

University of KwaZulu-Natal
College of Health Sciences
Discipline of Occupational Therapy

**A Qualitative Study to Understand the Experiences and Coping
Processes of Primary Caregivers of Children with
Autism Spectrum Disorder**

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Research report submitted in partial fulfillment of MPhil of Group Work Therapy

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Ethical Clearance Number: HSS/1189/012M

Date: April 2014

Permission to submit form is in the original document

DECLARATION

I, Deborah Leigh Fewster, student number 9252649, declare that:

(i) The research reported in this dissertation, except where otherwise indicated, is my original work. It is my original work both in concept and execution, and that apart from the normal guidance from my supervisor I have had no other assistance in writing this dissertation.

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DEDICATION

I dedicate this dissertation to my loving husband, Ryan, without whom this project would not have been possible. You have been my pillar of strength, inspiration and driving force.

To my two beautiful boys, Douglas and Troy, Mommy dedicates this to you knowing that you too will realize your dreams one day.

To Dad, because you loved books and studying. Wish you could be here to share in my joy. Here's to living life without limits.

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OPERATIONAL DEFINITIONS

Aetiology: Causes of a condition or disease.

Autism Spectrum Disorder (ASD): Autism Spectrum Disorder/s are a group of pervasive neurodevelopmental disorders characterized by 1) deficits in social communication and interaction and 2) restricted, repetitive behavior; interests and activities (Kaufmann, 2012). The term Autism can be used in place of ASD and will be used interchangeably in this study.

Coping Strategies/Processes: The manner in which people cope and methods they use to fulfil this goal.

Courtesy stigma: Stigma of affiliation (Gray, 2002).

Emotion focused coping: A less effective coping method that is based on avoiding crises and not dealing with emotions constructively (Cappe, Wolff, Bobet, & Adrien, 2011).

Enacted stigma: Stigma is real and a person is the target of ridicule (Gray, 2002).

Felt stigma: Perceived stigma or fear of stigma (Gray, 2002).

Health professionals/medical professionals/health care professionals: Doctors and therapists with and without experience of ASD. These terms are used interchangeably.

Lived experiences: Day to day experiences of parents.

Meltdown: A 'tantrum-like' response in an Autistic child who is not coping in their environment. It is not a tantrum but it has elements of a tantrum such as manipulation,

anger and loss of control. Unlike a tantrum the child is “overtaken” by the experience and loses control ("Autism meltdowns versus temper tantrums," 2009)

Neurotypical: Neurotypical is a term used in the Autistic community to describe those who do not have ASD (Kim, 2013).

Primary caregivers/parents: The biological mothers and fathers who live with the children with ASD. These terms are used interchangeably in the study.

Problem focused coping: The more effective method of coping where a person makes a change to their environment or situation that reduces their stress levels (Cappe et al., 2011).

Proactive Coping: An active form of coping that involves changing something. It is often premeditated as parents understand the stressful circumstances that may arise.

Social relatedness: The ability to communicate and socialize with others. Also includes the ability to read and respond to body language and social cues.

Stimulation Centre: A centre that does not have a formal education program. Stimulation programs and therapies are provided for the children.

Typically developing: This term is related to children who are developing well according to age appropriate norms.

ABBREVIATIONS

ASD	AUTISM SPECTRUM DISORDER
ASA	AUTISM SOUTH AFRICA
ADHD	ATTENTION DEFICIT DISORDER
DSM IV	DIAGNOSTIC AND STATISTICAL MANUAL FOR MENTAL DISODERS FOURTH EDITION
DSM V	DIAGNOSTIC AND STATISTICAL MANUAL FOR MENTAL DIOSRDERS FIFTH EDITION
KZN	KWAZULU-NATAL
MMR	MUMPS, MEASLES AND RUBELLA VACCINATION
UK	UNITED KINGDOM
US	UNITED STATES

ABSTRACT

Aim: The aim of the study is to gain deeper understanding into the lived experiences of parents at a stimulation centre in KwaZulu-Natal, South Africa, and the coping strategies they employ in caring for their children with Autism Spectrum Disorder (ASD).

Significance: As literature has focused on international studies this study has provided deeper understanding of the lived experiences and coping strategies of parents of children with ASD in a local setting within South Africa. Experiences across the age spectrum of children, gendered differences in coping and the meaning behind having a child with ASD provides a unique outlook on ASD as opposed to literature that focuses on other areas.

Methods: Eleven parents participated in semi-structured interviews. These interviews were triad, dyad or one-on-one interviews. Interviews were audiotaped and transcribed verbatim once completed. Thematic analysis was used to analyze the data and extract themes.

Findings: The lived experiences of parents included stressful and devastating experiences as well as positive meaning. Daily challenges were navigated by positive and negative coping strategies with gendered differences in coping being evident. Parents expressed mixed feelings about the benefits of support groups and provided a road map of advice for other parents of children with ASD.

Conclusion: Parents of children with ASD undergo enormous stress and emotional upheaval in caring for their children. However in addition to negative experiences, they gain some positive meaning and see it as character building. Their experiences provide useful information for other parents undergoing the same journey.

CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

The old English proverb “Before criticizing a man, walk a mile in his shoes” speaks to the heart of the research question for this study. In her clinical practice, the researcher worked closely with parents of young adults with Acquired Brain Injury and parents of children with Autism Spectrum Disorder (ASD). She observed that most parents did not seek help or support until they were in crisis. It was a mystery to the researcher because she believed that timely support would help these parents cope better with their daily struggles. To better understand the parents’ perceptions and perspectives the researcher embarked upon a journey focusing on understanding the lived experiences of parents of children with ASD.

A qualitative method of inquiry was undertaken in order to gain deeper understanding into the experiences and coping strategies of parents who have children with ASD. This understanding was gained through the use of one-on-one, dyad and triad interviews. Firstly, it is hoped that this study will provide knowledge on the mechanisms of coping in these parents, with a view to extracting the best ways to cope. Secondly, this knowledge will enable health professionals to enhance the service they provide to these parents, and to help other parents in similar circumstances cope better. This chapter will present the problem statement, the research question, aims, objectives and significance of the study.

1.2 BACKGROUND AND PROBLEM STATEMENT:

The researcher has found the need to investigate this area given the chronic nature of ASD and the debilitating effects on the child with ASD and the family. Autism Spectrum Disorder is a largely unknown condition resulting in people with ASD and their families being subject to stigma. The byproduct of stigma is isolation with potential development of psychological dysfunction in the families of children with ASD. The impact of the

condition on parents and the coping processes that work would be of value to health professionals and other parents of children with ASD.

The researcher believes the knowledge gained from parents will have therapeutic value and debunk the mystery of ASD, reducing stigma and isolation.

Gray (2006) reports that ASD is believed to rank amongst the most stressful of childhood developmental disabilities. The combined problems of communication, emotional expression and antisocial behaviors place tremendous stress on the families of children with ASD, particularly the parents (Gray, 2006) . Other identified sources of stress are reported to include the lack of professionals specializing in therapy services; very costly specialized services; limited access to specialized help in low socio-economic environments; and small towns that lack access to resources (Dabrowska & Pisula, 2010). Furthermore, lack of public awareness around ASD; inappropriate labeling of children with ASD as disobedient or ignorant; lack of support during the diagnostic period, and lack of suitable schooling options (Glazzard & Overall, 2012) are stressors parents face. Even though the research initiatives and interest in ASD are growing internationally and locally; there remains a dearth of knowledge around the experiences and coping strategies of parents of children with ASD. Literature is focused on international studies specifically on prevalence, and research on parents' experiences usually addresses the experiences of mothers only. There is little research on parents' experiences and coping strategies from a South African perspective, hence this research will focus on this group.

Autism Spectrum Disorders (ASDs) are a group of pervasive neurodevelopmental disorders originally characterized in the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) by a triad of impairments in social interaction, communication and restricted, repetitive and stereotyped patterns of behavior, interests and activities (Neely, Amatea, Echevarria-Doan, & Tannen, 2012; Saddock & Saddock, 2007). The new DSM-V, published in May 2013, has collapsed the social interaction and communication components into one category, thereby creating a classification of ASD

with two sections rather than three (APA, 2013; Kaufmann, 2012). The nature and severity of these characteristics namely emotional, behavioural and communication problems, impact on the stress levels and burden of care on parents of children

with ASD (Lyons, Leon, Roecker Phelps, & Dunleavy, 2010). Given the stress that is experienced by parents and the entire family, it is pertinent to revise the prevalence of this condition in order to address the demands and burden of care.

The prevalence of ASD has increased over the last 20 to 30 years (Baird et al., 2006; Russell & Norwich, 2012) which may be attributed to an improved diagnostic process. The prevalence of ASD is unknown in South Africa. However Springer, von Toorn, Laughton and Kidd posit that given the US prevalence of ASD of 110 per 10 000 in 2007; South Africa has a potential prevalence of 270 000, people with ASD increasing by 5000 each year (Springer, van Toorn, Laughton, & Kidd, 2013). According to their research, Autism South Africa (ASA) indicates the prevalence of Autism in the country to be 1 in 150 live births (ASA, 2013). This significant number means an increase in the number of families and parents exposed to this burden of care. Caregiver burden is more onerous when the child has emotional, behavioural and communication problems (Dabrowska & Pisula, 2010), therefore intervention for these parents is needed to enable them to deal with the psychosocial sequelae of caring for a child with ASD.

The nature of ASD places a tremendous strain on parents. However, little research is available on the experiences and coping strategies of parents of children with ASD in the South African context. The aforementioned factors and the researcher's clinical experience of the tremendous caregiver stress and burden parents face, highlight the problem in this area. The research problem piqued the researcher's interest and warranted deeper investigation.

1.3 RESEARCH QUESTION:

The central research questions for this study were:

1. What are the lived experiences of parents of children with ASD?
2. What are the coping strategies of parents of children with ASD?

1.4 AIMS AND OBJECTIVES

The aim of the study was to gain deeper understanding into the lived experiences of parents with children who have Autism Spectrum Disorder (ASD) who attend a stimulation centre in KwaZulu-Natal (KZN), South Africa, and to explore the coping strategies they employ in caring for them.

Objectives of the study:

1. To understand the experiences of parents living with children who have ASD.
2. To explore the nature of the stressors experienced by parents of children with ASD.
3. To describe the positive and negative coping strategies of parents who have children with ASD.
4. To understand the positive meaning, if any, that may be gained from caring for a child with ASD.
5. To generate recommendations for intervention strategies that may be used by health care professionals to support parents with children who have ASD.

1.5 SIGNIFICANCE OF THE STUDY

This study will add new knowledge about the experiences and coping strategies of parents of children with ASD. This study will generate local knowledge on South African parents' experiences and coping strategies, as most research in this area is international. Important information to the body of work around ASD in general, and specifically in an African context will ensue from this work.

The sparse literature on the prevalence of ASD in developing countries shows lower rates of ASD as opposed to the United States (US), Canada and the United Kingdom (UK) possibly due to stigma, lack of awareness and poor medical infrastructure (Hughes, 2011). Research in Nigeria, the most populous country in Africa, revealed that there is a lack of knowledge and awareness about ASD in the community and among healthcare workers (Pietrangeli, 2011).

Beliefs ranged from describing ASD as a disease of affluence, affecting the educated or white people (Raudacille, 2011), to 40% of nurses in a study sample at 4 psychiatric institutions in Nigeria, attributing ASD to a supernatural or spiritual cause (Hughes, 2012). These beliefs further impact on reliable prevalence rates, as children are first referred to traditional healers, often leading to no diagnosis or misdiagnosis (Hughes, 2012), and a delay in diagnosis and accessing treatment.

The cultural misconceptions of ASD that exist in African culture in South Africa (Oliphant, 2013) further inhibit parents from seeking and obtaining the help they need for their children. This new knowledge will increase awareness around ASD, and direct health professionals to provide better services to these parents, in addition to establishing possibilities for new therapeutic interventions and further research. Gaining new insights will provide adaptive coping strategies for parents in similar circumstances, thereby reducing the effects of caregiver burden in parents of children with ASD.

Aside from the burden on parents, research shows that the entire family of a child with ASD is impacted by the condition. Deeper knowledge into the effects of the condition will highlight further areas of need, potential therapeutic interventions, and research opportunities.

1.6 STUDY OUTLINE

The background, problem statement, aims, objectives, research questions and the significance of the study have been outlined in chapter one. Chapter two will outline the literature relating to ASD in terms of definition, symptoms, aetiology and prevalence. Parental experiences, stress and coping processes in relation to ASD will be addressed. A model of coping will be introduced as a theoretical framework to understand coping in people so that it can be compared to parents of children with ASD. Chapter three presents the methods used including research design, sample population, data collection, data analysis, trustworthiness of the study and ethical considerations. Chapter four describes the findings of the study indicating the parents' experiences of raising a child with ASD, coping strategies and advice for other parents of children with ASD. Alongside the findings chapter four presents the discussion around the findings. Chapter five provides the conclusion and recommendations emanating from the discussion, and limitations of the study.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

The literature review for this study looked at the most recent, 5 to 10 years of research focused on experiences and coping strategies of parents of children with ASD. The review begins with a definition of ASD to assist the reader in conceptualizing the possible demands this condition can place on the parents. Parental stress was unpacked and a coping model was considered as a foundation for understanding the mechanisms parents may use to cope with having a child with ASD. Lastly recent research into parents' experiences and coping strategies used were investigated. International, African and South African research perspectives have been discussed.

2.2 DEFINING AUTISM SPECTRUM DISORDER

Autism Spectrum Disorders (ASDs) are a group of pervasive neurodevelopmental disorders that are characterized by developmental delays in social interactions, communication skills, behavioral challenges and impairments in imaginary and pretend play (Neely et al., 2012). The three types of disorders classified under ASD are Autistic Disorder, Asperger Syndrome, and Pervasive Developmental Disorder – not otherwise specified (CDC, 2013; Ramisch, 2012), with Childhood Disintegrative Disorder being included in the new Diagnostic and Statistical Manual-V(DSM-V) (APA, 2013).

The DSM-IV defined the condition as a triad of qualitative impairments in social interaction, communication and restricted, repetitive and stereotyped patterns of behavior, interests and activities (Neely et al., 2012). The new DSM-V has combined the social interaction and communication categories as they are closely related to each other, therefore ASD is characterized by deficits in social communication and interaction and restricted, repetitive behavior; interests and activities (APA, 2013; Baron-Cohen, 2013).

The following table represents the criteria for ASD as shown in the new DSM-5 (Kaufmann, 2012).

Table 2.1 :The Diagnostic Criteria for ASD according to the new DSM-V (Kaufmann, 2012)

Currently, or by history, must meet criteria A, B, C, and D
<p>A.</p> <p>Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:</p> <ol style="list-style-type: none"> 1. Deficits in social emotional reciprocity. 2. Deficits in nonverbal communicative behaviors used for social interaction. 3. Deficits in developing and maintaining relationships.
<p>B.</p> <p>Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:</p> <ol style="list-style-type: none"> 1. Stereotyped or repetitive speech, motor movements, or use of objects. 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change. 3. Highly restricted, fixated interests that are abnormal in intensity or focus. 4. Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of environment.
<p>C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities).</p>
<p>D. Symptoms together limit and impair everyday functioning.</p>

2.2.1 Symptoms of ASD

Children with ASD can present with a wide range of symptoms namely lack of emotional reciprocity towards others, including their parents (Cappe, Wolff, Bobet, & Adrien, 2011); anger and aggressive behaviors (Ho, Stephenson, & Carter, 2012); disturbed sleep; epileptic seizures and marked deficits in social relatedness (Lilley, 2011).

Symptoms of ASD can become apparent in children from as young as 1 year old (resulting in) children being routinely screened for ASD at 18 months (Glazzard & Overall, 2012). However another study suggests that ASD is usually recognized between 4 and 6 years of age and, in some cases, even later when the child is following a formal school curriculum (Dabrowska & Pisula, 2010).

As Autism Spectrum Disorder is a spectrum disorder, symptoms range from very mild to severe, with great variation of symptoms in individuals (CDC, 2013). While one child may present with no communication; another child may be verbal with remarkable intellectual abilities yet possess poor awareness of social cues. Another child may have co-morbid conditions such as attention deficit disorder or obsessive compulsive disorder (Cappe et al., 2011). As there is great variability in presentation of symptoms, it follows that there will be differences in handling and coping in parents of children who have ASD.

The types of symptoms common to ASD, cause a great deal of stress on parents of children with the condition (Cappe et al., 2011; Kheir et al., 2012; Ramisch, 2012). Further frustrations in the diagnostic process; uncertainty of aetiology; lack of consensus of preferred treatment and lack of resources, add to the stressors that parents of children with ASD experience (Lilley, 2011; Neely et al., 2012).

2.2.2 Aetiology

All the definitive causes of ASD are unknown, but those that are implicated may be categorized under two headings: idiopathic (primary) ASD or secondary ASD. The latter is a result of another medical condition such as Fragile-X syndrome or Rhetts Syndrome. Idiopathic ASD occurs when ASD symptoms are present with no evidence of other underlying medical conditions. Causes for idiopathic ASD include genetic, environmental, psychological and neurological factors (NHS, 2012). The unknowns around the condition of ASD would most likely lead to further confusion for parents of children with ASD, further propagating myths around the condition.

A number of myths have been refuted in literature. The myth that ASD is caused by vaccines has been retracted by the journal that first published this information (Harris, 2010). However, the researcher has found personal testimonies on-line of parents who had typically developing children that regressed after the Mumps, Measles and Rubella (MMR) vaccine (Obradovic, 2013). These stories paint a picture of a distinct difference in their children after the vaccine. Therefore these children may have been predisposed and genetically vulnerable to ASD, and the vaccine may have triggered the onset. Researchers refuting this concept state that there is no evidence that the contents of the vaccine can trigger such a response. However parents with firsthand experience of the effects of the MMR vaccine will not be convinced otherwise.

The notion that bad parenting or emotional distress experienced by the mother during pregnancy has been refuted as the definitive cause of ASD (Neely et al., 2012). A further misconception is that children will outgrow ASD and problematic behaviors. Despite literature indicating that behaviors seem to improve with age and over time (Ho et al., 2012), ASD is a life-long disorder with no cure (CDC, 2013; Neely et al., 2012), as succinctly encapsulated in the following quote, "A child with Autism will become an adult with Autism" (Neely et al., 2012 p 213).

2.2.3 Prevalence

In the United States of America (US) the prevalence for ASD in children was 110 per 10 000 in 2007 (Springer et al., 2013). Prevalence studies in Africa and South Africa are limited; therefore the actual prevalence is unknown. Despite this uncertainty in prevalence, Autism South Africa (ASA) estimated the prevalence of Autism in the country to be 1 in 150 live births (Atkins, 2011), and as posited by Springer et al the possible number of people with ASD in South Africa is 270 000 (Springer et al., 2013).

The prevalence of ASD in developing countries is unknown, and research initiatives have started with rigorous Autism screening projects underway in South Korea, Mexico, India and South Africa (Hughes, 2011). The average age when children are diagnosed

in Africa can be above the age of 8, given the poor infrastructure, limited medical personnel trained in Autism, low level of knowledge about the condition and challenges in help-seeking behaviours (Bakare & Munir, 2011). Further literature indicates that age of diagnosis can range from 3.8 years to 8.2 years depending on the severity of symptoms in the child (Maenner et al., 2013). A review of six studies undertaken between 1982 and 2010 in Nigeria, Tunisia, Kenya and Tanzania revealed that there were only a few dozen cases of ASD found at clinics in these countries (Hughes, 2012). As South Africa is a developing country, these findings can be generalized to the lower socioeconomic sectors of South Africa. It is assumed that parents with access to better medical facilities, education and greater socio economic resources will seek assistance should their child not meet their developmental milestones timeously.

However, research has shown that the age of diagnosis is dependent on the number of symptoms or criteria that are met when presenting to a doctor for an initial consultation, with severe cases of ASD resulting in earlier diagnosis (Health Health 2013). Parents lacking awareness of normal developmental milestones in lower socio-economic and under resourced areas of South Africa may seek help later than parents who are better educated in this regard. As a result of outreach initiatives in developing countries, sadly there are reports of adolescents being diagnosed with ASD for the first time (Hughes, 2011), having negotiated childhood without a diagnosis or appropriate intervention.

In May 2013, the National Department of Social Development in South Africa issued a media statement entitled "Help for children with Autism". The statement confirmed the lack of awareness and understanding about ASD in South Africa, with specific reference to the misconceptions from cultural beliefs, dismissing children with ASD as demon possessed or mentally ill (Oliphant, 2013). The Department of Social Development does not have a specific programme of intervention for ASD in South Africa, but has started an early development initiative that may assist in identifying children in need sooner (Oliphant, 2013). Parents of children with ASD should benefit from this initiative as well.

2.3 DEFINING PARENTAL STRESS AND STRAIN

In their seminal work on stress and coping, Lazarus and Folkman state that stress originates from the interactions between an individual and their environment (Folkman, 1984; Lazarus, 1980). According to their theory, if the individual experiences the stressor as superseding their resources, they employ coping mechanisms, which may be adaptive or maladaptive, to restore function. If the coping mechanisms are maladaptive, the resultant outcome is stress (Hayes & Watson, 2013).

Parental stress occurs when the functioning of a family cannot be restored after the introduction of a stressor (Hayes & Watson, 2013). Additionally, parenting stress is the affective response to the overwhelming demands of being a parent, which is the norm and should be expected from the parenting experience (Tajalli, Hooman, Afrooz, & Bonab, 2011). However, parenting stress becomes problematic when it is elevated to the extent that it negatively impacts on parenting practices and the parent-child relationship (Morgan, Robinson, & Aldridge, 2002). Parents consequentially experiencing high levels of stress may be less likely to implement interventions to help their children (Tajalli et al., 2011), which may unduly disadvantage children with disabilities.

Parenting stress is more pronounced and evident in parents of children with disabilities and special needs; and is referred to as caregiver strain (Kenny & McGilloway, 2007). Specific to this study, parents of children with ASD experience high levels of stress and depression (Estes et al., 2009; Hayes & Watson, 2013). Typically they experience concerns about their child's future (Ogston, Mackintosh, & Myers, 2011), restricted access to services (Redmond & Richardson, 2003) and a lack of formal and informal support (Egan & Walsh, 2001). Other stressors include family conflict around issues of the child's impairment, financial strain and constricted social and recreational life (Pearlin et al., 1990, in Kenny & McGilloway, 2007).

In a study of 109 parents in Australia, parents were asked to complete self-report questionnaires to ascertain their predictors of stress.

The results showed that behavioural problems and emotional impairments exacerbate parental stress, causing anxiety and depression (Firth & Dryer, 2013). Furthermore, behavior problems in a child with disabilities has also been identified to cause stress in primary care givers, resulting in depression in the parents; social isolation; restrictions in their parenting role; and decreased feelings of competence in their ability to deal with their children (Gupta, 2007).

In summary coping is very much an individual experience which is further described according to the Lazarus and Folkman Transactional Model of Stress and Coping.

2.4 THEORETICAL FRAMEWORK FOR COPING

Stress is defined by Lazarus and Folkman as the relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources of coping, thereby threatening his or her wellbeing (Lazarus & Folkman, 1984). The person evaluates the stressor in this relationship by determining the relevance and significance of the stressor with resulting impact on personal goals (Ntoumanis, Edmunds, & Duda, 2009). This initial evaluation is called primary appraisal (Lazarus & Folkman, 1984), and can take one of four forms, namely harm or loss appraisal; threat appraisal; challenge appraisal or the stressor will be perceived as benign.

A stressor is appraised as harm or loss when injury or damage has been inflicted; as a threat if there is potential or impending harm, as a challenge if the opportunity for personal growth and mastery has been identified, and benign if the stressor has no significant impact on personal goals (Folkman, 1984; Jones, Rowe, & Becker, 2009; Ntoumanis et al., 2009). The appraisals are not independent of each other, and may

occur simultaneously with beliefs of control, goal commitment and the novelty of the stressor being determinants and mediating these appraisals (Folkman, 1984).

Folkman further describes that the secondary appraisal process is reliant on a situational appraisal of control, where the person appraises the stressor according to their ability to control the stressor, resources at their disposal and options available to them (Ntoumanis et al., 2009).

The Lazarus and Folkman's Transactional Model of Coping (Lazarus & Folkman, 1984) may be used to further explain the process of coping used by parents of children with ASD. The model is deemed to provide a good theoretical framework for understanding stress and coping in parents in this study. Firstly it allows for different mechanisms of coping to be investigated through the use of the concepts of appraisal and re-appraisal. Secondly the model explains two types of coping, namely emotion-focused and problem-focused strategies, which will be of interest to the study in ascertaining when and why parents of children with ASD may use these types of coping strategies, and thirdly research suggests that parents also experience positive aspects (Cappe et al., 2011) in caring for a child with special needs, and the model will allow the researcher to investigate these positive outcomes.

Despite Lazarus and Folkman describing this model as dynamic, it appears to be limited in allowing for personality traits, motivation and resilience of parents to be addressed. The effects of gender and culture on coping behaviour are not expounded in the model. These areas, and other limitations arising, will be addressed by obtaining theoretical frameworks that speak to these limitations. Where necessary relevant frameworks will be used to further discuss and interpret the participants' coping strategies.

2.5 PARENTS' EXPERIENCES OF RAISING A CHILD WITH ASD

As discussed previously each child with ASD presents with a unique set of symptoms. Likewise the parents of children with ASD have different experiences which are unique to their family and context (Weiss, 2002). There is a distinct change in lifestyle with parents of children with ASD who often reminisce about their losses (Ramisch, 2012) .

High levels of stress in mothers of children with ASD has been well documented (Boyd, 2002) with gendered experiences being highlighted in the literature (Ludlow, Skelly, & Rohleder, 2012). Experiences of parents of children with ASD include isolation, depression, fatigue, lowered self-esteem, interpersonal conflict and stress (Boyd, 2002; Ramisch, 2012; Weiss, 2002). Specific time demands are expressed around finding child minders and other forms of respite care (Boyd, 2002), and the demands of work commitments and needing flexibility at work to cater for their child's needs (Matthews, Booth, Taylor, & Martin, 2011). Difficulties in accessing health care facilities was raised in the literature (Ramisch, 2012), as were the difficulties in the diagnostic process (Braiden, Bothwell, & Duffy, 2010; Russell, Steer, & Golding, 2011; Saint-Georges et al., 2011).

The mental health of parents is impacted by the specific characteristics of the child with ASD (Boyd, 2002; Firth & Dryer, 2013), further compounding their stress. These characteristics include the child's temperament as well as their behavioural and cognitive abilities. Behavioural problems displayed by children with ASD are associated with increased parental stress more than any other characteristic (Lecavalier, Leone, & Wiltz, 2006). Parents experience difficulties in managing behaviors which impacts on social gatherings (Firth & Dryer, 2013). These behavioural problems dominate the family life of parents of children with ASD, and restrict social and recreational activities (Neely et al., 2012).

Furthermore parents worry about their children's acceptance in society, their poor social relatedness and about society's lack of understanding of ASD (Davis & Carter, 2008;

Ramisch, 2012; Weiss, 2002). Parents' perceptions of public places relate consistently to themes of stigma (Ryan, 2010).

Due to the extremely disruptive antisocial behaviour, and lack of public knowledge about ASD, despite the child's normal appearance, there is a high probability that parents will be stigmatized if they have a child with ASD (Gray, 2002).

The theoretical constructs to understand stigma were developed by Goffman in the early 1960's (Gray, 1993). Although his seminal work stands, there is new research to further elaborate, and in places refute his work (Farrugia, 2009). However for the purpose of this study Goffman's construct on courtesy stigma will be explained.

Courtesy stigma is a stigma of affiliation. It is not as a result of any characteristic about the person but by their mere association with a group or specific person they are stigmatized (Gray, 2002). Goffman posits that courtesy stigma could be temporal depending on the person's location, for example if the parent was shopping without their Autistic child, they could be free from this label. Gray disputes this notion that a parent of an Autistic child could disown this stigma and rather proposes two types of stigma experienced by parents (Gray, 1993).

Enacted stigma is the stigma that is real. For example the parent of an Autistic child is confronted about their child's bad behaviour in public. Felt stigma is the fear of rejection or feelings of shame that the parents perceive, without any outward action to confirm their feelings (Gray, 2002). In a study of 53 parents of high functioning Autistic children, Gray used interviews to determine the frequency that parents experienced these two types of stigma (Gray, 2002).

Parents expressed that they experienced *felt* stigma more as opposed to *enacted* stigma. This was mostly due to the fact that the parents felt others were critical of their child rearing skills which resulted in embarrassment (Gray, 2002). Felt stigma was

experienced mostly in public places. Half of the parents had experienced enacted stigma where they received negative feedback from people. These situations resulted in avoidance of or staring back the parent and child. Rude comments were more difficult for parents to ignore, which they tried to diffuse by providing information about their child's condition. The felt and enacted types of stigma place extreme stress on the parents who already face daily struggles in raising their children.

Research indicates that the parental experiences of ASD are more difficult than parental experiences of other disabilities (Altiere & von Kluge, 2009; Matthews et al., 2011; Neely et al., 2012). These difficulties are experienced due to the complex demands that behavioural and emotional problems place on the parents of children with ASD, resulting in frustration, embarrassment and distress at home and within the community (Firth & Dryer, 2013). The social impairments of the children such as lack of emotional reciprocity, lack of empathy, poor eye contact and communication difficulties, further impact on the reward the parents may experience from parenting a child with ASD (Firth & Dryer, 2013; Papageorgiou & Kalyva, 2010).

2.5.1 Parents' Experiences and Perceptions about the Diagnostic Process

It has been established by research that there are significant difficulties experienced by parents of children with ASD in relation to diagnosis of the condition. The diagnostic process is a catalyst for high levels of stress in parents of children with ASD (Howlin & Moore, 1997). The diagnostic "rubric" has been described as imprecise (Grinker, 2007) with a diversity of presenting symptoms among children (Williams, MacDermott, Ridley, Glasson, & Wray, 2008).

Co-morbidities such as attention deficit disorder, epilepsy and obsessive compulsive disorder complicate the diagnostic process as clinical presentation is affected (Malcolm-Smith, Hoogenhout, Ing, Thomas, & de Vries, 2013). Clinicians are reluctant to provide a formal diagnosis before the child is three years old, as diagnostic tests do not provide definitive answers, and the diagnostic criteria are more stable as the child becomes

older (Braiden et al., 2010; Lilley, 2011). The instability in the diagnostic process results in delays and re-evaluations of the diagnosis, with a subsequent emotional reaction from parents including anger, confusion and doubt (Lilley, 2011). Consequently parents of children with ASD seek out second opinions and rely on internet research in search of definitive answers (Lilley, 2011).

Many parents of children with ASD express a concern with their child's development from 18 months of age, and some know intuitively that something is different with their child from birth (Braiden et al., 2010; Saint-Georges et al., 2011). On initial consultation with health care professionals, parents experience difficulties in articulating their concerns and doubt themselves, while professionals minimize parents' concerns blaming the symptoms on lack of maturity (Braiden et al., 2010; Ryan & Salisbury, 2012). This process results in frustration towards the professionals, and parents feel isolated, humiliated and angry (Ryan & Salisbury, 2012).

Recently media coverage on ASD has provided people with more information about the condition. Family and friends can confirm the uncertainties parents experience in relation to their child's development (Lilley, 2011). This support from family and confirmation from pre-school teachers working closely with the children, allows the parents of children with ASD to persevere towards a diagnosis (Braiden et al., 2010).

As indicated above, the relationship between the parents of children with ASD and health care professionals is crucial. The manner in which the parents are treated on initial consultation, and subsequent confirmation of the diagnosis by professionals impacts on the parents' emotional experience and confidence in the professionals (Braiden et al., 2010; Ryan & Salisbury, 2012).

2.5.2 Parenting the Neuro-typical Siblings of Children with ASD

Siblings of children with disabilities adjust to their stressors in diverse ways (Giallo & Gavidia-Payne, 2006). The majority of siblings adjust well, with a small number at risk of developing adjustment difficulties (Rossiter & Sharpe, 2001). Poor parental functioning (Amato & Fowler, 2002; Fisman, Wolf, Ellison, & Freeman, 2000), family conflict (Mandleco, Olsen, Dyches, & Marshall, 2003), poor problem solving and communication difficulties (Van Riper, 2000) are some factors that impact on the siblings' ability to adjust. Parents of children with ASD worry about their non-Autistic children as well (Services, 2004).

Characteristics that aid adjustment in siblings include family hardiness, family time, routines (Giallo & Gavidia-Payne, 2006), closeness to each other, confidence and optimism about their ability to cope (Mackay, 2003; Walsh, 2003). These characteristics allow families, including siblings, to implement effective coping strategies (Mackay, 2003; Walsh, 2003).

Research confirms that siblings internalize problematic behaviors (Rossiter & Sharpe, 2001). As children with ASD often present with behavior problems, their siblings are at risk of taking these behaviors personally resulting in a psychological affect such as depression or anger. These difficulties the non-Autistic children face contribute to their parents' stress and concern.

2.5.3 Impact of having a child with ASD on the Marriage

There is a perception that marriages in families with a child with ASD are at risk of divorce, with some statistics quoting an 80% probability of this (Abbott, 2013). However, research has refuted this as there is no empirical evidence that supports this claim of a higher risk of divorce, compared to a family with typically developing children (Abbott, 2013). Despite this, research acknowledges the high levels of stress placed on a marriage by children with ASD (Abbott, 2013; Johnson, 2012). The diagnostic

process places stress on the marriage, as parents experience grief and guilt, facing a drastic change to the lifestyle they know and anticipated for their future (Abbott, 2013).

2.6 COPING RESPONSES TO HAVING A CHILD WITH ASD

Caregiver strain can culminate in positive or negative consequences, depending on the primary caregivers' appraisal of the situation, their response to stress and the meaning they give to their child's disability that manifests in either maladaptive or healthy coping strategies and behaviours (Tajalli et al., 2011).

Maladaptive behaviours or emotion-focused coping strategies focus on the problems and the child's limitations, with parents viewing the seeking of social support as a weakness, and blame others for the child's disability (Tajalli et al., 2011). Adaptive or problem-focused forms of coping could include seeking social support such as family support; or developing relationships with health professionals, schools and other parents in similar situations (Kerr and McIntosh, 2000; Pritzlaff, 2001, in P. Tajalli, Hooman Ali, Afrooz Ali, & Bonab Ghobari, 2011). Use of these adaptive behaviours arguably reduces the level of stress experienced by primary caregivers of these children.

Parents of children with ASD experience high levels of stress with poor emotional functioning and well-being (Samadi, McConkey, & Kelly, 2013). These parents tend to rely on emotion-focused coping strategies rather than problem-focused coping strategies (Samadi et al., 2013). In a study on quality of life in parents of children with ASD, Cappe et al showed that parents found emotion-focused coping strategies as a less effective means to coping (Cappe et al., 2011). Emotion-focused or avoidance strategies such as denial, withdrawal, fantasy and self-blame resulted in higher levels of stress and poor mental health in parents of children with ASD (Cappe et al., 2011).

Research in this regard also revealed a small study undertaken in the Western Cape among 34 families with Autistic children who attended a special needs school. This

study demonstrated the following resilience factors in families of Autistic children, which enabled the parents to cope better with their children. These factors were identified as higher socio-economic status, social support, open and predictable patterns of communication, a supportive environment, family hardiness, a positive outlook on life and family belief systems (Greeff & van der Walt, 2010).

Social support, internal locus of control, hardiness and optimism contribute to positive coping outcomes, with these parents expressing the psychological benefits from raising a child with ASD (Cappe et al., 2011).

The following strategies implemented by parents of children with ASD that have a positive impact included managing and treating the condition, advocating for Autism, planning for their child's future, accepting reality, being hopeful and relying on a sense of humor (Hall & Graff, 2010).

Autism Spectrum Disorder is a devastating condition that renders the parents helpless and hopeless as they face the daily challenges of the condition. They are exposed to stigma from society as awareness around the condition is limited. The intense symptoms of their children such as behaviour problems, poor social awareness and emotional detachment impact on the parent's emotions and ultimately affect their physical and mental health.

To cope with these stressors parents find adaptive and maladaptive ways to cope. Problem focused coping is more effective than emotion focused coping. Other promotive factors towards coping are higher socio-economic status, social support, open communication in families, a supportive environment, and a positive outlook on life.

The experiences and coping strategies of a small group of parents of children with ASD were investigated in this study. A phenomenological research design and interviews as

a data collection tool were chosen to gain in-depth insight into parents' lived experiences and coping strategies. The methodology used to accomplish this is discussed in further detail in the next chapter.

CHAPTER THREE

METHODOLOGY

3.1 INTRODUCTION

A qualitative method of inquiry was used in this research as this was deemed the best way to answer the research question given that it was investigating the lived experiences of parents. Data was collected in semi-structured interviews. The participants were parents recruited at a stimulation centre in Kwa-Zulu Natal (KZN) that caters for children with Autism Spectrum Disorder (ASD) and other disabilities. A pilot study in the form of a triad interview was undertaken to test the interview questions. After data collection was completed, the data was analyzed using thematic analysis.

3.2 RESEARCH DESIGN:

An **interpretive paradigm** was used, which is based on the premise that people make choices and decisions according to their personal understanding of situations (Carballo, 2003). This was deemed particularly relevant in understanding how parents make sense of their experiences with a child with ASD, and coping mechanisms they employ to cope with the situation.

The interpretive paradigm uses **social constructionism** as a mechanism to understand that reality is socially created (Carpenter & Suto, 2008). This construct is based on the premise that our world is socially constructed in a certain way at a particular time in history and that another group of people or society may construct a different reality. The relevance of this paradigm was that under similar circumstances parents of children with ASD will construct different coping strategies and create a different reality and meaning to living with a child with ASD. The paradigm allowed participants to interpret their own thoughts and behaviors, thereby making sense of their lived experiences. The interpretive paradigm was used in analysis of the data as participants' experiences and perspectives were interpreted through inductive reasoning.

Inductive reasoning emerges directly from the data, and is influenced by the unique characteristics of the child, parent, their culture and context. The researcher also brings her own meaning and is not separate from the process.

Inductive reasoning was used to draw attention to knowledge, new and old, in order to develop theories and create concepts (Carpenter & Suto, 2008). As multiple realities are understood and explored through inductive reasoning, parents' experiences will be different as they socially construct different interpretations of their lives and experiences. This new knowledge about parents' experiences, and the ways they cope can add to new theories and concepts that may contribute to health care professionals providing better service delivery to this population and providing insight for new parents of children with ASD.

Furthermore, deductive reasoning is used to compare the parents' coping to a particular coping model as a frame of reference to determine if these parents coped in this way, or an alternative way.

As the researcher wanted to gain an in-depth view of the participants' lived experiences a **phenomenological approach** was used in this study. A phenomenological study allows the researcher to learn more about peoples' viewpoints, opinions and understanding of a particular situation (Leedy & Ormrod, 2005). Phenomenology aims to describe what the phenomenon is according to the meanings that individuals apply to it (Willig, 2001); which is closely linked to the social construction of knowledge. In terms of the present study, the phenomenological approach was concerned with understanding the experiences and coping processes of parents caring for a child who has ASD.

To gain further insight, the process of phenomenological reduction was used, which describes the *how* and *why* meanings arise in data. In conjunction with reduction, the researcher employed *bracketing* (Carpenter & Suto, 2008) where all judgments and preconceived ideas were set aside in order to see the parents' view point, and describe the findings in a non-judgmental manner.

3.3 PILOT STUDY

A Pilot triad group was conducted with 3 parents from the centre who were not included in the study. The participants were employees at the centre, and mothers of children with special needs, including ASD. Their insight was deemed useful as they had personal and professional experience with children with ASD and their parents.

The participants were requested to provide feedback regarding the manner in which the group was conducted, for example, the ability of the group facilitator to reorient herself to newly emerging facets of a particular theme, to redirect and re-conceptualize issues based on the responses to questions asked, and to promote an interactive environment in the group. The degree to which she showed bias or restricted the course of the discussion was also evaluated. The spontaneous and thought provoking discussion that ensued at the pilot study indicated that the data collection method was valid and reliable to gain rich, in-depth data. Specific aspects such as redundant questions and repetition of information were noted and appropriate amendments were made.

3.4 SAMPLING

The study site, sampling strategy, inclusion and exclusion criteria, and sample size will be discussed.

3.4.1 Study Site:

The stimulation centre was approached as a possible venue to conduct research. The centre was chosen as it serviced more children with ASD than any other disability; thereby increasing the probability of gaining access to parents of children with ASD.

The centre provides an opportunity for family members to enjoy respite by leaving their children with ASD there for the day. Children can attend on a daily basis, which is most common, or for a few days a week. The programme comprises of general stimulation and a basic curriculum that covers basic concepts and life skills. The centre charges fees for running costs. However, families who cannot afford the fees are sponsored or allowed to pay what they can afford.

3.4.1.1 Staffing

The centre has 20 staff members. A physiotherapist and speech therapist consults weekly at the centre. A physiotherapy assistant works with the children on a daily basis. The researcher provides occupational therapy services for the children once a week at the centre. The centre is multicultural and multiracial, servicing five Black children; eight Coloured children; 14 White children and 14 Indian children currently in November 2013.

The largest group of children catered for at the centre are those with ASD. The most general enquiries for admissions tend to be for children with ASD. This further highlights the need for intervention and support for these children and their families. More specifically, understanding the experiences and coping strategies of caregivers

will be beneficial for health care professionals and staff at the centre, enabling current intervention strategies to be reviewed.

3.4.2 Sampling Strategy:

A purposive sampling method was used as participants were selected according to specific criteria from a stimulation centre in KwaZulu-Natal, South Africa (Acharya, Prakash, Saxena, & Nigam, 2013).

The anticipated potential sample size for the study was 27 (n=27) before the participants were recruited. The following is an outline of the recruitment procedure:

- Ethical clearance was obtained on 18th December 2012 (Ethical Clearance number: HSS/1189/012M) (See Certificate in Appendix 1).
- Thereafter a permission letter was sent to the Board of Members at the stimulation centre in order to obtain gatekeeper permission (see Appendix 2). The letter requested permission to implement the research project at the centre, to contact the parents of children with ASD at the centre and to use the centre's facilities to run the focus groups and interviews.
- Once the permission was granted in writing (see Appendix 3), the parents of children with ASD received letters inviting them to participate in the study (see Appendix 4).
- The initial response from parents of children with ASD was poor, with parents not responding to the invitation and one parent declining to participate.
- A poster calling for participants was placed up at the centre, and email invitations, with an attached informed consent and consent form (see Appendix 5), were sent to each participant.

This method of recruitment was more effective, and the process continued with numerous phone calls to set up focus groups and interviews that accommodated all the participants. Difficulties in recruiting participants for focus groups were encountered, and will be discussed further.

There were three participants who were unreachable telephonically or via email. One participant was interested in participating in the study, but unavailable due to work commitments. Another participant committed to participate in a focus group but did not arrive on the day of the focus group. Five participants were not interested in participating. Five male participants were “excused” by their wives as they expressed that their spouses would not be agreeable to participate, or were busy with work commitments.

The final sample size was 11 (n=11), which means that 40.7% of the anticipated potential sample size was recruited successfully.

Data collection was completed with all participants. Saturation was achieved by the third interview, as parents were sharing the same experiences, and similar themes were elicited through the data collection phases.

3.4.3 Sample Inclusion and Exclusion Criteria

There were inclusion and exclusion criteria stipulated for participation.

Inclusion criteria:

- The participants had to be the biological parents, including mothers and fathers, of the children with ASD.
- The children’s ages were not a determinant for participation; however parents were placed into specific groups according to their children’s ages namely: 6- 12 years old; 13-17 years old and 18-26 years old.
- Participants’ children had to be learners at the stimulation centre.

Exclusion criteria:

- Employees of the centre who had children with ASD attending the centre were not eligible to participate.

- Biological parents of children at the centre who had other disabilities apart from ASD were not eligible to participate.

3.4.4 Sample Size:

Once the inclusion and exclusion criteria had been applied the sample size was 11 (n=11), of which the sample included 8 women and 3 men.

3.5 DATA COLLECTION

The data collection method initially considered was a combination of focus groups and interviews to elicit maximum participation. A focus group is a discussion which takes place in a group setting of 4-10 individuals with data collection being undertaken on a topic that is common to the group, offering various perspectives as participants share their experiences, views and ideas on the topic (Wilkinson, 2000). An interview is a verbal discourse taking place between the researcher and the participant, where the emphasis is on listening and following direction from the participant (Fielding, 2003; Law et al., 1998).

The participants for the focus groups were recruited according to homogeneity for gender of the parents and the age groups of the children. This was deemed necessary as each age group of children with ASD has their own characteristics and particular set of difficulties. This categorization allowed the researcher to analyze different coping processes across the different stages of development, and to determine the meaning behind these differences, and if they made an impact on the parents' experiences.

- The youngest group (6-12 years) included nine children with ASD who may have been recently diagnosed, or had behavioral difficulties. These behaviors were probably not yet managed optimally through medication or behavior modification techniques.

- The adolescent age group (13-17 years) may have presented with hormonal imbalances, although behavioral difficulties have generally stabilized by this stage.

The second characteristic of the focus groups was *homogeneity for gender*. This was done as research has shown that men and women experience stress differently and their coping processes are also different (Dabrowksa & Pisula, 2010).

The option of joining a semi-structured 90-minute focus group or a semi-structured individual interview was offered to participants to increase the response rate. The focus group method of data collection was deemed as the most suitable method for this study as it provides a wide range of perspectives on the same subject. As this was a phenomenological study the phenomenon of caring for and coping with a child with ASD would be investigated. By collecting data using focus groups many perspectives could be obtained, maximizing the amount of data collected.

Despite intending to use focus groups as the primary data collection tool, the researcher was unable to recruit enough participants to form a focus group. Interviews were scheduled according to the availability of participants. Two mothers' groups were arranged with 3 in each group, however in the second group the one mother did not arrive and the researcher proceeded with this dyad. Two parents were interviewed individually, and 2 couples indicated that it would suit them better to meet for a couple's interview.

Tabulated overleaf is the final sample that participated in the data collection process, indicating the data collection methods used and relevant biographical data.

Table 3.1: Participants' biographical details and data collection methods

No. of P	Data Collection Method	Gender of P	Race of P	Age of P (in yrs)	Age of P's child with ASD (in yrs)	Gender of child with ASD	Marital status	Work	Other children	Ages and genders of other children
3	Triad interview	F	2 x I 1 x W	1 x 30 1 x UD 1 x UD	3 x 8	2 x M 1 x F	2 x Ma 1 x D	2 x E 1 x SAHM	Y	F 0.6 F 4 F 11 M 10
2	Dyad interview	F	2 x I	1 x 45 1 x UD		2 x M	2 x Ma		Y	F 22 M 21 M 10
2	Dyad interview (c)	M & F	2 x C	M: UD F: UD		1 x M	Ma	2 x E	Y	F 12
2	Dyad interview (c)	M & F	2 x C	M: 49 F: 46	1 x 22 1 x 19	2 x M	Ma	2 x E	N	none
1	One-on-one interview	M	1 x W	47	1 x 8	1 X F	D	1 x SE	Y	F 11
1	One-on-one interview	F	1 x B	42	1 x	1 x F	Ma	1 x E	Y	F 6

Key: P = Participant

F= Female;

M= Male

E= Employed

SE= Self-Employed SAHM= stay at home mom

MS= Marital Status

Ma= Married

D= Divorced

I= Indian C= Colour W= White B=Black

UD=undisclosed

(c) = married couple

A co-facilitator was present for the triad interview and first dyad interview in order to take field notes. These notes included group dynamics, themes the fieldworker noticed emerging, and observations regarding the participants' non-verbal behaviors. The interviews were consistent in providing rich data and the 11 participants added their own perspectives on the topic, thereby providing multiple diverse perspectives.

3.5.1 Dyad and Triad Interviews:

A dyad is a social group that consists of two members and a triad has three members. Dyads and triads form the basic foundation for sociological analysis (Miller, 2007), as most social processes can be found in these interactions which form the basis for social interactions and relationships (Miller, 2007). Triads (3-on-1's) or dyads (2-on-1's) are also called mini groups. These mini groups allowed for greater flexibility and deeper psychological and emotional probing into the experiences of participants (Clarion, 2012). In this study both the triad and dyad interviews provided rich data and participants found the process of sharing their narratives non-threatening.

3.6 DATA COLLECTION TOOL

An Interview Schedule was used as the instrument to collect data (see Appendix 6). The questions for the interviews were formulated after reading the literature on ASD. As the interviews were semi-structured, the researcher added questions that were necessary for clarification of information, eliciting richer data. The researcher took guidance from the participants during the interviews and mini group discussions. Employing this tactic helped the groups and individuals speak freely and comfortably without constraining data collection.

3.6.1 Trustworthiness

To increase trustworthiness, Guba has developed constructs to address the four criteria of credibility, transferability, dependability and confirmability within qualitative research (Guba, 1981).

These constructs, as defined by Guba, will be discussed further in relation to this project.

3.6.1.1 Internal Validity

Internal validity or credibility is concerned with *did I accurately record the phenomena under investigation?*. Internal validity was achieved in the study by:

- **Adopting well established methods of data collection.** The interview is the most common method used for data collection in qualitative research (Gill, Stewart, Treasure, & Chadwick, 2008), hence its credibility has been scrutinized and was therefore the method of data collection in this study. To ensure reliability in the interviews, the questions were appraised by an independent academic and clinician who were identified as experts within the fields of research methodology and Autism. The questions were reviewed by an Occupational Therapist working in the field of Autism, who is undertaking Master's research in Autism, and by a Paediatric Occupational Therapist who was an expert in this area.
- **Developing an early familiarity with the organization where the research will be conducted.** This was achieved as the researcher is employed on a part time basis at the facility where the research was conducted. The researcher had an established relationship with the organization before the project had commenced.
- **Employing tactics to help ensure honesty in informants.** This was achieved in the study by allowing voluntary participation where participants were free to leave the research project at any time. This ensured that participants were willing to participate and share freely.

- **Allowing for iterative questioning.** To confirm the honesty and obtain the correct information from participants, the researcher used probing and clarifying questions within the interviews.
- **Engaging frequent debriefing sessions.** The researcher discussed and unpacked ideas with her supervisor and within a master's cohort program to ensure her methods and procedures were valid and reliable.
- **Allowing peer scrutiny of the research project.** This was facilitated by formal and informal discussions with peers about methodology and emergent themes.
- **Keeping a “reflective commentary”.** The researcher has kept notes on a continual basis and reflected on the research question to ensure that it was being answered correctly and without bias.
- **Making use of member checks.** Participants were given the opportunity to comment on the final emerging themes. They were emailed and asked for their comments; however no-one commented specifically on the themes indicating that they were most likely in agreement with them.
- **Providing thick description of the phenomena.** This allows the reader to experience the actual commentary from participants. Quotes from participants were used to support statements made by the researcher.

3.6.1.2. Transferability

In this study the reader has been provided with thick descriptions, thus allowing the reader the opportunity to place the data in context and further decide on the transferability of the information to other contexts (Houghton, Casey, Shaw, & Murphy, 2013).

3.6.1.3 Dependability and reliability

Dependability or reliability is that characteristic in research that allows the study to be replicated in another context with the same results as outcomes from the research (Shento, 2004).

By providing detailed information on the context and participants, the methods in this study could be replicated at another centre in another part of the country.

3.6.1.4 Confirmability

Confirmability is the researcher's ability to remain objective and represent the facts as communicated by the participants. As this project started as a reflective journey for the researcher, her subjective voice may at times be heard in the form of reflections. However her objectivity was ensured in presenting the data accurately by keeping an audit trail of decisions made throughout the research process, keeping a reflective journal and meeting frequently with her supervisor to unpack her emotional response to the participants' stories in order to reduce bias. As discussed under the researcher's role and reflectivity the concept of bracketing was used to reduce the risk of bias.

3.7 Data Analysis

The triad, dyad and individual interviews were audiotaped. These recordings were transcribed verbatim prior to analysis. All names that appear in the text are pseudonyms in order to maintain the anonymity of the participants. Inductive reasoning was used to sort and categorize the data until a small set of abstract, underlying themes emerged (Leedy & Ormrod, 2010).

The researcher used thematic analysis to analyze the data and interpret the results by following Braun and Clarke's recommended steps for conducting thematic analysis (Braun & Clarke, 2006).

The following steps were followed during the thematic analysis:

1. The data was transcribed after the interviews. The researcher became familiar with data by reading and re-reading the data. The reading was done in conjunction with listening to the audio tapes to ensure consistency in the transcriptions.

2. While reading, the researcher noted initial themes. The highlighted themes were generated into initial codes by coding the frequency and interesting features of the data and collecting it in a systematic fashion. This was achieved by using tables and thematic maps.
3. Themes were collated into the codes, and data relevant to the themes were gathered in the form of quotes made by the participants.
4. The information was divided into units of meaning (Leedy & Ormrod, 2005). A thematic map of the themes was created by grouping units of meaning into categories.
5. The themes were compared across the triad, dyad and individual interviews to determine the frequency of themes and their hierarchy.
6. Themes were defined and named, according to main themes and sub themes.
7. Divergent perspectives and themes were identified and noted if they were relevant to the study.

3.8 ETHICAL CONSIDERATIONS:

3.8.1 Vulnerability:

The participants can be considered as a vulnerable population as parents of children with special needs. The probability and magnitude of harm was anticipated to be minimal in the research.

The participants' inclusion in the research was voluntary and they were allowed to leave the research at any time. The natural benefit of sharing with one's peers brought catharsis for some participants, and an atmosphere of camaraderie was cultivated in the mini groups. The couple's interviews allowed for more in-depth sharing, and at times the participants became tearful. The researcher acknowledged the participants' emotions and checked that they were willing to continue. At the onset participants were warned that they may feel vulnerable at stages of the interview process. They were

reassured that should they have felt the need to talk further, the researcher would consult with them privately to determine whether further counselling was necessary.

The researcher had a list of potential, local counsellors and their contact details that she could access if the need arose. However, each interview ended on a positive and uplifting note without the need for further support or psychological intervention.

3.8.2 Informed consent: (see Appendix 4)

Informed consent was done by giving the participants sufficient information about the purpose and nature of the study, so that they could make an informed decision as to whether they would like to participate in the study. An invitation and informed consent was sent out to all potential participants explaining the research project in detail. The participants were encouraged to ask the researcher questions to clarify any doubts they may have had about risks or benefits that may arise from the study.

As there were potential participants who were Zulu-speaking, the informed consent was made available for these participants in isiZulu (see Appendix 6). The informed consent was translated into isiZulu and back translated into English. Amendments were made to the isiZulu translated version of the informed consent to ensure consistency between the two versions. The participants who were isiZulu-speakers chose to read and sign the English version of the informed consent at the interview as their English comprehension was of a good standard.

The participants gave written consent by completing the informed consent form at the interview. All participants were literate, and able to read and understand the informed consent document. To further ensure clarity the informed consent was explained verbally to all participants before they agreed to participate and all queries were addressed at the time.

3.8.3 Privacy of participants:

The participants were reassured in the interview that all information shared was confidential. This confidentiality was ensured in the form of anonymity, where each participant was assigned a number during the interview process. Pseudonyms were used in the transcribed text rather than numbers to maintain an element of personalization of the participants' stories.

The importance of maintaining confidentiality within the group sessions between participants was explained in the session. The interviews were conducted behind a closed door and the participants' privacy was respected at all times.

3.8.4 Non- Maleficience:

The principle of "first do no harm" was adhered to. Despite the participants being adults and able to manage their own feelings, no participant was asked to share on a certain topic if they felt uncomfortable to do so. In fact, positive effects, rather than adverse effects were anticipated to emanate from the research.

3.8.5 Storage of data:

To maintain anonymity and confidentiality data was stored on password encrypted files. This has been done to ensure that the data would not be tampered with. Data will be kept for a period of 5 years and thereafter destroyed, in keeping with the Data Protection Act of South Africa ("South African Law Reform Commission," 2009)

3.8.6 Researcher bias and power:

Even though the researcher was employed at the centre on a part time basis, it must be noted that the researcher had little or no contact with the participants in this study. The researcher had not been involved in counseling of the participants, and they were not subjected to covert coercion from her to participate in the study.

3.8.7 Reciprocity:

The researcher was of the opinion that the research experience would be a beneficial one for the participants, as sharing common experiences would increase camaraderie and universality i.e. “I am not alone” and a sense of well-being (Yalom & Leszcz, 2008). The interview would provide the same benefit as the participants had the opportunity to share on a one-to-one basis.

Despite the participants’ sacrificing their time to participate in the study, they benefitted from the process as well. The group dynamics, the ease with which the participants shared, and the energized atmosphere after the interviews were testament to the benefits that the participants gained from the experience.

3.8.8 Dissemination of findings

The participants received the themes that were extracted from the interviews for them to comment on and verify the findings. A journal article on the research will be published in a peer reviewed journal, and be given to each participant. In addition the findings will be shared with parents, clinicians and academics working in the field. This will be done in the form of an educational talk at the centre or at a local support group meeting to be convened. The general public will be invited to this talk to disseminate the findings as widely as possible.

3.8.9 Researcher’s Role and Reflexivity

The researcher fulfilled the following role functions:

- Placed the participants at ease to ensure maximum participation and sharing.
- Provided appropriate and relevant probes, and clarified ambiguous statements made by the participants.
- Asked open-ended questions, stimulating discussion on the research topic.
- Listening attentively to the participants, while taking note of body language and group dynamics.

Bracketing was practiced by the researcher, and this played an integral role in the qualitative research process. As interaction and collaboration took place between the researcher and the participants; the researcher's context needed to be considered from the insider versus outsider perspectives. Research has shown that both the **insider** and **outsider** roles in research have benefits and challenges (Kerstetter, 2012).

An advantage of being an insider is that the participants would accept the researcher more readily (Dwyer & Buckle, 2009), and the disadvantage would be the insider's difficulty in separating his or her personal experiences from those of the participants (Kanuha, 2000). Conversely the advantage of being an outsider is that his or her objectivity is valued by the participants (Kerstetter, 2012), with a disadvantage being difficulties in accessing participants (Gasman & Payton-Stewart, 2006). In this study the researcher is employed as a part time consultant at the site, and may be perceived as an insider. However the researcher is also an outsider as her biological children do not have ASD. She is also a health care professional which may impact on the types of knowledge the participants are willing to share with her. *The space between* is used to describe the allowance for the researcher to possess both roles of insider and outsider, and understanding the similarities and differences between the researcher and participants (Dwyer & Buckle, 2009).

To deal with any judgments that characterize an insider role, the researcher embarked on a reflexive journey where field notes and journals were kept, to track feelings and important decisions made in the research, forming an audit trail. The power dynamics between researcher and participants were resolved by providing explicit information about the research intentions and her position as researcher (Swauger, 2011). Although employed at the site, the researcher had limited contact with parents which reduced the power dynamics and allowed for minimal bias. The researcher has reflected on any bias that may have arose during the study, (Swauger, 2011), thus minimizing the risk for bias.

Chapter four provides an in-depth introduction to and of the emergent themes.

CHAPTER FOUR

FINDINGS AND DISCUSSION

4.1 INTRODUCTION

This chapter is a combination of the research findings and the discussion emanating from the study. Three themes and various subthemes emerged from the research. Quotes were included to support the themes as well as strengthen the discussion around the themes. This chapter includes reflective comments from the researcher which are excerpts from the researcher's diary. The participants are described briefly to allow the reader to place them in context. In the quotes the participants are represented by the letter "P" and a number as indicated below. When names appeared in the text pseudonyms were used.

4.2 THE PARTICIPANTS

The participants were parents of children with ASD who attended a stimulation centre in KwaZulu-Natal, South Africa.

The Triad (T1) interview was held with three mothers. They will be represented as P1, P2 and P3. Two were Indian with boys with ASD (P2 and P3), and the third mother (P1) was White with a daughter with ASD. All the mothers have other children apart from their child with ASD. Their children with ASD were all 8 years of age. Two of the mothers worked full time (P1 and P3). One mother (P2) was a stay at home mom, part-time student and was expecting her third child at the time of the interview. Two mothers were married and one was divorced (P1).

The first dyad (D1) interview was held with two Indian mothers whose children with ASD were 13 and 17 years old respectively. They will be represented as P4 and P5. They have other typically developing children, and work part-time. One mother is extensively involved in Autism advocacy work (P4). The mothers are married.

The second dyad (D2) interview was held with a Coloured couple who work full time and have an 11 year old son with high functioning Autism, epilepsy and attention deficit disorder (ADHD). They have a typically developing daughter. They will be represented as P6 (husband) and P7 (wife).

The first individual interview (In 1) was held with a White father who was self-employed and had an 8 year old daughter with ASD. He had a typically developing daughter as well and his children's mother was in the T1 interview. The father was divorced. He will be represented by P8.

The third dyad (D3) interview was held with a Coloured couple who work as educators. They have two sons diagnosed with ASD aged 19 and 22 respectively. They will be identified as P9 (wife) and P10 (husband).

The second individual interview (In 2) was held with a Black mother who was employed as a teacher assistant at a special needs school. Her daughter with ASD was 13 years old and she had a typically developing younger daughter. The mother was married. She will be identified as P11.

4.3 THEMATIC ANALYSIS

The data was analyzed using Braun and Clarke's method of thematic analysis (Braun & Clarke, 2006), which was described under the methodology chapter. Once the data was transcribed, the researcher checked that the recordings and transcriptions correlated. Initial themes were noted during this process.

Initial themes were written under each interview and compared across interviews. Codes were given to themes that were repeated over interviews. Main themes, primary themes and secondary themes emerged which will be introduced and discussed further

4.4 INTRODUCTION TO DISCUSSION OF THEMES

During my clinical practice I often wondered why parents of children with special needs did not seek help. Receiving support seemed a logical option to me as a clinician. I assumed it was that they felt helpless, finding themselves in a vicious cycle of fatigue and hopelessness, making seeking support a tedious or overwhelming task. However listening to eleven parents' stories has given me insight that has touched my soul and it has been an honour listening to and understanding their stories. (Researcher's Diary 17th August 2013).

The research questions for this study were: “*What are the lived experiences of parents of children with Autism Spectrum Disorder?*” and “*What are the coping strategies of parents of children with Autism Spectrum Disorder?*”. This study has yielded rich data about parents' experiences, perspectives, perceptions and coping with a child with ASD.

The main themes that emerged were: “The Experiences of Parents of children with ASD”, “Coping in Parents of Children with ASD” and “A Road Map to Coping with ASD”. The former two categories included both the positive and negative aspects as these were not mutually exclusive but rather converging themes. By way of example the parents' either found their marriages taking strain or in most instances strength was gained through their struggles. In this chapter the themes will be discussed in greater detail.

Overleaf: Figure 4.1 and 4.2 provide diagrammatic representation of all themes and theme one respectively.

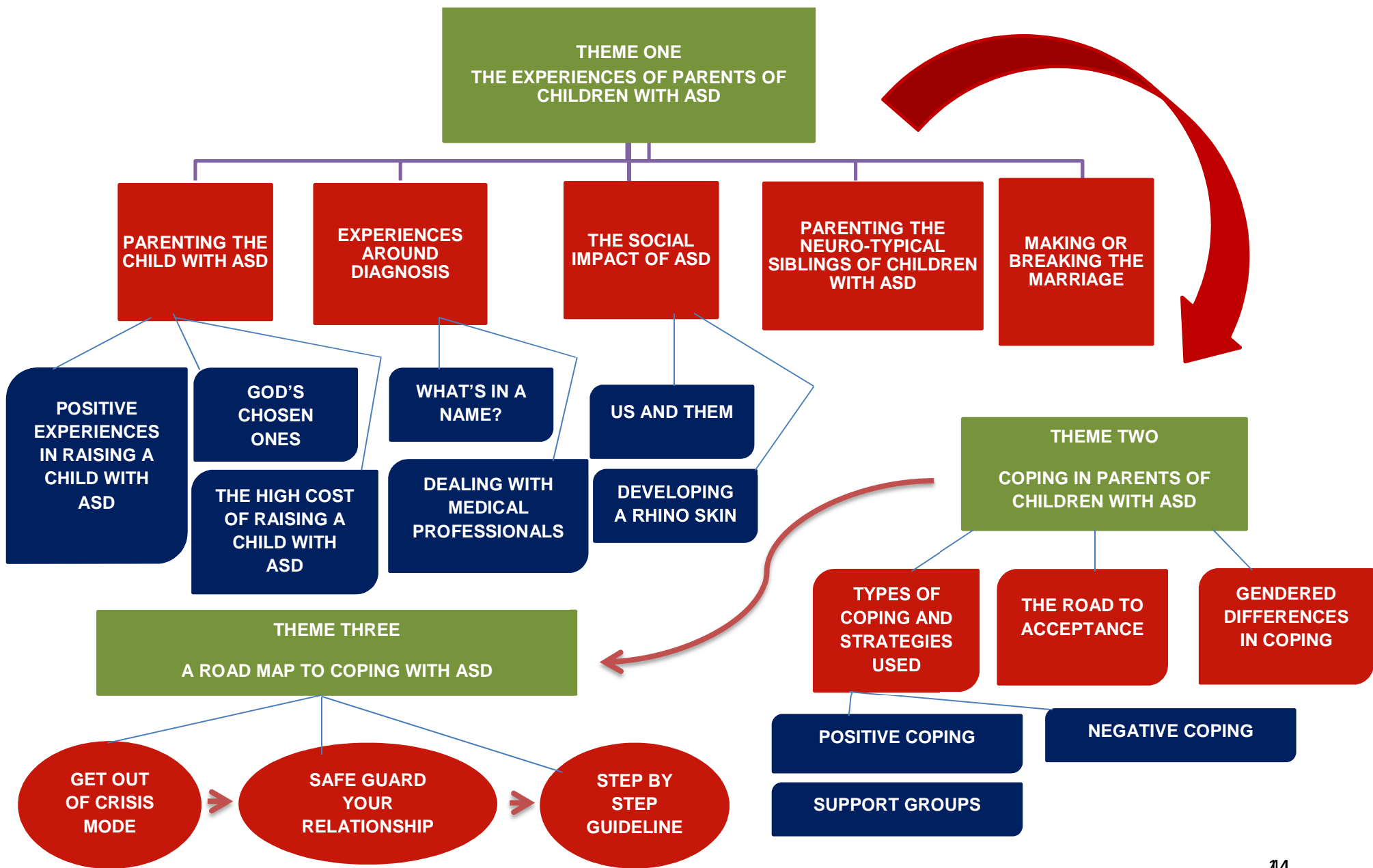


FIGURE 4.1 OVERVIEW OF THEMES

KEY: MAIN THEMES PRIMARY THEMES SECONDARY THEMES

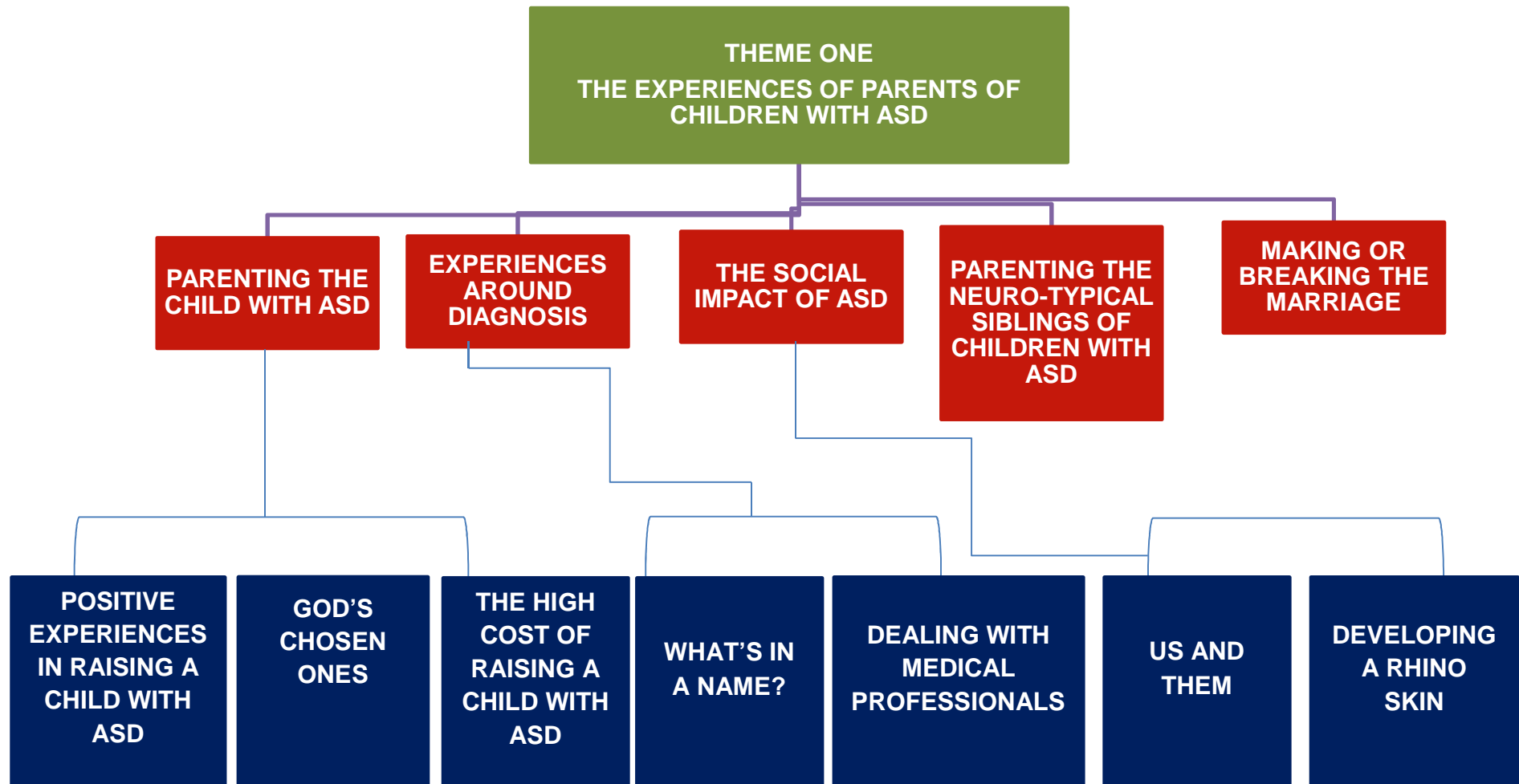


FIGURE 4.2: THEME ONE THE EXPERIENCES OF PARENTS OF CHILDREN WITH ASD

KEY: MAIN THEMES PRIMARY THEMES SECONDARY THEMES

4.5 Theme One: The Experiences of Parents of Children with ASD

This theme identified positive and negative experiences expressed by the parents. The theme was divided into five primary themes, which were further divided into secondary themes. The primary themes were parenting the child with ASD, experiences around the diagnosis, the social impact of ASD, parenting the neuro-typical siblings of children with ASD and making or breaking the marriage.

4.5.1 Parenting the Child with ASD

This theme looked specifically at the positive and negative experiences of parenting and caring for a child with ASD. Three secondary themes arose from it namely positive experiences from raising a child with ASD, God's chosen ones and the high cost of raising a child with ASD.

4.5.1.1 Positive Experiences from Raising a Child with ASD

The positive experience of having a child with ASD was reflected in the parents' ability to derive meaning from raising a child with the condition. Lessons were learned from their special children and special moments were remembered. Another positive experience was the increase in awareness of ASD now, as compared to years gone by. The parents indicated that their children with ASD became easier to manage as they got older which resulted in positivity and hope.

"But I must say the older they have grown especially with Sam¹, the easier it is to manage. When he was 8, 9, 10. ...there was no understanding at all, understanding was very minimal. (It was hard)." (P9)

The increase in awareness of ASD has increased the support and resources available to the parents. These resources make caring for children with ASD more manageable currently than years ago when awareness and knowledge of ASD was poor.

¹ Pseudonyms were used in quotes to maintain the personal context of the stories while upholding the anonymity of the participants.

“...and I think what is helping is that there is a growing awareness, a growing support system where as you would have had nothing you know 16 years ago, and I think now it is changing and that is positive.” (P4)

All the parents attested to the fact that they had learned something valuable from their children with ASD. Most parents described their children as special, providing purpose and meaning to their lives.

“.....despite everything, he is actually a loving child. On the days that he’s not having a bad day, he is most co-operative, most loving, most easy going. He is genuinely the most beautiful child to have around.” (P6)

This experience of positivity had a deeper spiritual meaning for parents where some felt they were especially chosen by God to care for these children.

The negative experiences made a huge impact on parents of children with ASD, however, the positive experiences were what gave the parents hope. As ASD is largely unknown and people feel uncomfortable around those with ASD, families of children with ASD feel stigmatized and marginalized (Gray, 2002). Positive aspects identified by parents, included finding hope in the fact that their children improved with time, increased awareness of ASD resulted in positive gains within their communities like understanding and empathy, and existential lessons were learned from their children.

The passage of time brought some relief to parents. There was consensus among parents that their children improved with age. Improvement was noted in their behaviour and the parents’ ability to manage that behaviour. This provided hope for the parents knowing that they were able to adapt to the difficulties presented in ASD.

“...I have noticed with Simon that there are not that many melt downs... I think from the time he turned about 6, or maybe when his sister was born because I have noticed he is a little more grown up now...” (P2)

Comparing the experiences of the parents of younger children in the triad group interview, with those with older children, there was a difference in the types of problems noted and the sense of hope expressed by the parents. Even though improvement was noted in their children, the parents with younger children had less experience with this. The younger children were more dependent on their parents and had many behavioural difficulties. They were not toilet trained, needed assistance with all activities of daily living, had difficulties with sleeping, and experienced sensory difficulties and had meltdowns. Furthermore parents suffered from sleeplessness and marital discord. These struggles were perceived as never ending, and their despondency was felt by the researcher.

At this stage in the triad group I felt helpless and I felt the situation was hopeless. How could I help these parents? I have small children under the age of 5 and I thought it's like my children never growing up, or dealing with these difficulties in the formative years until your child is 8, 9 or 10. (Researcher's Diary 5th March 2013).

In contrast to this bleak picture, the parents of older children expressed positivity in that their children had improved and they expressed a greater sense of hope and peace as opposed to the parents in the triad group.

"But I must say the older they have grown especially with Sam, the easier it is to manage. When he was 8, 9, 10. ...there was no understanding at all, understanding was very minimal. (It was hard)." (P9)

The older children's difficulties were short lived and included age related difficulties such as puberty, hormonal changes and medication needed for their maturing bodies. The comparison over the groups in this study revealed a distinct difference in the parents' experiences, abilities to cope and types of problems experienced at each age level of the child with ASD. The parents of older children also expressed having gained more positive meaning from their children as opposed to their counterparts, most likely due to the high caregiver burden and demands of having a younger more dependent child with

ASD. It appeared that parents of older children had “grown with” their children and it became easier to manage them. As parents put strategies in place and children became more independent, parents were able to reflect and reassess the meaning behind all the struggles they faced.

Gray found in his 2006 research “Coping over time” that parents found their children significantly easier to live with, reporting lower levels of emotional stress. There was less need to adopt various coping strategies.

The parents had adapted to their situation and the child’s living skills had improved tremendously resulting in greater independence in the children (Gray, 2006). Gray’s findings are supported by the current study as the couple with the young adults with ASD were more relaxed and at “peace” with their circumstances than the younger parents.

Of the few longitudinal studies on children with ASD that have been undertaken, there is a contradiction in evidence that children improve with age. A longitudinal study by Marsha Mailick, director of the Waisman Center on Mental Retardation and Human Development at the University of Wisconsin, Madison, began in 1998. Mailick’s participants included adolescents from age ten and older, which were studied over a 10 year period. She assumed that adolescence was a time of difficulties, however these children’s behaviour and symptomatology improved as they reached their teens (DeWeerd, 2013). Conversely a larger study that followed 300 children from the age of 2 to 21 years found that only 10% of the children had improved by their mid-teens, and 80% of the children’s symptoms were consistent and stable over time (DeWeerd, 2013).

Therefore given the findings from this study it is not necessarily the children that improved with time, which was true in some cases, but the parents’ ability to adapt and

cope overtime. The hope of children improving is important for younger parents as it reduces despondency and gives them a goal to strive towards.

The increase in awareness in ASD has added to the resources and support parents can access. The media has played a great role in making the public aware of ASD.

"I think in that year 2005/6 you never heard of Autism now it's becoming – there is much awareness....you know when I saw a show on Oprah...it actually made me think about my son."(P3)

It was noted by one of the parents that the Oprah Winfrey Show presented a documentary on ASD in April 2007. This media coverage by a reputable and popular talk show host appeared to reduce the "stigma" of ASD, allowing people the opportunity to learn more, and become more accepting of the condition. Autism Spectrum Disorder is subject to stigma as people are generally unfamiliar with the condition, therefore socially acceptable means of increasing knowledge through the media and social networking can reduce stigma for parents of children with ASD.

In a South African and African context, educational media on ASD needs to be available in African languages, in order to reach the larger population. Although media is a beneficial tool to create awareness, its impact is only felt within a certain sectors of the country. Louise Taylor, the Outreach Officer for Autism South Africa (ASA) in 2010, stated that the awareness of ASD in South Africa (SA) and more specifically in rural areas is dismal with stories of children being abused, neglected and shunned from communities, given the cultural beliefs about these children being demon possessed.

Taylor suggested that *"what we really need are some traditional media awareness efforts – television and radio, particularly radio – which can reach the more rural areas of the country, so that people understand what autism is"* (Field, 2010). Autism South

Africa (ASA) distributes pamphlets on ASD in seven official South African languages which contributes towards awareness of ASD in SA.

There was consensus across the interviews in relation to noticing an improvement in their children with age, that the increased awareness around ASD was positive, and that the parents had gained positive meaning from raising a child with ASD. This positive meaning was often attributed to existential and spiritual descriptions by the parents.

4.5.1.2 God's Chosen Ones

For some parents there was a strong spiritual connotation to having a child with ASD, which was perceived as a positive by them, and added purpose and value to their lives.

“ For me, the way that I can deal with it is on a Spiritual and logical level, I firmly believe that God has chosen us to care for these special ones.” (P10)

The meaning the parents derived from having a child with ASD left the researcher with the impression that these children were special, with qualities related to spirituality and innocence.

Reflecting on the positivity that the parents have shared rang true to my own experiences in working with children with ASD. Initially I felt scared, apprehensive and unsure of myself...almost awkward. Yet I have grown to love these children. They have taught me to be gentle, to slow down and to really listen. Listen, not to words, but to what they are communicating in their own way. I find myself getting excited by even the smallest improvement; eye contact or engagement. I feel I am privileged, even honored to work with these precious children. (Researcher's Diary 25th October 2013).

Most parents described their children with ASD as special, providing purpose and meaning in their lives. The positive meaning the parents derived from raising a child

with ASD ranged from personal growth, gaining existential meaning, benefiting from their children's difference, and perceiving their children as gifts from God.

Parents expressed that they grew personally, developing attributes such as patience, understanding and empathy.

"Patience lots of patience, I was not a very patient person but with Simon you have to learn to be patient you don't have a choice." (P2)

These attributes extended to how they dealt about others with disabilities, and people in general. Perceiving life differently, slowing down and multi-tasking were tools the parents gained through their parenting experience.

"...it's also given me a different perception of disabilities, people out there. I think if we didn't have children with special needs, we would not have appreciated others with special needs... Learning to accept people that are different (is) very rewarding". (P9)

The parents described their children as perceiving life differently to typically developing children. This allowed parents to experience life differently, and find deeper meaning. Other existential factors such as the purpose of life and destiny became sharply defined from raising a child with ASD.

"... (This experience) is an incredible joy, having a little person in your life that makes you rethink who you are, rethink your purpose in life." (P4)

Parents stated they appreciated the simple things in life that parents of typically developing children may take for granted, such as achieving milestones. The meaning of life for one mother was simplified to appreciating small things like watching a bird.

"I guess having a child with Autism you start knowing the meaning of life. I think appreciating even the smallest things – "hey mommy see it's a bird" and I can spend a few minutes looking at that bird where once I wouldn't have done it, so we start to appreciate, I see a lot of life through his eyes... and life is not a bad thing..."(P5)

As described by the parents, their children with ASD have a unique quality. They think differently and are perceived by their parents as innocent and authentic. A mother of two boys with ASD found solace in the fact that her boys were not like 'typical' teenagers. She was able to sit and enjoy her boys company as young men, being the envy of friends, whose boys were living independently, enjoying life on their own.

"...I just love sitting down and being with them (her children) and people say to me : In a way you are so fortunate just look at our teenage sons... they are driving and girlfriends, you know there is so much out there that is challenging us, but your boys will never have those challenges.... (our) children (with ASD) are so ...not materialistic and there is so much out there brand name clothing, brand name iPods. I look at my nephews and nieces and I see the lifestyle they have and I think of the boys, its different, it's alien to me." (P9)

This unique quality was portrayed beautifully in this following quote by a mother (P4) who confirms the positivity found in her son's 'differentness'.

She confirms that 'what you see is what you get' which is refreshing in life, where people often do not portray their true selves.

"...they can just intrinsically be, whether they are being angry or being happy or, they are just them. It's not filtered through anything like envy and jealousy, and all the other layers and fronts that we put up, they just are, and that is just incredibly authentic and real."(P4)

Despite the struggles these parents have faced raising a child with ASD, it is the very nature of their children that forces them to re-evaluate life, look at it from a different perspective and gain insights into the meaning and purpose of life. The parents of teenagers and young adults described their children as 'gifts' and linked the experience of having a child with ASD to a spiritual meaning.

“ For me, the way that I can deal with it is on a Spiritual and logical level, I firmly believe that God has chosen us to care for these special ones. To see it as that I believe if I see it as that actually it's a privilege to be given this special duty, then it makes everything worthwhile. It makes me see that I have a real purpose. God has picked me out for a purpose and that's the way I deal with it.” (P10)

The spiritual meaning allowed the parents to cope better, and make sense of a stressful situation by finding peace in that they have been chosen to care for these children. Perceiving life differently and placing spiritual meaning to their circumstances helped the parents justify the sacrifices they made, for example leaving a career to care for their child, and the costs they endured for having a child with ASD.

It is common in African culture to believe that people with ASD are demon possessed (Oliphant, 2013), therefore this perception that one is chosen by God may be perceived differently by an African mother. This mother may believe she is being punished for having a child with ASD and may experience anxiety, guilt, and fear. Additionally she would most likely be ostracized by her community. There are also Christians who believe that the child may have a generational curse and that the child needs prayer and deliverance (Yih, 2013).

In this study it was noted that one mother was told by an elderly lady that she should just pray for her child. These perceptions are contrary to the feelings of most parents who shared that their children were gifts from God.

One mother struggled to accept her son's condition and questioned God. She also did not understand how other parents were so happy to have a child with Autism. She was honest and acknowledged her anger towards God. Anger in this context is seen as a positive as it is one of the stages of coping with ASD and ultimately ended in acceptance. In questioning God's purpose she found acceptance, as she was able to work through her feelings of anger, frustration, fear and uncertainty. The spiritual significance of Autism was found in the parents' improved coping, knowing that they were chosen by God to care for this child. There were some parents in the study who did not mention God, however all parents agreed that they had learned lessons from their children, which included spiritual and existential meaning.

Research confirms the positive side of ASD experienced by parents. In a study of 26 married couples almost every couple stated in interviews that they had positive learning experiences from raising a child with ASD. These positive aspects included personal improvement, friendships, strengthening of the family bonds, and love for their child (Altiere & von Kluge, 2009). Despite literature confirming the positive side of ASD, the difficulties seem to outweigh the positives. It is these "good days" and positive aspects that help parents cope through the daily challenges they face raising a child with ASD.

Despite the parents' positive experiences and meaning derived from having a child with ASD, the parents expressed the stressors and negative experiences they faced as well. These negative experiences will be described under "The High Cost of Raising a Child with ASD".

4.5.1.3 The High Cost of Raising a Child with ASD

These negative experiences included the parents making sacrifices in relation to their careers, lifestyle, finances and health.

Parents, especially the mothers left their careers to look after their children with ASD.

".....(it's) an incredible impact on your life, I mean you have this career and you have your life laid out before you and suddenly you are winded. This just comes and lands in your lap, you know and it changes your life direction, because your focus then becomes that child and getting the support and help for that child...."(P4)

This sudden change of focus and intense attention directed to the child with ASD results in the child's condition dictating the direction of the parents' lifestyle and social life. The parents of children with ASD explained that their social lives, and life in general, was restricted by their children with ASD. The family fitted in with what the child with ASD wanted, and their mood often dictated the course of events for the day. Decisions about events always needed to be made with the child with ASD in mind.

"We will stay a while until he reaches a point where he is fed up...so I go by his moods" (P2)

The parents indicated that they experienced financial strain in relation to raising a child with ASD. Lastly the parents were directly impacted negatively in their health, both physically and mentally.

"... my blood pressure was high and that kind of thing." (P10)

Specifically at the time of diagnosis, the burden of care, and intense emotions of shock, confusion, fear and denial were experienced by the parents.

The devastating impact on the parents' emotions was overwhelming for me. Such an intense roller coaster of emotions and feelings of loss. Despite having gained the positives previously mentioned these parents have endured a great deal of emotional hardship, pain and mourning the loss of normality. Who can truly relate to their struggles? Not us as medical professionals. It is good for me to feel this intensity so

perhaps I can understand and empathize even a little bit with why parents may be paralyzed to seek support. They are just surviving to get through today. (Researcher's Diary 15th November 2013).

The emotions parents experienced included shock, relief, denial, frustration and anger at the time of the diagnosis of their child. There was a period of mourning, the loss of hope of a normal life for their child. This often led to feelings of guilt.

"It was our first child and we had high hopes and dreams and you get this thing you have never heard of Autism... it affected us quite badly, our first child, we didn't know whose fault it was , was it my fault, his fault who's fault?" (P5)
"...its like mourning a death of your child because for me he was normal, ok he was slower but normal...and then you get told the child is Autistic."(P7)

The condition of ASD is permanent and evidence to support causes and cures is minimal, resulting in this reaction of hopelessness and fear. Some parents were able to deal effectively with these emotions, and others internalized their child's condition, resulting in some cases of marital discord, depression, loss of faith in God and lack of acceptance. The following quote describes the immense strain and pressure experienced by one mother.

"...It was just too much... it is a burden having a child with Autism. Why would God give you a child like that, and expect you to cope? Sometimes I pray God to take him away. Once I was in the bath with him, I felt like pushing his head under water. I wanted to put him out of his misery....it took me a long time to accept it." (P7)

This mother felt that she was being punished by God and wondered what she had done wrong to deserve this fate. Her impulsive thoughts to end her child's life were a reaction to the overwhelming emotions she felt and were most likely directed by depression and

stress she experienced concurrently. The prolonged stress can offset depression in a person especially if they have a genetic predisposition to depression (Nordqvist, 2009).

Before you judge this mother, consider her predicament. In her love for her child she felt being dead was an escape from this awful condition he had. He was aggressive, angry and destructive, not only towards others but to himself. It is hard for me to share these stories as they are so intense. The good and bad of raising a child with Autism is interconnected, a grey space, neither black nor white. As the reader, consider the fluidity of these experiences and you will hear that each family has a story confirming the resilience of the human soul. (Researcher's Diary 16th November 2013).

This story and others like it directly impacted on the parents' health, especially when they did not acknowledge negative feelings or seek help for it. The following is a quote that describes a father's battle with anger that he kept bottled up, which eventually affected his health.

"I was angry for many years and I think the children felt the anger, because you know when I used to shower them in the mornings or the evening. I would shower them but I had anger in me you know... I used to wash them with anger, and I think the kids felt that.... Maybe I wasn't coping because my blood pressure was high and that kind of thing." (P10)

Parents also experienced difficulties in their mental health with specific reference to depression. The continual onslaught of intense emotions of anger and sadness, and an inability to overcome them was a direct result of the condition. ASD is a permanent condition leaving the parents feeling hopeless, believing that nothing would change. These high levels of stress and depression experienced by the participants correlate with literature on the effects of ASD (Estes et al., 2009; Hayes & Watson, 2013).

There is a biological reaction in response to continual stress and emotional strain which impacts negatively on physical and mental health (Fields, 2010). Managing their stress such as learning stress management techniques were essential for parents of children with ASD to learn.

“...it's never going to be smooth sailing. Things can go backwards in an instant. It's never going to come to an end.” (P6)

This quote relates directly to the loss of hope. Hope is a motivational factor which helps initiate and maintain action towards a goal. It is linked to happiness, perseverance, achievement and health (Arnau, Rosen, Finch, Rhudy, & Fortunato, 2007). The never ending stress and struggles parents faced result in loss of hope, and ultimately mental illness such as depression and anxiety. It is most likely this loss of hope that strips the parents of the motivation to initiate help seeking behaviour towards the goal of support.

The other costs incurred while caring for a child with ASD were work, financial and social factors.

Work:

Mothers specifically indicated that they chose to seek part time employment or became house mothers in order to care for their child. There was an indication from parents that they needed flexibility from work and understanding from their employers. Despite employers displaying leniency and empathy, parents still felt guilty if they did not fulfil work commitments due to the demands of their child.

“...you can't tell your boss, I am having problems with my child. So now anywhere we have to go, if we are late we are late but it's a bit difficult work wise you know...” (P7)

Mothers staying at home expressed a loss of income which further compounded the financial strain of having a child with ASD.

*"It makes an incredible impact on your life, I mean you have this career and you have your life laid out before you and suddenly you are winded. This just comes and lands in your lap you know and it changes your life direction, because your focus then becomes that child and getting the support and help for that child."
(P4)*

Research on the work-family relationship reveals that there is a bi-directional effect between these two aspects. Each area can negatively or positively impact on the other (Matthews et al., 2011). One study found the need for increased support from the work place and adequate time was needed to recover from work during leisure time. For parents of children with ASD, it was difficult to recover during leisure time due to the demands at home (Matthews et al., 2011). Although the parents in this study did not allude to these difficulties, they are potential hazards to consider.

Financial:

The high medical costs and extra care needed for their children was expressed as a challenge by parents. Medical needs such as medication, therapy, EEGs, blood tests and doctor's appointments placed a huge financial strain on parents. Medical aid funds are exhausted early in the year thereby creating further stress for parents as they attempted to cover medical costs from their day to day income. Extra costs are incurred to employ specialized caregiver services when needed and home renovations are needed when children have broken mirrors, windows and other household items.

*"...our house it was like homeless people or addicts staying in our house because we have our mirrors, windows broken, whatever he can get hold of he throws, cup at the TV or throw it at us out of frustration."
(P7)*

“...financial strain huge financial strain, when you go away for the weekend you need to pay for someone to care for the kids. Your whole life is centered around them. Your plans need to be centered around them you can't just make plans, so yes it has restricted us to some degree and even places we go it's not always where we want to go.” (P9)

The latter quote attests to the financial strains, and to the social costs incurred while raising a child with ASD.

Research confirms the financial plight parents experience in having a child with Autism. It is the daily costs of raising a child with ASD that are debilitating for parents. These costs include therapies, doctor's visits, medication and caregiver wages (Cottle, 2012). One parent, most often the mother leaves her job to become a full time caregiver which further depletes the household income (Howe & Braverman, 2013). The annual cost of Autism to the US government has tripled since 2006 to an astronomical amount of \$126 billion (Cottle, 2012). It is anticipated that the financial burden on parents will not subside as an Autistic child becomes an Autistic adult and facilities for adults with special needs are limited (Cottle, 2012; Howe & Braverman, 2013)

Social:

The parents of children with ASD explain that their social lives, and life in general, was restricted by their children with ASD. The family fits in with what the child with ASD wants, or their mood dictated the course of events for the day. Decisions about events always needed to be made with the child with ASD in mind.

“We will stay a while until he reaches a point where he is fed up...so I go by his moods”(P2)

“Like a river you go with the flow. Whatever you find is reasonable and okay you sort of do that...in certain situations we would work around certain areas. Like going to Pick n Pay was a no-no. It still is a no-no. She was uncomfortable in

these situations, only comfortable in three places, the car, our house and Granny's." (P8)

Social situations cause significant stress for parents especially when their child displays inappropriate behaviour. In the book "That's Life with Autism" a mother shares a story of how her autistic son had a meltdown at a local grocery store, where he ran down the aisles screaming and throwing himself on the floor. Customers became concerned and watched the little boy with disgust. Feeling traumatized and embarrassed the mother never went back to that shop, thereby confirming that parents' movement in the community are restricted by their child with ASD (Ross & Jolly, 2006, pp. 161-163).

The costs the parents endured were daily challenges which began with the diagnosis of their child.

4.5.2. Experiences around the Diagnosis of the Child

This was a primary theme that had further secondary themes linked to it. Across all interviews the parents expressed negative experiences in relation to the diagnostic process, including the emotions when receiving the diagnosis, and frustrations with health care professionals. One couple experienced these emotions twice as both their children were diagnosed with ASD.

Across all interviews the parents expressed negative experiences in relation to the diagnostic process including the emotions on the diagnosis and frustrations with medical professionals. One couple experienced these emotions twice as both their children were diagnosed with ASD. Another couple shared their positive experiences after receiving the correct diagnosis for their son, who was managed by a competent and caring medical doctor.

The experiences of parents around the diagnosis of their child with ASD have been well documented in research. Many experiences and frustrations parents shared in the

interviews confirmed the literature on this subject (P. Howlin & Asgharian, 1999). Parents shared that they knew something was wrong with their child but could not obtain a definite diagnosis.

4.5.2.1 What's In a Name?

The parents shared experiences about their intuition and knowing that something was wrong with their child from an early age. At times children were typically developing and then their development suddenly stopped. The following quotes describe the parents' first experiences with ASD, from that first "knowing", to receiving a diagnosis, including their feelings at that stage.

"...putting a label, you label this thing, you know the relief is short lived because once you get the relief there's startling reality, permanence.I can't really remember I just remember when I read the outcome of children with this, I was beside myself." (P9)

While contending with their emotions in relation to receiving a diagnosis of ASD, the parents felt frustrated by the health care professionals they had contact with because of their lack of care, poor follow up, pessimism about ASD and lack of direction as to the steps to follow after receiving a diagnosis.

When receiving a diagnosis of ASD, a label is given to the child. It provides an explanation for the child's developmental delays, communication difficulties, and antisocial behaviour.

Russell and Norwich published an article in 2012, which described the results from a study undertaken with 17 parents of children with ASD. Eight parents were not actively seeking a diagnosis for their child, and nine parents had already obtained a diagnosis for their child. The researchers conducted semi-structured interviews with the

participants and found that the parents had mixed feelings about receiving a diagnosis (Russell & Norwich, 2012). On one hand they wanted to know what was wrong with their child but on the other they wanted to remain in denial. Conversely other participants were devastated by the news of the diagnosis as they knew nothing about the condition and were overwhelmed by the permanency of the condition (Russell & Norwich, 2012). These accounts compare two different reactions to receiving a label for their child's condition.

Labeling theory states that placing a label on a person can be damaging as it becomes a self-fulfilling prophecy, and society projects their cultural beliefs on the person with the label, assuming that they will behave accordingly (Kroska & Harkness, 2008; Scheff, 1974). Research has shown that society places people in categories according to labels given to them, thereby introducing stigma (Kroska & Harkness, 2008). However the study above indicated that parents responded differently to the news of a diagnosis and subsequent label. Some parents chose not to seek out a diagnosis to ensure their child was not labeled. This would have resulted in increased financial implications, as social and medical assistance is not granted without a diagnosis.

This links to the current study where parents described mixed emotions towards receiving a diagnosis.

"...putting a label, you label this thing, you know the relief is short lived because once you get the relief there's startling reality, permanence.I can't really remember, I just remember when I read the outcome of children with this I was beside myself."(P9)

Relief at the time of receiving a diagnosis was short lived due to the shock about the prognosis of the condition.

The participant quoted above has two sons with ASD, and the impact of receiving a second diagnosis was as devastating as receiving the first diagnosis. The quote below is from the husband of this couple.

“it’s like another hammer blow, another hammer blow, because you are just recovering from the first realization, so it was a huge set back, but in a way we were prepared because we kind of knew what to expect, obviously the kids were different in many ways on the spectrum. No it was a massive blow for me, a massive set back. You harbour hopes that one child will be so called ‘normal’ and that wasn’t to be,... so yes a huge set back...”(P10)

Despite knowing about ASD and being prepared for a diagnosis, the father still suffered emotionally from the shock of his second child’s diagnosis as his hopes for a typically developing child remain unmet. The dichotomy between wanting to know and not wanting to know about the diagnosis is possibly related to the intense emotions that the parents need to deal with. They want to help their children, but the reality of the emotions is too intense to endure, coupled with the permanence of the condition.

For some parents receiving a label allowed them to lay their concerns to rest and plan ahead. In the context of this study the parents appreciated a label as the process of getting a diagnosis was tiresome. They were often misunderstood and had communicated difficulties with medical professionals. The one mother was relieved that she was not just imagining her son’s difficulties and stated she did not feel like a “drama queen”, in receiving a diagnosis for her child. Despite the relief, the shock experienced by parents cannot be negated.

The parents shared that they had never heard of ASD, which was an even greater shock.

"It was a big shock.... we didn't know what autism was... that was the worst I think not actually knowing what was wrong with her as I said (we had) no family with Autism we did not know anyone with Autism"(P1)

Research shows that the diagnostic process is stressful, takes a long time with many professionals being consulted prior to the actual diagnosis, and the children with more severe symptoms are diagnosed quicker (Moh & Magiati, 2012; Siklos & Kerns, 2007). A couple in the current study shared how they did not have enough "evidence" to prove that there was something wrong with their son. He was higher on the spectrum and had softer signs of ASD together with co-morbid conditions of Epilepsy and Attention Deficit Disorder which most likely made the diagnosis process more difficult.

The high levels of stress experienced by parents around the diagnosis itself are similar to the symptoms of the stages of grief namely shock, grief, anger, helplessness and guilt (Siklos & Kerns, 2007). The following quote expresses a mother's grief at the time of the diagnosis of her daughter.

"At age of three it was not easy for me. She could not talk. I used to be stressed. I used to cry a lot, cry all night" (P11)

All these emotions have been expressed by the parents either at the stage of diagnosis or years later. This correlation to the grieving process may explain the need that parents expressed to mourn. These stages will be discussed later to understand their impact on parents' ability to cope.

One mother aptly worded the ASD diagnosis she received for her son as a "life sentence" and stated how she longed for compassion from medical professionals.

4.5.2.2 Dealing with Medical Professionals

This relationship according to the majority of the participants was one fraught with anguish and difficulty. The parents felt unheard, frustrated and inadequately informed. The parents showed little faith in medical professionals, often seeking second opinions or receiving advice through other avenues.

These avenues included advice from teachers, sharing advice with other people who knew about ASD and gaining insight through the media.

“(the Paediatrician)she checked him and went through all his milestones, and she said there is nothing wrong with him, and I don’t even think you should take him for speech therapy he will come into that and all of that.... We actually changed the paediatrician.” (P3)

One couple however found a doctor they could relate to and who provided a good service.

“...she referred us to Doctor (M), since then it has actually been fantastic, not that I’m deeply religious but I would like to believe that it must have been divine intervention as it was fantastic as Andrew progressed.” (P7)

“They (medical professionals) do not reassure a person... they give you a life sentence without the necessary support.” (P4)

All the participants expressed frustration and lack of faith towards medical professionals. Most participants knew there was something wrong with their child even though their child looked normal.

Participants found it difficult to express what they thought was wrong with their child, frequently receiving incorrect feedback from doctors that their child would grow out of these problems.

“...from around one and a half, his behavior started changing and I kept taking him back to the Paediatrician and he said ‘No it’s fine it’s nothing to worry about, boys are just slow or the terrible two’s or whatever’, so eventually I got fed up when he reached three, I said you know what... this child has stopped learning anything new,... his behavior is becoming aggressive now, he will end up hurting himself and his speech is like stopping...(took him for a) second opinion and immediately that Paediatrician said you know we suspect autism” (P2)

This notion of not being heard and the intense “knowing” that something was wrong led participants to seek second opinions. Participants felt that some medical professionals were unsure, inexperienced and could not provide definite answers to the parents’ queries.

“They actually want the diagnosis to come from you and they would just sign it off type of thing. Surely medical science is so advanced and we actually discovered that they know very little about this disorder. It was actually very frightening in that sense that these were one of our top professionals and they were not sure of themselves you know, it was very disconcerting to say the least.” (P10)

This perception of medical professionals not knowing was consistent across the interviews. Therefore despite the current age of the children in this study, the participants’ experienced this uncertainty around diagnosis many years ago. Despite an increase in awareness around ASD, knowledge within the general medical world remains lacking. This uncertainty led parents to seek other avenues of diagnosis and support.

Once their children went to school, participants were cautioned by teachers that their child may have ASD. This confirmed the participants' suspicions, giving them impetus to fight further for an accurate diagnosis. The media played a beneficial role in educating the public about ASD which allowed friends and family to affirm the participants' concerns.

One couple shared their faith in their medical doctor, whom they highly recommended. His approach was different to other doctors, he cared about them as parents and provided regular follow up. He listened to the parents' concerns and took time to answer any queries they had.

"...now Doctor (M)..... as opposed to just treating him through medication, he had a more intimate approach to treating Andrew and not just treating his disorder."(P6)

I understand how these parents could be so frustrated with "the system". However it was difficult to hear their stories of frustrations, as I am a medical professional. Then I justified it and put myself in another category by saying 'well I'm not a doctor'. Does that let me off the hook? No. I judged these parents for not seeking support without truly knowing the devastation this condition can cause. Having walked through the words of these parents, picking them up, scrutinizing them I have gained new understanding and deeper compassion for what these parents have had to endure. (Researcher's diary 15th November 2013)

Considering the participants' concerns with the medical profession in relation to knowledge of ASD and the diary reflection noted above, we as professionals need to re-evaluate our position. It is clear that ASD is a "strange" disorder presenting with "weird" symptoms. Even as professionals we do not always know how to manage these children, frequently feeling out of our depth. A study undertaken with 247 medical

professionals in Pakistan revealed a lack of knowledge about ASD and misconceptions about the disorder (Imran et al., 2011).

Family physicians and paediatricians had no undergraduate training in ASD, which was concerning as they were the first medical professionals consulted when the parents had concerns about their child's development (Imran et al., 2011). This research can aid SA to ensure newly qualified medical professionals, in their community service year, have adequate training in ASD. Medical professionals need to be honest about their knowledge, or lack thereof, and provide support to the parents who so desperately need it.

"... Honesty is extremely important. I think a lot of parents go through denial so when a Health Care Professional says "Maybe I think?"....., and you say well this is what you are going to get and this is what you can experience and this is how you can get help and from my perspective as an OT, or my perspective as a psychologist or my perspective as a speech therapist, these are the steps that I recommend,just acknowledging what this parent is going through this –, but you also want the Health Professional to be hopeful, because there is hope with the right intervention you know, there is support for your child.you are also finding a lot of negativity from Health Care Professionals.you want them to be positive you want them to be truthful just a sounding ear when the parent wants to vent...not experience or coping or advice." (P4)

Ultimately the quality this mother valued the most was a medical professional who would listen and acknowledge her and other parents' predicaments.

4.5.3. The Social Impact of ASD

This was the third primary theme and had two further secondary themes linked to it. The parents experienced the social impact of having a child with ASD in their immediate family, extended family, their community and in society as a whole. The following title of

“Us and Them” describes the alienation parents experienced in relation to their children with ASD in the social context. Educating others and being involved in advocacy work increased society’s awareness, and was viewed positively by the participants.

Parenting the child with ASD has a direct impact on the child’s and family’s social life. The positive impact is that family and communities rally around the parents and family. The negative impact is that parents feel stigmatized by society, and remain isolated and restricted socially. The parents showed great ability to rebound from these difficulties by “developing a rhino skin”. In the National Autism Plan (United Kingdom), Professor O’Brien states that of all the disorders, autism is the most socially excluding (Autism, Screening, & Assessment, 2003).

4.5.3.1 Us and Them

This feeling of alienation and isolation began at a family level, which included immediate and extended family members.

“...they do understand his condition but it’s like they don’t live with him... they don’t understand he has his impulses at times...”. (P2)

The second level of alienation and isolation was felt at society level. There was a consensus across the interviews that there is a stigma attached to having a child with ASD.

Society seems to judge parents of children with ASD, and is largely ignorant about ASD. Parents become frustrated with the continual need to explain to people about their child’s condition.

“People’s reaction to my child are very, well negative... and they think what is wrong with me as a parent, they always look at the parent...” (P1)

Most participants felt they had the support of their families. Their family members were proactive in learning more about ASD, and made their homes child-friendly to cater for the children's specific needs. One couple shared that their parents' home was a "home-away-from-home" for their children. Although she had their support and help, one mother felt she could not totally allow herself to trust anyone with her son due to his epilepsy and frequent seizures.

There is a dearth of literature to support or encourage the need for family support. However an improvement of the support from family and friends was shown to decrease feelings of stress in parents (Margetts, Le Couteur, & Croom, 2006).

This social isolation and alienation was voiced by the participants in this study. There were factors that appeared to make it difficult to take the children on outings or family functions. The children needed routine, resisted change and required constant attention. These aspects made it impossible for parents to enjoy socializing as they never got a break and their children presented with "meltdowns". Meltdowns are often perceived by people as tantrums or poor behaviour (Ryan, 2010).

These perceptions of society impacted on parents as they were worried about people's reactions, people blamed their parenting skills and lack of discipline, and everyone had advice for them as to how to handle their child. One mother affectionately recalled an elderly woman saying that she should "just pray for your child".

One mother shared how her family had rallied around to assist at family functions,

"With regards to the other family members, I am fortunate with my brother in-laws that when we have any gatherings they know Paul has to be with us all the time and under supervision and they will actually take him to give us a break to have a meal.... I used to be very possessive over Paul, I would never want anyone to actually keep him for the simple reason that he would act up on them and they would not know how to react basically how to deal with him." (P3)

In contrast one couple shared that their family found their son so destructive and naughty that at one stage they were not invited to family functions.

“initially we had a problem with my family, they basically thought he was naughty And very dangerous....because of his strength – you know it got to appoint where no one wanted us to go, no one would invite us anywhere.” (P7)

Stories were shared about confrontations in community settings as community members challenged parents on their child's behaviour. Participants expressed becoming tired of sharing the same story and one mother said *“we (I) have reached a point where I was so frustrated about explaining to everyone that I just sat at home I didn't take him anywhere...” (P2)*. These frustrations have been echoed in literature where other parents had similar confrontations which they either chose to avoid or tackle. When they exposed themselves and tackled the confrontation head on, they felt empowered as did the other siblings and family members (Neely-Barnes, Hall, Roberts, & Graff, 2011). In the current study the parents of two young adults with ASD attested to the benefit of being vulnerable in public.

This vulnerability included exposing their children to others by taking them everywhere. The parents took on informal and formal opportunities to educate people about ASD, which allowed their community to move from ignorance to understanding. Making socializing a norm for their children allowed them to become accepted into their society where the family could attend church together rather than the parents taking turns to go on their own. This process was challenging but the parents found it was ultimately beneficial. To socialize their children the parents shared a quality in this study called “developing a rhino skin”. Being able to go to church as a family had a positive impact on them.

Enacted and felt stigma as described by Gray (Gray, 2002) were evident in the recollections of the participants. However, there was a definite “fighting” for their rights

to be socialized and to be a part of the community. Research shows that parents are concerned about their child's future (Ogston et al., 2011).

This concern drives the parents to socialize their children and expose them to society in order that they may adapt to social settings in the future. The parents want to prepare their children for when they cannot care for them.

“Yes I think that is mainly it, the fear of what is going to happen to these children one day when they are adults? I think that is our biggest anxiety, one day we are gone who cares for them I think that is any parent's biggest fear. You know our kids in most cases are not able to help themselves they need assistance for everything so for me that is my biggest worry my biggest fear” (P10)
And for me is to give them a purpose, the fear that they won't be able to make a contribution you know within society. When they get up one day they will be 25, 26 will they just be staying at home you know will they have a little job to do, that is one of my fear is that they will just sit and stagnate another one of my fears (P9)”

In response to their families' and society's perceptions, the parents developed a resilience that enabled them to accept society's ignorance and continue living their lives for the betterment of their children both with and without ASD. This characteristic of resilience is described as “Developing a Rhino Skin”.

4.5.3.2 Developing a Rhino Skin

This subtheme relates to the parents' response to their families' and society's perceptions of ASD. Resilience, tenacity and perseverance are the underlying characteristics of the parents that seemed to resonate with this theme.

“I think initially it's a fear of embarrassment and rejection when we take the children out... people will stare and stuff... and eventually you think my child

deserves an opportunity to be socialized, you develop a rhino skin, and people just have to deal with it.” (P10)

Developing a Rhino Skin testifies to the parents’ ability to turn negative experiences into positive lessons. Despite this indomitable spirit, these parents continue to experience negative aspects in parenting a child with ASD. Furthermore this ability to turn negative circumstances into positives is further related to parenting the neuro-typical siblings.

There was a quality that resonated through the interviews. It was a determination from participants that their child deserved to be socialized, and deserved a place in society despite society’s perceptions.

A possible characteristic to describe this hardiness would be resilience, which is a quality seen in families that face adversity such as those with disabled children. Resilience is the ability to rebound from hardship, becoming stronger and more resourceful (Bayat, 2007). In the case of “Developing a Rhino Skin” the parents found strength within themselves to fight stigma by asserting their rights to socialization and freedom of movement for their children. The following quotes describe this phenomenon:

“so I think through years you have to make yourself strong and say you know what my son comes first, and I come first so to hell with everybody. It took a lot of years for me to do that but I had to because I found myself being pulled from all directions and it’s not a good place to be...” (P5)

“I think initially it’s a fear of embarrassment and rejection when we take the children out people will stare and stuff and eventually you think my child deserves an opportunity to be socialized, you develop a rhino skin, and people just have to deal with it.” (P10)

These sentiments were shared predominantly by the parents of teenagers and young adults. This indicates that society's perceptions of ASD are still problematic, therefore to live a normal life the parents decided to place peoples' opinions aside, educate them and proactively expose their children to different social settings. The mothers of younger children adapted their schedule or environment to accommodate for the children's antisocial behaviours. For example, one mother would take her child to the park very early in the morning to avoid people and limit the possibilities that her son would need to share his swing with another child.

In addition to the stressors faced with their children with ASD, the parents also had to deal with issues with their neuro-typical children.

4.5.4 Parenting the Neuro-Typical Siblings of children with ASD

Neuro-typical is a term used to describe people who do not have ASD (Kim, 2013). Through literature and the results of these interviews it is known that the entire family is impacted by the condition of ASD.

The parents tend to focus more attention on the child with ASD, resulting in the typically developing children expressing feelings of rejection, and parents' trying to create normality for these children.

".....I guess unintentionally our lives are focused on the autistic child... that the other siblings can get pushed aside unintentionally..." (P5)

Accounts of positive character traits being developed by the neuro-typical siblings are also shared in the study.

"I must say they have become very responsible and very socially aware with people." (P4)

Although there were positive aspects like character building and maturity observed in the typically developing siblings in response to having a sibling with ASD, the parents shared their concerns over these children as well. The mother with siblings in their twenties noticed that having a brother with ASD had a positive influence on her typically developing children. They had to mature quickly, take responsibility and cope in a different world. They had difficulties, however they became active in advocacy work, and embraced the new purpose that came into their lives. Their brother was diagnosed when they were 12 and 11 respectively.

“And I think with having them older has made a difference because I rope them in with all the advocacy work ... there is a greater understanding... when (T) was diagnosed ... suddenly they had to take on greater responsibility because mom just had to step back and let them be

they have become very responsible and very socially aware with people...you must remember that, there is some positive, although the negative is bad, it's tough bringing their friends around...you know come to your place normal teenager thing, it was tough going out as a family you know it's always tough going out as a family making them aware and making them conscious of disabilityshown in their career paths.... lean more to the health care professionals.Even now when my daughter complains I say “excuse me” (lots of laughter) you're ok you have all your faculties about you. She finds it very hard sometimes, but yes they become very self-reliant as well.” (P4)

The other parents had younger children. They expressed concerns that their typically developing children felt neglected, had no-one to play with and the smaller children needed as much attention as the child with ASD. The typically developing children verbalized these concerns to their parents or acted out when they did not get attention.

“ I guess unintentionally our lives are focused on the autistic child, that the other siblings can get pushed aside unintentionally and as much as I try to make my

son, my second child Mark who is 11 have a normal life, it is different ... our life in general is different and how can you give him a normal life when he is in a different environment. So at the moment where I am standing is my greatest worry is not so much Eric who is Autistic, but Mark... because here is a child that is living in an autistic world but he has to go to a normal school, and when you look at Mark he is different, way different, because of his upbringing, because of his environment so my biggest worry is more Mark than Eric at the moment.” (P5)

Another sibling of a brother with ASD was vocalizing being unloved and was always stressed by her brother’s aggressive outbursts.

“She (sibling Katie) is 12 years old, it may not be immediately obvious but we know its taking strain on her, she’s stressed. She got to the point where she has to be prescriptive with Andrew eg she would say, “no don’t do thatwe have to bend the rules, the bottom line is we have to adapt our lives around him, and it’s quite messy, and Katie suffers the brunt of it.” (P6)

“She feels neglected... she says we love Andrew and we don’t love her. She has started to vocalize that now. She has become very needy.” (P7)

“She’s getting second best.....yes she’s got to play second fiddle.”(P6)

Research shows that the siblings of disabled children adjust and adapt to their stressors in different ways. For the most part they cope well, but some are at risk of experiencing adjustment difficulties (Giallo & Gavidia-Payne, 2006). In an article titled “Paying for Finn” the father shares affectionately how his typically developing daughter “looks out” for her brother, draws him pictures and communicates with him in her own way (Howe & Braverman, 2013).

All the parents with typically developing siblings focused on the needs of the child with ASD, adapting their social calendar around this child. However they also made

adjustments to accommodate for the other children by planning special “date” days and sending them to grandparents. This allowed the other sibling to have respite, and appease the parents’ concerns about neglecting their needs. Other parents changed their typically developing child’s environment completely.

Controversially, two families had made arrangements to send their typically developing child to live with other family members in order to give them a “normal” life. Another couple encouraged their typically developing children to embrace the world of autism, and facilitated their involvement in advocacy work.

It will only emerge later in years to come, what the effects of parenting styles and context on these children will be. This needs further investigation and research.

4.5.5 Making or Breaking the Marriage Relationship

Experiences within the marriage relationship differed depending on the couples. One couple was divorced due to conflict about having another child. The wife was afraid they would have another child with ASD. However, others had struggled in their relationship, but had found strength from each other, which cemented their relationships further.

“...we are fortunate that we’ve been able to stay together for so long, in many cases the marriage does not last, we are just lucky that we have been able to work through the issues together. It has been a huge challenge let me tell you right now”. (P10)

The speculated rate of divorce in parents of children with ASD is 80%, however there is no empirical evidence to support this speculation (Freedman, Kalb, Zablotsky, & Stuart, 2012).

Hartley et al ran a longitudinal study of 391 families with adolescent and young adults with ASD with specific attention to separation and divorce issues. The data was compared to normative studies of the same age group with parents of typically developing children. The divorce rate with the families with autistic children was 23.5% and the rate in families with typically developing children was 13.81% (Hartley et al., 2010). Although this is one study with a fairly small population the rate of 23.5% is significantly lower than speculated 80%. Regardless the rate of 23.5% is almost twice that of 13.81%, which shows the immense strain of having a child with ASD on a marriage. There is evidence that the risk for divorce is no higher in families with children with ASD than in families with only typically developing children (Freedman et al., 2012).

In the current study there was a couple who were divorced and the others were still married. One mother stated that her husband had been close to leaving her due to the stress, but with support re-evaluated his decision. Despite the marriages being intact the participants expressed instances of marital discord, and that having a child with ASD placed tremendous strain on the relationship.

In contradiction to these results, others shared how the experience of having a child with ASD had strengthened their relationship. Furthermore participants expressed the need to keep communication lines open and to support each other.

“In the 13 years we have been together we have been through a lot as people and been thru more than people who have been married for a life time... we have really been through a lot and as much as sometimes we fight, whatever we seem to be closer you know more closer and more accepting of each other” (P7)

“ Everything just strengthens our resolve, our love, for each other more now. I have become a lot more protective of my family, the relationship I have with (Pat) as my wife and the mother of my children, I don't let them mess her around. I have to take on that role being father and husband.” (P6)

Research confirmed the strain marriages take in caring for a child with ASD, however it also attests to the fact that parents can draw closer to each other from the experience (Johnson, 2012). After a period of adjustment, parents re-evaluate their goals and find new ways to cope in their family and married life (Johnson, 2012).

Research has shown that couples feel communication is essential to keeping their marriage together and wives expressed that they needed ‘me’ time in order to “give back” into their marriage (Ramisch, Onaga, & Oh, 2013).

Keeping communication lines open, having their own passions and hobbies, and spending time together away from the children, were ways the current research participants nurtured their marriage.

The parents shared various ways of coping which is the second theme.

4.6 Theme 2: Coping in Parents of Children with ASD

This theme was divided into three primary subthemes namely Types of Coping and Strategies Used, The Road to Acceptance and Gendered Differences in Coping with ASD”. Overleaf, figure 4.3 provides a diagrammatic representation of this theme

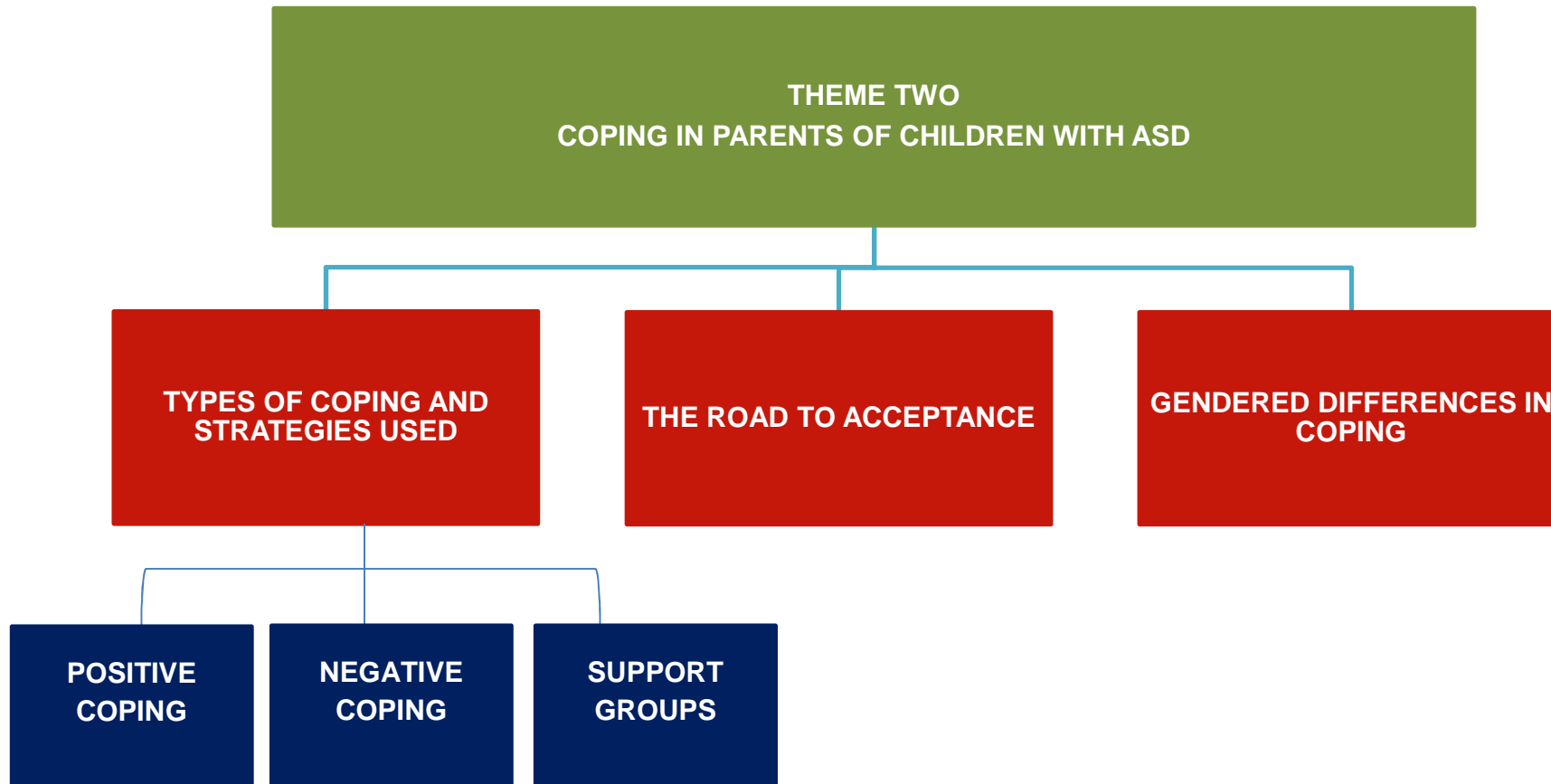


FIGURE 4.3: THEME TWO COPING IN PARENTS OF CHILDREN WITH ASD

KEY: MAIN THEMES PRIMARY THEMES SECONDARY THEMES

4.6.1 Types of Coping and Strategies Used

The types of coping employed by parents were either positive or negative. Using support groups as a form of coping was also investigated further.

The parents in this study used a variety of coping strategies that dealt with their specific stressors. Their types of coping did not match the Lazarus and Folkman Transactional Model of Coping exactly, but elements alluded to in the model were noted. The model looks at appraising a stressor and deciding on an effective coping strategy. In the current study, the researcher has found that the parents have continual stress of varying degrees, therefore strategies are put into place before a stressor arises to reduce the effects of the problem. It seemed that most of the parents were coping with the strategies that they had put in place prior to a problem arising.

4.6.1.1 Positive Coping

A positive strategy used to cope with the child with ASD was problem focused coping, as this dealt with the direct needs of the parent, and facilitated change in the environment, thereby alleviating the stressors. These strategies included finding moments to be at peace with their child, have 'me' time and environmental adaptations to aid coping.

"... I enjoy being in my kitchen, I enjoy cooking, I enjoy being in my garden... you know touching soil and planting so to fit in those things is very important..." (P4)

Finding a passion aside from their children and their relationship with God helped parents cope better. By doing something totally different the parents go into "a different world". Parents found respite in following their own passions and hobbies.

“... I have my own passion aside from my kids and home. My passion is rugby..... that is something that takes me away from the situation and it’s a passion that I can run with” (P10)

Talking about it; reading about it and educating others about ASD assisted in helping parents of children with ASD cope. Journalling was a method employed by one of the mothers to cope.

“I have always (kept a journal), since the boys were little..... it is like conversations with God.” (P9)

Parents spending quality time together as a couple helped them cope in their adversity. They captured snippets of time together at home in the evenings.

“... when the kids have fallen asleep we watch a movie we enjoy it ... we just watch what we want to watch uninterrupted, in our room insulated from any worries or troubles that befall us.” (P6)

The parents also employed negative types of coping and emotion focused coping strategies, which will be discussed later.

In relation to positive coping the researcher would like to propose that the parents used a proactive method of coping as a type of coping that they employed:

Proactive Coping

As the parents dealt with stress every day they become familiar with the stressors they encountered. To counteract and reduce these stressors the parents incorporated strategies that became a part of their daily lives. Proactive coping is like problem

focused coping, as it deals with the direct needs of the parent, however, is set in place before the stressor arises, akin to antecedent coping.

Proactive coping may include changing the environment or schedule, further education, advocacy, structure and discipline. Changing the environment or schedule requires the parents to be flexible. They will leave appointments or cancel functions at the last minute depending on their child's mood.

"When Andrew was small we could not get him in the car and had to take him naked to school, take him to crèche with his clothes in the car, then get to the parking lot to change him there,... that was just ridiculous, and that was just how it used to be you know. So now anywhere we have to go, if we are late, we are late" (P7)

"I try to go towards when it's very early when it is quiet so he can have his time to play because he does not understand that each child has to have a turn..." (P2)

Parents shared the realization that knowledge was empowering and reduced their anxiety levels and stress. Reading and keeping up to date with the latest information on ASD was a beneficial method of coping.

"That is how I also cope with it, talking a lot about it, reading up about it and that for me gave me some kind of release" (P9)

Sharing knowledge with other parents at support groups was another proactive way of dealing with their own stress.

"Of late I have given one talk to parents at AIA(support group)... for parents it was very cathartic for me as well. To be able to talk, to be able to sit down and parents are asking me questions, parents with young kids and we are able to assist where I could. It's nice to feel you are actually finding a purpose outside

your adversity to be able to assist others and I am doing another talk in May to a group on retreat so the talking about it does help to relieve, to release that emotion it helps you to heal so that is another way.... it was very painful to, but now I am able to talk to people. When I spoke to that group it was a huge release for me and now again in May I will speak. And I find that by me talking about it I am actually able to communicate and get through to other people who might be feeling or experiencing a similar type of thing. Its such a joy.”(P10)

This father's initial coping in talking to others was emotion focused and now has become a proactive way for him to cope; giving purpose to his struggles and walking the journey of autism with others.

Another way to cope proactively and look outside of oneself, as expressed by the parents was through advocacy work.

“...and also the advocacy work I am driven by that, and hmm bringing people together... we had a Spit meeting on Saturday and we had eighty parents there and it created mounds of networking, of people speaking to each other engaging with each other, professionals engaging with you. So that drives me... and I spend a lot of my time doing that... I think it's my saviour...” (P4)

This research has shown that proactive coping is about providing routine and structure for the child with ASD as well. Strict discipline and expectations put in place at an early age allows the child to develop the necessary social skills, and gives the parent a solid foundation to reduce potentially stressful situations.

“...and I was in terms of behaviour modification I was very big on that, very big on discipline, because I felt how do you establish where the condition ends, and normal naughtiness of a child begins? I was always very firm with them all the way through I always said I expected a certain standard of behaviour from them

at all times... and maybe that is the thing that has helped us. Because how they behave – they behave suitably when they go to Church, they behave nicely so that behaviour is respected. We go to the restaurant and if Peter doesn't tow the line I say we spoke about this, this is not the kind of behaviour I expect. So I think for me it was very important in that I really pushed the discipline line with them and maybe it's paid off, I don't know but maybe I'm pulling at straws... but I think it has helped." (P10)

Some positive emotion focused strategies were enjoying times of peace with their child, talking to a friend and journaling.

One mother kept a diary and called it conversations with God. It was her way to release her frustrations and work through her problems in a constructive way. This brought peace for her in the midst of her emotional turmoil.

Respite Coping

Respite coping was a form taken by parents to take themselves away from the stressors faced with a child with ASD. Respite is a short break from the normal stressors of one's life. Usually a loved one is sent somewhere, like a day care, for the carer to receive respite or a break. All the parents expressed the benefit of sending their child to the centre daily. This provided the parents with respite and peace of mind that the child was safe and stimulated, and gave them time to restore themselves.

As it was difficult to find child minders adequately trained to care for a child with ASD, the parents made times of respite for themselves at home by watching movies, and having their own interests outside the home such as running, enjoying 'me' time and spending quality time together.

Sometimes parents were unable to implement positive coping strategies and negative coping methods were also employed.

4.6.1.2 Negative Coping

A negative response to dealing with the child's behaviour was physical discipline and was a response from a parent as they could not cope adequately.

"Yes it was very hectic. My husband at one stage he used to lose it, he used to actually hit (John) a lot, so it was very difficult, it was his way of dealing with it..."
(P5)

The parents displayed emotions of sadness and anger to release stress, by crying or screaming as a way to vent their pent up emotions.

"I cry, when I was totally irritated and angry I started crying". (P1)

The researcher would like to propose an opposite of proactive coping that emerged from the study, namely reactive coping.

Reactive coping

Reactive coping would include strategies that are emotion focused and ineffective for example screaming, crying, venting and physical discipline of the child. These strategies seemed to be employed with younger children. At this stage the parents may not have adapted to or accepted ASD, and the younger child's symptoms are therefore more difficult to manage. Crying was considered a positive emotion focused strategy for most parents especially mothers. Understanding that they could not always change their circumstances, having an emotional release allowed the parents to continue facing their stressors. Emotional release also came from sharing with others in the same situation in the form of support groups.

4.6.1.3 Support Groups

Parents had mixed feelings about support groups and their participation in them.

“For me I was not sure whether being surrounded by people who had similar challenges was necessarily the healthiest thing... ok how much can you talk about the same thing to the same people who have been through the same thing.” (P10)

Despite reluctance most parents participated in one particular support group and benefitted from it. Parents were involved in different capacities in the support group. Some just attended the social functions and others were guest speakers.

Support groups were viewed with mixed feelings. Some parents found them helpful whereas others did not want to share their stories continuously, finding the topic of ASD morbid. Another mother was grateful for the support group she attended as it saved her marriage. However, she did find it difficult to find the time and energy to attend regularly.

“You are dealing with it and you know how you absorb what other people are going through? You want to talk to people with different challenges. That’s why I think for me the whole support thing, it works for some people even with PAC, with PAC I found we talked about same old, same old, and then you are also comparing... your child can talk, and mine can’t, and you just get more depressed...” (P9)

As a researcher this answers my personal question about parents not attending support groups or seeking help. They live with autism all day, and now they must go speak about it on the weekend as well! I would go insane! Support groups need to be different, social functions and opportunities to just be....with someone around to cater for the children (Researchers Diary 16th November 2013).

Parents either started accepting their child's condition on their own or with support from others.

4.6.2.1 The Road To Acceptance

Accepting their child's condition was a crucial aspect that the parents needed to consider in order to cope better. This journey included mourning for all the dreams they had for their children that would never be realized.

"... it's like mourning a death of your child because for me he was normal... ok he was slower but normal...." (P7)

As mentioned previously the high levels of stress experienced by parents around the diagnosis of ASD are similar to the stages of grief (Siklos & Kerns, 2007). The stages of grief were introduced by Elisabeth Kubler-Ross in her book "On Death and Dying" in 1969. The stages as conceptualized by her were: 1) Denial and Isolation, 2) Anger, 3) Bargaining, 4) Depression and 5) Acceptance (Kübler-Ross, 1969). These stages are most likely felt by parents as their children are typically developing at birth until 18 months old. Therefore they have hopes and aspirations as they would for a typically developing child. Parents face these stages when the child is diagnosed with ASD. The stages will be discussed in more detail with specific reference to ASD. The emotions noted in the stages were verbalized by the participants during the interview.

In the denial and isolation stage the person denies the reality of the loss of a typically developing child, holding onto the dreams and hopes for that child as a defense mechanism to buffer the immediate shock of the news. As reality emerges, the person experiences anger as he cannot cope with the reality of having a child with ASD. Bargaining begins where the person rationalizes, for example, "if I were a better parent this wouldn't have happened" or bargaining with God occurs, promising an action or making a vow in return for a better prognosis. Depression and Acceptance follows thereafter. Depression can be a clinical onset of depression, or a deep and quiet sadness in order to grieve privately. Acceptance is a period of withdrawal and calm, not

necessarily depicting happiness (Axelrod, 2013). The stages are not necessarily experienced in order, and one may spend a longer time working through certain stages than others (Axelrod, 2013).

The participants in this study experienced similar emotions, however the denial stage was described as shock and was short lived. There appeared to be more relief at knowing the diagnosis and prompted action. The other emotions explained above are emotions expressed by the participants in the course of dealing with their child with ASD. The emotions of isolation, rejection and fear were shared by some parents.

“ I mean it’s the normal thing of going through denial crying then you do the net and the Google number and you hear the worse things under the sun so you think it’s almost like a death sentence.... rejection, you don’t only feel your child has been rejected, you feel you have been violated and rejected so in that sense it is really, really tough and a tough journey for most parents...”(P4)

“Well initially it was very difficult, at first it was disbelief, I think you start off with that, confusion... the strangeness of dealing with this for the first time, and then I think with me as I have learnt more about Autism, then fear set in... and heart break...” (P9)

Despite experiencing these emotions it is different to the stages of grief. Although they mourn the loss of what may have been, parents tend to rally and fight for this child because they love them, and it is not a permanent loss, as in death.

This is personified by Jeff Howe and Beth Braverman: “Despite it all--the broken glass, the tantrums, the bite marks, the faeces pollocked across his bedroom wall--I quite love my sweet, strange boy. There are mornings when I get up early and steal into Finn's room. I drift back off to sleep, but wake to find him smiling mysteriously and running his hand over my cheek, entranced by the sensation of stubble against his inner arm. Then he giggles and tries to do a headstand on my stomach. Finn is my son, and I love him. It

has come as unwelcome news, then, that it's not clear how we'll afford to give him everything he so desperately needs.”.

The need for acceptance of ASD in a child is shared by participants. Their acceptance may share elements of similarity, however it is a different acceptance to the one described in the stages of grief. Acceptance is a concept that needs to be developed in order to move on and cope adequately with your child with ASD.

One mother shared with intensity the road that she has had to walk. It has taken her ten years to accept her son's condition. Her son's extreme symptomatology, including aggression, co-morbidity and continual experimentation with medications (under medical management) became too much for her to manage. She had a breakdown and suffered from severe depression. She described herself as emotional and found it difficult to switch off.

“For me as a parent, as a mother, I know it's a female thing I took it very hard, I ended up with severe depression. It was almost like I had a breakdown. Andrew is 10 now, and towards the end of last year I really started accepting it, it took very long to accept it. I was actually explaining it when we went for therapy, and it's like mourning a death of your child because for me he was normal, ok he was slower... but normal” (P7)

Her child is higher functioning and has progressed up the spectrum. However, his initial “normality”, extreme symptomatology, co-morbidity and her mental health made the road to acceptance long and arduous.

Another mother shared how she was expecting society to accept her children, however she had not accepted them herself. She believes acceptance is a process and there are levels to acceptance.

“Acceptance. Yes there are levels of acceptance – and there is always a maybe, ‘if’ kind of thing. But it’s a process... a daily process, some days are better than others, but I think it will be a life time, our journey of acceptance. I don’t think acceptance just happens...” (P9)

In this study, acceptance of their child’s condition and the “new” life they needed to embrace was achieved by parents as a protective factor that would assist them in moving forward. This acceptance allowed parents to become advocates for ASD, fight for their children’s’ rights and take on a proactive stance towards their daily struggles. It was evident that once the parents had accepted their situation, they were able to cope better because they began dealing with the real issues.

4.6.3 Gendered Differences in Coping with a Child with ASD

It was found from the study that men and women coped differently in raising their child with ASD.

All the parents of children with ASD felt that men and women coped differently with the condition.

“Men generally don’t speak about things, they don’t speak about their issues. You know they could be crying inside... but they are not going to tell you that...” (P5)

The different parenting styles also assisted in the parents coping. The one father was strict on structure and discipline, which helped him cope with his children’s behavior.

“...I was very big on that very... big on discipline.....how do you establish where the condition ends, and normal naughtiness of a child begins?”. (P10)

One mother stated that she was more emotional, and that her husband's ability to problem solve and be less emotional made him accept the situation quicker.

"Bert actually accepted it quicker than me, he deals with it better than me. For me it's just late because I am very emotional..." (P7)

In coping with Autistic children, mothers and fathers cope differently (Lee, 2009). In the study all participants agreed with this statement. A variety of coping strategies are used by men and women, however women use a greater variety of methods and seek help quicker than men (Daughtry & Paulk, 2006). Research confirms that women tend to employ emotion focused coping (Garnefski, Teerds, Kraaij, Legerstee, & van den Kommer, 2004; Howerton & Van Gundy, 2009). These emotion focused techniques include crying, seeking help and pondering on their stressors (Howerton & Van Gundy, 2009).

When events are uncontrollable and higher levels of stress are experienced, avoidant or emotion focused strategies are used more readily (Howerton & Van Gundy, 2009; Lee, 2009).

Mothers employ problem focused and avoidant coping more easily (Lee, 2009). Men and women made use of *social support* and *reframing* as coping strategies to cope with their child with ASD (Luther, Canham, & Cureton, 2005).

Coping is a process which is not clear cut, and strategies used are interrelated (Folkman, 1984; Howerton & Van Gundy, 2009). Participants used a variety of strategies, and some had a preferred strategy that worked for them. The current study showed a difference in the men and women's coping strategies where men tended to remain in the avoidant coping style longer than women at the time of diagnosis. Women relied on this strategy for a shorter period and moved onto emotion focused strategies like crying, venting and talking. The women used problem focused methods

like changing their environments in order to cope better. The quicker shift from avoidant coping for women was most likely due to the fact that they are the primary caregivers, and could not afford to languish, but had to deal with the day to day tasks. Fathers focused on work and income generating activities which allowed them to avoid facing the day to day challenges of their child resulting in suppressing these emotions.

“He’s been away from the house, he’d just avoid it , being with her. That was his way of coping, I mean he would work but after years of it I picked up he was trying to be away because he couldn’t cope with her. That was just his way...”
(P1)

One mother who is an Indian Muslim stated that the differences between men and women were cultural. She related this to her context as well as the South African context.

“We chat, men don’t. It’s just a cultural thing and even if you find our support group meetings and we have our awesome super moms pamper day, I mean you’ll find more women than you will find men, it’s just a fact. If we could change that dynamic as well then men just need to go and speak to each other not necessarily you but some other father who is going through the exact same experience because it’s their tough journey as well.” (P5)

“Men generally don’t speak about things; they don’t speak about their issues. You know they could be crying inside but they are not going to tell you that...”
(P4)

In the majority of South African cultures it is less likely that men will talk about their difficulties. A father in this study shared that autism is a “morbid topic to discuss” and would rather deal with it on his own. Another father expressed the same sentiments, and escaped by working and playing sport.

"I think I was, to a certain extent I was, I did a lot – besides releasing, I did a lot of thinking about it in my head. I did the grocery shop, walking up and down those aisles was cathartic for me. I worked through a lot of things in my mind and somehow I coped, buried myself. At one stage I was involved in club rugby, school rugby and whatever... sometimes I went too far on one side in order to cope... and eventually it took strain on me and parent 1 said to me I need to give up one thing. Maybe I wasn't coping because my blood pressure was high and that kind of thing (P10)

*So physically your body started saying ok something is not right (moderator)
Yes so I think ever since I have opened up I think things seem to be better, a lot better. (P10)*

At that time I felt parent 2 was running away from the situation involving himself in everything else, running away from the situation. (P9)

To escape (P10)

To escape from what was going on... he just could not deal with it (P9)"

Another perspective from a mother was that given their different roles, her husband's need to cope with ASD was different to hers. She was a full time carer for her son and her husband worked long hours. He generally saw his son just before bed time, for a short while daily when he was calm, therefore it was seldom that he saw or had to deal with his son's difficult behaviours.

Given all the coping strategies parents have learned and employed over the years, they provided valuable advice for other parents of children with ASD.

4.7 THEME THREE: A ROAD MAP TO COPING WITH ASD

This theme was divided into three primary themes namely Get out of Crisis Mode, Safe Guard your Relationship and Step by step Guidelines.

Advice given to parents of children with ASD may include information about the condition, schooling, managing difficult behaviours, nutrition and treatments available (AutismSpeaks, 2013; NIMH, 2011; Tilton, 2010). The participants shared advice that spoke specifically to the parents of autistic children. Their advice provides a road map for new parents who embark on the journey of autism. It also serves as a tool that medical professionals can use in caring for the carer. Overleaf figure 4.4 provides a diagrammatic representation of this theme.

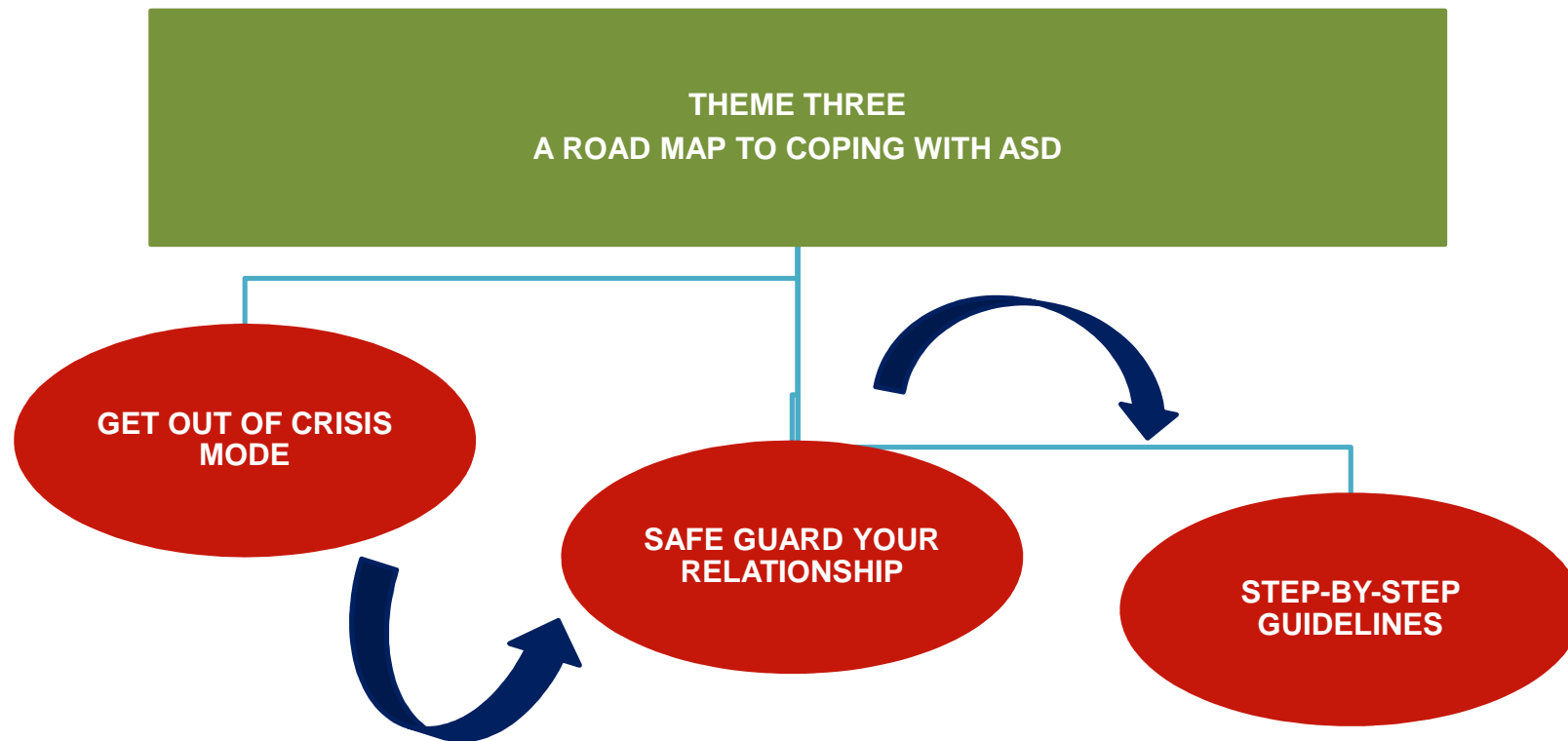


FIGURE 4.4: THEME THREE A ROAD MAP TO COPING WITH ASD

KEY: MAIN THEMES PRIMARY THEMES

4.7.1 Get out of Crisis Mode

Most parents felt that it was beneficial to get out of crisis and attain stability. This involved getting a good night's rest, connecting with other parents and finding the right doctor.

"...how do I get out of crisis mode Come to support group at least if you come to one than you can hear what others are saying and you realize you are not alone.... get you a little stable and have that peace at night because you are up most nights, so you can sleep because sleeplessness is a huge problem...." (P4)

One mother shared from her experience in advocacy work where she has counseled and walked alongside many parents. "Getting out of Crisis Mode" encourages you to deal with the practical issues that can provide stability before embarking on the long journey. The focus is to deal with the specific problems that parents are dealing with. The parents may not be getting sleep, or their child may not be eating, or their behaviours are just too difficult to handle.

Sleep difficulties are common in children with ASD with a prevalence rate ranging from 44-83% of children experiencing difficulties with sleeping (Wiggs & Stores, 2004). The sleep problems are related to sleep onset and maintenance (Wiggs & Stores, 2004). The following quote confirms a father's difficulty with his daughter falling asleep.

"She was up till 12 (at night) and I lost a large amount of sleep" (P8)

Each parent should be advised according to their immediate practical needs. "Getting out of Crisis Mode" also includes networking. Putting parents in touch with others through support groups or other parents you may know is a useful exercise. This intervention will encourage the parents to realize that they are not walking this journey alone, and others understand their struggles.

*“...so how do we get out of crisis mode? Whether it’s to help get your child to bed so that you’re sleeping you know so you give the advice on an immediate level, how do I get out of crisis mode Come to support group at least if you come to one then you can hear what others are saying and you realize you are not alone.... get you a little stable and have that peace at night because you are up most nights, so you can sleep because sleeplessness is a huge problem....”
(P4)*

The quote above confirms the fact that carers, together with their children, need support. Cashin (2004) confirmed the range of emotions felt by these parents results in turmoil. Providing the necessary support will aid the parents in transforming their lives by creating realistic goals and expectations (Cashin, 2004).

“Getting out of Crisis Mode” would also include guiding the parents to the correct diagnostician so that the correct treatment and care is given for the child. One couple also advocated for a good relationship with the doctor and feeling comfortable with him or her.

“ I would tell them to get a good doctor that you feel comfortable with that you can have a rapport with, because you can have the best doctor... but you don’t have that relationship with them, you have to be comfortable your child has to be comfortable with them.” (P7)

Once the parents have taken care of themselves and are able to cope with the immediate and daily needs of their child, focus should be on maintaining the marriage.

4.7.2 Safe Guard Your Relationship

The parents felt that due to the many stressors of ASD, the demands placed on them were huge. They believed one should work on developing a strong marriage as support was essential.

“...just the help and support they can give each other first.... As long as they are standing together...” (P3)

“Just the help and support they can give each other first before they can help their child. As long as they are standing together, they will be able to cope with this child” (P3).

These encouraging words from a mother speak of the unity and stability that is needed in the parental relationship in order to survive the stressors of ASD.

Although the mother traditionally takes on the primary caregiver role, the father has an important role to play in providing financially for the family, maintaining marital stability and family unity (Meadan, Halle, & Ebata, 2010). Other than caring for the children and the home, the mother needs to consciously make time for her partner. This ability to spend time together is difficult as the mothers struggle to find time for themselves (Kenny & Corkin, 2011; Ramisch et al., 2013) . Making time to spend together was something two couples said was essential to nurturing a marriage.

“ I think also we do support each other, we are able to talk to each other about things, we work through issues like that and we are fortunate that we’ve been able to stay together for so long, in many cases the marriage does not last , we are just lucky that we have been able to work through the issues together.

It has been a huge challenge let me tell you right now. It places a huge strain on our relationship and marriage and we have just been fortunate enough to work through it and support each other in many ways and I think that has been our

saving grace. We have our own passions but we have also come together to help cope so, but it's important to have an outlet to take you away from the situation, I think if you are in that situation the whole time it's not good." (P10)

Parents need to make time for themselves individually, in the form of hobbies, sport and other outlets in order to give back into the marital relationship and family. Communication was another area deemed as essential in keeping the marriage together (Ramisch et al., 2013).

"Support each other as parents, I think you have to communicate and keep the channel of communication open."(P1)

4.7.3 Step By Step Guidelines

Parents agreed that there was no manual to raising a child with ASD, however one couple shared step-by-step guidelines that will help new parents gain fresh perspectives and cope better. These steps will be shared in detail in the discussion.

The data provided themes about experiences, perceptions, ways to cope and advice which will be discussed further in the next chapter.

This study confirmed that there is no recipe book to coping with ASD. However, there are guidelines from parents who have walked this road.

"The doctor said to us that there is no hard and fast way in treating Autism." (P6)
" I think a lot of the stuff we have learnt about the kids its hit and miss, I don't think there is a manual on exactly how to do this. I just went about it the best way that I could and we hope that we have done everything." (P10)

Parents of children with ASD agree that they have nothing in common due to the broadness of the spectrum and the uniqueness of each case (J. B. Howe, 2013). However to survive the journey of autism a couple in this study, who are walking the road with two young adult autistic boys, share the following guidelines that may help parents embarking on this journey.

"...mourn for your child... but not forever. You need to also go through the grieving process you need to and once you have gone through that you have to realise that this is your child at the end of the day... this is your child and just do

the best you can. Don't try to be a super mom..... , love your child and do whatever you feel you have to and I always go with what you feel is right , never what's in my head....experience has taught me to go with my heart and most times it works. " (P9)

"You need to have an outlet that takes you away from the situation, whether it's sport or a hobby You need to have your own private space and time to process it (living with Autism)." (P10)

"Develop a rhino skin mentality... you need to realise that your child deserves a place in society." (P9)

"Don't hide your child away." (P10)

"Go out there and carve that spot in society. They deserve it, you deserve it and you need to empower yourself with everything you need to know to reach that stage ...you can invest in them. Knowledge is power." (P9)

"Intervention is the key" (P10)

“Don’t procrastinate. Your child is just a child but autism is just that, and a child is still a child, his personality, his character all that makes him..... Just to embrace your child and it’s just a journey as I say, it’s a journey, it’s a lifelong journey; it’s something special and it’s not about what you can do for them it’s what they teach you, I always say they are our biggest teachers, our children will be for me our biggest teachers, they will teach you things... tolerance, they never say a unkind word, they never lie... they don’t know what it is to lie. (P9)

“Spend time with them even if it’s just silent time. Time is time. Time is quality time as long as you are together and you are just with them, it’s so important.” (P10)

“...and take them everywhere...” (P9)

“That’s a challenge that’s the biggest challenge.” (P10)

The Road Map to ASD can be used by other parents and is a work in progress. Professionals can use it as a supportive tool for new parents facing the long and arduous journey of Autism.

My question as researcher and clinician has been answered. I began this journey feeling frustrated and wondered why parents don’t seek help. My frustration is based on passion for them knowing that support will help them in their journey. However, I see now that parents of children with ASD suffer tremendous strain, stress and heartache. It takes all their energy, physically, mentally, emotionally and spiritually just to get through a day. I have gained insight into the difficulties they face and realize they do what they can to survive. I have also realized that what I consider as supportive is not necessarily beneficial and relevant to all parents. They have taught me there are many ways to cope and survive the journey of Autism. (Researcher’s Diary, 6th December 2013)

CHAPTER FIVE

CONCLUSION

5.1 CONCLUSION

This study began as a reflective journey for the researcher to gain deeper understanding into the lived experiences and coping strategies of parents of children with ASD. Given the high demands and burden of care experienced by parents of children with ASD (Deffner, 2013; Gray, 2006; Phelps, Hodgson, McCammon, & Lamson, 2009) and the researcher's clinical experience of parents not seeking support it was deemed relevant to investigate this area further.

The objectives set out for the study have been realized.

- Understanding into the lived experience of parents of children with ASD has been gained.
- The nature of the stressors experienced by parents of children with ASD has been explored and unpacked.
- The positive and negative coping strategies these parents employ to cope with their children with ASD have been investigated.
- The positive meaning gained from caring for a child with ASD was found and explored further.
- Recommendations for intervention strategies that may be used by health care professionals to support parents of children with ASD have been generated.

The main themes emerging from the interviews included experiences, perceptions and coping of parents of children with ASD, and a road map of advice for new parents of Autistic children.

Although the high demands and burden of care experienced by parents of children with ASD was confirmed by the parents in this study, the positive meaning derived from raising a child was as significant.

The parents experienced a sense of gratitude and joy in having a child that taught them to be patient, appreciate life, empathize with others with disabilities and view life from a different perspective. Some parents described their children as gifts from God and felt privileged to be their parents. The positive meaning gained was expressed by all parents, however it was deeper and more life changing for the parents of older children as opposed to the parents of younger children. This was as a result of the higher demands and dependency placed on the parents of younger children. The parents of older children had opportunity to see their children improve with age, develop appropriate coping skills and “grow with their children”. The parents of older children described their children as gifts from God and gained deep existential meaning from raising a child with ASD. These positives could not be appreciated by parents without having experienced the high cost of raising a child with ASD.

The high costs of having a child with ASD were felt by the parents from the time of diagnosis. These demands were characterized by emotional strain, stigma from family and society, marital strain and discord, health problems and difficulties with their non-autistic children’s adjustment. The parents were mostly relieved by the label and knowledge they had gained from obtaining a diagnosis but were overwhelmed by the prognosis and permanent status of the condition. Ignorance around the disorder was shared by parents, family and society alike. Parents became proactive, educating themselves to increase their awareness and knowledge of ASD. However, family members and society generally stigmatized parents and their children with ASD as they did not understand the condition. In specific response to stigma from society the parents were resilient and made every effort to socialize their children.

Socializing their children included exposing them to the community, family events and taking them everywhere. This was a challenge for parents as antisocial behaviours from children were seen by society as a direct result of poor parenting skills and disobedient children. However ‘developing a rhino skin’ where parents ignored society’s opinions and persevered with socializing their children resulted in positive rewards.

Increased exposure of the children also allowed the community to become familiar with them, and led to the destigmatization of Autism.

In some instances, the neuro-typical siblings of children with ASD did not adjust well to the home environment and were sent to extended family to aid them in living a 'normal' life. This response was as a result of the parents' guilt in unintentionally neglecting their neuro-typical child, the high degrees of stress placed on the neuro-typical sibling, the parents' desire to provide a 'normal' life for their neuro-typical child and the intense behaviour problems the child with ASD directed to the neuro-typical sibling. A refreshing contrast is that one mother stated that her other children "just needed to deal with it" and they did. They developed empathy and greater responsibility. Each parent made the decisions according to what best suited their circumstances, personality and ability to cope.

Raising a child with ASD caused tremendous strain on the marriages resulting in divorce for one couple. Although attesting to the strain placed on their marriage, most couples felt that their marriage was strengthened by the adversities of having a child with ASD.

Other difficulties in raising a child with ASD were work related and financial factors. Mothers, specifically made choices to stop working or change their career focus. The parents' focus and finances were dictated to by the care of their Autistic child. The stressors experienced by parents were dealt with in a variety of ways.

The parents used both problem focused and emotion focused coping. The men and women coped differently. Men displayed more avoidant coping behaviours, initially and most experienced denial longer than their wives. The women initially responded with emotion focused coping which quickly became problem focused as they focused on the needs of their child. An emotion focused coping method used by parents that was positive and effective was crying to release emotional tension, talking to friends, journaling and enjoying moments of peace with their Autistic child.

The emotion focused coping methods which were reactive rather than proactive, were used by some parents. Examples of reactive methods of coping included screaming, crying, venting in anger at their children, and using physical discipline.

As the parents became aware of the potential stressors, they employed a proactive type of coping. This included adapting their environment or lifestyle, educating people about ASD, doing advocacy work and implementing discipline and routine for their children. Parents found that respite helped them counteract reactive methods of coping. Respite included having independent interests, spending time together and enjoying 'me' time. Most parents found sending their children to the stimulation centre to be a significant form of respite.

Joining a support group provided mixed feelings for parents. Although they understood the benefits of a support group and for the most part enjoyed those benefits they also expressed reservations about this as a potential form of support. These reservations included reluctance to talk about a morbid subject, reluctance to talk about ASD all the time, experiencing feelings of failure as others seemed to be coping better, and time constraints made it difficult to attend the groups. The parents preferred the social aspect of the groups as it was less overwhelming and felt more natural to talk informally about their challenges.

Acceptance of ASD seemed to be a prerequisite to coping with the condition. Accepting their situation helped the parents reach out to others. The parents who had accepted their child's condition and instituted subsequent lifestyle changes seemed to cope better. Acceptance was described as a process and some parents reached this point of acceptance at different entry points. It was harder to achieve acceptance if the emotional strain was too overwhelming for the parent, if the parent was in denial, and if they were using reactive methods of coping.

Advice for new parents of children with ASD included dealing with immediate needs to minimize the crisis of the situation, safe guarding the marriage relationship, mourning the loss of normality for their child. It was also advised for parents to develop a rhino skin and become resilient in relation to society's perceptions, seeking out timely intervention, and spending time with their children with ASD.

The study revealed an intriguing and insightful lens into the lived experiences of parents of children with ASD. Coping strategies were positive and negative. The best coping methods used by parents were proactive in nature, and included developing independent hobbies and passions, spending time together as a couple and alone, seeking respite opportunities, journaling, talking to others, educating people about ASD, engaging in advocacy work, and providing structured routine and discipline for their children.

5.2 LIMITATIONS

- The study was undertaken with a middle socio-economic population and did not represent the experiences of parents from lower socio-economic and disadvantaged backgrounds. Parents of children with ASD in rural and less resourced communities within South Africa would most likely have different lived experiences and ways of coping.
- There was limited access to fathers and therefore limited information on their perceptions and coping in this study. Couple interviews or one-on-one interviews may have increased the participation rate of fathers as focus groups were most likely intimidating for them.
- Although interviewing eleven participants was valuable and rich data was collected, interviewing fewer parents may have afforded the researcher time to revisit questions with parents to deepen discussion on topics such as being a working parent with a child with ASD and unpacking other interesting topics that arose from the interviews.

- The inherent limitation of qualitative studies is that you cannot generalize to bigger populations.

5.3 RECOMMENDATIONS

- Medical professionals including doctors, nurses and therapists need education and greater awareness of ASD and the implications on the caregiver, in order to provide an effective service to this community. This can be accomplished by providing talks at undergraduate level to health science and medical students so that awareness is instilled prior to graduation.
- Wider media coverage on a national and international level is needed to reduce stigma and increase awareness around ASD. A governmental campaign that provides a roadshow type education platform to rural areas would be beneficial. This may be done after educating and familiarizing community leaders with the condition and the benefits of early intervention.
- Further research is needed on the impact of ASD in lower socio-economic and disadvantaged areas.
- Education and implementation of a screening tool at a primary care level in clinics to improve screening and early intervention at lower levels in the health system.
- Therapists involved in caregiver support should receive guidance from parents as to the types of support they need and can relate to.
- Supportive interventions are required for the neuro-typical siblings of children with ASD within these families such as support groups, life skills groups dealing with conflict management and ways to cope better and socio-emotional groups where they have an opportunity to express their problems in a safe environment.

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APPENDIX 1
ETHICAL CLEARANCE



18 December 2012

Mrs DL Fewster 9252649
School of Health Sciences – Occupational Therapy
Westville campus

Dear Mrs Fewster

Protocol reference number: HSS/1189/012M

Project Title: A qualitative study to understand the experiences and coping processes of primary caregivers of children with Autism spectrum disorder”.

Full approval notification – Full committee reviewed

This letter serves to notify you that your application in connection with the above has now been granted full approval following your response to queries raised by the Humanities and Social Sciences Research Ethics Committee.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the school/department for a period of 5 years

Best wishes for the successful completion of your research protocol

Yours faithfully

.....
Professor Steven Collings (Chair)
Humanities & Social Sciences Research Ethics Committee

cc Supervisor Ms T Gurayah
cc Academic Leader Professor HJ van Heerden
cc School Administrator Ms P Nene

Professor S Collings (Chair)
Humanities & Social Sc Research Ethics Committee
Westville Campus, Govan Mbeki Building

Postal Address: Private Bag X54001, Durban, 4000, South Africa

Telephone: +27 (0)31 260 3587/8350 **Facsimile:** +27 (0)31 260 4609 **Email:** ximbap@ukzn.ac.za / snymanm@ukzn.ac.za

Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville



APPENDIX 2

LETTER REQUESTING PERMISSION FROM GATEKEEPERS OF THE STIMULATION CENTRE TO RUN THE RESEARCH PROJECT AT THE CENTRE



3rd January 2013

To Members of the Board
[REDACTED] Stimulation Centre
3 Baden Road
Westville
3629

Dear Chairlady and Members of the Board,

Re: Permission to conduct research at [REDACTED]:

I am currently studying my Masters in Philosophy of Group Work at the University of KwaZulu Natal, which includes a research component.

My research project is aimed at exploring primary caregivers' experiences when caring for a child who has been diagnosed and treated for, Autism Spectrum Disorder (ASD). The data collection method will be in the form of focus groups and one-on-one interviews.

The focus groups and one-on-one interviews will be approximately 90 minutes in duration, and participants are free to withdraw from the research at any time without any negative consequences to themselves. The focus groups and interviews will be audio recorded, but any reference to names and places and other personal details will be changed, in order to maintain anonymity. All data collected will be treated confidentially and with care. The focus groups and interviews will be led by myself and will be under the supervision of my supervisor, T. Gurayah of the University of KwaZulu-Natal. The focus groups will also include a co-facilitator who is experienced in working in groups.

It is hoped that this research will lead to a greater understanding of primary caregivers' experiences when they are so closely affected by ASD. A journal article will be published on the research findings.

I request permission to undertake the research at ; run the groups and interviews on the premises of over a few weekends; have access to the caregivers' personal details and invite the caregivers to participate in the research project.

Please find my ethical clearance letter attached with my research proposal being available on request for perusal.

Should you require further information about the project, please do not hesitate to contact me on 084 692 5899 or debbiefewster@telkomsa.net. In addition, you may also contact my supervisor at the University of KwaZulu-Natal for further information: T. Gurayah on (031) 260 7402 or email gurayaht@ukzn.ac.za.

Yours faithfully

Debbie Fewster

Student number: 9252649

T. Gurayah

Research Supervisor

APPENDIX 3

PERMISSION LETTER FROM GATEKEEPERS OF STIMULATION CENTRE

(to maintain anonymity the letter head has been deleted)

Non-Profit Organisation Reference: 031-777
Public Benefit Organisation Reference: 18/11/13/82

7 January 2013

To Debbie Fewster
Student Number: 9252649

Dear Debbie

Re: Permission to conduct research at :

Permission is granted by the [REDACTED] Board of Governors for you to conduct your research at [REDACTED].

You may have access to the [REDACTED] premises to run groups and interviews over weekends.

You may have access to the caregivers personal details and invite the caregivers to participate in the research project.

Participants are free to withdraw from the research at any time without any negative consequences to themselves.

All data collected should be treated as confidential.

We wish you every success in your research project

Yours faithfully

J. H.
For [REDACTED] Board of Governors

APPENDIX 4

INVITATION TO PARTICIPATE IN RESEARCH



8th January 2013

Dear Parents/Primary Caregivers

Re: Informed consent to participate in research at Pathways:

I am a Masters student running a research project as part of my Masters in Philosophy of Group Work which I am undertaking at the University of Kwa-Zulu Natal. The study has received ethical clearance and I would be grateful if you would consider participating in the project.

My aim is to gather information on your experiences with having a child with autism and how you have coped thus far. There will be various focus groups and/or interviews depending on the participant numbers.

The focus groups and one-on-one interviews will be approximately 90 minutes in duration, and you would be free to withdraw from the research at any time without any consequences. The focus groups and interviews will be audio recorded, but any reference to names and places and other personal details will be changed, in order to keep information given anonymous. All data collected will be treated confidentially and with care. The focus groups and interviews will be led by myself and will be under the supervision of my supervisor, Mrs. Gurayah of the University of KwaZulu-Natal. The focus groups may also include a co-facilitator who is experienced in working in groups.

You would have access to the research findings via a posted report or through a journal article.

Should you require further information about the project and would like to participate, please do not hesitate to contact me on 084 692 5899 or debbiefewster@telkomsa.net. In addition, you may also contact my supervisor at the University of KwaZulu-Natal for further information: Mrs. T. Gurayah on (031) 260 7402 or email gurayaht@ukzn.ac.za.

Yours faithfully

Debbie Fewster
Student number: 9252649

Mrs. T. Gurayah
Research Supervisor

APPENDIX 5

INFORMED CONSENT AND CONSENT FORM



PARTICIPANT CONSENT FORM

I, _____ (full name) hereby confirm that I understand the contents of this document and the nature of the research project surrounding the exploration of the experiences of primary caregivers with children who have Autism Spectrum Disorder (ASD). I have voluntarily consented to actively participate in this research project. I understand that the focus groups and interviews will be audio recorded for research purposes and that any personal or identifying details will be treated carefully and confidentiality and anonymity will be maintained. I understand that this study forms part of the research component of the Masters in Philosophy of Group Therapy that Deborah Fewster is undertaking at UKZN. I understand that this study has received ethical clearance and the ethical clearance number is.....

I understand that I am at liberty to withdraw from the focus group, interview or research project at any time, should I so desire. Any additional queries may be directed to the supervisor mentioned below.

Signature: _____

Date: _____

Deborah Fewster (student number 9252649) _____

Contact number 084 692 5899 or (031) 266 5028

Email: debbiefewster@telkomsa.net

Thev Gurayah (Supervisor) – gurayaht@ukzn.ac.za or 031-2607402

APPENDIX 6

INTERVIEW SCHEDULE

As the interviews were semi-structured the main questions changed slightly and other prompting questions were used. Below is an example of the main questions used in the Triad interview.

Interview schedule:

Introduction:

Thank you for agreeing to participate in this interview, the aim of the interview is to gain more understanding into the experiences, and coping methods of parents of children with Autism. My research interest is in the parents or primary caregivers as I would like to gain more insight into how they cope and how to help if they are not coping. It is hoped that this insight would help give professionals guidance how to best serve and help parents and to gain more knowledge in how parents cope. At the onset I am aware that sharing these experiences is an emotional process and I thank you for the privilege to listen to your stories. As you may feel vulnerable at any stage you are free to stop the interview at any stage. The interview is confidential and even though it is audio recorded, anonymity will be maintained by using pseudonyms for names mentioned in the interview and your names will be represented by a number. As your input is highly valuable please speak as loudly and clearly as possible so that your voice can be recorded effectively. Are there any questions before we start?

A. Experiences of parents/primary caregivers of children with autism:

- A 1. Would anyone like to start by sharing what it has been like having a child with Autism?
- A 2. How did it feel when your child was diagnosed with Autism?
- A 3. How has having a child with Autism impacted on your family and life style?

B. Coping as a parent/primary caregiver of autistic children

B 1. How are you coping? What do you do to cope?

B 2. In your opinion does your spouse experience having a child with autism differently and do they cope differently ? Is it different to you and how?

C. Positive meaning and experiences

C1 . What meaning have you derived from the experience of being a parent of children with autism?

C 2. How has having children with autism changed your life and view of life?

D1 Thank you for your valuable insights and experiences shared. Lastly to round off the interview, if you could give any advice or words of encouragement to a parent starting on this road of autism what would it be?