

**THE KNOWLEDGE AND EXPERIENCES OF SINGLE MOTHERS RAISING AN
AUTISTIC CHILD IN A LOW-INCOME COMMUNITY IN THE WESTERN CAPE**

By

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**Submitted in fulfilment of the requirement for the Masters by dissertation in Psychology in
the Department of Psychology at the University of the Western Cape, Bellville.**



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ABSTRACT

Parental knowledge and experiences regarding autism spectrum disorder have a huge effect on the life of the caregiver. Once a child has been diagnosed and needs treatment, parents/caregivers have to adjust in many ways. The adjustment will vary depending on the needs of the child at that particular point. Caregivers to an autistic child have to acquire comprehensive knowledge regarding autism spectrum disorder. A support system plays a pivotal role in the raising of an autistic child. The objective of this study was to explore the knowledge, experiences and coping mechanisms of single mothers raising an autistic child in a low-income community in Western Cape Province. A qualitative research approach was employed to gain access to the experiences of single mothers raising an autistic child, and in-depth interviews were conducted with six single mothers from a low-income community. Transcriptions were analysed in accordance with the approach of thematic analysis. Results indicated that participants experience many challenges: lack of knowledge, inexperience, personal challenges, and society's perceptions of autism were highlighted. Participant's social support given by family, community and organisations they allowed for coping and resilience to outweigh the challenges. The single mother's experiences varied however the resilience has allowed them to cope and gain the needed inner strength to embrace the experience each day. Further research is needed to highlight fathers' experiences and their coping mechanisms in raising an autistic child.

DECLARATION

I declare that THE KNOWLEDGE AND EXPERIENCES OF SINGLE MOTHERS RAISING AN AUTISTIC CHILD IN A LOW-INCOME COMMUNITY IN THE WESTERN CAPE is my own work, that it has not been submitted before for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged as complete references.

Bronwyn Sarah Mthimunye



November 2014

Signed: _____

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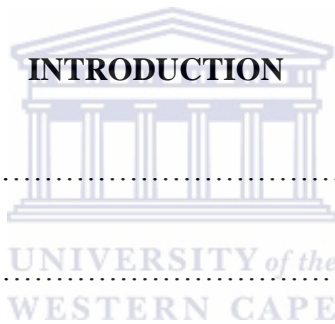
I convey my appreciation to all those who have made this journey of mine successful. I thank God for giving me the strength and spirit of endurance to enable me to complete my thesis. I am very privileged to have had Professor Mwaba as my supervisor and grateful for his guidance and support throughout the process. I am also grateful to Dr Athena Pedro for her motivation and faith in me. Thank you to my husband Katlego Mthimunye and my son Kgethego Mthimunye for their support and encouragement and allowing me the time to work hard and make a success of it. Autism Western Cape has played a crucial role in completing my thesis; thanks to all the staff for their support and energy that went into making my work valuable. To all the participants who volunteered: I am happy and thankful for your contribution and making my thesis worth reading. Thank you to all staff and colleagues at the Psychology Department of the University of the Western Cape for your support and accommodating me throughout the process. To all my friends and family: I appreciate your support and words of encouragement and motivation.

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CHAPTER 1

INTRODUCTION

1.1 Background

The autism spectrum, or autistic spectrum, describes a range of conditions classified as neurodevelopmental disorder in the *Diagnostic and Statistical Manual of Mental Disorders* 5th edition (*DSM-5*). Globally the incidence rates and prevalence of autism spectrum disorder (ASD) is rising significantly (Richmond, 2011). The World Health Organisation is in full favour of developing support and putting plans into place to support the worldwide population of persons with ASD, owing to the increase in prevalence globally (WHO, 2008). ASDs are characterised by social-interaction difficulties, communication challenges and a tendency to engage in repetitive behaviours. However, symptoms and their severity vary widely across these three core areas. Taken together, they may result in relatively mild challenges for someone on the high functioning end of the autism spectrum. For others, symptoms may be more severe, as when repetitive behaviours and lack of spoken language interfere with everyday life (American Psychiatric Association, 2013).

Current statistics of autism worldwide indicate that the number of children diagnosed with autism is 1 in every 100 (Jacklin, 2011). International trends show that the prevalence of autism is increasing as a larger number of people are diagnosed as having an ASD. In many parts of South Africa the prevalence of ASD is unknown, owing to a lack of research conducted in Africa

(Ametepee & Chitiyo, 2009). ASD can be found in every country, ethnic group and socio-economic group. ASD cannot be cured but can be treated (Richmond, 2011). In South Africa, according to Autism Western Cape, 1 in 86 children under the age of 6 years are affected by it. Autism is 4 times more prevalent in boys than in girls. When parents learn that their child has been diagnosed with autism, they immediately start a whole new journey. At this stage, the parents go through many different emotions and interactions with various healthcare professionals (Taylor, Wall, Liebow, Sabatino, Timberlake & Farber, 2005). Initially, parents may feel isolated and alone, and not know where to begin their search for information, assistance and understanding as well as support (Mc Gill Smith, 2003).

1.2 Rationale



The motivation for undertaking this study is to gain more knowledge about the experiences of single mothers raising an autistic child in a low-income community in the Western Cape. ASD is rife in our communities, whilst not many caregivers are knowledgeable and indeed have many misconceptions of autism (Richmond, 2011). There are, however, many parent-training programmes worldwide to increase knowledge and insight on the disorder as well as increase the communication skills of children with ASD (Krishnamurthy, 2008; Lang, Machelicek, Risopoli & Regester, 2009; Wang, 2008; Whittingham, Sofronoff, Sheffield & Sanders, 2009). Even though these programmes are available in various countries, access to these facilities still remains a challenge in many communities (Richmond, 2011). A study in both India and China focused on psycho-educating parents and caregivers on diagnostics and treatment (Kalra, Seth, & Sapra, 2005; Wang, 2008). These sessions were reported as being very informative and the most

useful of all treatment sessions (Wang, 2008). Educating parents/caregivers is very important where there is a lack of public awareness. Even though many treatment modalities are available, parents are still concerned about ASD service delivery in our communities. A more structured referral system for treatment options, especially after ASD diagnosis has been made, is needed (McCabe, 2008). Services are neither readily available nor accessed by all families owing to lack of time and financial difficulty (Krishnamurthy, 2008). Long waiting times for patients needing services to be rendered could be a problem and a reality for many people, which could lead caregivers to adopt alternative treatment methods that are not advised by the health professions (Richmond, 2011). Despite the challenges that parents face, and particularly the single mother, there are single mothers coping well with the problems presented by an autistic child. Current research done in this field is limited in South Africa; this forms the basis of the motivation for this current study.



1.3 Problem statement

Autism is an illness that is stressful for both the child and the parent, but mostly for the parent. A typical day for the ASD child and caregiver would be structured and have a set routine that must be adhered to. Many changes would occur in the life of the caregiver, as much attention is needed in raising an autistic child. This has a significant impact on the daily functioning of the family (Marvin & Pianta, 1996; Turnbull & Turnbull, 1990; Waggoer & Wilgosh, 1990). Having a child can be a wonderful experience, but the diagnosis that one's child has an ASD can be terrifying. Adding to the terror would be being a single mother, which might be an unbearable situation. In South Africa, women commonly raise children on their own, in the absence of the

father of the child (Eddy & Holborn, 2011). This circumstance can only exacerbate the management of this disorder and difficulty in caring for the child, from a single mother's perspective, and in dealing with this very stressful disorder (Gupta, 2007). Many researchers have reported higher levels of stress in single mothers raising a child diagnosed with ASD than amongst mothers of children with other developmental disabilities, such as Down syndrome (White & Hastings, 2004). Autism could probably be ranked as the most stressful childhood developmental disorder for the families of these children (Brown, Espinosa, Hastings, Kovshoff, Remington & Ward, 2005). Autism affects the economic state, quality of life and welfare of the families involved, and much more so for the single mother (Beecham & Romeo, 2007).

1.4 Research questions

In-depth interviews were conducted to gain insight into the knowledge of single mothers and their experiences in raising an autistic child in a low-income area. Amongst the questions were:

1. What does a single mother identify as her coping strengths and resilience?
2. What does the single mother identify as an everyday stressor?
3. How does the resilience of a single mother emerge in a family structure with a child diagnosed with autism?

1.5 Aim of the study

The main aim of this study was to explore the knowledge and experiences of single mothers raising an autistic child in a low-income area.

1.6 Objectives of the study

1. To gain insight into parents' knowledge of ASD.
2. Ascertain the experiences of single mothers in raising an autistic child in a low-income community.
3. To explore the coping mechanisms used by single mothers in the community.

1.7 Significance of the study

The study is intended to contribute towards combating the lack of autism research done locally and internationally. The experiences of single mothers raising an autistic child have been highlighted and ascertained, including as to whether resiliency plays a part. The study has focused on single mothers as their tasks are more demanding. Literature has shown that, in both developing and developed countries, women are particularly the main caregivers. Mothers are the most likely to give up their work and take care of their child with ASD (Wood, 1994). The present study has gained insight into the experience of single mothers raising an autistic child in a low-income community. As there are a growing number of ASD children affecting single parents, and particularly single mothers as the primary caregivers, there is a lack of knowledge surrounding the experiences of single mothers raising an autistic child in a low-income community, namely Cape Town, South Africa. In addition, this study attempts to contribute to the existing body of knowledge.

1.8 Overview of the study

The thesis consists of five chapters, each focusing on various aspects of the main theme.

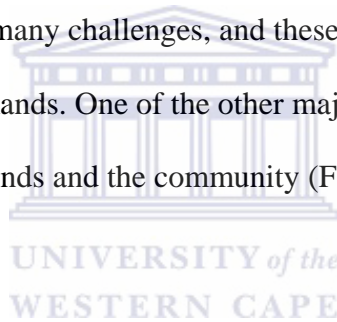
Chapter One is a brief introduction focusing on the main considerations of this thesis, comprising the research problem being addressed and discussed, and stating the purpose of the study. **Chapter Two** focuses on the literature review and that related to the topic. It covers various aspects of the thesis such as the prevalence of autism and the current work done on the topic both locally and internationally. **Chapter Three** includes the methodology used for this study, and describes the method, data collection, analysis, selection of participants and ethical considerations. **Chapter Four** is the presentation of the results that were collected and analysed. A thematic analysis approach was used for analysing the data. **Chapter Five** includes a discussion of the analysed data and the results, as well as the implications of the findings. A brief consideration of the limitations of the study will also be discussed, including recommendations for future research studies.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

Research related to ASD has been increasing over the past decade as more and more workers are entering the field. While reading various articles, I realised that more studies should be done concerning parents and their experiences of how they cope and manage their children. Research indicates that an autistic child has many challenges, and these can affect the caregiver who has to meet the expectations of those demands. One of the other major challenges is resources and the necessary support from family, friends and the community (Fallon & Russo, 2003; Fujiura & Yamaki, 2000).



The following literature review focuses on autism and the issues related to autism. I highlight a few of the importances of autism and discuss them from both local and international perspectives. ASD is known across the country and growing numbers of children are being diagnosed; this calls for more research and detailed findings.

Most of the data found in the literature are related to the international context; within South Africa, not much research is done. International statistics are more up to date than local statistics, but recent studies attempt to address the need locally as many African countries do not have the latest statistics and lack evidence on the topic (Ametepee & Chitiyo, 2009). The literature review covers some of the available research and literature related to ASD.

2.2 Defining autism spectrum disorder

ASD is a neurodevelopmental disorder that affects the way a person's brain and body works. Children with ASD exhibit a wide range of behaviours. Children with ASD find it difficult to make friends with other children as result of the difficulty in communication. Imaginative play is difficult, and some children may not speak at all. Other signs include obsessions; fears; a lack of awareness of danger; ritualistic play and behaviour; inappropriate eye contact; hypersensitivity to sound, light and spinning objects; and hand flapping. A child does not have to show all these signs to be diagnosed with ASD, and some children displaying these symptoms may not have ASD. Some children may be diagnosed as having Asperger's syndrome or high-functioning autism. Children diagnosed with Asperger's syndrome have fewer problems with language than those with classic/Kanner autism, and often speak fluently, though their words can sometimes sound formal or stilted. The level of intellectual functioning differs from person to person and to various degrees (Autism Western Cape, 2014). The level could range from average to above average, and severe intellectual difficulty (Baio, 2012). ASD is characterised by what is known as the quadrant impairments; these include impairments in the following areas: language and communication, socialisation, rigidity in thinking and behaviour, and sensory disturbances (Autism Western Cape, 2014).

2.3 Diagnosing autism spectrum disorder

According to the *DSM-5*, the following criteria should be met when diagnosing a child with ASD.

Diagnostic criteria

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

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 in sharing imaginative play or in making friends; to absence of interest in peers.

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 verbal nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take the same route or eat the 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 interest).

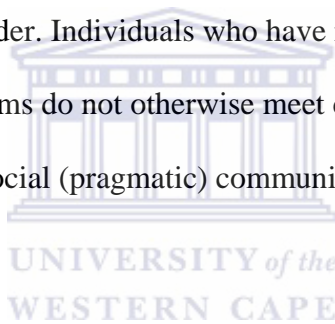
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

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.

2.4 The prevalence of autism spectrum disorder

According to the Centers for Disease Control (2012), ASD affects 1 in 88 children globally and is four times more common amongst boys than girls. In the Western Cape, approximately 10 children are diagnosed each week via 3 government hospitals. It is estimated that the number of people diagnosed with autism grows by 500% each year. Data show that ASD is almost five

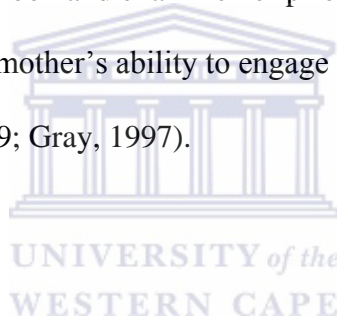
times more common amongst boys than girls (Baio, 2012). The estimated population of South Africa is approximately 50 590 000; with 19.48 babies being born to every group of 1000, it would suggest that, in the year 2012, an average of 985 493 children were born in South Africa, of whom 11 198 were likely to develop an ASD (Autism South Africa, 2012). On estimate, this indicates that 933 new cases of children will be diagnosed each month, 216 cases per week and 31 cases per day; therefore, one can conclude that every 45 minutes in South Africa a child is born who will develop ASD (Autism South Africa, 2012).

2.5 The impact of autism spectrum disorder on the parents

In our society there are many children living with a disability whether a physical, neurological or psychological impairment. Parents of children with a disability tend to experience higher levels of stress than a parent of a typically developing child (Hodapp, Ricci & Fidler, 2003; Johnson, Hessel, Blasey, Eliez, Erba, Dyer-Friedman, Glaser & Reiss, 2003). Raising a child with autism is no easy task for any parent. Having a child diagnosed with autism creates a huge amount of stress (Kuhaneck, Burroughs, Wright, Lemanozyk & Darragh, 2010). The parents' ability to cope and manage these stressors depend on the personal characteristics such as hardiness, self-image, and problem solving skills, as well as upon external factors that plays a crucial role. The availability of support within the family as well as external support is of vital importance in order for the parents to cope (Fallon & Russo, 2003; Fujiura & Yamaki, 2000). Most mothers perceive the support of a spouse very important and serve as both expressive and instrumental support having direct contact and assisting with the challenging tasks being presented (Bristol, 1984; Bristol, Gallagher & Schopler, 1988). Fewer mothers were diagnosed with depression and

happier marriages when having a supportive spouse. Support is particularly important for single mothers raising an autistic child (Bristol, 1984).

The primary caregiver being the mother, who not only bears the practical aspects of taking care of the child but is also saddled with numerous challenges. These challenges vary from lifestyle change, termination of employment or limited career progression, loss of income and leisure time, difficulty in terms of communication, as well as available resources (Beecham et al., 2007). This could be associated with the fact that the maladaptive behaviours of autistic children are very pervasive (Carter & Kuhn, 2006). Raising a child with autism impacts on the mothers live in a huge way she would have to relook and examine her priorities and this means adjusting to the child's lifestyle, as a result the mother's ability to engage in social activities declines (Goin-Kochel, Mackintosh & Myers, 2009; Gray, 1997).



2.6 Parental resilience

Within our society today parents deals with many challenges that may lead to various stressors. These stressors could be of various natures and have a great amount of impact and stress on the family. Resilience is the ability to withstand and rebound from crisis including adversity (Walsh, 1996). Resilience resided within an individual and the individual is able to access inner strength (Walsh, 1996). Centre for the study of social policy stated that parents who are emotionally resilient are able to maintain a positive attitude, creatively solve problems, and effectively rise to challenges in their lives. Parents who cope with everyday life stressors including the occasional crisis have resilience (Forthun, Carannante & Diehl, 2011). They have the ability to bounce back

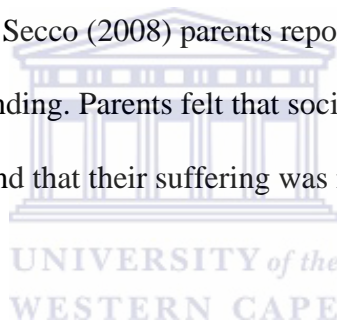
and have the strength needed to survive despite the circumstances. Parents with resilience can generally cope on their own, they are however aware that they can seek help should they need it. All parents have the inner strength or the resources that allow one to be resilient (Walsh, 1996). Parents require understanding and patience and this can be a huge challenge for any parent raising a child with autism. Parents that show resilience tend to have a close relationship with their children and provide them with the adequate attention (Forthun, Carannante & Diehl, 2011).

2.6.1 A theoretical understanding of resilience

Resilience is sometimes defined as psychological process that develops when one is under a great amount of stress and pressure, this stressor can affect the individuals health. Resilience is having the ability to withstand life's challenges and still have the inner strength to persevere despite the obstacles. The terms resilience reflects the ability that an individual has to main a relatively stable mental function throughout a course of events (Ballenger- Browning & Johnson, 2010). There are a few common resilience constructs referenced in literature, it is difficult to say whether they are all valid reliable factors due to the manner in which resilience can be defined in various literature. More research is needed to determine if these factors impact resilience. The following resilience constructs are mentioned, active coping styles, physical exercise, positive outlook, moral compass/ spirituality, social support, cognitive flexibility, cognitive explanatory style, reappraisal, acceptance and stress inoculation are all factors that determine resilience (Ballenger- Browning & Johnson, 2010).

2.7 Community knowledge of autism spectrum disorder

There is a lack of knowledge of ASD in our communities, they lack the understanding of autism and other disorders associated with ASD. Upon diagnoses many parents are not aware of the condition and this provokes anxiety and raises many concerns. There are families with children with a severe disability reporting that there is a significant lack of trained professionals to support and psych-educate families and children (Wang and Michaels, 2009). Society's lack of knowledge and understanding of ASD makes the situation for parents more challenging. In a study done by Woodgate, Ateah & Secco (2008) parents reported that they felt isolated as a result of society's lack of understanding. Parents felt that society does not see the challenging nature of raising an autistic child and that their suffering was not being recognised.



2.8 Impact of raising a child with special needs in a low-income community

There are many people, mainly in low- and middle-income countries are unable to access needed health services as these service are too expensive (Richmond, 2011). In South Africa, health-care access for all is constitutionally enshrined; yet, considerable inequities remain, largely due to distortions in resource allocation (Ataguba,Goudge & Harris, 2011). Access barriers do not allow people to have easy access also include vast distances and high travel costs, especially in rural areas. Patients need to stand in long queues and this disempowers patients. Globally policy attention has turned to universal health coverage as a remedy for inaccessible, unaffordable health services. Socio-economic status, race, insurance status, and urban-rural location were

associated with access to care, with black Africans, poor, uninsured and rural respondents, experiencing greatest barriers. Doctors and teachers play an important role in the caring for an autistic child. An autistic child doesn't only need adequate intervention but the parent needs support and guidance with the daily stressors of an autistic child (Sanders & Morgan, 1997).

2.9 Accessibility of resources and services

Literature speaks about the challenges mothers face in raising their child that suffers from ASD. Parenting an autistic child with the demands of a developmental disorder and its demands can be depressing for many. In order for a child to be supported fully and they require a great amount of services such as physiotherapist, speech and occupational therapist. Comprehensive schooling is also of vital importance. The demands of an autistic child outweigh many other disabilities (Haltermann et al., 2009; Biedel & Rao, 2009). These services are not always at the disposal of the parent for assistance. In low-income areas it's challenging for parents to access these services adequately and promptly. Many communities have access to the local clinic or community day hospital that is situated in the community. Mothers have to wait on waiting listings to be seen by a health professional as they can only be referred to the relevant persons once the child has been seen by a health care practitioner. Early intervention is highly recommended for children diagnosed with ASD. This is not always possible within our low-income areas. Schooling is a huge challenge for many parents of autistic children. Not many schools are accommodative and the few schools that are available have certain criteria and if the child gets accepted and placement for schooling is not successful this child then has to stay home (Autism South Africa, 2012).

2.10 Epistemological position of this study

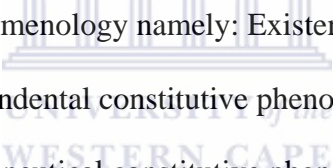
A phenomenological epistemological framework was employed for the purpose this study. This framework employed enables the researcher to gain and understand the lived experiences of single mothers raising an autistic child with a low income community. Epistemology relates to the relationship between the researcher and that which can be known (Terr Blanche, Durrheim &Painter, 2006). Edmund Husserl is known as the founder of phenomenology (Koch, 1995). Husserl's aimed at capturing the truth in lived experiences by establishing rigours science (Mapp, 2008) that enabled him to access the theory of experience (Mortari &Tarozzi, 2010).

Husserl believed that a researcher could access the meaning of lived experiences through one-on-one interaction with the object and listen attentively and be observant (Wojnar & Swanson, 2007). Husserl's approach also gave rise to the descriptive phenomenological approach. Husserl also believed that human interaction influences what individuals perceive as being real (Flood, 2010). He also suggests that scientists should focus on subjective information in order to grasp a better understanding. The discipline of phenomenology may be defined as study of structures of experience, or consciousness. Literally, phenomenology is the study of phenomena and includes the appearance of things or the things that may appear in our experiences. Phenomenology studies conscious experiences that are experienced and views from the subject or person involved.

Phenomenology studies the structure of various types of experience ranging from perception, thought, memory, imagination, emotion, desire, and volition to bodily awareness, embodied

action, and social activity, including linguistic activity. The structure of these forms of experience is referred to as “intentionality” a direct experience towards the world.

We all experience various types of experiences including perception, imagination, thought, emotions, desire, volition and action. The domain of phenomenology is the range of experiences including these types. It is expected that the researcher abandons personal lived experiences in order to provide a pure account of the phenomenon that is being investigated. Husserl calls this abandonment of personal experiences “bracketing” or epoche. The key of this phenomenology is to provide a collective description which captures the real meaning of individual experiences with a particular phenomenon (Creswell, 2007).



There are seven variations of phenomenology namely: Existential constitutive phenomenology, generative phenomenology, transcendental constitutive phenomenology, and naturalistic constitutive phenomenology, hermeneutical constitutive phenomenology, realistic constitute phenomenology and genetic constitutive phenomenology. This epistemological phenomenological framework aligns well with the aim of this study, which is to gain insight into the lived experiences of single mothers raising an autistic child in a low income community. It allows for the researcher to gather data from participants and data that are from their lived experiences and to capture these moments in the way they were perceived. Employing this framework allows the researcher to understand and make meaning of what attributes to the single mothers’ experiences and how they manage with raising an autistic child. With using this framework the researcher is reminded to separate his/her personal biases, beliefs and attitudes from the research process to uphold a standard of reflexivity (Flood, 2010).

2.11 Conclusion

This chapter focuses on the literature relating to autism and the challenges single mothers encounter while raising an autistic child. In the discussion I looked into the prevalence and statistics to indicate the status of ASD in our South African context. International literature indicated more accurate statistics whereby South Africa is still lacking much research in the field. ASD is being diagnosed more and more each day and many parents especially single mothers journey can either be a fruitful one or an unbearable one. The nature of ASD impacts the life on the individual diagnosed as well as the caregiver, in most cases the mother. ASD is both a physical challenge and an emotional one for the parents.

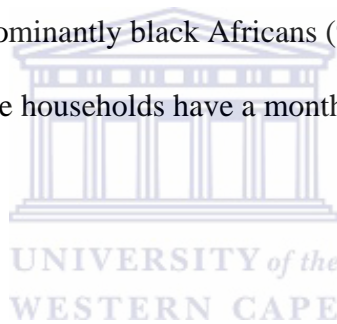


CHAPTER 3

METHODOLOGY

3.1 Research setting

The study was conducted in Khayelitsha situated south east of Cape Town. In-depth interviews were conducted and a qualitative design has been employed through accessing single mothers from the autistic support group from the community under the auspices of Autism Western Cape. The community population is predominantly black Africans (99%) and 1st language predominantly isiXhosa, 74% of the households have a monthly income of R3200 or less (Census, 2011).



3.2 Research design

The study employed a qualitative research design as it will enhance the richness and depth of the enquiry. The qualitative method has enabled me to seek in-depth understanding of single mothers' experiences.

A qualitative research method has been used and this approach offered me and the participant the opportunity to explore a certain phenomenon. In this study the aim was to capture an in-depth understanding of single mothers' experiences. The approach assumes that peoples' subjective experiences are real, that people should be heard and listened to and that the most suitable

methodology would be qualitative research (Terre Blanche & Kelly; 2001:123). The single mothers' experiences are all unique in their own way and therefore one can draw so much from this approach as this methodology seeks an in-depth understanding of the participant's experiences. As qualitative research allows one to gain access to the phenomena through the interview process, therefore this approach is best suited for the study.

3.3 Participants and sampling

The sample consists of 6 participants purposively selected until saturation was reached.

Purposive sampling allows the researcher to recruit participants that are knowledgeable and who are willing to provide the information and experiences the researcher is seeking (Bernard, 2002).

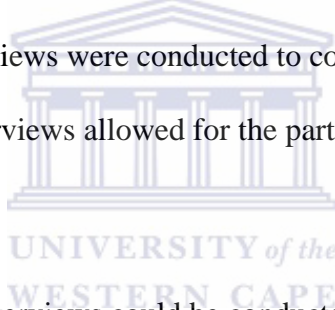
Participants were all single mothers and primary caregivers to their artistic child. Participants were actively involved in the raising of their child and aware of the needs and challenges. This enables the researcher to capture the experiences and gain authentic data.

Participants were single mothers and have a child currently in primary school aged between 7 and 13 years. At this age a child with autism can have various demands such as extra attention needed, fully dependent on the caregiver to provide assistance placing more pressure on the caregiver (Forthun, Carannante & Diehl, 2011).

3.4 Data collection

In-depth individual interviews were conducted with each participant. Semi structured interviews were held with all 6 participants. The qualitative interviews allow for the participant to understand the world from their point of view and to unfold their experiences. The interview schedule has been constructed with the aim of letting participants tell their story (Willig, 2001).

The interviews were structured and consisted of open-ended questions (Appendix C). The open-ended questions explored the experiences of single mothers raising an autistic child in low income community. In depth interviews were conducted to collect the data as well as validate the data. The face to face in depth interviews allowed for the participants to describe their experiences in their own words.



Participants were asked whether interviews could be conducted and recorded on a voice recorder. In-depth interviews were conducted and they were asked to discuss certain questions posed. The questions that were addressed were related to their experiences raising an autistic child and specifically in a low-income community. The interviews were conducted at the Noluthando School of the Deaf with their permission. The interviews were done within one hour and participants were assured that the information will only be used for the purpose of the study and that anonymity and confidentiality is of utmost importance.

3.5 Procedure

Permission was granted by the Director of Autism Western in Mowbray. Autism Western Cape is currently conducting support groups for parents with an autistic child. All support groups were conducted and facilitated by Autism Western Cape where participants were requested permission to participate in the study. In-depth interviews were scheduled for 6 single mothers that agreed to participate. Autism Western Cape selected the single mothers and appointments were set up according to an interview schedule. The organisation prepared all the logistics and allowed for the interviews to take place at their head office in Mowbray. An information briefing was held with each participant where the purpose of the study was explained and more in-depth information about the study was given to give more clarity. Upon meeting the participants the consent forms were given to complete. The participants were single mothers with a child between the ages 7 and 13 years. All interviews ranges from 45mins to 60minutes in length. The interviews were then conducted and transcribed; all participants were informed regarding the confidentiality and anonymity.

3.6 Analysis

All interviews were analysed and transcriptions have been organised, reduced and sense have been made of the data (Babbie & Mouton, 2001). The data collection and the analysis aid the researcher to formulate and construct the participant's responses. All interviews were transcribed and transcriptions have been analysed in accordance with the thematic analysis approach.

Thematic analysis focuses on the identifiable themes that are identified during the interviews. Once the interview was conducted the recordings were immediately transcribed whilst the interview was still easy to remember.

Braun and Clarke (2006) outline six steps for thematic analysis: (i) familiarising yourself with the data by transcribing and reading it; (ii) generating codes in an organized way and coding points of interest in the data; (iii) searching for themes by collating codes into themes; (iv) reviewing themes in relation to the coded extracts; (v) defining and naming the themes as part of an ongoing analysis, and refining the specifics of each theme; (vi) producing the report.

Once all the interviews were completed and transcribed successfully the analysis could then start. Interview transcripts were then used to create a themes or emergent concepts (Babbie & Mouton, 2001). Themes emerged and brought together ideas and experiences, which are often meaningless when not brought together (Terr Blanche & Durrheim, 1999). The data obtained from the interviews were coded and clustered, this enabled one to see the patterns and how everything would come together. Different codes were then given to each theme and then applied to each interview, this allowed for identification of patterns within the participants interview.

3.7 Ethics

Ethics in research is a serious matter and researchers need to adhere to the strict rules (Kosslyn & Rosenberg, 2005). As a health professional and researcher it is my obligation to protect the rights of the participants. The human rights and human dignity of all the participants have been treated with respect (Babbie & Mouton, 2003). Permission was granted to conduct the proposed research

at UWC has been sought from the Senate High Degrees Committee at UWC. Before data collection commenced a letter was drafted for all participants to read and one all was understood the participant was asked to sign upon a agreeing to participate in the study. This written consent has been requested from all participants that meets the research criteria. They were informed of all processes involved including an information sheet, where the study was explained in-depth to ensure that the participant is well informed before they participated. Participants were employed on voluntary basis and they were not obligated to partake in the study. The term was explained to all participants and they could withdraw at any stage.

Participants were given a small token of appreciation after the interview session, they were not aware of this prior to the interview. The monetary token of appreciation was given for transport costs as many of the mothers were unemployed and experiencing financial difficulty.

Confidentiality was important as information shared was only used for the purpose of the proposed study. Participates were informed and reassured that the interview recordings will be destroyed upon completion of the study. Participants were made aware that they could withdraw from the study at any time. All data are kept safe and in a secure area to maintain and uphold confidentiality (Kosslyn & Rosenberg, 2005).

At the end of each interview participants were probed by the researcher whether they would like any further support as a result of the interview. Psychological services were available to the participants that needed further support.

3.8 Trustworthiness

Trustworthiness described by Krefting (1991) was used in this study as it is conceptually well developed and used extensively in other studies. The credibility enhanced and according to Guba and Lincoln (1994) has recognized terms that describe rigor in qualitative research, namely credibility, dependability, conformability and transferability. It refers to being true and accurate to the participant's information without intentionally transcribing it to the researchers understanding. When conducting the study the researcher could have been biased and need to be aware of any pre-conceive ideas or assumptions, this refers to reflexivity (Langedrige, 2007). In order to further more enhance trustworthiness, a self-reflective journal was kept to facilitate reflexivity (Hycner, 1985).



3.9 Reflexivity

Reflexivity is intertwined thoughts and understanding of the researcher reflecting on the limitations and impacts they had on the research process (England, 1994). On commencement of the study I was fully aware that the area of research is a sensitive one. Being a mother myself and dealing with a child that brings along certain challenges can be demanding. From the time of conception throughout the birth process and till today it is an on-going day to day challenge. I had the opportunity to work with children from various backgrounds and children who are suffering from various psychopathologies, behavioural difficulties and with developmental challenges. I also had the privileged of mothering many of these children at a young age. I had some idea of the challenges being faced and how tough things can get. I was aware that once I

start my interviews with my participants they have experiences of their own and it is unique in their own way.

My interviews started off quite intense where participant's feelings evoked emotions in me. I constantly had to remind myself that I am the researcher and not the therapist. I viewed this as a big challenge, I kept wanting to advice, direct and counsellor. Participants became very emotional at times and wanted me to console them; I had to contain myself as I could empathise and see the deepened emotions of the participants. The challenges that participants had mentioned made me reflect on the minor challenges I have raising my own son. This made me realise how I should appreciate all I have and the adorable son God has given to me.

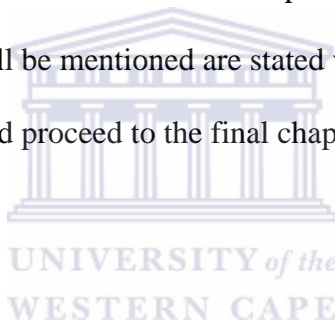
Interviews were conducted in English and most of my participants were Xhosa speaking they felt comfortable with English but I was aware of the language and kept reiterating information. I was aware of this but participants seemed to have enjoyed the interviews as they could speak and vent and add value to the research study.

CHAPTER 4

PRESENTATION OF RESULTS

4.1 Introduction

The purpose of this chapter is to present the results obtained from the interviews conducted with all 6 participants. I will be descriptive in mentioning the demographics of the participants that took part in the study. Thereafter I will be discussing the thematic analysis approach which plays a pivotal role in the analysing of data. The results will be presented in themes that I identified and formulated. The quotes that will be mentioned are stated verbatim, with grammatical errors. I will then conclude this chapter and proceed to the final chapter of the research study.



4.2 Demographic information

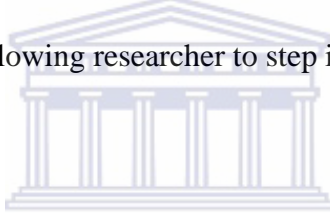
Brief demographic information was requested during the interview with participants. Participants had to meet certain criteria in order for them to participate in the study. All participants had to be from a low-income community, single mother and raising an autistic child between 7 years and 13 years of age.

Participants were African women aged between 30-45 years and from the “black community”. They indicated that they have been staying in the Khayelitsha area for more than a year and longer. All of the participants were from the Christian faith. One of the six participants was married and her husband passed away many years ago. Two of the participants indicated that

they are full time employed and have a fixed income while other participants reported that they have unemployed for a while now.

4.3 Analysis

Thematic analysis was conducted by using the 6 transcriptions of the participants. This type of analysis helps with the exploring of how participants in the study make sense of the personal and world around them. The analysis was chosen to best suit the study as the researcher aims to explore the experiences of single mothers raising an autistic child. Participant's experiences are sketched by themselves and they allowing researcher to step into their world of raising an autistic child.



Various themes emerged from the data while the data analysis process was taking place. Four themes were identified and numerous sub-themes were identified. The themes covered the knowledge and understanding of ASD, the challenges single mothers have raising an autistic child, social support and resilience and coping. These themes and sub-themes will be presented below.

4.4 Knowledge of autism spectrum disorder

This theme refers to the lack of understanding and knowledge of ASD, both parents and the community has a lack of knowledge. There will be sub heading as well and it will be discussed as we proceed. All participants felt that they were not informed of ASD and never heard of it

before until the day of diagnosis. All participants have reached the stage whereby they accepted that their child suffers from ASD. Participants had mixed feeling after hearing the diagnosis.

4.4.1 Signs - Participants reported that they could not understand the signs of ASD. Having the lack of knowledge participants could not identify the disorder immediately until seeking professional help.

“I know, what I know about it is that the child develops later. Example, my son, he has developed, he started walking at a later stage. He sit at a later stage and everything with him, all of those things, at a later stage” [Participant 1]

“I first noticed that, I think he was one years, six months, he was not talking. I was attending my clinic in Nyanga, I asked the nurse why at this age he’s not saying anything and they said maybe later he will speak and then they said, if he’s two, I must bring him back. I brought him back to the clinic, he was not speaking at all, so they transferred me to the Red Cross” [Participant 1]

“Firstly she was a premature, so I thought that it’s because, she started to speak, mamma, dada, bread and so, some few words, so when times goes by, she started to be very slowly now and wanted to play alone. So I took (Miglale?) to the clinic and they wrote a letter to the Red Cross, it’s when they diagnosed her” [Participant 2]

“I saw my child when he is 2 years, he didn’t talk proper and I took him to the clinic and the sister said, what’s wrong with that child. I said he can’t talk and I don’t know because other children, smaller than him, they talk, why he can’t talk” [Participant 4]

“.....sit down, then they tell me why the doctor, your child is not talking. You know about autism, that I didn’t know, but okay and then we go, he was right, my child is diagnosed autism” [Participant 5]

One participant mentioned that daycare does not have the needed knowledge to take care of an autistic child. Day care centres are not equipped to provide the needed assistance for children with ASD. Staff are not trained and are therefore not fit provide the service.

“daycare centres don’t have even the knowledge about autism, so that’s a problem that I have now, as a result, I’m starting to keep, to do some savings” [Participant 2]

After diagnoses there was that sense of confusion and participants not knowing what will take place next. The symptoms displayed by the child with autism now had a name but these single mothers did not know how to respond to the news that their child has been diagnosed with a life time disorder.

“I can say I didn’t feel bad because I didn’t understand what was autism then you see, but I can see he’s doing funny things, yes, funny things” [Participant 1]

“I didn’t even know what is autism and by that time there was no Autism Western Cape, so there were no counselors, so you just receive the news and go to the house and I have to

ask that doctor just to write it down for my husband because I don't know what is autism and there were no pamphlets” [Participant 2]

“.....no one talks about autism, we don't know, actually know what was it all about. I work at UCT also of Desmond Tutu HIV Research Foundation, so I did my own research regarding that and also Dr Richards helped me in that area also by sending me research stuff, so we researched together how we can help” [Participant 3]

“They told me, they see he's got autism and I am not feeling well at that time because I'm crying because I didn't know about autism that time” [Participant 4]

“I was shocked because I never knew about the autism. I never knew anything about it”
[Participant 6]



4.5 Parental experiences of raising a child with autism

Social support- Participants indicated that social support was of great assistance, both for coping physically and emotionally. The support is what made it possible for them to see themselves through this time and day to day.

4.5.1 Community support- Five participants indicated that they are receiving support from the community and positive support that enables the participants to learn and grow intellectually and emotionally.

“the first help I got it from the church and I must say, they were very supportive and the family. So I go to Autism Western Cape, I think 2010” [Participant 2]

“Autism Western Cape because whenever I have a problem I have to ask them what must I do, how must I do it and through their workshops and through the experiences that I’m getting from other parents, and it gives me the strength to know that even if I’m feeling down” [Participant 2]

“neighbours are very, like I would say supportive, they understand there are times that he cries for no reason or laughs for no reason” [Participant 3]

“I am struggling because he is too hyper because of autism, but I manage because I go to workshop, they teach us how to handle the child with autism” [Participant 4]

“The community accepts him like he is” [Participant 5]

“Yes, but the neighbours used to help me because I did told my neighbour but then the others also understand” [Participant 6]

4.5.2 Family support- Family support is crucial and participants shared their experiences of family serving as support. Participants shared both positive and negative thoughts related to family support given.

Positive responses

“My sister was helping me, as I was saying, and my mom, but on his father’s side, nothing” [Participant 1]

“My mom is always there” [Participant 1]

“I would thank again my sister and my son, cause they are doing everything, they are helping a lot” [Participant 2]

“I thank God I had support, not from his father, but I have a good support system from my sister. She was his caregiver up until now, if you do not have a good support structure, especially if you’re a single mom to such a child, everything will fall apart” [Participant 3]

“No it’s not support but in my family have support, in my family because they know him and if I go maybe far in the Eastern Cape, I take him to my cousin in another its better”[Participant 4]

“My mother, they are supportive, because if my child you need Coke Zero, immediately can give the money, go, straight to buy a Coke Zero. When it comes at work, at least at the back we keep the chips, at least supportive, they are supportive” [Participant 5]

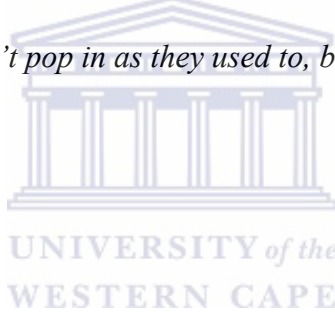
“Yes, and then from his side, like the family, they support us and mine also, they’re supporting us” [Participant 6]

“I’ve got supporters as well because my sister also, the one who is doing one, she’s doing one, yes, she likes him and he likes her” [Participant 6]

Negative responses

“Even with family, with my own family, you won’t believe, ever since my child is like that, it’s like people tend to avoid you if you have a special needs child, especially if it’s on the autism spectrum” [Participant 3]

“once they find out you have such a child, it’s almost like they slowly but surely, they don’t come visit anymore, they don’t pop in as they used to, but you just find as a parent of an autistic child” [Participant 3]



4.6 The challenges facing single mothers with an autistic child - Participants reported many challenges and these challenges are daily difficulties faced. Challenges would range from finances, schooling, and behavioural issues as well as societies perception of ASD. All of these factors makes things unbearable and tough on the single mother and creates stress.

4.6.1 Finances - Four participants indicated that they are unemployed and finding it very difficult to cope with the daily need of providing for an autistic child. One participant would settle for any work just so she could provide for the family while others felt they need to be home and take care of the child diagnosed with autism.

“I would say is not working cause depending on the grant money, it’s very hard to manage, the cost of living is too high, that’s my challenge, other than other things, so”

[Participant 1]

“I am not working, I am staying with my child with autism” [Participant 4]

“Like, cause I’m not working, cause I’m not working and I feel stressed. I was have a depression because is not happy to work, is not happy, because I feel unhappy”

[Participant 5]

“It’s very difficult in terms of finances, especially for him” [Participant 6]

Two participants indicated that they are employed and working full time, the challenge is having to attend to the child with autism and still fulfilling the financial responsibilities

“Like I’m working for Autism Western Cape, so because I’m a single mum I have to work two jobs” [Participant 2]

“I have a job, I’m working 5 days a week” [Participant 3]

4.6.2 Schooling- Participants have a great amount of stress regarding schooling for an autistic child. Poor access to schools is of great concern to many parents of an autistic child. Early intervention is important for the development of an autistic child. Four participants indicated that they had difficulty accessing schooling for their child diagnosed with ASD.

“he referred me to Vera school, but the waiting list is too long” [Participant 1]

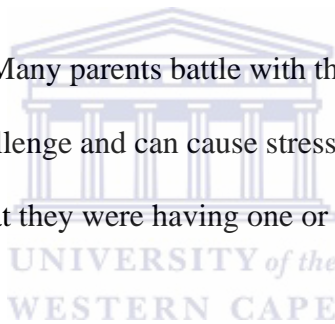
“We’ve got one school here in Khayelitsha and there’s only 11 spaces now and there’s a lot of kids that have been diagnosed every day and there are no daycare centres”

[Participant 2]

“As mothers of autistic children we have this battle again with schools” [Participant 3]

“It’s difficult because that school is a long list” [Participant 4]

4.6.3 Behavioural Challenges- Many parents battle with the behavior of an autistic child on a daily basis. This can be a great challenge and can cause stress and place pressure on the parent. Six of the participants indicated that they were having one or more behavioural challenges on a daily basis.



“challenges, it’s having to put the roll on, brushing of the teeth” [Participant 1]

“Very difficult, very difficult, in the process of going to toilet. If he wants to go to toilet that time, he just sits anywhere and that was very difficult” [Participant 1]

“a challenge that I have is the menstruation” [Participant 2]

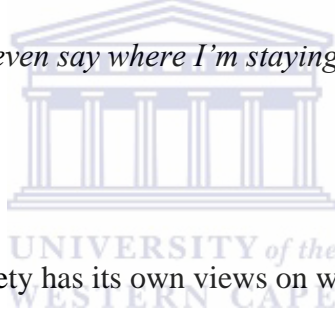
“Behavioural problems, it’s like with Matthew, he gets so mad, like he would pick up things and he throws it” [Participant 3]

“Tantrums overall, every child has tantrums, mainstream or special needs but their tantrums is in such a way, like I said, it becomes, stuff they throw or even with him, he physically takes his fists and bangs it against his head. So what I do is, I will hold him tight and rock him back and forth” [Participant 3]

“he beats another baby” [Participant 4]

“Okay, when throw, throw the, like he, when you eat, after finishing, he throws, throw away and then he drink the, drink the water then I spread over my face” [Participant 5]

“I was struggling of, the most thing I was struggling of it’s when he gets lost because he can’t say his name, he can’t even say where I’m staying” [Participant 6]



4.6.4 Society’s perception- Society has its own views on what autism is and how they choose to interpret the child’s behavior. Participant’s sense was that the community did not know what ASD is until they are informed. One participant indicated that the community is not interested in wanting to know more about the disorder. Five of the participants had a negative perception from society and their understanding of ASD.

“No, they just say, ah, this child has been bewitched, yes, because that child is bewitched, you must take your child to Sangoma here, because of the funny things he’s doing, yes, but all they say, oh, your son can’t speak, that’s all they know about, you see, but no”

[Participant 1]

“Now the people in our community associate autistic children as retards and you had to explain over again, they’re not” [Participant 3]

“because they don’t know what autism is about and most of them, even you try to explain to them, they’re not actually interested in that” [Participant 3]

“They say if I take my child to the, in my culture, sometimes the (richfel?) culture, they said if it is okay if I take the Eastern Cape. I said autism is autism” [Participant 4]

“I don’t know nothing about it, and even them, they don’t know nothing about autism”
[Participant 6]

One participant felt that there is knowledge in the community specifically more in the Khayelitsha area as there are more cases of children with ASD.

“in Khayelitsha they do understand autism because maybe I think there is a lot of children in that side, because in my side I think it’s only me and this lady I’m talking about”

[Participant 1]

One participant indicated that she does not allow society to dictate what she can and cannot do with her son. People’s perceptions do not have an impact on her and will not allow her son to be influenced by others negative perceptions.

“So even if you go out, Matthew talks in the taxi, I don’t have a car, we take public transport, so Matthew would say, oh, we go to Vangate, people look at me, at him, I don’t shush him, that is how it should be. He’s a child, he should be natural, I can’t say, shhh, no, I don’t, no, I allow him and just like I allow him to explore, that is his way of learning

to begin with, so I can't stop him to learn and he can tell you about things, which I like"
[Participant 3]

4.7 Coping mechanisms

4.7.1 Resilience and coping- All participants are striving for resilience and finding ways to cope despite the daily challenges being faced. Three of the participants are drawing strength from their religion and reference to their God. While other participants are coping and at times it can be tough.

"Yes, I'm coping, because I learn, I accepted it, cause I can't do otherwise, I am coping, at the same time I'm not coping but most of the time I'm coping" [Participant 1]

"I mean he was diagnosed at two and also gradually you got used to coping"
[Participant 1]

"So I don't take autism as a case or what, I take it as a, I think God gave me that child just to help others, because that's what I'm doing, so she is my favorite thing, my blessing, my inspiration" [Participant 2]

"You know what, I'm totally being honest with you, I wouldn't have been able to do this as a Christian without God" [Participant 3]

"Sometimes I am coping because there's no other option, I say, just stay strong because the baby is for her, not for others, stay with her baby, his baby" [Participant 4]

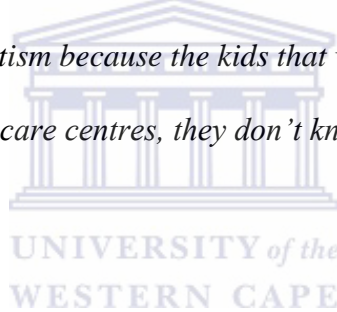
“Sometimes cope right, sometimes bad” [Participant 5]

“Yes, I was shocked because I never knew about the autism. I never knew anything about it. Then I accept it because God gave it to me” [Participants 6]

One participant indicated that she would want to start her own initiative and support mothers who are raising an autistic child and aid them with the needed skills to cope. As well as offer services that the crèche is lacking.

“I want just to build some few rooms, just to take those that the people don’t take and there are those that are still in the nappy. If I can get that chance, I would employ the mothers, the ones that knows about autism because the kids that we have, they are going to the daycare centres, to those daycare centres, they don’t know nothing about autism”

[Participant 2]



4.8 Conclusion

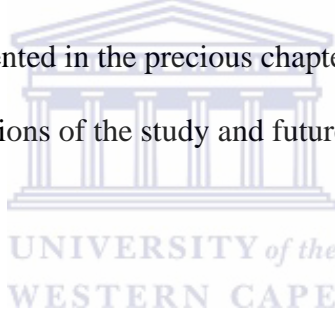
This chapter was focused on providing a description of the phenomena of single mother’s experiences raising an autistic child in a low-income community. The results presented the challenges and the difficulty mothers experience and how they overcome these challenges with the needed support systems and empowering themselves through the community workshops.

CHAPTER 5

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

According to Lester (2005), separating the discussion of the findings from the presentation of the findings allows for the researcher to ‘intrude’. This way the researcher can make interpretations and linkages, relating the findings to previous research done, value to the findings. This chapter will aim to discuss the results presented in the previous chapter and discuss the implications of these findings as well as the limitations of the study and future recommendations.



5.2 Discussion of results

In this section the results the focus will be places on following themes, the knowledge of ASD, the experiences and challenges single mothers have raising an autistic child, social support and resilience and coping. The discussion will include the sub themes for further in-depth understanding of the participant’s experiences.

5.2.1 Knowledge of ASD

It is clear and evident from the results that the mothers were not educated and informed about ASD. Children seemed to have had a delay in development and in some cases regression in development. The signs and symptoms were there and the delay was questioned by many of the mothers and the concern increases as time passed. The signs and symptoms were not very different for the participants interviewed they had a similar sense.

Demographically these mothers were from a low-income area where exposure to psycho-education is low. The community were not informed about such disorders and would make their own conclusions instead.

Acceptance in the beginning for these mothers was confusing and a tough time for them. Participants indicated that they had to gain the needed knowledge to understand the disorder more to enable them to assist the child diagnosed. Some of the participants felt that they were confused and lost at the given time and everything seemed overwhelming. Participants indicated questions they asked and the answers they received were not always what they had expected but they learnt and accepted as time went by. Participants mentioned that the lack of understanding forced them to enquire more about the disorder to make sense of the situation. The participants were not sure what to anticipate and this causes a great amount of stress.

In literature it is mentioned that parents are forced to gain knowledge learn the importance of learning every dimension of raising a child with autism. This means useful conversation with other single mothers and educating each other through their experiences. Being informed and knowing what the disorder entails could minimise stress. The most effective way a parent can

learn is from his/her own child. Parents constantly indicated that they are learning more and more about the disorder by spending time with their child (Woodgate, Ateah & Secco, 2008).

5.2.2 Parental experiences of raising a child with Autism

Social support is a great way of survival for all single mothers; this was reported throughout the interviews. If the support is good, things tend to work out for the better. However if the support system is poor this causes more stress for the individual. All participants indicated that they desire more social support and can never have enough support. Two types of support were highlighted by participants, community support and family support. Community support was given in most experiences shared by the single mothers and they were taking full advantage of the resources in the community that can empower them as single mothers. All participants were grateful for Autism Western Cape for investing time and effort to ensure that parents are being equipped and obtaining the needed support. The community may not be wealthy or rich in resources but the participants were very happy to report that they are getting the assistance they need. The skills obtained during workshops and support groups are aiding the single mothers with the needed tools to be better mothers and having more faith in their own abilities. In the community there were incidents of negativity and judgement as community members were not informed about the disorder.

Family support has been reported by participants as both negative and positive. Family would either withdraw or show interest. Participants reported that family served as a great support structure and allowed for the single mother to cope better. Many participants are not staying

alone; they have family as immediate support. The appreciation and gratitude was shown during the interviews. Family would assist with the raising of the child as well as providing financial support. One participant reported that family support was no longer the same and once they heard of the diagnoses they withdrew and no longer visits. Participants have found a way to draw on the strengths of the family members that are supportive despite the child's diagnosis.

Boyd (2002) suggests that one of the main concerns mothers have is that they might have a decline in support. Research has shown that support acts a protective factor for mothers in times of stress or crisis and serves as a mediator (Krauss, 1993; Allen, Han, McCubbin, McCubbin, & Thompson, 1997). It has been proven in research that parents who receives no support they withdraw from society (Boyd, 2002).

According to Dyson (1997), community based support groups are fundamental in assisting parents with an autistic child. He goes on to say that it is beneficial for parents and allows them to vent and discuss their difficulty. Community and family support is much needed as a single mother and in the absence of a spouse to assist or fulfil the role of a father. The mother's role becomes dual and the success of this cannot be done without support from the community and family members. Therefore the support system is crucial and valued by all participants interviewed.

5.2.3 The challenges facing single mothers with an autistic child

Participants identified many challenges and these challenges ranges from schooling, finances, behavioural issues and society's perception. These challenges created various experiences and

memories for each of the participants. During the interviews participants indicated that schooling is a great challenge for children on the Autism Spectrum. In Cape Town there are a limited number of schools for Autistic children. Of the few schools only one of the schools are for Xhosa speaking children. The participants were from the Khayelitsha area and the children would ideally have to attend Noluthando the school for Deaf. However the school is in high demand and learners are assessed prior to acceptance. Children are then placed on a waiting list were parents are asked to be patient and await feedback. Should the response be of a negative nature the child is then not able to attend school. This process is lengthy and stressful as participants reported this in the interview.

Day care centres are not equipped for taking care of child diagnosed with ASD. Teachers are not trained to deal with such cases meaning many mothers are obligated to care for the child that is unable to attend school nor day centre. Parents are then responsible for the development of the child and fulfilling the role of a teacher and mother. This places more pressure on the single mother.

In studies they place emphasise on the importance of early intervention after diagnoses. The child could benefit from early intervention programmes and treatment plans (Woodgate, Ateah & Secco, 2008). Not all parents are privileged to have this exposure and explore possible intervention programmes. These opportunities are not at the parent's disposal in essence the child is suffering. One participant highlighted the importance of early intervention and working with the child on a daily basis. Participants have reached a sense of empowerment and no longer feel sorry for themselves but speaks with confidence because of the psycho-education that took.

Participants reported that financial stress and challenges are sometime unbearable. Raising a child with ASD has many demands that must be met, most of which are needs and not wants. Participants indicated that they were not working and had to stay home and take care of the child with ASD, this takes a huge financial strain on the mother as well as the rest of the family. Unemployment was amongst four of the participants and of which two reported that they are working but have two jobs to survive. An autistic child has his/her own diet and refuses to eat or drink certain foods. This makes it more challenging for the mother that has to provide and the finances are low. Health care and other needs are financially demanding and only two participants reported that they have medical aid for the children. The community clinic and Red Cross Children's Hospital are one of the only accesses to medical care. However the waiting lists are long and they cannot afford to pay for private health care services. A child cannot be left with anyone should the mother want to find employment. Many survive on the social services grant that is provided by government each month, this amount does not indicate survival for month but only covers the needs of the child.

Research studies show that a child with ASD parents faces numerous challenges in terms of parenting a child with many developmental demands. A great amount of services are needed such as physiotherapy, speech therapy and occupational therapy as well as comprehensive schooling (Halterman, Magyar, Montes, 2009; Biedal & Rao, 2009).

Many of the participants have a daily task of having to deal with behavioural issues that can be a daunting task for any parent and even more demanding on the single mother. Child diagnosed with ASD has various behavioural tendencies that make helping them more of a challenge. Behaviour cannot always be explained nor is the behaviour constant; they might have a

melt-down or a break down at any stage. Behaviour is either repetitive or out of pure anguish and this cannot always be controlled. Participants shared their moments of difficulty as the child with ASD would act in an unpredictable manner or fight, bite, spit or refuse to listen. Many of these challenges are faced on a daily basis. One finds it difficult to discipline a child not diagnosed and with a child diagnosed with ASD it's more of a challenge. Such behaviour makes it difficult for the single mother to socialise and engage with others.

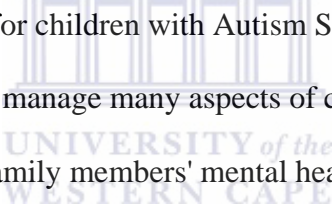
Society's perceptions of a child with ASD vary as different situations evoked different emotions. The community will have their perception based on what they see and heard by either community members or relatives. This information may not always be reliable and valid, as the lack of awareness may be poor. Once the community is better informed can they can then add value and support the single mother. Participants indicated that statements were made about their children and this hurts but they condoned the responses as they were aware that the community lacks knowledge and understanding. They will judge and be judgemental and make their own assumptions but not aware that the disorder is defined in a certain way. Society's views were taken lightly by many of the participants that were interviewed. Participants are fully aware that they also were not sure what ASD means.

5.2.4 Coping mechanisms

Resilience and coping

Participants were happy to report that they are coping and managing the situation whether good or bad. In the beginning things were really tough and hard on the mother receiving the news that

her child is diagnosed with ASD. Hearing the doctors mentioning that there's no cure, this could not have been easy on the mothers, especially knowing that you are single and having to deal with the news. Participants interviewed are attending workshops and support groups to keep empowering themselves and increasing the knowledge regarding ASD. Coping skills are being taught and how to deal with various issues related to ASD. These skills have allowed parents to remain positive and hopeful each day. The support group have been reassuring the mothers that they are not alone. The positive responses reported by the participants were all due to the support they are getting and the knowledge they receiving on an ongoing basis. The experience of raising an autistic child has been more of a delight than a challenge said by many participants as they cannot picture life without their child.



Worldwide, caregivers find caring for children with Autism Spectrum Disorder (ASD) challenging. Family members must manage many aspects of care giving, which is demanding, overwhelming, and can affect the family members' mental health. However learning how to be resilient may help family members overcome the stress and burden associated with caring for a person with ASD. Parents of children with ASD who possess indicators of resilience are better able to manage the adversity associated with caring for children with ASD. Thus, enhancing resilience among family members of persons with autism may be beneficial to both the caregivers and care recipients (Bekhet, Johnson & Zauszniewski, 2012).

5.3 Limitations of study

As in all studies, this research study has its limitations that are important to note. The study was conducted in a low-income community and only included one community. Other limitations include a sample that lacked cultural diversity and that was mainly composed of mothers. Only black single mothers were interviewed and excluding other racial groups. Participants were selected from a low-income area, excluding middle and upper income areas. The interviews were conducted at the head office of Autism Western Cape and participants might have misinterpreted the role of the researcher. There were participants that questioned my affiliation with the organisation, assuming I am employed by Autism Western Cape. Participants were identified by the support group leader. The director of the organisation and the researcher had no control over the manner in which information was disclosed prior to the interview. The participants did however meet all the criteria to participate in the study.

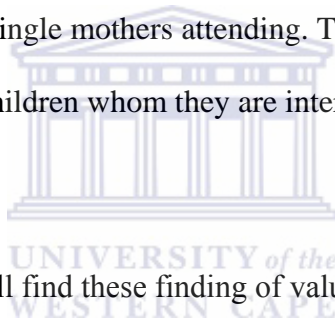
Interviews were conducted in English and participant's first language was isiXhosa, participants felt comfortable speaking English but allowing them to speak their mother tongue would have been better.

Participants were compensated for the study to assist with transport costs; this could place a limitation on the study. Some participants might have seen this as a money making opportunity as they knew payment would be once they participate. However there is no clear indication that this might have happened.

5.4 Implications of findings

The findings have important implications for the personnel working in the field of autism. The findings will have great meaning to the organisation that assisted with the recruiting of participants. The organisation works directly with the participants who participated in the study. The study indicates that support groups are needed and more intervention should be considered as there are more and more children being diagnosed with ASD daily. Parents want more support and more opportunities made available to assist with coping skills and everyday life.

The personnel working in the field must be made aware of the good work that they are doing and what positive impact it has on the single mothers attending. They should also be made aware of the role they play in the lives the children whom they are interacting with whether in support groups and even at their homes.



All NGO's involved in the field will find these finding of value and will certainly add towards the development of the field.

5.5 Recommendation for future studies

The results in this study indicate that ASD is not familiar to many people and especially parents in our communities. Future research could therefore focus on the lack of awareness in our communities regarding ASD. Furthermore studies should include fathers and their challenges faced in having to raise an autistic child in a low-income community. For future studies the researcher should consider conducting the study at a neutral place where the role of the

researcher is clearly stated and no room for confusion. Future studies could employ a quantitative study to ascertain the level of ASD knowledge. The study was done using a qualitative approach that captured the experiences and not much focused statistics and facts. Recommendation for future studies should explore the experiences of raising an older child. Older children will display different behaviour and challenges would vary compared to a younger child.

5.6 Contribution

This study will give every reader a better and deeper understanding of single mothers' experiences of raising an autistic child in low income community. The experiences might be similar but the coping mechanisms vary as every parents experience is different in its own way. Many other single parents can gain insight from other parent's experiences of raising an autistic child. This study will not only contribute towards literature but also contribute towards the field of research at large.

5.7 Conclusion

Results of this study indicate that single mothers experiences of raising an autistic child is challenging and that they had to find ways to cope and survive. Social support turns out to be the major coping mechanism enabling single mothers to cope and draw strength from each day. The skills and techniques taught in the support group and workshops enabled them to cope better and

strive for better understanding. Participant's social support given by family, community and organisations they allowed for coping and resilience to outweigh the challenges. The single mother's experiences varied however the resilience has allowed them to cope and gain the needed inner strength to embrace the experience each day.



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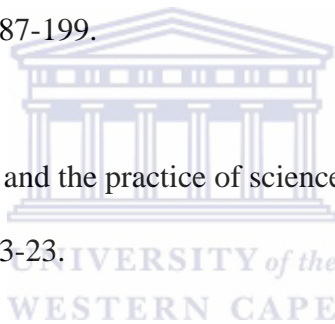
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APPENDIX A INFORMATION SHEET

Project Title: The knowledge and experiences of single mothers raising an autistic child in a low-income community in the Western Cape.

What is this study about?

This is a research project being conducted by Bronwyn Mthimunye at the University of the Western Cape and I'm inviting you to participate in this research project. The purpose of this study is to gain more insight into the experiences of single mothers raising an autistic child within a low-income community.

What will I be asked to do if I agree to participate?

An in-depth interview will be conducted and you will be asked to discuss certain questions posed. The questions that will be addressed will be related to your experiences raising an autistic child and specifically in a low-income community. The interview will be conducted at the Noluthando School of the Deaf with their permission. The interview will be done within an hour.

Would my participation in this study be kept confidential?

I will do my best to keep your personal information confidential. To help protect your confidentiality, the information you provide will be totally private; no names will be used so there are no way you can be identified for participating in this study. Your information will be anonymous and treated confidentially. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There are no known risks associated with participating in this research project.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the experiences of single mothers raising an autistic child in a low-income area. We hope that, in the future, other people might benefit from this study in order to understand the experiences of a single mother raising an autistic child. The findings will provide greater insight into how they cope with the challenges and strive for resilience.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify. Participation in the research is not a course requirement.

Is any assistance available if I am negatively affected by participating in this study?

Every effort has been taken to *protect you from any harm* in this study. If however, you may feel affected in any way by the questions asked in this questionnaire, you will be provided with information to seek help such as counselling.

What if I have questions?

This research is being conducted by *Mrs Bronwyn Mthimunye* at the University of the Western Cape. If you have any questions about the research study itself, please contact Mrs Bronwyn Mthimunye, email: brooi@uwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.



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APPENDIX B

CONSENT FORM FOR PARTICIPANTS

Title of Research Project:

The experiences of single mothers raising an autistic child in a low-income community in the Western Cape.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way. I agree to have the interview audio recorded and kept confidential.

Participant's signature.....

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact me:

Study Coordinator's Name: Mrs Bronwyn Mthimunye

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Telephone: (021) 959-2819

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APPENDIX C

INTERVIEW GUIDE

1. Tell what do you know about autism spectrum disorder? Diagnosis, Treatment & Intervention
2. How did you find out that your child had ASD? What was noticeable? What have you done about it?
3. Where did you go for help? Who sent you? Who told you where to go?
4. What were your reactions after finding out that your child has been diagnosed with Autism? Your thoughts? Your feelings?
5. When were you informed about the diagnosis? What was said to you at the time?
6. Any support? If yes who? What was their role in assisting you?
7. If no how did you cope?
8. Is there enough support in the community? What would you like to see in the community?
9. On a day to day basis what would you describe as a typical day?
10. What are the challenges you are facing on a daily basis?
11. Being a single mother what added stressors do you encounter? How do you deal with these stressors?
12. Would you say you are coping? Why?