symptoms.

2.3 Effects of Autism on parents

Storms (2012) reports that parents of children diagnosed with autism experience a range of difficulties and negative psychological effects. Vidyasagar and Koshy (2010) stated that when parents have received their child's diagnosis of ASD, they need to adjust to their own emotions and to how society reacts to their child.

Research conducted by Tait and Mundia (2012) in Brunei, found that a child's disability, specifically ASD, negatively impacts how parents perceive life satisfaction and their capacity to fulfill their duties. Gupta

and Singhal (2005) have also found that parents of children diagnosed with autism are at an increased risk of depression, social isolation, and marital discord.

Dzubay (2011) revealed that there are four characteristics related to a child's autistic diagnosis that makes parenting especially challenging: 1) the child's unpredictable and inappropriate behaviour, 2) the child's need for routine and sameness and their response to a disruption in routines (DeGrace, 2004), 3) difficulties related to the child's ability to process sensory stimuli, and 4) the child's inability to communicate emotion and form an emotional bond. Lindsay and DePape (2015) similarly note that the behavioural deficits portrayed by a child diagnosed with ASD can be difficult for parents to manage.

2.4 Positive factors related to parenting a child diagnosed with ASD

Despite the challenges of having a child diagnosed with ASD, parents have shown a number of positive changes in their lives as a result of having a child diagnosed with ASD. Bayat (2007) states that many parents report that it has strengthened their faith and improved their spiritual self, as they develop an inner strength that allows them to better work through problems related to having a child diagnosed with ASD. Dzubay (2011) also reports that parents find that they are more compassionate and thus have more empathy towards others. Parents also find new and understanding friends through their involvement in

support groups. Parents gain confidence in their abilities, not only as parents but also in all areas of their lives (Dzubay, 2011).

2.5 Effects of children with low and high functioning Autism on Parents

Gray (2002) states that individuals with high functioning autism experience problems through social interaction namely stigma. Stigma impacts the individual, and has the potential to extend to the family as well. Research studies (Baxter, 1989; Gray, 1993) have found that parents of children with disabilities including low functioning autism, experience stigmatizing reactions from others.

A study done by Patricia Rao and Deborah Beidel (2009) found that parents of children with higher functioning autism have increased levels of stress and restricted family functioning compared with families with children with no psychological disorder. They further found that these parents also have more psychological problems and poorer mental and physical health than normal control families (Rao & Beidel, 2009).

2.6 Challenges of single parenting

Today we see all forms of single parent families: headed by mothers, headed by fathers or headed by grandparents raising their grandchildren (American Psychiatric Association, 2016). Life in a single

parent household, even though it is quite common in South Africa (South African Institute of Race Relations, 2013), can be very stressful for the adult and the child. There are certain stressors that single parents experience that the traditional family (consisting of a mother, father, and children) does not. These include stressors such as visitation and custody problems, the effects of continuing conflict between parents, less opportunity for parents and children to spend time together, effects of the breakup on children's academic performance and peer relations, disruptions of extended family relationships, and problems caused by the parents dating and entering new relationships (American Psychiatric Association, 2016).

A study done in Turkey by Kavas and Gunduz-Hosgor (2013) found that single parents particularly single mothers face the following primary challenges. These include maintaining authority in a new family setting that they have formed, struggling to keep a sense of a complete family and managing negative societal attitudes towards single mothers and toward children from single mother families.

Single parents have been reported to have the highest level of family challenges, work and conflicts compared to couple-parent individuals. A study by Bellavia and Frone (2005) found that single parents struggle to cope with many family demands. Milkie, Mattingly, Nomaguchi and Bianchi (2004) also reported that single parents further suffer from the highest rates of time-strain based conflicts.

2.7 Reasons for single parenthood

Ochonogor (2014) states that single parenthood is a long time issue that was caused by slavery, or having given birth out of wedlock, separation, divorce or death of a spouse. Kotwal and Prabhakar (2009) give another explanation stating that the single parent family is created in a number of ways, which include death of one parent, divorce, separation and desertion. In the mid-twentieth centuries, majority of single-parent families came about because of the death of a spouse. In the 1970s and 1980s, majority of the single-parent families were the result of divorce. Then in the early 2000s, more and more single parents never married and that became the main contributor to single parent families globally.

2.8 Challenges of parenting a child with a mental illness

Clifford and Minnes (2013) report that mothers of children diagnosed with ASD experience stress, anxiety and depression, which leads to poorer health and wellbeing. Furthermore, mothers of children with ASD are reported to experience these health issues more than mothers of children with other mental illnesses. Mothers of a child diagnosed with autism had higher levels of parenting stress and were also more likely to report poor or fair mental and emotional health compared to mothers in the general population (Montes & Halterman, 2007). This

can be attributed to the behavioral challenges of many children diagnosed with ASD, and the difficulty in accessing services and communicating with health professionals who work with their child (Osborne & Reed, 2008).

Pisula in 2007 found that mothers of children with autism were specifically concerned about their children's dependence on the care of others, which contributed to being one of the stressful factors in having a child diagnosed with autism. The study also reported that mothers of children with autism experience difficulties in understanding their children's developmental problems and are less effective in coping with such problems.

Mothers of children with mental illnesses also reported negative judgments and social isolation (Bourke-Taylor, Howie, & Law, 2010). Woodgate, Ateah, and Secco (2008) also found that mothers of children diagnosed with ASD experience ignorance and insensitivity towards their child in public.

Lindsay and DePape (2015) found that parents of children with ASD encounter challenges both at home and in the community. Compared to parents of children without ASD, they are more likely to experience financial strain and poor physical and mental health as well as higher divorce rates. Another challenge is with access to treatment for their children, as parents have encountered poor communication with health

care professionals, paying out of pocket for services and travelling long distances to access services.

2.9 **Stigma**

Goffman (1963, p.3 in Kinnear, Link, Ballan, & Fischbach, 2016) has defined stigma as an “attribute that is deeply discrediting” and reduces the individual “from a whole and usual person to a tainted, discounted one”. Kinnear and colleagues (2016) have found that stigma and the child’s autism related behaviors play the biggest role in making parents’ lives particularly challenging. Further they found that while stereotypes and peer rejection are not significant predictors of the difficulty of having a child diagnosed with ASD, the difficulty of stigma plays a significant role in predicting how challenging life is for parents.

Stigma is considered one of the most challenging aspects of public encounters experienced by families with a mental illness (Gray, 1993). Such families often find that the way in which the public reacts to them is stereotypical and negative. Gray (1993) has found that almost all parents with children diagnosed with ASD have felt stigmatized in public situations.

2.10 **Coping strategies of parents of children diagnosed with ASD**

Milshtein, Yirmiya, Oppenheim, Koren-Karie, and Levi (2009) found that parents who were able to reach a stage of resolution regarding their child's diagnosis of ASD were enabled to move forward and integrate both their previous life and present life. Thus resolved parents come to an understanding and acceptance of their child's abilities and limitations and look at the benefits in the situation whilst still acknowledging the challenges they face.

Research also suggests that when parents of children diagnosed with ASD have a strong social support network they demonstrate a greater capacity to cope and adapt to new and difficult situations (Altiere & Von Kluge, 2009; Pottie & Ingram, 2008). Furthermore, parents who were part of a support group, showed a strong sense of faith and spirituality and a supportive extended family, felt much better equipped to cope, and also had a higher degree of satisfaction with their current lives.

2.11 **Resilience**

Resilience is defined as a "dynamic process of passing positive adaptation within the context of significant adversity" (Luthar, Cicchetti, & Becker, 2000, p. 545). Parents who are able to cope with everyday life stressors even the occasional crisis have resilience (Forthun, Carannante, & Diehl, 2011). As such these parents have the capacity to recover and have the strength needed to survive difficult situations. Bekhet, Johnson and Zauszniewski (2012) state that parents of

children diagnosed with ASD who possess indicators of resilience are better able to handle the challenge of raising a child diagnosed with ASD. Additionally, parents that are resilient tend to have a close relationship with their children and show them a sufficient amount of attention (Mthimunye, 2014).

2.12 Conclusion

In conclusion, ASD is a neurodevelopmental disorder that can be identified by three core characteristics: the child's lack of social understanding, the child's decreased capacity to have reciprocal conversations; and the child's strong attachment and interest in a specific object or subject. This chapter also highlighted the lack of reliable statistics on the prevalence of ASD in South Africa. Previous research has shown that ASD not only impacts on the individual but also presents with challenges for the parents. Research has also shown the positive effects of raising a child diagnosed with ASD.

Single parenthood has become increasingly popular due to a number of factors that have been addressed. Further single parents experience stressors that traditional families do not. However studies pertaining to the experience of raising a child with ASD from a single parents' perspective are limited, especially in a South African context.

2.13 **Theoretical or paradigmatic point of departure**

2.13.1 **Phenomenology**

Phenomenology can be described as the philosophical study of “Being”. The paradigm has two important historical phases (Larkin & Thompson, 2012). The first is the transcendental, where Husserl attempts to identify the significant core structures of a particular experience. The main area of “focus for Husserl was the study of phenomena as they appear through consciousness” (Lavery, 2003, p.23). The second is hermeneutic (interpretive) phenomenology. Heidegger (1962) believed that humans are hermeneutic beings that are capable of searching for significance and meaning in their lives.

2.13.2 **Descriptive phenomenology**

A descriptive phenomenological paradigm will be employed in the study. Edmund Husserl (1970) viewed phenomenology as the science of essence of consciousness and specifically, focused on defining the concept of intentionality and the meaning of lived experiences from the first-person point of view. A central tenet of this approach is the belief that the meaning of lived experiences can be uncovered through one-to-one transactions between the researcher and the objects of the research. Furthermore, these transactions should involve attentive

listening, interaction and observation to create a representation of reality (Husserl, 1970).

Lastly, another central tenet of descriptive phenomenology is the view that human beings are free agents responsible for influencing their environment (Wojnar & Swanson, 2007). “Husserl focused more on the epistemological question of the relationship between the knower and the object of study” (Lavery, 2003, pp.26-27). Moreover, Husserl took exception to the Cartesian split between mind and body (Jones, 1975) and argued that while such a sharp distinction does not exist, individuals were able to grasp consciousness, through intentionality and bracketing (Polkinghorne, 1983).

Giorgi (1997) stated that a descriptive phenomenological approach is used when there is not much known about a certain phenomenon, and the aim of the study is to clarify and understand the significant meaning of a phenomenon from the perspective of those involved. Accordingly, the use of a descriptive phenomenological approach is well suited to examining the experiences of single parents of children diagnosed with autism, especially given the limited literature about the subject.

2.13.3 Research based Phenomenology

Research based on phenomenology is descriptive and attends to the structure of experiences, the organizing principles that give form and

meaning to the lived experience (Polkinghorne, 1983). It further aims to illustrate the essences of these structures as they appear in consciousness (Polkinghorne, 1983).

Husserl (2001) introduced the idea of transcendental subjectivity, which refers to a condition of consciousness where the researcher can successfully abandon his or her own lived reality and describe the phenomenon in its pure, universal understanding. This condition can be accomplished through a process of bracketing. Bracketing can be described as a process of consciously and actively seeking to break down prior experiential knowledge and personal bias for the purpose of not influencing the description of the phenomenon being explored.

Husserl (2001) believed that through bracketing it is possible to gain insight into the common elements of any lived experience. Bracketing can be addressed by using field notes in the form of a reflective diary to write down the researcher's observations, assumptions and concerns (Wojnar & Swanson, 2007). Husserl referred to these elements as universal essences or eidetic structures and considered them to represent the true nature of the phenomenon under study (Lopez & Willis, 2004).

2.14 **Conclusion**

Phenomenology is the philosophical study of being. The present study made use of descriptive phenomenology as the study sought to explore the meanings attached to the experiences of single parents raising a child diagnosed with ASD.

CHAPTER 3 – METHODOLOGY

3.1 Introduction

This chapter will present the research design, methods and procedures used in conducting this study. The following aspects will be discussed: research design, sampling, data collection, data analysis, credibility, dependability, transferability, confirmability and ethical considerations.

3.2 Research Design

This study used a qualitative phenomenological research design. Qualitative research is deemed to be an appropriate method for describing and interpreting people's feelings and experiences in human terms (Terre Blanche, Durrheim, & Painter, 2006). The study was designed on the basis of the descriptive phenomenological approach.

3.3 Sampling

The participants for this study were single parents of children with autism. The participants are from UNICA School for autism in Pretoria, South Africa. Purposive sampling was used and ensured cases that are typical of the population to be selected (Terre Blanche et al., 2006). This was an appropriate method to select the participants for a study using a descriptive phenomenological approach because the aim was

to understand and describe a particular phenomenon from the perspective of those who have experienced it. An open invitation letter was sent, with the assistance of the school, to all parents of children attending UNICA. The letter specifically invited single parents of children diagnosed with Autism, to volunteer to participate in the interviews (See Appendix 4). Six single parents (across gender groups), from any racial background who have children with ASD were invited to participate in this study.

3.4 **Data Collection**

Prior to data collection, participants were given an informed consent letter (see Appendix 2) and informed consent form to complete (see Appendix 3).

The researcher made use of an interview schedule that enabled the researcher to use as a lens for phenomenology (see Appendix 1). The interviews were conducted face-to-face; this ensured that the researcher captured the rich descriptions of the phenomena. As the interviews were face-to-face, anonymity could not be protected, as such pseudonyms are used in the dissertation to protect the rights of the participants. The researcher also made use of probes to obtain rich detailed information and clarity on the phenomena (Starks & Trinidad, 2007).

The interviews were semi-structured; this allowed participants to discuss their experiences in raising a child with autism. Furthermore, the interviews were recorded with an audio recorder. The interviews were held at the University of Pretoria in an appropriate room for interviews or at the participant's home if the participants invite the researcher. The location was determined according to the place that was deemed more comfortable for the participants.

3.5 Data Analysis

Once the interviews were done the data were then analysed using the technique of thematic analysis (Braun & Clarke, 2006).

3.5.1 *Thematic Analysis*

Thematic analysis, which is a qualitative type of analysis, was used to analyse the data in this study (Ibrahim, 2012). It is used to analyse classifications and present themes that relate to the data. It allows for the researcher to illustrate the data in great detail, which is suited to the phenomenological approach. It shows which themes are important in the description of the phenomenon under study (Daly, Kellehear, & Gliksman, 1997).

Braun and Clarke (2006) state that there are six steps in analyzing data using thematic analysis. The first step is familiarization with data; this

involves immersion where one has to constantly read through the data in search for meanings and patterns. This step also requires transcription of the recorded verbal data used in the interview, into written data, which the researcher did. The second step is generating initial codes; codes will be given to any features of the data that appear to be interesting to the analyst. The next step is searching for themes; the researcher looked at the initial codes from the previous step at a broader level to highlight potential themes and look at whether some themes could be enmeshed into one theme. The fourth step is reviewing themes; this involved reading through the data set to determine whether themes are relevant to the data set. The fifth step is defining and naming themes; the researcher further specified and improved on the themes that were presented. Further it is important to find the essence of what each theme represents, which fits well with descriptive phenomenology. The last step in producing the report, involved the final data analysis and write-up.

By employing thematic analysis, the data was analysed so as to identify and categorize emerging patterns of the understanding of ASD from the perspective of single parents, the experiences of raising a child diagnosed with autism and the meaning of single parents' experiences.

3.5.2 *Reliability and validity of data*

In qualitative research credibility, dependability, transferability and confirmability are important criteria in ensuring that research is trustworthy.

3.5.2.1 *Credibility*

Credibility is concerned with whether the study is believable to critical readers (Williams, n.d.). Furthermore, credibility establishes whether or not the research findings present plausible information drawn from the participant's original data (Williams, n.d.). This technique allows participants to talk more naturally and freely about their experiences (Terre Blanche et al., 2006). In the interviews, single parents shared their knowledge and experiences of raising a child with autism: this ensured internal validity, which is the degree to which causal conclusions can be drawn from the study (Terre Blanche et al., 2006).

3.5.2.2 *Dependability*

As the phenomenological framework was used in this study, the same results were not expected to be repeated as required by reliability (Terre Blanche et al., 2006). Rather, individuals or groups may most certainly express opinions that are different in changing conditions or contexts, thus findings should be dependable. Such findings can be achieved through in-depth descriptions that show that the opinions that arise and develop out of contextual interactions are dependable (Terre

Blanche et al., 2006). Dependability was assured by obtaining in-depth descriptions of single parents' experiences of raising children with autism.

3.5.2.3 *Transferability*

Transferability is used as an alternative to generalizability to other settings. De Vos (2002) states that transferability is the degree to which the findings of the research inquiry can be applied or transferred to settings beyond that of the research, thus the research can be applicable in other contexts. To address transferability the researcher provided sufficient contextual information, that is, details regarding the context in which the research takes place, to enable the reader to make such a transfer (Shenton, 2004).

3.5.2.4 *Confirmability*

Confirmability in qualitative research refers to the quality of the results (Williams, n.d.). It concerns the steps taken to help ensure that the research findings are as a result of the experiences and knowledge of the informants, rather than the knowledge of the researcher (Shenton, 2004). An audit trail and a reflexive journal were kept to achieve confirmability. An audit trail includes an examination of the inquiry process and result to validate the data, the researcher accounted for all the research judgments to show exactly how the data was collected,

recorded and analysed (Bowen, 2009). The researcher also kept reflexive documents in order to reflect on, tentatively interpret and plan data collection (Koch, 2006).

3.6 Ethical Considerations

Emanuel, Wendler and Grady (2008) have published a framework that consists of eight guiding principles that if applied correctly should improve the ethical issues pertaining to the research. The eight principles include: collaborative partnership, social value, scientific validity, fair participant selection, favourable risk/benefits ratio, independent ethics review, informed consent and ongoing respect.

3.6.1 *Collaborative partnership*

Emanuel and colleagues in 2008 state that this principle requires the researcher to ensure their research is done in collaboration with the target population. This study, being a qualitative research design, ensured that the participants were involved in the research process. The participant's voices were heard during the data collection stage of this study, as the interview questions were all open-ended.

3.6.2 *Social Value*

The research produced must address those questions that are of value to the society or certain communities within the society (Leach, Stevens, Ferrero, & Korkut, 2012). The beneficiaries of the research findings are the single parents of children diagnosed with ASD that attend UNICA. They will benefit by being made aware of how other single parents understand and cope with being a parent to a child that is diagnosed with ASD.

3.6.3 *Scientific Validity*

This principle refers to whether the research design, the sample, data collection and analysis of the study is rigorous, justifiable and leads to answers that are credible and applicable to the research questions (Leach et al., 2012). This study ensured that each part of the research process was done using valid and reliable means as well as ensuring that the threats to the credibility, dependability, transferability and confirmability were addressed adequately.

3.6.4 *Fair Participant Selection*

The research questions should be applicable to the population that is chosen for the present study (Leach et al., 2012). The selection of participants was chosen from the specified target population; that is single parents of children diagnosed with ASD who attend UNICA School.

3.6.5 *Favourable Risk/Benefit Ratio*

This principle requires a fair distribution of the research burdens and the benefits (Leach et al., 2012). In the social sciences, researchers must seek to achieve the best balance between risk and benefit that achieves the greatest benefit for the participants (Harper & Thompson, 2012). There were no risks for those participating in the research study. The benefits were that participants became aware of their experiences and they were empowered by letting their voices be heard.

3.6.6 *Independent Ethics Review*

This study submitted a research proposal to the faculty ethical committee at the University of Pretoria. Before commencing with data collection, ethical approval was granted by the ethics committee (see Appendix 5).

3.6.7 *Informed Consent*

A letter of request to the participants (see Appendix 2) was given to all single parents of children attending UNICA, explaining the nature of the study and the details of the interview process along with contact details of the researcher and supervisor.

Attached to that letter was an informed consent form (see Appendix 3) with additional consent for audio recording, which participants then signed.

3.6.8 *Ongoing Respect*

The last principle requires that research participants be treated with respect not only during the research study but to be continued afterwards as well (Harper & Thompson, 2012). Participants were allowed to withdraw from the interview at any stage. Respect was given to participants' privacy by maintaining confidentiality and anonymity, by not using their name's in the write-up. The researcher did monitor participants well being throughout the research and gave participant's direction to relevant mental health services if they needed any psychological help as a result of participating in the study.

3.7 **Conclusion**

A qualitative phenomenological research design was used in this study. Purposive sampling was used to ensure that typical cases of the target population were selected. Participants were interviewed using an interview schedule. The data was then analysed using thematic analysis to identify and categorize key themes. To ensure the validity and reliability of the data, credibility, dependability, transferability and confirmability were addressed. Emanuel and colleagues (2008) eight

guiding principles for ensuring that research is ethically sound were followed.

CHAPTER 4 – RESULTS

4.1 Introduction

In this chapter, the findings of the current study will be presented. The collection of data gained from the participants who were single parents of children diagnosed with autism was done in accordance with the study's research objectives: (1) to describe what single parents of children diagnosed with Autism understand about the disorder, (2) to explore and describe the experiences of single parents of children diagnosed with autism.

As this study was done using the phenomenological approach, it was important to gain a rich and descriptive understanding of the population of interest. The technique used to collect the data was individual semi-structured interviews.

After data collection, the research data was analysed using thematic analysis. The collected data was categorized into two groups: understanding of the disorder, the experiences and the meanings of these experiences. The overarching patterns found in the data were then organized into main themes with some subthemes.

4.2 Demographic Information

All participants had to be single parents of a child diagnosed with autism that attended a school for autism. Participants for this study were African women (N = 6) aged between 38 and 45-years. All participants had a minimal educational level of having a matric and were also employed full time.

4.3 Main themes

4.3.1 **Research objective one:** To describe what single parents of children diagnosed with autism understand about the disorder. This first objective was explored with the following interview questions:

1. How did you find out that your child had autism?
2. What do you know about the diagnosis (symptoms)?
3. As autism is a spectrum disorder, where would you say your child falls; is he/she on the lower, middle or higher level of functioning?
4. How have mental health practitioners explained the diagnosis?
5. What treatment or interventions are available that you are aware of?

4.3.1.1 Theme 1: Empowerment through knowledge

The results of the study show that most of the participants (e.g. P1, P2, P4, P5, P6) experienced a general lack of knowledge concerning what was happening with their children, and particularly with understanding what the diagnosis of autism means for their children. However,

participants explained that they took it upon themselves to read and research the disorder further, which helped them to better understand autism as well as to understand the implications of the disorder for their children. The following participants stated:

I have to say they did but it didn't make sense to me, I had to do my own research to find out what is autism and how do I assist my child...(P4)

I only heard about autism when I read it in the books long time ago I didn't actually know what it is, to understand to actually understand what it means for my daughter to be autistic (P5).

4.3.1.2 Theme 2: Signs

Many of the participants reported (e.g. P1, P2, P4, P6) that they were initially unaware of the signs of autism. As they had a lack of knowledge they were unable to identify the disorder immediately, they thus had to seek medical and professional assistance. The following subthemes will be discussed: developmental delays and level of functioning.

a) Developmental Delays

The following participants indicate that they had noticed that their children had a speech developmental delay and had then taken their children to the necessary medical professionals:

...everything was fine, and all those things and because my mom was a nurse we only realized when my child was 2 and a half years old in 2008, we said na na no, this child she's slow on something else but now this is taking too long, she can't even say "mama" and what's happening you know kids at some stage they start to imitate but my child was unable to imitate, even a single word, that's when we started going up and down, through and fro and the first appointment that I made, my brother Prof...(P1).

So he had speech delay so at around 1 year 6 month or so he had flu so I just normally took him to the Doctor so the Doctor was like you know they ask you normal developmental questions, what he does, what he does not do and he said no, it's a bit odd that he's not saying any words (P2).

...he was 3 years 6 months we noticed that there is no speech at all and we, the GP (General Practitioner) referred us to a speech therapist (P4).

b) Level of functioning

All participants reported that they were presently aware of where in the spectrum their children fall; they attributed the level of functioning to achievement of developmental growth and from the report from the school.

I can see that she is in the middle, why so because you cannot drive with my daughter, without having your handbag, she will make sure that the car is locked when you stop anywhere... I can say the middle, she's not that low low, but she doesn't want to write or anything she can count 1,2, because the speech is not, I can say her speech with the speech, if I had to give her out of 10 I'll give her a 1 (P1).

On the middle...Yes like he has, eventually he developed speech at around 8,9...But his speech is not, like we are having a conversation, you can't have a conversation with him, but he would call my name but he would call like in your adverts he would know your standard bank adverts he would know things he would name them (P2).

I don't think she's on the upper level because I've seen some kids much more higher level than her, and I don't think she is on a low level as her difference compared to other typical kids is

quite clear, also all the tests we've done so far classify her in the middle range (P3).

He is classified now in the Higher functioning class, the module, in the report we have received he was mild or moderate I can't remember, I know the signs of autism and how they behave and whatever, so he's level now in class he is a higher functioning in class, he understands, he struggles a bit (P4).

...think she's at the lower, I don't know I think so because she's non-verbal (P5).

From the reports that we have been given from his school, they more or less stated that he is in the middle level, like his speech is much better, although he may not be able to hold a conversation for that long and even though he now does play with other children he still does prefer to play alone most of the time (P6).

4.3.1.3 Theme 3: Medications and therapies

Participants reported that they were also aware of certain medications and therapies, which include speech therapy and occupational therapy. These medications and therapies are currently available and

accessible to participants. This awareness and knowledge comes from personal experience of treatments given to their children.

Occupational therapy, speech therapy and your normal medications...(P2)

First, the therapies: which include applied behaviour analysis, sensory integration, speech therapies, occupation therapies, physical therapies and so on, secondly, the medical intervention that includes drugs given to the child because they're not sleeping or they may, they may harm themselves, or have seizures...(P3)

Well there are the medications that help with their behaviour such as Ritalin, which my son is on, and then Occupational therapy, which helps, and then I know that there is also speech therapy (P6).

The participant reports that she is aware of Ritalin for children diagnosed with autism; she further states there are also behavioural interventions available.

I know Ritalin is available for other children, I'm aware that there are behavioural interventions that is available, I'm aware that there are other I-learn and I-play toys ...he's got a speech

therapist, he's got an O.T (occupational therapist) and he's got a social worker (P4).

The following participant explains that her child has taken Risperdal, and is currently taking Abilify, which are both medications.

... it was Risperdal before that was not making her realise that now I've got a number 2...at the moment for her age she's on abilify, abilify is the only thing that can calm her down...(P1)

This participant also reports that along with the medications available there are also special diets that the child can adhere to.

I know that therapies like occupational therapy, speech therapy, medical, biomedical, uhm, the uhm, I think that's what I know, there's also this one diet, where you look at what the child eats the custard free, the gluten free (P5).

4.3.2 Research objective 2: To explore and describe the experiences of single parents of children diagnosed with autism. The second objective was explored by the following interview questions:

1. What were your reactions after finding out that your child had been diagnosed with autism?

2. With regard to the condition of your child, what added stressors do you encounter?
 - a. Being a single parent, how are you coping with the condition of your child?

4.3.2.1 Theme 4: The journey to acceptance

All participants indicated that when they were first told that their children were diagnosed with autism, it came as a shock, they were left with feelings of sadness and confusion.

I didn't know what would be my next steps and what should be the best way to handle this. In addition, it sounded like a death sentence to me, as this is my only child (P3)

...so I was highly shocked and confused and I also remember being unwell, crying a lot at the time (P6).

Although participants were left with mixed and difficult emotions some (e.g. P1, P6) stated that coming to accept that their child is diagnosed with autism helped them to cope.

...it is not easy to accept, but once you accept you'll deal with it, because from my side as well I was crying almost everyday and having headaches...(P1).

I don't know if I cope but it helps when you accept it, I think if I didn't I also wouldn't be able to function (P6).

4.3.2.2 Theme 5: Financial strain

Many of the participants (e.g. P1, P2, P3, P6) indicated that one of the challenges they face as single parents is with finances, even though they are employed.

The cost of the therapy and special schools is quite high. It's barely covered by the insurance, and to get a good nanny who does have some training in this area is quite a challenge (P3).

...one definitely the cost, the school fees, the amount of money I spend on his check ups like to the Doctor and to the occupational therapist (P6).

4.3.2.3 Theme 6: Stigma

Participants report that another challenge that they face is that from the public, there is a stigma around having a child diagnosed with autism. As many people are unaware of what autism is and how it presents, therefore participants indicated that they were judged as parents as well.

...first of all community doesn't accept us with our kids, we struggle with our kids, they'll tell you, you must teach your child manners, they don't understand what your going through... they say your child is spoilt your child is spoilt they don't understand what you're going through I think often I fight with people for this child... (P1).

...so its hard to take him out into public places like to the shop, because of you know people also tend to judge you as a parent (P6).

4.3.2.4 Theme 7: Coping and Resilience

Participants have indicated the capacity for resilience and find ways to cope with being a single parent of a child diagnosed with autism with all the challenges that they face. Participants mentioned having the support of family and friends. A few other participants also reported turning to their faith in God as a source of coping.

a) Family support

I'm coping because of the support of my siblings because my mum passed on and because of my daughter...(P1)

...and my family also helps out which take a bit of the strain of (P6).

b) Faith in God

I try to take one day at a time. I have a good support system; the friends I run to when I am down. And above all I hold unto my faith in God (P3).

I think for myself, uhm faith and the belief in God helps a lot (P5).

4.3.2.5 Theme 8: Life adjustments

Some participants have had to not only accept but also adapt to their child's diagnosis of autism. For instance, one parent even had to sacrifice her career goals and status. Another participant also reported that she does not have time to spend on herself, as having a child with autism is demanding, especially being a single parent.

...he wants me to attend to all his needs and everything that he wants, I must do so even I come back from work, and I'm tired you can't have time for yourself because he cannot understand the concept I'm tired... (P2).

I was a senior manager then at Absa, I had to approach my manager and say please can you take me backwards, I can take my career backwards, because I have this situation and I don't

understand what is autism, and people around me and my colleagues are saying that you are mad... because on Sunday she's off and your free, at least you can do your own things, because 24/7 you must keep an eye on those kids... (P1).

The participant further reported that being a single parent comes with making important yet painful decisions by herself, in the best interests of her daughter.

...the sad part is last year I had to make a hysterectomy to her and I was admitted to the hospital with her because she was without speech so it's a very sensitive process that I went through as well being a single parent but my siblings were around me...(P1).

a) **Behavioural problems**

Another challenge that participants have experienced is with their child's behaviour, however they have had to adapt in order to respond appropriately.

...I'm painting like every second week, because the walls are dirty she's sometimes does the kicking and she's fighting... my daughter was actually uhm she was preferring toothbrushes and wherever we go to visit she would know where the bathroom is

and go and get a toothbrush where irrespective if its dirty or what but that was killing me a lot and those days I was crying everyday because I end up buying 20 toothbrushes you know the 24 that you buy (P1).

...its like okay, is there progress and he was extremely hyper active so that was also draining and challenging because you take him to the shops, he grabs peoples stuff he runs out of shops... (P2).

4.4 **Conclusion**

The data was analysed using the technique of thematic analysis. From the analysis emerged eight overarching themes. Relating to the first research objective: to describe what single parents of children diagnosed with Autism understand about the disorder, three overarching themes emerged. The first theme was empowerment through knowledge. Although participants initially lacked the knowledge of what autism is, they took a personal undertaking to read and research the disorder further, which empowered them as parents to understand their children better. The second theme was signs; which had subthemes of developmental delays and level of functioning; participant's indicated that before the diagnosis they were able to recall certain developmental delays such as with speech, all participants were also aware and understood the level at which their child functions

according to the spectrum of autism. The third theme was medication and therapies, participants were aware of the medical treatments and behavioural interventions available for children diagnosed with autism.

For the second research objective: to explore and describe the experiences and meanings about these experiences of single parents of children diagnosed with autism, five main themes emerged from the data. The first was the journey to acceptance, after being given the diagnosis, participants reported feelings of shock, and confusion but coming to accept the diagnosis has helped them to cope as single parents. The second theme was financial strain, participants reported that one of the biggest challenges they face is with the finances, the cost of the school, medication and with therapies, becomes financially taxing. The third theme was stigma, participants found that the public tends to judge them as a parent mainly because they do not understand what autism is, and how it presents. The fourth theme was coping and resilience with subthemes; family support and faith in God, participants reported that they cope with the support of family members and with their faith in God, which gets them through the days. The last theme was life adjustments with the subtheme of behavioural problems, participants found that that because of their child's diagnosis with autism they have to make adjustments such as with their career, they have also as single parents had to make important yet painful decisions for their children, participants also indicated that another

challenge they experienced is with their child's behaviour, but they have had to adapt in order to respond appropriately.

CHAPTER 5 - DISCUSSION

5.1 Introduction

This chapter will discuss the findings of the present study. The purpose of the study was to explore the experiences that single parents have in raising children diagnosed with ASD. Specifically identifying how single parents understand the disorder and the meanings that they attach to their experiences. The themes that have been presented under the previous chapter will be discussed further using relevant literature as support. This chapter will end with recommendations and limitations of the present study as well as with a conclusion of the study's findings.

5.1.1 Empowerment through knowledge

Participants in this study experienced a general lack of knowledge concerning what was happening with their children and especially with understanding what autism means for their children. However participants took it upon themselves to do further reading and research into the disorder, which helped them to understand autism and the implications for their child. Woodgate, Ateah and Secco (2008) also found that parents stressed the importance of learning all aspects of raising a child with ASD. Lindsay and DePape (2015) also reported that parents felt empowered by educating themselves about autism.

A study by Kuhaneck, Burroughs, Wright, Lemanczyk and Darragh also found that for mothers of a child diagnosed with ASD, it was critical to know the facts and information regarding their child's disorder and also to be educated about laws, resources and services that are available, processes and structures within the school system. Their knowledge was pivotal to them being a successful advocate for their children (Kuhaneck et al., 2010).

5.1.2 Signs

Many of the participants reported that they were unaware of the signs of autism initially. Lindsay and DePape (2015) found that parents did notice early atypical behaviours but did not immediately think of the diagnostic possibility of ASD. Parents also attempted to make sense of this behaviour through reference points such as by comparing their child's behaviour to that of a sibling (Lasser & Corley in Lindsay & DePape, 2015).

As participants had a lack of knowledge, they were unable to identify the disorder immediately; they thus sought help from medical and other specialist professionals.

All participants reported that they were presently aware of where in the spectrum their children fall. Participants attributed their child's level of

functioning to achievement of developmental growth and from the school report.

5.1.3 Medication and therapies

All of the participants indicated that they were also aware of certain medications and therapies, which include speech therapy and occupational therapy. These medications and therapies are currently available and accessible to participants. Woodgate, Ateah and Secco (2008) state that treatment services for children include speech therapy, psychical therapy, psychiatry services and respite services.

Participants indicated that the medications that they are aware of include Ritalin, Risperdal and Abilify, which their children have been taking. Some other participants also mentioned behavioural interventions as well as special diets.

Furthermore, the extent of the treatment given to the child depends both on what services are available and what parents can afford (Woodgate et al., 2008). This awareness and knowledge came from the participant's personal experience of treatments given to their children.

5.1.4 The journey to acceptance

All participants reported that when they were first told that their child was diagnosed with autism, it came as a shock, they were left with feelings of sadness and confusion. Dzubay (2011) explains that as parents come to terms with the diagnosis of ASD they express feelings of grief and sadness as well as implications of the diagnosis become reality. Midence and O'Neill (1999) found that parents experienced mixed feelings of relief and devastation, regarding the implications of their child's diagnosis. Parents felt devastated only as they begun to worry about the long-term impact that the diagnosis had on their child (Altiere & Kluge, 2009; DeGrace, 2004)

Although participants were left with mixed and difficult emotions some stated that coming to accept that their child is diagnosed with autism helped them to cope. DeGrace (2004) and Koydemir-Ozden and Tosun (2010) state that some parents in their study found a new normal for their family, some parents also got into the routine of caring for their child with ASD and stopped trying to fix their child.

5.1.5 Financial strain

Many of the participants reported that one of the challenges they face as single parents is with finances, even though they are employed. Altieri and von Kluge (2009) also found that parents reported changes in their financial situation following their child's diagnosis of ASD.

Parents also described the need to work to provide financially for their child with ASD (Fletcher, Markoulakis, & Bryden, 2012).

Tait and Mundia (2012) found that in their study the financial impact of having a child diagnosed with ASD posed a threat to parent's perceptions of life satisfaction and their ability to fulfil their responsibilities.

5.1.6 Stigma

Participants reported that another challenge that they face is that from the public/communities, there is a stigma around having a child diagnosed with autism. Most people in the communities are unaware of what autism is and how it presents; therefore participants indicated that they were judged as parents as well. Woodgate, Ateah and Secco (2008) state that parents expressed feelings of isolation because of what they perceived was a lack of understanding by society of what autism was and what was involved in caring for a child with autism. Further, parents felt that society placed less value on the lives of the children with autism and subsequently felt stigmatized, which added to their feelings of isolation (Woodgate et al., 2008).

5.1.7 Coping and resilience

All of the participants have the capacity for resilience and have found ways to cope with being a single parent of a child diagnosed with ASD with all the challenges that they have faced. Participants also indicated having the support of family and friends. A few other participants also reported turning to their faith in God as a source of coping. Tait and Mundia (2012) explain that in a state of need and emotional distress, parents and relatives turn to religion.

Studies by Bayat (2007) and Cripe (2013) have shown that despite the challenges faced by parents and families of children diagnosed with ASD a significant number of these parents show evidence of resilience. These parents and families react to adversity by becoming stronger and having more of an optimistic outlook.

Bekhet, Johnson and Zauszniewski (2012) state that parents who possess the indicators of resilience are better able to handle the challenges of raising a child diagnosed with ASD.

5.1.8 Life adjustments

Participants have indicated that they had to not only accept but also adapt to their child's diagnosis of autism. For instance, one parent even had to sacrifice her career goals and status. Tunali and Powers (2002) found that parents especially mothers have had to re-evaluate their career goals due to their child being diagnosed with ASD. Parents

found that by placing less importance on their career and more importance on their parenting and family they had a greater capacity to enjoy life and felt less stressed (Tunali, & Powers, 2002).

Another participant also reported that she does not have time to spend on herself, as having a child with autism is demanding, especially being a single parent. Another challenge that participants have experienced is with their child's behaviour, however they have had to adapt in order to respond appropriately. DeGrace (2004) and Fletcher and colleague's (2012) state that caring for a child with ASD affects many aspects of daily life. Fletcher and colleague's (2012) found that parents felt frustrated by the lack of time they had for themselves and their family.

Parents also experienced a range of behavioural problems with their child, such as tantrums that they were unsure on how to manage with (Shu, Hsieh, Hsieh, & Li, 2001).

5.2 Recommendations

As all of the single parents indicated that upon diagnosis none of them knew what ASD was and what such a diagnosis meant for their children's capabilities and future. Therefore awareness campaigns should be implemented across the country to educate the public on ASD. This will also avoid the stigmatization that single parents of children diagnosed with ASD receive from the public. Another

recommendation is for Government to provide assistance to single parents and parents of children diagnosed with ASD, in areas such as financial support, and with providing a budget for research into treatments and a cure for ASD.

It is also recommended that health and mental health professionals, be sensitive to parents of children diagnosed with ASD as many do not know what ASD is. Therefore professionals should give parents a good overview and understanding of how ASD presents and the various treatments options that are available. It will also be of value for health professionals to request for family and friends of the child diagnosed with ASD to receive such a overview to help and support the child and single parent, as raising a child with ASD presents with many challenges, that were found in this research.

5.3 Limitations of the study

This study was done using a population of children diagnosed with ASD who were quite advantaged, attending a specialized ASD school. The participants were from middle to higher income population of which all were employed. Results cannot be transferable across all racial groups and across both genders as only Black South African single parents were accessed for this study.

Thus research should be carried out across all racial groups and to both genders in order to increase transferability. Although this study addressed single parents, only single mothers were reached, as a result it would have been more beneficial to have the experiences of single fathers of children diagnosed with ASD.

This research study was also limited to participants in Pretoria, Gauteng, and thus cannot be transferable to the whole of South Africa; therefore research should be conducted in the other cities and regions of South Africa.

5.4 **Conclusion**

The findings of the present study have shown the following. Single parents of children diagnosed with ASD have felt empowered by taking it upon themselves to further research and understand what the diagnosis of ASD means for their child. Participants did have the knowledge about where in the spectrum their children fall, as well as the various treatments and interventions that are available to their children:

Single parents have described having feelings of sadness and shock, when they were first informed that their children had been diagnosed with ASD, but as they had come to accept the diagnosis it became much easier to cope with.

Single parents have experienced the following challenges of raising a child diagnosed with ASD. These included behavioural problems, financial implications and the stigma that single parents are faced with.

The single parents in this study showed ways of coping through resilience, as they were able to use resources that are available to them. Above all single parents of children diagnosed with ASD have had to make adjustments in their lives, to ensure that their child is given the biggest priority.

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Appendices

Appendix 1: Interview schedule



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Interview Schedule

1. What are your experiences in raising a child diagnosed with autism?
 - a. Probe – How did you find out that your child had autism?
 - b. Probe – What were your reactions after finding out that your child has been diagnosed with autism?
 - c. Probe- as autism is a spectrum disorder, where would you say your child falls; is he/she on the lower, middle or higher level of functioning?
 - d. Probe – With regard to the condition of your child, what added stressors do you encounter?
 - e. Probe – Being a single parent, how are you coping with the condition of your child?

2. Tell me what do you know about autism?
 - a. Probe - what do you know about the diagnosis (symptoms)?
 - b. Probe – How have mental health practitioners explained the diagnosis?
 - c. Probe - What treatment or interventions are available that you are aware of?

Appendix 2: Informed consent letter



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YUNIBESITHI YA PRETORIA

Dear Participants

Informed Consent

I, Swadhi Purmasir am conducting a research study, to look at the experiences that single parents have in raising a child diagnosed with autism. Please understand that your participation is voluntary and you are not being forced to take part in this study. The decision to participate or not, is your choice alone. However, I would really appreciate it if you share your thoughts and experiences with me.

What is involved in the study?

If you decide to participate you will be asked questions in the form of an interview about your experiences of being a single parent to a child diagnosed with autism. I think this will take you approximately 45 minutes. I will be asking you questions and request that you be as open and honest as possible in answering the questions. Some questions may be of a sensitive and personal nature, you may choose not to answer these questions.

The researcher may stop the study or take you out of the study at any time that's judged in your best interest. The researcher may also remove you from the study for various other reasons.

Your rights as a research participant?

All information will be treated with confidentiality. Participation in this study is entirely voluntary. You have the right not to participate at all or to leave the study at any time. Deciding not to participate or choosing to leave the study will not result in

any penalty or loss of benefits to which you are entitled, and it will not harm your relationship with anyone.

Anonymity will be assured as I will not be recording your name anywhere on the interview, and no one will be able to link you to the answers that you give. Only the researcher will have access to the unlinked information. All individual information will be kept confidential.

Contacts for any questions or problems?

Should you have any questions about the study contact me Swadhi Purmasir via Cell: 0820612706 or email spurmasir@yahoo.com or my supervisor Dr Makhubela from the University of Pretoria, School of Humanities, Discipline of Psychology via email malose.makhubela@up.ac.za

Appendix 3: Consent form



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Consent Form

I hereby agree to participate in research regarding the experiences of single parents in raising a child diagnosed with autism. I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop this interview at any point should I not want to continue and that this decision will not in any way affect me negatively.

I have received the telephone number of a person to contact should I need to speak about any issues that may arise in this interview.

I understand that this consent form will not be linked to the questionnaire, and that my answers will remain confidential.

I understand that, if possible feedback will be given to me on the results of the completed research.

Signature of Participant

Date

Additional consent to audio recording

In addition to the above, I hereby agree to the audio recording of this interview for the purposes of data capture. I understand that no personally identifying information or recording concerning me will be released in any form. I understand that these recordings will be kept securely in a locked environment and will be destroyed or erased once the data capture and analysis are complete.

Signature of Participant

Appendix 4: letter of invitation for participation



UNIVERSITEIT VAN PRETORIA
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YUNIBESITHI YA PRETORIA

27 March 2017

To: Parents of children attending UNICA school of Autism

Request for participants in a study titled: Experiences of single parents of children diagnosed with Autism: A phenomenological study.

I, Swadhi Purmasir am a Masters in Clinical Psychology student at the University of Pretoria. I am conducting a research study on the experiences of single parents of children diagnosed with Autism. The study aims to establish what single parents of children diagnosed with autism, understand about the disorder. Secondly, the study aims to explore and describe the experiences of single parents of children diagnosed with autism.

Face-to face interviews will be used to collect data. Participation in this study is completely voluntary. Participants may withdraw from the study at any time during the interview. The name and identities of all participants will be used in the study and confidentiality is guaranteed.

If you are interested in participating please contact me Swadhi Purmasir via Cell: 0820612706 or email spurmasir@yahoo.com or my supervisor Dr M. Makhubela Tel: 0124202830 or email silas.makhubela@up.ac.za from the University of Pretoria, Faculty of Humanities, Department of Psychology

Thank you,
Swadhi Purmasir

Appendix 5: Ethics letter



UNIVERSITEIT VAN PRETORIA
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Faculty of Humanities
Research Ethics Committee

4 May 2017

Dear Mr Purmasir

Project: Experience of single parents of children diagnosed with autism
Researcher: S Purmasir
Supervisor: Dr MS Makhubela
Department: Psychology
Reference number: 16397828(GW20170403HS)

Thank you for the application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** at an ad hoc meeting held on 4 May 2017. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely

Prof Maxi Schoeman
Deputy Dean: Postgraduate Studies and Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:tracey.andrew@up.ac.za