

The Financial and Psychological cost of raising a child with Autism Spectrum Disorder

A qualitative study

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DECLARATION

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ACKNOWLEDGEMENTS

Dedicated to all parents raising a child with Autism Spectrum Disorder.

I would like to express my deepest appreciation to the following:

To my family, especially my parents, for their emotional and financial support.

To my supervisor, Zethu Memela, for your patience and guidance throughout this journey.

Lastly, to God, for making all of this possible.

ABSTRACT

This is a qualitative research project looking at the financial and psychological challenges and needs of parents of children with Autism Spectrum Disorder. Raising a child with ASD can be a very challenging and strenuous experience. Families who are raising children with ASD appear to experience an overwhelming amount of stress and consist of many responsibilities whilst not having much support from others, signifying the need to study this phenomenon further. The study involves a sample of biological mothers living in Gauteng who are the primary caregivers of a child with Autism Spectrum Disorder. This study focuses on parents' lived experiences and their perspectives of the psychological and financial costs of raising a child with this neurodevelopmental condition.

The findings of this study correspond with findings from other literature; highlighting the significance of these challenges. Results indicated that parents living with an ASD child experience various psychological challenges such as feelings of grief and fear, physical and emotional exhaustion, disruption to the family's lifestyle, and tremendous financial strain; influencing their well-being. This study aims to highlight the financial and psychological needs of parents interviewed in this study to create insight and awareness to others living with Autism Spectrum Disorder as well as professionals working with these families.

Keywords: Autism Spectrum Disorder; Financial Cost; Psychological Impact; Families; Experiences; Stress

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CHAPTER ONE

INTRODUCTION

This study explores the various psychological and financial difficulties families in South Africa face when having to raise a child with Autism Spectrum Disorder and subsequently determine whether parents are able to cope with the challenges involved.

Through the use of interviews, parents were provided with the opportunity to comment on their personal well-being, their children's welfare, as well as the risks and financial challenges involved when raising a child with Autism Spectrum Disorder. More so, parents were given the opportunity to voice their opinions regarding professional care and assistance provided in the context of South Africa as this is a crucial phenomenon contributing to parents' health.

1.1 Background to the problem

Being a parent is one of the life-changing events many people look forward to. When people create a family of their own, it becomes the most important emotional system, which they will belong to (McGoldrick and Carter, 2001). The relationships and type of attachments people have with other members of their families will outline and determine the outcome of their lives.

According to McGoldrick and Carter (2001), family relationships can be described as an interdependent system where changes in one part of the structure will cause a disruption or changes in another part of the system. Most parents have hopes, expectations, goals, and dreams for themselves and their children which they all have to live up to, but often these aspirations become, or seem, unreachable due to unforeseen circumstances such as the upbringing of a child with atypical patterns of development. This is the reality parents and/or caregivers have to face when raising a child with an Autism Spectrum Disorder (ASD).

Raising a child with ASD can be a very challenging and strenuous experience, as nearly every moment of the day seems to revolve around the care of an autistic family member. Caring for an autistic child can be very costly and therefore, the financial features of caring for a child with ASD can hold many financial problems for these families. More so, if the siblings feel that the money that could be spent on them is spent on their brother or sister who has Autism Spectrum Disorder.

Developmental disorders are becoming a major problem for people living in South Africa. Many people are not familiar with neuro-developmental disorders, especially Autism Spectrum Disorder, in the context of South Africa and consequently hold future risks, as they are unaware of what the disorder entails as well as different ways it could manifest.

Autism Spectrum Disorder goes beyond gender and cultural barriers and is not limited to one specific ethnic group or social class. Diagnosis of ASD is rising dramatically and experts estimate that as many as two million South Africans may have the developmental disorder (eNCA, 2015). The prevalence of Autism Spectrum Disorder is increasing dramatically and therefore it is fundamental to gain a thorough understanding of families' experiences when having to raise a child on the autism spectrum. Since Autism Spectrum Disorder is rapidly growing worldwide, it is crucial to know what parents' experiences are and what they find to be the most difficult as it creates insight into the phenomenon whilst discovering an opportunity for growth towards a more supportive environment and health system.

Research has shown that families with an autistic child face many challenges but also proves that families have gained unique experiences in raising a child on the spectrum. Some studies have found that raising a child with Autism Spectrum Disorder can be more stressful than raising a child with any other childhood disorder such as ADHD or Down's syndrome (Rodrigue, Morgan & Geffken, 1990; Sanders & Morgan, 1997).

Autism Spectrum Disorder is considered as one of the most severe childhood disorders consisting of complex developmental patterns (Newsome and Hovanitz, 2006). Various research studies focus on the challenges that parents face while raising a child with Autism Spectrum Disorder and subsequently use evidence-based research to raise awareness to the public regarding emotional experiences involved (Gray, 2006; Newsome and Hovanitz, 2006; Sivberg, 2002). Although Autism Spectrum Disorder causes challenges for the family, it also holds many difficulties for the diagnosed child, which is another field of study that has received minimal attention in the context of South Africa. It is therefore essential to do further research in a domain where the emphasis is placed on positive factors and strengths involved when raising an autistic child as this could possibly produce hope and encouragement.

The behaviours of an autistic child alone are a challenge for parents and could limit parents' social engagement, increasing their need for support from their social networks, extended family and

friends in order to cope with their child's disability; contributing to their psychological well-being (Twyo, Connolly and Novak, 2007).

1.2 Motivation for the study

A paucity of information remains with regards to children on the autism spectrum and the financial implications thereof, especially in the South African context, which contributes to the purpose of the study. The purpose of this study is to understand how ASD influences the family system psychologically and financially. The study aims to gain a qualitative understanding of parents' feelings, experiences and perceptions of raising a child with Autism Spectrum Disorder, therefore, focusing on assessing the psychological and financial needs of parents raising a child with Autism Spectrum Disorder.

Parents face many focal issues when raising a child with Autism Spectrum Disorder which increases the need for attention and exploration. An autistic child presents with many developmental difficulties that contribute to the pressure and stress experienced by his or her parents.

The following are conceded by literature:

Firstly, parents of autistic children have had some kind of interaction with health professionals (i.e. Doctors, Psychologists or Psychiatrists) in order to obtain clarity regarding their child's 'odd' behaviour. Emphasis was placed on the parents' perceptions of their interactions with health professionals and treatment options involved. Hecimovic and Gregory (2005) discuss the parents' difficulties in dealing with psychologists and medical professionals as well as the difficulties that doctors experience when diagnosing a child with Autism Spectrum Disorder. Concluding a diagnosis and ensuring an appropriate diagnosis entails high costs to multi-disciplinary teams within the health profession, therefore, the treatment processes required for a child with Autism Spectrum Disorder is an extremely high expense adding to the financial strain parents may experience when raising a child with Autism Spectrum Disorder. Parents are forced to seek advice from specialised professionals such as Psychiatrists, Doctors, Occupational Therapists, Speech Therapists and/or Psychologists in order to obtain appropriate advice relating to their child's diagnosis. In addition, the consultation fees, assessments, and adequate interventions required for a child with Autism Spectrum Disorder consist of enormous financial costs.

Secondly, due to the autistic child's challenging behaviours and increased need for care, the routines and relationships within the family can be influenced which contributes to a difficult and challenging home life. Cherry (1989) focuses on the child's behaviour that exacerbates the challenging home environment. Some of the behaviours described by Cherry are the child's sudden changes in affect; the social development of the child; limited functional skills of the child (e.g. self-feeding); and destruction and disruptive behaviours of the child. Parents are not prepared for the impact and change that surface when raising a child with Autism Spectrum Disorder. Relationships between parent-autistic child, parent-siblings and siblings-autistic child are few examples of connections within the family system that can be disrupted.

Thirdly, as the child with Autism Spectrum Disorder requires significant and ongoing care, parents might be concerned about their child's future and future care of the child. Emphasis was therefore placed on the psychological effects on the family as it could exacerbate feelings of exhaustion, guilt and hopelessness.

Fourthly, literature speculated that parents of children with Autism Spectrum Disorder have many difficulties in their lives due to the amount of care and attention required for the autistic child. Parents might lack support from other family members which can have a tremendous impact on their mental health and well-being. Hecimovic and Gregory (2005, p. 123) explain that parents require a lot of support, which could be obtained through engaging with others who are having similar experiences:

“It is helpful to hear stories of other families to put into perspective the feeling of ‘Are we the only ones who ever had something like this happen to us?’ ...having access to common questions can often be helpful”.

Lastly, literature speculated that raising a child with Autism Spectrum Disorder could be extremely costly due to their increased and ongoing need for care. Sharpe and Baker (2007) support this notion as they have found that raising a child with Autism Spectrum Disorder places a large financial burden on those who care for them.

1.3 Problem and rationale for the study

The motivation for this study is to assess the psychological and financial needs of parents who have an autistic child in order to create awareness, increase insight, and give feedback to other health

professionals such as teachers, psychologists, doctors, social workers and child therapists as well as other parents of children with Autism Spectrum Disorder.

The information could increase health professionals' insight into the expectations of parents and their autistic children who seek treatment or professional help and generate a better understanding into the emotional and financial experiences of caregivers whilst promoting a good alliance with them. It can provide others with an understanding of how costly it is to care for a child with Autism Spectrum Disorder. Information obtained from this study can also assist parents with useful information to prevent them from feeling overwhelmed and isolated in their experience of raising a child with Autism Spectrum Disorder. Most importantly, this study serves to inform and influence government policy about the issue by highlighting the challenges these families encounter on a daily basis.

It is imperative to gain a deeper understanding of parents' perspective around what it is like to raise a child with Autism Spectrum Disorder, as many are unaware of these experiences. Society tends to place a lot of attention on the child who is diagnosed with Autism Spectrum Disorder but tend to overlook the challenges parents, siblings and extended family members might have to deal with.

1.4 The research question

The research question can be defined as a workable plan that leads to the objectives and goals of the study (Farrugia, Petrisor, Farrokhyar, & Bhandari, 2010). The research question of this study is: "What is the financial and psychological cost of raising a child with Autism Spectrum Disorder (ASD)?"

1.5 Aim and objectives of the research

The aim of this study is to determine the financial implications of raising a child with Autism Spectrum Disorder. Research regarding the financial aspect of raising a child with Autism Spectrum Disorder has been minimal in the context of South Africa. Secondly, to determine how a parent of a child with Autism Spectrum Disorder is being affected physically, emotionally, and mentally.

The **objectives** of the study are:

- To determine the financial burden for families raising a child diagnosed with Autism Spectrum Disorder.

- To understand the psychological impact of raising a child with Autism Spectrum Disorder.
- To explore, through semi-structured interviews the parents' feelings, experiences and perceptions of raising a child with Autism Spectrum Disorder.

Working with children with ASD normally involves relationships within healthcare sectors. This can get very costly for parents/caregivers of a child on the autism spectrum. The study aims to gain insight into parents' views, experiences, and feelings of having a child with Autism Spectrum Disorder.

This research study was guided by the following questions:

- What financial impact does the child's diagnosis have on the family?
- How much do parents spend to support and care for their Autistic child?
- What additional expenses do you have to assist your child with their disability? For example, doctors, therapists, caregivers, transport, special schools, medication, etc.
- How does having a child with ASD impact the family system as a whole?
- How do other family members within your family cope with the child having ASD?
- What are parents' concerns towards the autistic child's future?
- Does the experience of having a child with Autism Spectrum Disorder impact on the social and work circumstances?

1.6 Definition of main concepts

The main concepts pertaining to the study will be discussed in this section.

Autism Spectrum Disorder

Autism Spectrum Disorder is a developmental disorder that ranges from mild to severe according to the variance in characteristics and degree of symptoms (Hoffman, 2012). Autism Spectrum Disorder can be defined as a mental condition, present from early childhood, which can be characterised as experiencing difficulty with establishing relationships and difficulty communicating with others (Baron-Cohen, 2005) however, Baron-Cohen has fallen out of favour with the Autism Spectrum Disorder community as he perceives those with ASD as mentally disturbed. Others have criticised Baron-Cohen and his colleagues mainly for making claims about people with Autism Spectrum Disorder based on small sample sizes and not taking into account the diversity of symptoms and level of functionality among those diagnosed with Autism Spectrum Disorder.

Adams, Edelson, Grandin and Rimland (2004) defines Autism Spectrum Disorder as

...a disability that typically involves delays and impairment in social skills, language and behaviour. ASD is a spectrum disorder, meaning that it affects people differently.

Parent

A dictionary's definition of a parent is a caregiver of the offspring in their own species; who has a child; a father or a mother. A parent is someone who promotes and supports the intellectual, physical, social and emotional development of a child from birth to adulthood.

Maluleke (2014) defines the term parent as the legal guardian of a child who is responsible for providing love, care and attention to the child. Once you have a child you are given the label of being a parent. In this study, the researcher will refer to the parent as the biological mother of the child who acts as the primary caregiver of the child with Autism Spectrum Disorder.

Caregiver

A caregiver can be defined as any person who cares for another person who is young, old, or sick. This term also refers to someone who provides for the needs of others, especially children, who are ill or cannot provide for their own needs (Cambridge Dictionary, 2008).

Financial Costs

The term *financial costs* refer to the expenses or an amount that has to be paid or given up in order to get something (Selden and Nanassy, 1984). In this study, financial costs will refer to the lifetime expenses parents have to cover to raise and care for a child with Autism Spectrum Disorder. This can range from costs involved to care for a child with Autism Spectrum Disorder; costs to obtain an appropriate diagnosis; costs to treat the child accordingly, and other substantial lifetime costs.

Psychological Costs

The term *psychological cost* is used to describe the various psychological impacts such as spiritual, social, mental, and physiological aspects that are influenced when raising a child with Autism Spectrum Disorder. According to Gellman and Turner (2013, p. 103), psychological costs refer to the "effect caused by environment and/or biological factors on an individual's social and psychological aspects". An experience of a traumatic event or unexpected event such as giving birth to a child who is diagnosed with Autism Spectrum Disorder may cause a wide range of psychosocial impacts and subsequently cause an individual to present psychiatric symptoms.

CHAPTER TWO

LITERATURE REVIEW

A preliminary literature review was conducted prior to the collection of data in order to gather background information on Autism Spectrum Disorder and parents raising a child with Autism Spectrum Disorder. Information was then gathered by conducting interviews with parents of children diagnosed with Autism Spectrum Disorder.

This section reviews the literature on the family's experiences of raising a child with ASD and the emotional and financial burden that it entails. Obtaining a diagnosis of Autism Spectrum Disorder is usually accompanied by significant lifetime costs to an individual as well as their family. Due to the paucity of research and lack of knowledge regarding ASD in the context of South Africa, the following section will define ASD whilst focusing on the aetiology, comorbidity, and prevalence of ASD and subsequently create a better understanding into why this disorder is such a complex phenomenon.

2.1 What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is defined by the American Psychiatric Association's Diagnosis (2013) and Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as a single disorder that includes disorders that were previously considered separate — Autism Spectrum Disorder, Asperger's syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified. It is characterised by abnormalities in communication skills, social relationships, cognitive functioning, sensory processing and behavior (American Psychiatric Association, 1994).

The diagnostic criteria for Autism Spectrum Disorder, as documented in the Diagnostic and Statistical Manual of Mental Disorders – 5th edition (DSM-5, p. 50), are “persistent deficits in social communication and social interaction across multiple contexts” and includes restricted, “repetitive patterns of behavior, interests, or activities” manifested by “stereotyped or repetitive motor movements”; obsession with sameness; “highly restricted, fixated interests that are abnormal in intensity or focus” and “hyper- or hypo-activity to sensory input or unusual interests in sensory aspects of the environment”.

There are many common symptoms shared by those with Autism Spectrum Disorder that are not mentioned or included in the diagnostic criteria. It would be important to mention that these symptoms are just as prominent as other symptoms and they are commonly found in children with Autism Spectrum Disorder. These symptoms include abnormal eating patterns, aggressive behaviour, abnormal activity levels as well as odd responses to stimuli (Gillberg and Coleman, 2000); and abnormal sleeping patterns (Balfour, 2007).

Autism Spectrum Disorder is a lifelong developmental disorder affecting sensory, social, imagination and communication skills. There are several common characteristics, which are present in children with ASD such as difficulty with forming relationships and being sociable; difficulty with verbal and non-verbal communication; difficulty in developing appropriate play and imagination; difficulty with sensory modulation; resistance to change in routine. These symptoms influence the well-being of parents who care for children with Autism Spectrum Disorder and emphasise the challenges parents face throughout the upbringing of a child with Autism Spectrum Disorder.

2.2 Aetiology of Autism Spectrum Disorder

Unravelling the causes of ASD is a difficult task as Autism Spectrum Disorder is a condition with several manifestations that changes with age. A report from the Medical Research Council, commissioned by the Department of Health, outlined the current state of scientific knowledge about the epidemiology and causes of Autism Spectrum Disorder (MRC, 2001). The cause of ASD mainly contains a genetic component. However, the mechanism by which this operates is not yet clearly understood. WHO (2013) continues by asserting that high maternal and paternal age, as well as genetic mutations, are considered risk factors for the development of ASD. The difficulty in finding a cause for the neurodevelopmental disorder complicates the treatment process as not one single intervention can be perceived as better than the other and subsequently differs from one child to another based on the severity of their diagnosis and behavioural problems. The complex treatment process is a factor that may become extremely costly and lead to financial difficulties within the family.

Parents of autistic children have a strong desire to understand their child's given diagnosis whilst searching for the cause thereof; however, this need drives many parents to develop their own answers and beliefs, many of which could adversely disturb the family as a unit, the child, as well as

the relationship between the parent and the child. For example, a mother who was interviewed in a study by Elder (1994) stated that her child was traumatised by another child in a day-care setting and believed that this was the reason for her son to be autistic. It was also noted that some people used to believe that child immunisation was another factor causing ASD, which is another example, used to indicate the extremity of beliefs developed by others. This indicates that parents' lack of knowledge regarding Autism Spectrum Disorder may increase their risk to become more stressed about the situation and eventually influence their well-being. It is therefore extremely important for knowledgeable professionals to address these unsubstantiated beliefs parents hold in order to avoid severe repercussions. It is essential for parents to be informed about their child's disorder and receive counselling from a sensitive and well-informed professional.

2.3 Comorbidity

Autism Spectrum Disorder is frequently associated with other neurodevelopmental disorders such as intellectual impairment and language disorders. People who are diagnosed with Autism Spectrum Disorder often consist of psychiatric symptoms which are not included in the diagnostic criteria for ASD and “about 70% of individuals with ASD may have one comorbid disorder, and 40% may have two or more comorbid mental disorders” (DSM-5, p. 58). ASD is also associated with disorders such as ADHD, depressive disorders, epilepsy, and anxiety disorders. The high comorbidity complicates the diagnostic and treatment process, forcing parents to make several visits to health professionals and other specialists in order to assist the child; increasing parents' financial expenses. The complex process of finding the appropriate diagnoses and having the child on effective treatment can force parents to carry a massive financial burden due to the costs related to such care.

2.4 Prevalence

In recent years, reported frequencies for Autism Spectrum Disorder across the U.S. and other countries have reached 1% of the population (APA, 2013). ASD is an extremely complex group of neurodevelopmental disorders that affects a staggering one in every 160 children worldwide (WHO, 2016). Another study done by the Autism and Developmental Disabilities Monitoring (ADDM) network indicated an overall prevalence of ASD to be nine in every 1000 children (Rice & CDC, 2009). The increasing rate of this disability presents profound challenges for parents and other members of the family.

Autism Spectrum Disorder appears to be growing at a rate of 10% to 17% per year, emphasising the need to raise awareness to the society regarding this disorder; however, some argue that the growing rate referred to, refer to the growth of awareness and not the increase of ASD diagnoses.

2.5 Autism Spectrum Disorder Profile

There are low and high functioning children with Autism Spectrum Disorder. However, they are the same in their core deficits, but their IQ determines their level of functioning (Gillberg & Coleman, 2000). Approximately one-quarter of people with Autism Spectrum Disorder function in the normal range of intelligence. The following profile of people with ASD is generalised across the levels of functioning.

2.5.1 *Severe restriction of the ability to engage in reciprocal social interaction*

Severe restriction of reciprocal interaction can be described as a noticeably decreased capacity for reciprocity in social interactions, extreme egocentricity and failure to recognise the uniqueness of other people (Gillberg & Coleman, 2000). For example, children diagnosed with ASD fail to participate in group activities; don't respond when they are being called, lack of awareness of others around them, indifference to affection or inappropriate affection and lack of social or emotional empathy. For example, a child with ASD might harm another child without showing any guilt, remorse or shame.

2.5.2 *The inability or restriction to communicate reciprocally*

A child diagnosed with ASD fails to grasp the meaning of communication and has difficulty comprehending gestures and speech (Balfour, 2007). The child barely makes use of any social communication skills and has a deficit in the use of social imitation. Coupled with this difficulty, is the child's misinterpretation of facial expressions (Balfour, 2007). It is a common phenomenon for children with Autism Spectrum Disorder to have a delay in their development in speech. The speech that the child with Autism Spectrum Disorder does develop tends to have an oddity in their vocal pitch and volume (Gillberg & Coleman, 2000). Some autistic children never develop speech, which complicates matters for those around them as it is unclear what they are trying to communicate. Not only is this a challenge for others, but also for the child as it can cause severe frustration for children who try to communicate something but do not have the capacity or ability to express their feelings or emotions.

2.6 Treatment

There is no cure for Autism Spectrum Disorder and no standard medicine for the treatment of Autism Spectrum Disorder; however, early intervention is crucial and so is exposing the child to special education which can be very beneficial but time consuming for the parents. Special education and some medication can address some of the challenges associated with this disorder (Baron-Cohen, 2005). Early intervention can help to minimise disruptive behaviours. Special education may assist the child in acquiring the necessary life skills to function more independently and subsequently help the parents cope better, reducing the risk for further mental health issues. Receiving ongoing assistance from informative professionals and consistent therapy with the whole family will be very beneficial; however, this is very difficult and somewhat impossible as parents might find it difficult to afford such treatment.

2.7 The psychological impact of raising a child with Autism Spectrum Disorder

It is well established that families caring for a child with ASD experience increased psychological distress compared to other families (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005). This section will focus on a variety of psychological effects that many parents experience when having to raise a child with Autism Spectrum Disorder.

2.7.1 *Feelings of grief, depression, and other related mental health issues*

For some parents, the diagnosis of Autism Spectrum Disorder can bring a sense of hope or relief because they finally have clarity regarding their child's mysterious behaviour, however, for others; the diagnosis may come as a shock and could result in denial or depression.

A study conducted by Kuhn and Carter (2006) have found that parents often report feelings of loss, confusion, grief, sadness, denial, isolation and guilt soon after their child's diagnosis. Upon receiving their child's diagnosis, a study found that in parents, "52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame" (Banach, Iudice, Conway, & Couse, 2010, p. 70). One of the significant experience for parents is that of grief which is triggered by the event of loss, whether it is the loss of a child parents imagined having, or the loss of presupposed future hopes and dreams, it can result in a myriad of emotions ranging from anxiety, fear, depression, anger, denial and loneliness.

Many children with Autism Spectrum Disorder often struggle to keep up with their daily routines and tasks causing parents to feel stressed and overwhelmed by their child's behaviour. Parents may encounter many challenging behaviours of their child such as keeping them from running away; managing meltdowns, poor appetite and disruptive sleeping patterns, driving to and from therapists or doctors which are all factors influencing parents' health. These stressors may become chronic and eventually "wear down the body, particularly the cardiovascular, immune, and gastrointestinal systems" (Miodrag and Hodapp, 2010, p. 407) and consequently reduces the parent's ability to follow the child's behaviour plans and implement Autism Spectrum Disorder interventions. This then may cause parents to feel burnt out, stressed, and hopeless for the future as they find it difficult to adapt to their new life of raising a child with Autism Spectrum Disorder.

Although parents may experience a lot of exhaustion and hopelessness, they also experience fear, as they are concerned about the future of the child; not knowing what to expect or how to prepare the child for life. According to Hecimovic and Gregory (2005), parents are constantly concerned about the future of their child, especially concerned about what will happen after they the parents die or when they are no longer able to care for the child. Parents worry about whether their child will be cared for and whether the child will ever be able to cope without them. Due to children with Autism Spectrum Disorder being severely dependent, parents stress increases as they realise the child's inability to cope on their own. A study by Balfour (2007) indicated that mothers future concerns entails concerns about the immediate future; concerns about the child's life after schooling; concerns about the child possibly regressing, and concerns about the child not receiving any support. Other parents are concerned about their child being alone without a caring environment around them (Cosser, 2005). More so, parents are also concerned about the child being stigmatised in the future by others who do not understand him/her, as they will not always be there to protect the child. The constant worry about the child's future may increase the parent's level of stress, leaving them worried and anxious.

It is important to note the similarities of the emotions experienced by parents with Elizabeth Kubler-Ross's stages of bereavement. According to Kubler-Ross (1969), stages of grief include denial, anger, bargaining, depression, and acceptance which are all emotions experienced by people who experience loss. Green (2002) inferred that parents who raise a child with Autism Spectrum Disorder actually experience a "double loss" – a loss of culturally defined future life and the loss of a child they had expected to have. This suggests that the 'build-up' parents create while expecting the child

could be linked to greater dissatisfaction or loss when receiving the diagnosis due to experiencing the unexpected. Parents are forced to abandon previous dreams and expectations they used to have for their child and have to develop new expectations taking into account their child's diagnosis which could be a possible explanation as to why parents experience a deep sense of loss. This links to feelings of anger, fear, denial or depression as parents cannot cope with the diagnosis given to the child, knowing that the child will never meet up to their own or others' expectations.

Parents may experience scattered emotions throughout the course of an autistic child's life. *Denial*, which is the refusal to accept facts relating to a particular diagnosis (Kubler-Ross, 1969), is a feeling parents experience as they are faced with unsuspected changes in priorities of goals, values and beliefs. This suggests that parents have to adjust the idea of the role of being a parent into something less familiar and something more challenging which can make receiving a diagnosis aversive and result in denial. *Anger* is another common emotion experienced by the parents resulting in verbal, physical or other nonverbal aggressive behaviours. Parents who respond with resistance to the controlling event of a diagnosis of Autism Spectrum Disorder may react with anger towards the child, other family members, and professionals. *Bargaining* occurs when parents attempt to negotiate or make decisions to solve the problems that accompany an Autism Spectrum Disorder diagnosis while striving for a balanced lifestyle (Skinner, 1953), for example, parents might bargain by negotiating something like "if my child's ASD disappear, I will quit smoking", "if my child's development improves, I will give my 10% to the church", or "if you don't let my child be autistic, I will be faithful towards my husband".

The myriad of emotions experienced by the parents and other family members can cause future risks when not treated appropriately and it is, therefore, crucial to seek advice or treatment from others and professionals to avoid future mental health problems such as depression and anxiety. According to Kuhn and Carter (2006), the period soon after the diagnosis exacerbated parents' anxious and depressed states. *Depression* and *anxiety* might manifest in the form of inattention to important visual or verbal stimuli, fatigue, abnormal eating, and apparent low effort responding (Friedman, 2012). These emotions are often precipitated by feelings of *guilt* and self-blame. This alludes to the fact that raising a child with Autism Spectrum Disorder holds consequences for those who are responsible for the care and nurturance of the child. Parents who experience guilt could feel entirely responsible for the child's diagnosis and therefore blame themselves. Mothers who use substances during pregnancy, for example, may feel that they should be blamed for their child's current

diagnosis while others who don't use substances during pregnancy seek alternative explanations and create their own beliefs as to what they have done wrong that resulted in the diagnosis of Autism Spectrum Disorder. Lainhart (1999) have found that there is an increase in the rates of developing psychiatric disorders such as anxiety, depression, and social phobia in parents of children with ASD. The increased rate of social phobia amongst parents of children with ASD could be related to the fearful event of going out in public with an autistic child who could experience a meltdown; causing parents to feel embarrassed and judged by others who do not understand the behaviour associated with Autism Spectrum Disorder. There is a possibility of this being directly related to the stress parents experience and the burden of living with and caring for a child with Autism Spectrum Disorder.

2.7.2 Disruption to the family system

Families who have a child with Autism Spectrum Disorder experience stress because having a special needs child is a phenomenon of significant magnitude that demands a change in the family system (Cherry, 1989). Having an autistic child can lead to disruption in the dynamics of the family, however, other external influences such as environmental factors and the lack of appropriate services can contribute to the disruption of the family system. 'Many traits of Autism Spectrum Disorder exacerbate the most challenging aspects of parenting any child' (Siegel, 1997, p. 753) and it is important, therefore, to acknowledge the potential impact that parental stress may have on the management of a child's disorder (Lecavalier, Leone, and Wiltz, 2006).

Caring for a child with ASD can be difficult and time-consuming as they require special assistance and constant observation to keep them from injuring themselves or taking part in dangerous activities. Cosser (2005) found that the daily routine of the family needs to be adapted as a child with Autism Spectrum Disorder requires more time and attention from their parents than a neurotypical child. Working mothers raising a child with Autism Spectrum Disorder have less time for personal care and leisure than working mothers raising a typical child (Brandon, 2007) which increases their risk for future psychological problems and mental health complications such as frequent mental breakdowns, panic attacks, fatigue and tension.

The child with Autism Spectrum Disorder sometimes splits the families up; the child "acts as another wedge separating these families from normal family life" (Glass, 2001, p. 130). Family activities have to be carefully planned around the child with Autism Spectrum Disorder as the child

might not be able to cope in the public settings and/or might be extremely distressed and disturbed when in a busy, over-stimulated environment. This causes parents and caregivers to experience emotions such as guilt, hopelessness, and even embarrassment. Managing a difficult child's behaviour in the public setting can lead to feelings of embarrassment as parents feel stuck and responsible for the child's meltdown, adding to their self-blame.

2.7.3 Interpersonal relationship difficulties within the family

The parental well-being is important for the family system but having a child with Autism Spectrum Disorder can put the marital relationship in danger. In Cosser's (2005) study, it was found that there was conflict between spouses, due to frustration about the one parent not being as involved with the child as the other parent. Parents become caught up with the management of the child's behaviour which allows little to no time for others in the family. This put the relationships under pressure causing a disruption to the family system and its dynamics. The child's diagnosis of ASD could negatively influence other relationships such as the relationships between autistic child and parent, autistic child and grandparents, autistic child and peers, as well as autistic child and siblings.

2.7.4 Impact on Siblings

Literature indicates that the siblings of children with ASD often experience various stressors related to their brother or sister's condition. A study by Giallo and Gavidia-Payne (2006) found adjustment difficulties, emotional symptoms and peer problems in the siblings of children with a disability. Siblings might find it difficult to understand the eccentric behaviour and abnormal traits of the autistic child as it might be very unfamiliar to them. Siblings might not be able to form safe attachments to one another due to the one sibling being "different". Autism society (2011) has found that siblings experience embarrassment when they are with their peers and feel awkward and nervous to introduce their peers to the autistic child.

A common factor in children with Autism Spectrum Disorder is that they present with strange, odd or aggressive behaviours that others might label as "weird". This causes the brother or sister to avoid bringing any friends home, as they fear the unknown and never really know what the autistic child's behaviour will be like. A study by Orsmond and Seltzer (2007) indicated that siblings 7-20 years of age, that has a sibling diagnosed with Autism Spectrum Disorder, mentioned feelings of embarrassment and awkwardness.

Jealousy can be another stressor for the siblings. An autistic child requires a lot of attention and care which can cause a disruption in the family home as other members of the family, especially the siblings, feel ignored and unloved. In turn, the typically developing child may act out and throw tantrums with the hope of receiving some of the parent's attention (Autism society, 2011), possibly causing greater chaos and disruption to the family system. Although the global impact of Autism Spectrum Disorder on the sibling's life is not the core focus of this study, it is pivotal to consider the aspects influencing the family system as it has implications on the family's functioning.

Frustration is another experience of siblings as they are often unable to understand and communicate with the autistic child. This can be very exasperating for the siblings, especially young siblings, as they do not know how to engage or interact with their autistic brother/sister. Miscommunication, no communication or the constant fight for a parent's attention can become an obstacle for the children and subsequently lead to sibling rivalry, adding to the parent's frustration. In addition, siblings might behave in a strange manner when they are concerned about their parents' grief and stress which may cause them to constantly worry about their parent's well-being. Therefore, siblings can feel pressured to make up for the deficits of their autistic sibling (Autism society, 2011). They also remain concerned about the autistic child's future and feel obligated to take over the responsibility of caring for the autistic child when the parents cannot do so any longer (Orsmond and Seltzer, 2007).

The presence of a child with Autism Spectrum Disorder in the family can be severely traumatic as members of the family, including siblings, may find it difficult to adjust to the autistic child's condition and behaviour. This can influence the comorbidity with other conditions such as depression and anxiety, resulting in siblings with mental health risks and problems.

Although having a sibling with Autism Spectrum Disorder can be very challenging and embarrassing at times, research also indicates that siblings often become protective over the child with Autism Spectrum Disorder and feel the need to protect them from further harm (Balfour, 2007), for example, a sibling might experience anger when someone makes fun of their autistic brother or sister. The sibling learns to cope with a sibling that has special needs and their insight relating to their general understanding of others increase; causing a positive influence on the sibling's life. The siblings may be concerned or resentful about any future roles as carers for their sibling.

A study by Orsmond and Seltzer (2007) have found siblings to report significant concerns regarding the future of their brother or sister's disorder as they consider the child with Autism Spectrum Disorder's level of functioning and development when thinking about the future. A sibling might feel responsible for taking over from the parent once they seem incapable of caring for their child with ASD; however, the sibling may become fearful, as they feel impotent to provide. It has been found that many siblings often take on a care-taking role and may help look after the child with Autism Spectrum Disorder, or they may adopt the "older sibling" role (Suzannah, Ferraioli, and Sandra, 2009) in an attempt to help their parents cope with the child. It is important to note; however, that there is paucity in research regarding the siblings' experiences as most research studies involve the perspective of parents rather than from the siblings themselves (Mandeleco & Web, 2015); emphasising the need to explore this domain further.

2.7.5 Social isolation and the impact on extended families

Parents of children with Autism Spectrum Disorder need and want support from their peers as well as professionals. A study by Broady, Stoyles, and Morse (2017) found parents to experience a lack of support from their extended families and friends, which indicated that this was particularly difficult to deal with – both practically and emotionally. An autistic child can be frightening for other family members and friends which lead to avoidance as they do not enjoy being around the child due to his or her odd behaviours. "If support is not provided, a build-up of worries, the pressure of responsibilities, the tiredness due to dealing with the demands of the disorder, and feelings of disappointment may result in stress-related problems and depression at a later stage, and in some cases become at risk for marital problems" (Hoffman, 2012, p. 90).

Parents raising an autistic child may feel that they are burdening others with their problems and therefore withdraw from any social activities or family events in order to deal with their difficulties on their own which leads to social isolation and feelings of worthlessness and hopelessness as mentioned before. This increase the difficulties parents face as they become isolated and develop feelings of loneliness which could possibly result in burnout, exhaustion and/or depression. A study conducted by Hoffman (2012) has found that families felt less supported by friends and families when these individuals did not understand the struggles and challenges parents face when raising a child with Autism Spectrum Disorder.

To maintain the dynamics in the family whilst trying to manage the autistic child's behaviour, parents lose track of their own personal well-being and about the importance of self-care. According to Rodrigue et al. (1990), mothers of autistic children reported on experiencing a disruption in their daily planning, caretaker burden, family burden and recurrent use of self-blame as a coping strategy. This may put mothers at risk for psychosocial difficulties as they experience parental isolation and loneliness. The study by Rodrigue et al. (1990) does not focus on the experience of fathers as much, which requires further exploration in order to determine whether the use of self-blame is a general way of coping.

2.7.6 Inability to cope

Coping appears to be one of the most difficult things to do once a parent discovered that their child has been diagnosed with ASD but as time goes on, parents learn to adapt to their circumstances and learn to cope in different ways. According to Hooyman and Kramer (2006, p. 200):

“The grieving process associated with the birth of a child with disabilities is complicated by the parents’ grieving the death of the “expected” baby while at the same time trying to accept the “imperfect” baby. Even though they have the joy of being able to hold and love their baby, their life is suddenly and drastically changed”.

Communicating and networking with other families with autistic children is one way of coping with the stress of Autism Spectrum Disorder. In this way, parents can be comforted and exchange advice or suggestions that can be very useful. Parents have been found to use a wide variety of coping mechanisms such as the use of service agencies, religion, normalisation, social withdrawal and isolation, activism and individualism (Jardine, 2008), however, no single coping strategy has been found to be more successful than the other and families have reported using various coping strategies based on the problem they are facing. One coping mechanism might seem more appropriate than the other depending on the type and severity of the problem parents has to face. For example, service agencies could be useful in the case of assisting with the care for a child with Autism Spectrum Disorder, but service agencies might not be as useful when parents cannot afford the services. Gray (2006) has found that the use of service agencies and family support appeared to be the most successful coping strategy for parents. This indicates that families may find comfort and support from other members of the family, but this is not always practical in the context of South

Africa as many families from the lower social class already faces challenges of poverty and limited, inaccessible care themselves.

A study by Sivberg (2002) has found that there may be a negative relationship between the level of coping and the level of strain on the family system. Therefore, it is fundamental for parents to identify and acquire a range of adaptive coping strategies to evade future health risks. This proposes that parents raising a child with Autism Spectrum Disorder often use avoidant coping behaviours of withdrawal, distance and escape which increases their risk for psychological problems. Other parents make use of cognitive coping strategies such as adjusted expectations, appreciations of the 'little things' and living in the present to help them overcome the challenges and difficult times they have to deal with (Glass, 2001). Coping strategies also differ between genders. For example, mothers feel encouraged to join support groups, whereas fathers prefer avoidant coping behaviours such as distance and escape. This suggests that a parents' preferred style of coping may be linked to their gender and/or type of personality.

Parents raising a child with Autism Spectrum Disorder seem to find planning, being prepared and identifying difficulties that may arise within a given situation to be a strategy that helps them, and their child to cope. Mothers of a study conducted by Kuhaneck, Burroughs, Wright, Lemanczyk and Darragh (2010) have found proper planning and implementing set routines to be an effective strategy as it assists the child in transitioning from one activity to another and created sustainability of routine. This suggests that children with Autism Spectrum Disorder function better when they have a set routine and learn from repetition, however, it may not be accurate in all cases of Autism Spectrum Disorder, as the severity of the disorder will determine the effectiveness thereof. According to Gray (2006), parents have described that it was not realistic to plan for every single occasion as their lives are filled with unexpected events. Therefore, raising a child on the lower end of the autism spectrum could hold greater challenges for the parents when compared to parents of high functioning children with Autism Spectrum Disorder as the adaptability to routines are less challenging for those who are high functioning.

2.7.7 Positive effects of raising a child with Autism Spectrum Disorder

Many challenges arise when raising a child with Autism Spectrum Disorder and a lot of literature focus mostly on the negative experiences of raising a child with ASD; overlooking the positive influences, they might have on their parents. Conti (2015), for example, knew from personal

experiences that raising a child with Autism Spectrum Disorder could be very rewarding. She has conducted a study and found mothers of children with Autism Spectrum Disorder to endorse compassionate goals more strongly than the other mothers; causing them to feel satisfied with their way of parenting, family life satisfaction, and meaning in life (Conti, 2015). A study conducted by Altiere and Von Kluge (2008) has found that parents to experience a lot of joy while feeling grateful and blessed to care for a child with Autism Spectrum Disorder. For example, parents may experience tremendous joy when their child with Autism Spectrum Disorder reaches a milestone or shows affection towards one of the family members. Parents in a study conducted by Neely-Barnes, Roberts, and Graff (2011) mentioned that their child with Autism Spectrum Disorder saved them from illnesses due to their child's constant need for them; allowing the parents to feel needed and appreciated. It was found that the parents were more appreciative of life and grateful for the smaller, simpler things in life. Parents mentioned becoming more sensitive, understanding, supportive, and less judgmental towards others around them (Neely-Barnes et al., 2011). Overall, it appears that raising a child with Autism Spectrum Disorder could have many positive effects on the parents; increasing the parent's self-esteem and self-confidence while allowing them the opportunity to have more compassion, patience and unconditional love.

2.7.8 The Impact on Spiritual Wellness

Parents who raise a child with Autism Spectrum Disorder seem to have different experiences regarding their spiritual well-being and suggest that the parent's spiritual wellness is another factor that seems to be influenced by the child's diagnosis. Families of autistic children appear to have a markedly higher moral-religious emphasis (Bristol, 1984). The belief that the autistic child is part of "God's plan" and that "God will give strength to deal with my child" appear to be another way of accepting the child's diagnosis (Jardine, 2008). This emphasises the importance of personal religious beliefs in coping with the challenges and stressors associated with raising a child with ASD (Bristol, 1984). However, parents raising a child with Autism Spectrum Disorder, who are often very religious, frequently lose faith and become hopeless when facing the challenges that come with caring for a child with Autism Spectrum Disorder and could influence their health in an undesirable manner.

Bristol (1984) have found that parents seem to have less psychological problems when they look forward to their child's improvement and when they find purpose and meaning in having an autistic child. It is difficult to predict what the autistic child will achieve in the future; therefore, it is crucial

to focus on the here-and-now and taking it day-by-day, in order to avoid future health risks (Tommasone & Tommasone, 2000). Positive religious coping is associated with better religious outcome and greater stress-related growth, whereas negative religious coping was linked to an increased depressive affect and anxiety.

2.8 Financial impact and challenges

Raising a child with Autism Spectrum Disorder can have a major impact on the economic functioning of the family; however, there is a paucity of research that has investigated this aspect of family functioning, especially in the South African context. Most researchers tend to focus on coping, stress and other psychological dynamics whilst forgetting about a very important factor, the financial impact. Findings from international studies have revealed the existence of financial strain in families caring for an autistic child. Diagnosis of Autism Spectrum Disorder places a large financial burden on families who often must pay for expensive treatments out of their pockets (Sharpe & Baker, 2007). It is advised that children with ASD undergo therapy to help manage and treat their condition, adding to the financial strain. One factor worsening this experience is when a parent has to leave their job or work fewer hours in order to take care of the autistic child. This contributes to the disruption of the family system and caring for the child with Autism Spectrum Disorder becomes a strenuous task.

Early intervention is crucial for the treatment of a child with ASD. Applied Behavioural Analysis (ABA) is the most widely recommended and utilised behavioural intervention (Sharpe & Baker, 2007). Children are required to work one-on-one with a trained therapist for approximately 30 to 40 hours per week and this can cost up to \$30 000 (about ZAR 450 000) a year (Sharpe & Baker, 2007). Speech and language therapy, occupational therapy, and physiotherapy are only a few examples of some interventions necessary for the treatment of an autistic child. Treatment and care of an autistic child can be very expensive. The unexpected expenses can cause a disruption to the well-being of family members, especially parents, and influence their well-being. Each treatment requiring a specialist increases the cost and financial strain for parents.

Evidence from the UK showed that the annual costs for children with an ASD and a learning disability who are living in residential or foster placements are estimated to be £16,185–97,863 (about R 291330 – R 1761 534, ZAR) ,aged 0–17, for those living long-term in hospitals (Foundation for People with Learning Disabilities, 2007). A study by Järbrink & Knapp (2001) has

found that the lifetime cost for a person with Autism Spectrum Disorder exceeded £2.4 million where the main cost was for living support and day activities. They have also found that 10 percent of children with Autism Spectrum Disorder were hospitalised during a one-year period compared to 3 percent of all children. They reported that in the United States, the annual income associated with having an autistic child was \$6,200, or 14 % of the reported family income (Montes and Halterman, 2008). This proves that the care burden is significant.

A study by Sharpe and Baker (2011) found that in the UK, the average annual costs per child range between £16,185 and £62,536 (R291 330 and R1 125 648, ZAR) for children with low functioning ASD, depending on age and residential placement. Autism Spectrum Disorder is a significant predictor of family spending on education, medical, caring, and clothing, but not for amusement or education toys. Caring for a child on the autism spectrum requires a large investment of family and social resources. Another study by Lavelle, Weinstein, Newhouse, Munir, Kuhlthau, and Prosser (2014) stated that an individual with ASD had significant health care cost, \$3020 (R45 300) more than non-ASD-associated illnesses. They have found school costs to be the highest with a higher cost of \$8610 (R 129 150) compared to those who are not autistic (Lavelle et al., 2014).

South Africa's unemployment rate of 27.7% (Statistics South Africa, 2017) exacerbates the difficulties of raising a child with Autism Spectrum Disorder, making it more difficult for parents to support their families. A report in the USA Today stated that caring for an autistic child can add up to a lifetime cost of \$2.4 million (Karen, 2014). The high lifetime costs are suggestive of the continuous support parents have to provide in order to meet the basic needs of a child with Autism Spectrum Disorder as most of them are unable to care for themselves and subsequently become forever dependent on their parents. The latter emphasises one of the challenges of raising a child with Autism Spectrum Disorder. Most parents want to be able to provide their children with the best opportunities for success and happiness, but this appears to be very difficult especially in the case of parents from the lower social class as they do not have the necessary finances to do so. Treatment requirements for children with Autism Spectrum Disorder include medication, occupational therapy, physical therapy, sensory integration, paediatrician consultations and auditory processing which are all examples of consistent sources needed to help the child. Parents may experience feelings of guilt when such sources are not fully utilised (Fletcher, Markoulakis & Bryden, 2012).

Children with special health care needs diagnosed with ASD are significantly more likely to experience more problems regarding access to care and unmet needs. Therefore, families have greater time, financial, and employment burdens compared to other children with health care needs (Kogan, Strickland, Blumberg, Singh, Perrin and Dyck, 2008).

Other costs such as family-coordinated services and ASD-related therapies were not found to be significantly higher in those with Autism Spectrum Disorder (Lavelle et al., 2014) but costs related to having a child with Autism Spectrum Disorder that seemed to stand out the most was the high cost of a caregiver who cares for the child when the parents are away for work or busy with recreational activities. The cost of caring for a child with Autism Spectrum Disorder is ever increasing and as Lavelle et al., (2014, p. 525) states “the most severe level of ASD was significantly associated with \$21 313 higher caregiver time costs compared to a child with no ASD”. School services are a big contributor to costs associated with childhood ASD due to private and/or special educational services needed.

2.9 Summary of Literature

Various kinds of literature seem to concur that most families experience a tremendous amount of strain when living with a child with Autism Spectrum Disorder in the home environment. These stressors that families’ experiences differentiate from one family to another but a common theme that persists throughout the articles are the parental stress experienced and the influence on family and extended family members while highlighting the importance of support. Overall, parents raising a child with Autism Spectrum Disorder seem to experience more stress than those parents who have a child with no diagnosis.

This research study will explore the various lived experiences of parents raising a child with Autism Spectrum Disorder and establish whether the psychological and financial needs of these parents reflect those needs identified in the literature and subsequently work towards discovering important areas that require attention. The economic impact of raising a child with Autism Spectrum Disorder is a challenging aspect causing the treatment process to seem merely impossible for parents from the lower social class. The lack of research emphasises the relevance and importance of this research topic. The researcher aims to form a qualitative person-focused understanding of the financial and psychological experiences and needs of parents who are raising a child with Autism Spectrum Disorder.

CHAPTER THREE

THEORETICAL FRAMEWORK

The researcher will be using the Conservation of Resources (COR) theory. This theory, although mostly used in organisations, is an integrated model of stress that encompasses several motivation and stress theories (Hobfoll, 1989). According to this model, individuals are motivated to protect their current resources (conservation) and acquire new resources (acquisition). Resources may be objects (e.g., homes, clothes, food), personal characteristics (e.g., self-esteem), conditions (e.g., being married or living with someone who provides social support and financial security), and energies such as time, money and knowledge (Halbesleben, Neveu, Paustian-Underdahl, and Westman, 2014). The COR theory is an important theory of stress, burnout and trauma as it highlights objective elements of loss and threat.

Stress occurs when there is a loss of resources or a threat of loss. For example, literature indicates a higher rate of divorce amongst couples who have a child with ASD. This would indicate a loss of support as well as financial stability for the family resulting in a loss of resources. Conservation of resources may be both negative and positive. For example, parents with children on the spectrum tend to withdraw from engagements with community members for fear of “meltdowns” which is characteristic of children with ASD. This way, they protect themselves from being judged by people who may not understand the condition and at the same time may become reclusive which may exacerbate mental health conditions such as depression. This theory argues that resources define how individuals are able to cope with their situations, and resources the key components to determining individuals’ appraisals of events as stressful.

The COR model proposes that members of the family strive to acquire and maintain resources but result in stressful experiences once the environment is threatened by a loss of resources or a lack of gain in resources. In the case of a family raising a child with Autism Spectrum Disorder, the environment is easily threatened and loss is amplified; consequently causing a disturbance to the family system, however, according to Hobfoll (1989), the level of stress experienced by the system is determined by the amount and types of resources available in the environment or family system. An important aspect ignored by the literature is the parent’s accessibility to these resources and the level of motivation needed to gain adequate resources. The emotional exhaustion experienced by

parents may result in a further loss of resources as they become stuck in these threatened environments and escape may seem impossible.

The theory of COR is based on the belief that individuals are motivated to protect current resources and to gain new resources (Halbesleben, Neveu, Paustian-Underdahl and Westman, 2014) but this may not be as relevant in a family experiencing severe burnout from raising a child with Autism Spectrum Disorder as they become trapped in the emotional experiences, complicating the process of gaining new resources and eventually influencing the parent's well-being and their ability to cope. One of the main principles of the COR theory as described by Hobfoll (1989), indicates that individuals in resource-rich environments are most likely to acquire resource gains whereas those in environments with poor resourced environments are likely to accumulate resource losses, suggesting the importance of establishing a healthy family system consisting of loving and secure attachments to avoid future losses and threats.

The conservation of resources theory will be superimposed on the family systems theory, as both theories are utterly important in this study following the possibility of risk and loss of resources in a family system living with a child with Autism Spectrum Disorder. "A systems perspective sees the human behaviour as the outcome of reciprocal interactions of people operating within organised and integrated social systems" (Hutchinson, 2011). It is crucial to pay attention to each subsystem of the family including the ASD child, the parents/caregivers, the siblings, extended family members, as well as social support systems such as friends or community members as each subsystem are easily threatened by the loss of resources when living with a child with Autism Spectrum Disorder. A holistic view of the family system will generate a much clearer picture regarding a family's dynamics and the family's experiences of living with an autistic child.

The family systems and its resources within the environment may be threatened when raising a child diagnosed with Autism Spectrum Disorder as the child might find it difficult to engage with other family members due their symptoms hampering social interaction, forcing people to distance themselves from the child. Their uncontrolled, impulsive and odd behaviours may influence each subsystem and the relationships between these subsystems, causing a disruption to the family system; resulting in an event of loss, threat and/or trauma. For example, as explained by Bowen's family systems theory, fusion between mother and father could reduce tension by involving third parties such as the siblings who are then forced to choose sides; giving rise to triangulation,

threatening their environment and creating opportunities where resources could be at risk (e.g. loss of support). A study by Nealy, O'Hare, Powers, and Swick (2012) have found that mothers often feel unhappy about the quality of relationships with other children in the family as they are disturbed and sometimes irreparable due to the amount of time and attention demanded by the child with Autism Spectrum Disorder. The loss of well-established relationships within the family system put them at risk for losing adequate resources which could have aided them in many ways but instead individuals fall victim to emotional cut-offs, which consist of denial and isolation, in order to cope with unresolved attachments.

One of the strengths of the COR theory is that it provides parents and the family system with the opportunity to prevent future resource losses and describe various ways to cope with threats, however, these threats are often inevitable and difficult to handle when overwhelmed by other daily challenges of life. Conserving resources and acquiring new resources requires parents to have self-control which is another factor influencing the probability of losing resources amongst parents who are raising a child with Autism Spectrum Disorder. The advantage of using the COR approach along with the systems theory is that it allows one to gain a thorough understanding of how a system's resources are threatened or at risk when there is an event of loss or threat. For example, Matthews, Booth, Taylor and Martin (2011) have found working parents of children with Autism Spectrum Disorder to prioritise family over work, causing a possible threat to the work-family demands. This threatens the system's boundaries as they experience high levels of work-family conflict with little opportunity for recovery. Thus, this study is using the conservation of resources theory superimposed on the family system's theory to explain, predict, and understand the phenomena of raising a child with Autism Spectrum Disorder.

The cognitive appraisal theory by Lazarus and Folkman is another theoretical framework used in conjunction with the COR and the systems theory as it looks at the production of stressors by the environment as well as the individual's response to these stressors, and has found stress to be a product of transaction between a person and the environment. According to this theory, how an individual appraises a stressor will determine how a person copes with the stressor. Lazarus and Folkman (1984, p. 19) defines psychological stress as "particular relationship between the person and environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being."

Similarly to the COR, the cognitive appraisal theory is used to describe various ways parents tend to cope (emotion-focused coping vs problem-focused coping) with stressful experiences. Mothers of children with ASD, for example, will attempt to cope by seeking social support, escaping, avoiding, or by positively reappraising the situation. Lazarus's transactional model of stress is a useful model that describes the stress experience and provides a sufficient framework for studying stress and coping in parents of children with Autism Spectrum Disorder. According to Lazarus, the stress model includes (a) an external event or stressor; (b) cognitive appraisal of the event to determine whether it is harmful and threatening or not; (c) coping mechanisms to reduce the seriousness of the event; (d) consequential effects on the person's mind, or the reaction to stress. In this study, for example, the external event or stressor is the child diagnosed with ASD. The way in which parents perceive this 'issue' will determine their level of coping and, therefore, the interpretation of the stressful event by parents are more important than the event itself. According to this theory, as soon as a person become stressed and pressured when demands exceed one's resources, the ability to cope becomes impossible, for example, when the feeling of threat and vulnerability is too much for a parent of an ASD child, control will be lost and stress will intoxicate the parent's mind. Therefore, thinking carefully about one's situation prior to reacting/responding, will determine the outcome and emotion experienced by the parent.

CHAPTER FOUR

RESEARCH DESIGN AND METHODOLOGY

4.1 Introduction

The aim of the research is to explore the psychological and financial cost of raising a child with Autism Spectrum Disorder as this disorder is becoming more prevalent, causing parents to deal with numerous stressors. Chapter four focuses on the methods used during the course of this study and the researcher will clearly outline the procedures that guided data collection and analysis. This chapter will begin with a formulation of the problem that was explored as well as the design used to conduct the study. A description of the participants who took part in the study will follow thereafter. Ethical considerations will also be included in this section. This chapter concludes with a brief summary of aspects that were discussed in this chapter.

4.2 Problem Formulation

Autism Spectrum Disorder represents a profound stressor for the families of the children living with this condition (APA, 2013). Raising any child can often become a challenging experience as children require excessive care and attention, however, raising a child with a developmental disorder such as Autism Spectrum Disorder could hold many other challenges for the parents and the family system. A qualitative research study was conducted to determine the psychological and financial cost of raising a child with Autism Spectrum Disorder.

4.3 Research design

A qualitative research design generates information from raw data through observations in the form of words, descriptions, pictures and narratives. Data collection, analysis of data and an interpretation thereof form part of this design. Qualitative research is used to gain an understanding of underlying opinions, motivations and reasons regarding a specific problem or topic. It is based on the collection of other people's experiences, stories and narratives (Morse, 2016). It consists of structured or semi-structured interviews, which provide insights into a particular problem. Qualitative research can be seen as a design that is more descriptive and exploratory, giving the researcher a deeper understanding of participants' lives, feelings and behaviours. It gives the researcher an opportunity to explore the phenomena in greater depth. The researcher made use of semi-structured interviews to generate data; however, this will be discussed later on.

4.4 Sampling and Sampling method

Non-probability purposive sampling was used to reach a proposed sample size of 8-10 participants. Snowball sampling was then used to source additional participants. Of the 8 proposed participants, one withdrew from the study citing a busy schedule leading to a final total of 7 participants (n=7).

4.5 Process of obtaining the sample

The principal of a non-governmental school in Pretoria acted as a gatekeeper and sent out an email alert to all the parents of the school who had a child diagnosed with Autism Spectrum Disorder. This email contained information regarding the purpose of the study, the procedures associated with the study, the expected time of each interview and ethical considerations such as confidentiality and anonymity. Initially, five parents responded to the email stating that they were very interested to partake in the study; however, due to a small sample size, snowball sampling was used to source the other two participants. Thereafter, the researcher contacted each participant via messaging to schedule a time and place which were convenient for each participant.

4.6 Process of data collection and interviews

Upon meeting with the participants, a thorough explanation regarding the purpose of the study was provided and ethical considerations were discussed with each participant. Each participant was provided with informed consent and confidentiality agreements. Once consent was obtained and participants agreed on the ethical considerations, semi-structured interviews commenced.

Semi-structured interviews with specific questions and open-ended questions were held with the participants of the research study. The purpose behind the use of semi-structured interviews was to generate a better understanding of each family's experiences and dynamics. In semi-structured interviews, the questions are more general and allow the interviewer to ask further if necessary (Bryman, 2008). An audio recorder was used to record the interviews and additional hand-written notes were taken throughout the interview. The areas of interest that were focused on in the interviews were the child's condition and level of functioning; the effect on family life; support systems; treatment needs of the child; concerns and hopes for the future as well as the financial impact. The interviewer used these areas of interests as a guide to asking questions. The interviews were between 30 and 70 minutes in duration.

4.7 Sample description

The respondents in this study were seven mothers of children diagnosed with Autism Spectrum Disorder, living in the Pretoria area of Gauteng, South Africa. The ages of children ranged from nine to 24 years old and all have turned out to be male; emphasising the high prevalence amongst males. Although a person who is 24 years of age are considered an adult in the neurotypical environment, this is different amongst those with Autism Spectrum Disorder and may not necessarily be considered adult due to their life-long dependency and inability to function independently.

The respondents' ages ranged from 37 to 54 years old, which were females only. One of the seven mothers were divorced, six were married; however, three of them were not married to the autistic child's biological father. Three of the seven mothers worked in the field of Autism Spectrum Disorder, two were stay-at-home mothers, another mother worked in the field of pathology and the 3rd respondent worked in the field of state security. Participants were from different ethnic groups and reside in different geographical areas in Pretoria, South Africa.

4.7.1 Table 1: Summary of sample description

Participant	Gender of participant	Age	Race	Marital Status	Number of children	Age of ASD child	Gender of child	Geographical area
Mother A	Female	53	White	Married	3	24	Male	Garsfontein
Mother B	Female	54	White	Married	2	24	Male	Menlo Park
Mother C	Female	50	Black	Divorced	2	12	Male	Pretoria
Mother D	Female	40-50	White	Married	2	16	Male	Irene
Mother E	Female	54	White	Married	4	18	Male	Donkerhoek
Mother F	Female	NA	Black	Married	1	9	Male	Silver Lakes
Mother G	Female	37	White	Married	2	10	Male	Benoni

4.8 Data Analysis

Audio recordings were transcribed into text, known as transcription, and hand-written notes were added in order to gain sufficient summaries from the interviews. Data were analysed using the Analytic Framework approach, which falls under the thematic analysis approaches for qualitative data (Braun and Clarke, 2006). This approach is used to organise and manage data through the process of summarisation, resulting in a robust, flexible matrix output, which allows the researcher to analyse data both by case and theme.

The researcher familiarised herself with the summaries thereafter and notes were made regarding various ideas and concepts that were evident in the transcriptions. The next step was to generate themes, patterns and categories from the data obtained during the semi-structured interviews.

4.9 Ethical Considerations

To protect the autonomy of respondents and to prevent social stigmatisation and/or secondary victimisation of respondents, participants were informed about the purpose of the study prior to the commencement of interviews. Participants gave written consent and interviews followed. Participants were aware of the fact that the study is completely voluntary, and they could withdraw at any time. Furthermore, this study does not discriminate against any group based on race, culture, sex, and/or gender. Procedures of the study were discussed with the participants. Confidentiality of each participant was protected, and anonymity was maintained by giving each participant a pseudonym.

Participants were competent to give consent and they had sufficient information in order to make an informed decision. The anonymity of the participants was guaranteed throughout this study. All of the mothers were given a pseudonym to protect their anonymity. Throughout the interviews, mothers mentioned the names of other family members, professionals and peers. The researcher has omitted these names.

The researcher was the only person to have access to the audio recordings. Once the study has been completed, audio-recordings will be kept under lock and key with the research supervisor for 5 years. Consent forms and other relevant data from participants are kept in a locked filing cabinet.

CHAPTER FIVE

FINDINGS AND DISCUSSION OF RESULTS

This chapter is done according to the themes generated through the data analysis and presented as shown, namely, (a) psychological impact; (b) myriad of emotions; (c) family life; (d) financial impact; (e) expense of the child's basic needs and necessities; (f) expense of remediation; (g) other expenses; (h) financial support from the state; and (i) exhausted medical aids.

5.1 PSYCHOLOGICAL IMPACT

The first section of the interviews conducted with the mothers, deals with understanding how raising a child with Autism Spectrum Disorder, influence the family, mostly parents, psychologically. In the interviews conducted with the mothers, various themes surfaced throughout the exploration of psychological challenges and needs, which will be discussed in this chapter. The second section of this chapter (see 5.2) focuses on the financial strains and challenges of raising a child with ASD.

The impact of having a child with ASD can be quite petrifying and anxiety provoking. It is very far-reaching for parents as they experience a lot of confusion, uncertainty and guilt. Parents start looking for answers as to why their child is affected by this life-changing difference. It was found in this study that parents might become stressed, not only psychologically, but also socially throughout the process of understanding ASD while raising a child with Autism Spectrum Disorder.

5.1.1 A myriad of Emotions related to the condition

All participants interviewed in the study reported that raising a child with Autism Spectrum Disorder becomes emotionally burdening and extremely stressful which easily exhausts them as parents and bring upon a myriad of emotions throughout raising a child with Autism Spectrum Disorder. Parents described these emotions to be similar to that of an 'emotional rollercoaster' where positive feelings and attitudes on the one day, could easily lead to negative, depressed feelings on the next. The first section entails the psychological challenges and emotional aspects of raising a child with Autism Spectrum Disorder; how parents' reacted to the diagnosis received; how parenting a child with Autism Spectrum Disorder increases one's stress, feelings of guilt and denial; as well as the impact it has on fathers and the mother's committed relationships. A significant theme emerging from this section was the amount of parental stress; exhaustion and frustration; fatigue; and feelings of guilt experienced.

5.1.1.1 *State of shock, fear and denial upon receiving the diagnosis*

Upon receiving their child's diagnosis, all participants reported having experienced some feeling of shock, guilt, and denial. All respondents reported that the diagnosis was a result of a delay in the child's milestones when compared to other children and their siblings. The mothers interviewed in this study indicated that they went through a process similar to that of grief in response to the loss of a child they expected to have. Kuhn and Carter (2006) supported this finding as they have found parents to experience loss, grief, denial, isolation and guilt soon after the diagnosis was made which could eventually result in depression. The participants reported having experienced shock, anger, denial as well as acceptance. One of the mothers reported, despite knowing what Autism Spectrum Disorder was about, she initially refused to admit that her child had Autism Spectrum Disorder.

The Doctor said, 'but Mum your child is autistic' and I was like "OH!" [Shocked] and I knew exactly what Autism Spectrum Disorder was, but I could not see that as a mother. [Raises voices] I knew everything about autism, and I could figure it out, but I did not want to. – Mother B

Cosser (2005) had found many parents to experience a sense of uncertainty and confusion before the diagnosis was made and consequently made several visits to health professionals in order to confirm the diagnosis. Various literature indicates that many parents are found to experience high levels of stress when the diagnosis is made, corresponding with results obtained in this study.

Most of the mothers partaking in the study, like the above, struggled to accept the diagnosis given to their child and reported that it could have been because they were in denial and did not want to believe what was happening to them. One of the mothers said, *"I knew he should be able to talk and then I kept on saying 'ah well he is a boy'. I was not, I don't know, maybe I was in denial, and I did not realise it"*. Mother E stated the following *"you know, I think from the beginning you know that something is not right, but if you could say it then you could recognise it, and one rather chooses to avoid saying it, so it takes very long to accept it"*. Mother A said, *"If it was not for my father who told me that my child has a big problem that I should admit it and do something about it, and then I could be one of those parents who are still in denial today"*.

Three of the parents reported that one's lack of understanding regarding the diagnosis contributes to the increased fear and shock they experienced when they received the diagnosis.

Ooh, I don't know, but it was scary. It was a scary feeling, and I was like 'yee God, what must I do now'? I am going to live like this for the rest of my life or what? What are we going to do because you don't understand, you know. At first, you don't understand, because you have to remember, it was a new term for me. I had to go on to the Internet to Google what it is and how are the kids behaving and all that information. So, I was like 'oh ok', but for me, I was not like[pause] well I was scared at first, but then I had to accept and say 'ah you know'. I think kids are from God and I can't say 'no I don't want this child' so then I have had to adjust. - Mother C

My husband started crying because I know what Autism Spectrum Disorder is, but he did not know what autism was. So yes, we cried and cried and cried and [pause] I am sure he probably did not even know what was going on and here you are sitting knowing a few things about autism, but you did not want to hear it. I think any parent does not want to hear it. - Mother D

I think the most nerve-wracking thing is that you don't know what to do and you feel incapable uhm [pause], and then people say 'but God knows whom to give such children' but then it is like everything inside of you screams, and you don't know [laughs]. You don't know at all. - Mother E

Parenting any child can be an intimidating task; however, parenting a child with Autism Spectrum Disorder may become more overwhelming as parents may not be aware of what is normal and what is abnormal. It was found that a parent's lack of understanding regarding the diagnosis of Autism Spectrum Disorder, is closely linked to their emotional experiences during the diagnostic process, thus, possibly explaining the reasons to why the mothers were shocked by their child's diagnosis; due to a lack of awareness. According to Karst and Hecke (2012), the way in which health professionals pronounce the diagnosis could easily influence the way parents perceive the diagnosis and could have adverse effects on their well-being. It is, therefore, crucial for health professionals to educate and improve parents' insight into a given diagnosis prior to disclosing it. Parents' feelings of guilt, denial, shock and fear could be alleviated once professionals explain the diagnosis; support the parents; and suggest appropriate processes to follow. Schall's (2000) findings indicated that, when families received a diagnosis of Autism Spectrum Disorder, it was both horrible and empowering. In this study, most parents reported to have had a negative experience, however, one of the mothers, on the other hand, reported feeling grateful and a sense of relief as she could finally identify the problem and stop searching for answers; resulting in acceptance.

I think also being in the special needs industry, being at the school that I was, was a blessing for me when they said it is autism. I was like "aah it's okay". It is not okay, but it's okay. I have seen a lot worse. Also, you think that you have got the worst situation ever because it is all you know but for me, having seen children with feeding tubes and children with, you know, far worse disabilities, I was just relieved and grateful. - Mother G

One of the mothers, Mother F, reported being overly worried about the child's diagnosis but that it was not going to change anything and, therefore, she prefers focusing on "*what needs to be done*" in order to avoid further complicating the situation. She stated the following:

"She (referring to the child's psychiatrist) was just concerned that I am just too calm around the whole thing and I was like 'what you want me to do, jump on a table? Is the diagnosis going to go away if I jump on the table? [Laughs] It is not, so I just told her that I am just not like that. Tell me what to do, and I do what needs to be done'".

Similarly, to Lazarus and Folkman's cognitive appraisal theory, Mother F makes use of problem-focused coping as a way to cope with her child's diagnosis and behaviour. Instead of being overwhelmed by the severity of the stressor and perceiving the problem as threatening, Mother F chooses to focus on the problem and cope by positively reappraising the situation.

Rahi, Manaras, Tuomainen and Hundt (2004) have listed needs of parents that should be met throughout the diagnostic process: (a) the need for information; (b) need for information relating to social and educational services available; (c) the need for empathy and emotional support from health professionals; (d) the need for social systems; and (e) the need for support groups. Once parents' needs are accommodated during the diagnostic process, parents will feel a sense of relief and feel understood which would decrease their level of stress experienced throughout the diagnostic process and improve their psychological well-being.

5.1.1.2 Stress of raising a child with Autism Spectrum Disorder

A significant theme that surfaced throughout the interviews was the level of stress parents experienced when having to raise a child on the spectrum. Of the seven mothers interviewed, everyone reported that living with and caring for a child with ASD is a stressful experience as it holds many unexpected challenges. One of the mothers interviewed reported that raising a child with Autism Spectrum Disorder "kills you, emotionally because it is very hard work".

Another participant reported feeling overwhelmed by a state of confusion and therefore did not always know what to do. The high demands of her child contributed to mother C's state of confusion and stress experienced.

Oh yes! You do not know what to do. You do not know how to handle him at first because you do not know now [pause] eh this autism, what is it and then how does the child behave and then what would you do when he does not listen. Do they listen, don't they listen? You know. You are just confused as you are. You do not know exactly until you learn as he grows. – Mother C

Mother D, E and A reported that raising a child with Autism Spectrum Disorder is extremely stressful as life changes and overwhelming emotions become unbearable.

I mean, you have raised a normal child, and then autistic brother came along and it is, it is very stressful because you have to plan your day in such a way that when we leave the school, you don't have anything to buy, because you can't go to the shops with him. You cannot control him, and it is so much planning. – Mother D

You know, the day he turned 10, his birthday is on the 14th of April, I woke up the morning and thought to myself that ten years of my life is gone, it is just one huge dark hole! – Mother A

Uhm and a lot of conflicting emotions because you have close relationships and other times you feel like you could murder the child [laughs]. – Mother E

One of the mothers reported that the lack of communication is what frustrates her the most.

He suffers a lot from dyspraxia, so he thinks that he is verbalising and he will move his mouth and everything so there is a lot of frustration, and that is where most of his and my frustration comes from, you know. – Mother G increases her levels of stress and worry.

I think it does become more stressful, I mean I do not know otherwise but [laughs] I have not tasted the other side (referring to parenting a neurotypical child), but I think it does. I think for me it is more the future than the now. The now I am fine with, but you worry because you do not know when you are going to die and when you die you do not know who is going to look after him. So those are the things that stress you.-Mother F

The parental stress of raising a child with Autism Spectrum Disorder was found to be influenced by the amount of support parents receive from others; family, partners, extended family, professionals and peers. The high demands of children, lack of proper communication, and future concerns for the child were closely linked to the amount of stress experienced by the parents. While raising a child with Autism Spectrum Disorder appears to be overly challenging, some of the mothers reported having experienced immense feelings of guilt as well as emotional and physical exhaustion.

5.1.1.3 Feelings of guilt

Upon asking the participants about their emotional experiences, feelings of guilt appeared to be a significant subtheme amongst them. Three of the mothers reported that they had feelings of guilt, for example, Mother C said that she and her husband experienced a lot of guilt and stated *“[sigh] you as a mother feel guilty. You feel as if you did something wrong during your pregnancy. The dad is angry because he won't have a normal child that will be able to play cricket and rugby and do things with his dad because he is not interested in those things. So there is some rejection, but I think the mom carries the most guilt because you think you did something wrong when you were pregnant”*. She continued to explain that *“this was always my biggest guilt, I have a daughter but dad does not have his son to do everything with, and all his brothers have got sons”*. Mother E stated, *“I think emotionally, it is very bad because you always have feelings of guilt towards your other children and because they require so much cost you always feel like you could have done more for the others, with everything, with education, with opportunities”*. Mother C said, *“sometimes I could feel that guilt, Sjah, this child is suffering because I am here and then he is there and that sometimes they can leave him without eating”*. The feelings of guilt experienced by Mother C was due to her inability to constantly care for her child which forces her to leave the child with relatives who would often not worry as much about him as she does. This causes her worry when she is not around as she is concerned about the care he receives from relatives.

According to Rodrigue et al., (1990) parents tend to blame themselves and experience much guilt due to their child's condition as mothers feel inexperienced and incompetent in their role as primary caregiver and, therefore, experience loneliness and isolation. It is essential for parents to be aware of how reasonable the reaction of such devastating news is and should therefore not blame themselves further.

Although three of the mothers reported having experienced guilt, four of the mothers reported no such thing, and this appeared to be linked to their understanding of Autism Spectrum Disorder and what it entails, for example, Mother A said “No, never because I, I have never [considers] because I know it is not my fault and, uhm, it is in our genes”. Mother A and G had similar responses saying that they have not experienced any feelings of guilt regarding their child’s diagnosis.

5.1.1.4 Physical and Emotional Exhaustion

Parents had various explanations of what contributed to them reaching a point of being physically exhausted which includes high demands of children; challenging behaviour of the child; disturbed sleeping routines; all contributing to them feeling fatigued and physically drained. Mother G explained that the high demands of her child are keeping her extremely busy.

It is draining. It is very draining because they do not stop needing you, ever, and it is different for me. I think people are confused, because they seem to think that if your child has special needs and they are in a wheelchair, and they can't walk and things like that it is more draining, but I can't say that one is more draining than the other, because with children that are autistic or on the spectrum they are demanding. They are very demanding. They've got very demanding personalities.

Four of the participants agreed that children with Autism Spectrum Disorder are incredibly demanding and consequently feel physically exhausted by them.

Oh it affected me a lot like, uhm, even physically, because sometimes he will run away, and then you must also run after him, and then I get tired, and it is very draining, and then mentally you think and then sometimes you don't even sleep and then you think, 'what am I going to do now'. At some point, I had back pain all the time, and I had to go to the doctor to get an injection and then he told me that I needed to rest. – Mother C

Yes and that is also contributing to you feeling drained because we never had a housekeeper and when he plays in the veld, during winter, and gets wet then he makes everything wet, the bedding and his [laugh] everything. – Mother E

Physically, I mean you get tired because of lack of sleep when he does not sleep well, but luckily that phase is gone so most of the times he sleeps through. [thinking] – Mother F

One mother reported going through extreme ways to allow her with the opportunity to get some sleep as she was feeling exhausted.

I took a leash and fastened it around his body, and the foot of the bed and then I slept with the leash in my hand; otherwise, I could not get any sleep. Such type of things. - Mother A

The various emotions parents experience bring upon exhaustion and fatigue by the end of the day. Three mothers reported that it is such a challenging experience due to never finding the opportunity to ‘switch off’ and live a normal life.

But it gets, especially when they are young, it drains you emotionally because you only see the behaviour and you try to manage the behaviour and the emotions in the family that you do not even get a chance to attend to your child which is very sad. I think it causes a lot of emotional strain because, if the child has a fit, then everyone else gets worked up and I think that causes insecurity with the other kids. – Mother E

Mentally and emotionally! I guess you cannot get home and switch off after work because when you go home, it is like starting another shift until whenever he goes to sleep. – Mother F

If the routine is out, then there is trouble. Then the whole house has to suffer. So from that point of view, it is very emotionally draining, because sometimes you just want to lose it. You just want to scream, because you cannot now do the routine because life happens and if you throw that routine out, then it is a problem. – Mother G

Parental exhaustion was of significance and correlated with a study by Brandon (2007) who has found mothers to be extremely fatigued due to less time for personal care and recreational activities, however, parents raising a child with ASD are often overwhelmed by demands from other family members and work-related obligations which contributes to parents feeling fatigued and overburden. All mothers in this study reported some level of exhaustion, whether it was physical or emotional, but all reported to have reached a point in their lives of feeling burned out; thus, parents who care for children with ASD should create time for self-care and leisure as it could contribute to improving their psychological and physical well-being. Cosser (2005) supports this and indicates that parents should adapt their daily routines to the needs of the child with Autism Spectrum Disorder and subsequently invest time for personal care and quality time with others in the family.

5.1.1.5 Positive influences on parents

Although parents of children with Autism Spectrum Disorder experience much stress, research has shown that these parents eventually gain adaptive coping skills when raising a child with Autism Spectrum Disorder (Li-Tsang, Yau and Hon, 2001). Mother F and E, similarly to the literature, have found religion and faith to give them a purpose and guidance for dealing with the challenges of raising a child with Autism Spectrum Disorder. The belief that the child is “*part of God’s plan*” and that “*God will give me the strength*” appears to assist with coping. Bristol (1984) states that this reinforces the importance of religious beliefs in coping with stressors associated with raising a child with Autism Spectrum Disorder. Mother F further stated that her work is another good distraction that allows her to get a break from the chaotic home environment and uses it as her “*hiding place*”. As indicated in Lazarus and Folkman’s cognitive appraisal theory and the conservation of resources theory, Mother F often experiences a lot of stress when threatening events, such as her child’s behaviour, exceeds her resources to cope, resulting in avoidance of the situation and finding alternative ways, such as work, to escape the situation. As literature indicates, “*planning, acceptance, positive reinterpretation and growth, active coping, use of instrumental social support, and religious coping*” are common coping mechanisms used to help parents cope with a child on the spectrum (Andreica-Săndică, Patca, Panaete, Andreica, 2011, p. 480), however, parents preferred way of coping is greatly influenced by their availability of resources and personality style as indicated by the conservation of resource theory.

Every mother in this study reported having learnt something valuable throughout the journey. The valuable lessons acquired range from learning patience and unconditional love to the importance of support and being grateful. Kayfitz, Gragg and Robert Orr (2010) concluded higher levels of caring for a child with Autism Spectrum Disorder to contribute to reports of an increase in personal growth and maturity in mothers, corresponding to the findings of this study. Mothers described personal benefits that would not have existed without the presence of the ASD child.

Participant	Quotes verifying the positive influence
Mother A	<i>“It teaches you patience, and it teaches you unconditional love because you have to love as if you do not know what is coming next, but you do love. It teaches you determination because you do a thing 80 thousand, a hundred million times over and over and over! ”</i>

Mother B	<p><i>"I think it made me even more aware of how lucky we are... If he had been in a wheelchair, it is 20 times more difficult. I could not have taken him to the gym; I could not have taken him to wherever I go. So that is the one thing I am most grateful for."</i></p> <p><i>"...and you know that plusses for everything because we will have him forever and I will never have the 'empty nest syndrome' because I have got my boy [giggles]..."</i></p> <p><i>"He is a blessing; he brings us down to earth every day."</i></p>
Mother C	<p><i>"Yes, yes, yes, now he is a relief because now we can understand each other, you know."</i></p> <p><i>I had to accept, that is why I took him to that autism centre and then when they explained to me then I started to think "oh okay, this is what I am going to do".</i></p>
Mother E	<p><i>"The things you can learn from them, is unconditional love, to not get frustrated and to read emotions that we cannot read."</i></p> <p><i>"...you should not look at them through a disabled lens because they learn you so much hey..."</i></p>
Mother F	<i>"Raising a child with autism teaches you patience."</i>
Mother G	<i>"As long as he is constantly improving, then I am happy, and he is. I must say I am very blessed that he is constantly improving."</i>

5.1.2 Family life

"As surely as the functioning of the family affects the child, the development of the child affects the functioning of the family."

- Altieri & Von Kluge, 2008, p.84.

It was noted during the interviews that raising a child with Autism Spectrum Disorder affected the families in many ways that contribute to the high levels of stress and psychological problems parents' experience. The following categories identified from this theme are (a) changes to the family's lifestyle; (b) disruption of marriage and relationships; (c) sibling stress; (d) absent, shameful, avoidant, and fearful fathers; and (e) the relationship with mother. These are discussed in the following section.

Results of this study indicated that the autistic child dramatically influences the lives of families. All respondents in this study have mentioned several ways their child with Autism Spectrum Disorder has influenced family life and required a rapid adjustment in order to avoid further disruptions. Similar to Sanders and Morgan's (1997) conclusion that conflict in the marriage may occur as one or both parents struggle to accept their child's disability, the participants in this study also reported marital conflict and disruption which often resulted in divorce, due to their partner's difficulty in accepting the diagnosis.

5.1.2.1 Changes to the family's lifestyle

Mothers B, D, E and G felt that the presence of a child with Autism Spectrum Disorder in the family has a significant impact on the family. Mother B perceives her life as being different since having a child with Autism Spectrum Disorder stating *"you do definitely have a different life because we would have done like, we probably would have taken my daughter skiing. We will never go ski because what is my boy going to do there, you know, but otherwise we have tried to live as normal life as possible"*. Mother D mentioned that the family no longer does anything together unless they have made the necessary arrangements for someone to care for her child while they are away.

If we went camping, we had to put fences around because he will walk around, and he climbs into everyone's tents. So we do not go as a family. At this stage, he goes to the residence, but almost all the residences closed down at this stage, there is no accommodation for the child. So you do not plan unless you know there is a precaution for him to stay somewhere. - Mother D

According to Altieri and Von Kluge (2008, p. 84), "as surely as the functioning of the family affects the child, the development of the child affects the functioning of the family". Similarly, Mother E believes that having a *"disabled child in a family, causes it to be a disabled family"* as many changes are made in the household to adjust to the lifestyle of the autistic child. She said, *"it affects the whole household. Everything the special needs child requires or does have an influence on the whole household, so we eat very little gluten which is actually good for us. [Laughs] ...but it is also very expensive."* Mother G stated that it is *"difficult in the family"*, *"difficult [pause] because he is so demanding"*. Most mothers reported changes in their family's daily routine and to their family's lifestyle since living with a child with ASD, which corresponds with the concepts of the family systems theory.

5.1.2.2 Marital and Committed relationships

Three of the seven marriages failed due to difficulties experienced when raising a child with Autism Spectrum Disorder; however, the other four participants reported to have had some disruption in their marital relationships and current committed relationships due to a lot of stress experienced when raising a child with Autism Spectrum Disorder. The disruption or disturbance of an intimate relationship increases parent's psychological stress and therefore, although not the main focus of the study is it imperative to touch on important aspects contributing to the parents' level of stress experienced.

Mother A reported to have been in a few committed relationships since the divorce of her husband, the father of her autistic son and reported all relationships to have been very challenging, as her husband and the previous husband could not understand the child's disability.

He (referring to child with ASD) had a tremendous impact on the relationship I had with my husband at the time (referring to ASD child's biological father). Very, very much! Then I got remarried, and it is the exact same. He said that he got to know [ASD child] and he read up on autism and I probably warned him 50 times, and I told him that it is different when you come to visit me compared to when you come to live with me and to have a child with Autism Spectrum Disorder. Anyway, at this stage, I am not allowed to talk about [ASD child] at all; he (referring to current husband) has no contact with [ASD child] because according to him the child is 'just pretending to be autistic'.

Mother C reported being fearful of finding a new partner as one never knows what their reaction would be, however, although divorced from her child's father, she reported having met a new person and she is always anxious about her partner "running away" and said it is something she will "always be worried about". Mother E, still married to her husband, reported that her "faith and grace" is what mostly keeps her relationship together. She stated that "each one tries to manage the child in their own ways" which complicates the relationship. Mother G had a similar perspective and stated that "it's tough on interpersonal relationships, because you, you know the difficult thing for any parent is that there is no line between what's behavioural and 'what is just plain naughty' because it's difficult" and, therefore, relationships fail as each parent has their own opinion on how to manage the child's difficult behaviour which can result in constant arguments with their partner.

The marital conflict exists, as spending time with one's partner is a "luxury" and consequently as stated by Cantwell and Baker (1984) may weaken the affectional bond between the parents. Mother F mentioned that spending time alone with one's partner "*is a luxury*" due to the high demands of the child with Autism Spectrum Disorder. Mother F never spends time alone with her husband, despite the psychiatrist suggesting that it would be best, but prefers to rather "*take him with wherever*" they go. Mother E believes that "*a disabled family or a disabled marriage can fall apart so quickly and when it comes to the difficult behaviour, I do not think men or dads know what to do, and mothers also do not know*".

According to the conservation of resources theory, receiving support from one's partner, husband or wife, is a resource used to help people cope with their stressful situations. In this case, when resources are minimal due to loss in the family or divorce, family systems struggle to overcome the stressful experience; resulting in the loss of support and loss of financial stability for the family. It is, therefore, crucial for parents to protect current resources and acquire new resources in order to establish a healthy family system, however, raising a child with ASD can cause parents to become trapped in their emotional experiences, resulting in severe burnout, complicating the process of gaining new resources, and consequently influence a parent's well-being and their ability to cope as indicated in the results.

5.1.2.3 Absent, shameful, avoidant, and fearful fathers

A critical subtheme that surfaced in the data was that of absent, shameful, avoidant and fearful fathers. It appears that fathers who face unexpected challenges such as raising a child with Autism Spectrum Disorder are often unable to cope in these environments and either escape from the setting and flee from the family or withdraw from parenting the child entirely.

All seven mothers interviewed, reported that their child's father had difficulty accepting the diagnosis which resulted in various outcomes and subsequently influenced the entire family system. Despite getting a divorce while expecting her autistic son, Mother C reported that the father of her child is "*still not taking part*" in her child's upbringing and speculates that it might be because her child is not a typical child. She believes that having a child with Autism Spectrum Disorder, especially in the African culture, is extremely difficult as fathers "*run away when they see you with a child with autism*". Mother D had somewhat similar experiences with her husband as he wanted to avoid the child with Autism Spectrum Disorder and tried to find alternative situation. She explained

that her husband, initially, wanted to *"get himself an apartment in Johannesburg so he could be away from the chaos"*. She ways to escape the further explained that her husband *"avoided the child at some point when the behaviour was bad, and he wanted to put him (referring to child with Autism Spectrum Disorder) in a residence so he could have a normal life"*. Now that their child is much older and more relaxed, Mother D reported that her husband has *"got this guilty conscience because you cannot buy him anything for Christmas or his birthday because he does not play with anything"* while their daughter gets everything she wants.

Mother F reported that her husband *"struggles with...um... the tantrums and sometimes the aggression"* of their child and would rather withdraw himself, similarly to Mother A's husband who withdrew himself from the situation. Mother A reported that her husband of the time *"travelled a lot and to escape from the situation he started a relationship with someone else, and then he came home weekends and gave all his attention to the daughters, but he never took [ASD child] with him because he was ashamed due to the strange and odd things he did"*. Mother G had a somewhat similar experience to that of Mother A and reported that her husband of the time, *"left when their child was nine months old"* and *"decided that drugs were an easier option as he could not cope with [ASD child]"* and, therefore, got divorced.

Mother B, on the contrary, reported that her husband has been incredibly supportive and loving since day one. She reported that her *"husband is probably a better father than any other parent that you have ever met with a disabled child"*. She stated that, although her husband is sad for the sake of his son, *"his dad is even more protective and just [pause] sorry, they have an incredible relationship but then so does my daughter so I cannot say it was because he had autism or not"*. She further reported that her husband, till this day, *"is still cross with God"* and mentioned that *"he will have to get through it"*.

The loss of resources, such as the loss of a parent or having an uninvolved and careless mother or father, could hold many consequences for the family system as indicated by the conservation of resources theory and family systems theory. For example, a single parent may feel more overwhelmed and stressed and may find it more difficult to cope with an ASD child than those who receive adequate support from their partner. The event of a father or mother leaving the household could have adverse effects on the child, as well as the family system; resulting in a traumatic experience for everyone who is part of the system.

This study discovered that fathers find it difficult to cope with the diagnosis and odd behaviour of the child and often seek alternative ways to deal with the challenging environment such as escaping, withdrawing, or depending on substances to deal with the situation. Altieri and Kluge (2009), conversely, indicated that fathers found it helpful to cope by keeping family stability through the involvement of all family members in activities; however, this was not evident in this study and could be due to fathers not being the respondents in this study.

5.1.2.4 Relationship with mother

A significant theme that emerged from the results was the strong bond children had to their mothers, who are the primary caregivers of the child, and the distant relationship with their father. The results indicate that children with Autism Spectrum Disorder have stronger connections with their mothers due to their high demands and their challenging behaviour whereas fathers appeared to be either too busy, uninvolved, uninterested, or completely absent. The mother's nurturing personality style influences the parent-child relationship and, therefore, ensures a stronger relationship towards the mother who is forced to offer all of her time and attention towards the child with Autism Spectrum Disorder. Five of the seven mothers verbalised to have established a much stronger relationship with their autistic child due to the amount of time spent with them daily.

Participant	Quotes verifying strong bond with mother
Mother A	<i>Our bond is so strong that if I wake up in the morning and I feel anxious, then I phone him, and I know there is something wrong with him.</i>
Mother B	<i>But now, [ASD child] and I, we bond; it is like he is part of me. You could ask anybody, and he is like (interrupts self) I can read him from there [points into the distance] but so can my daughter and my husband, but he honestly is just a part of me.</i>
Mother C	<i>No, he made us very strong together, and I think now that he is growing, and we understand each other, he knows when I disagree with him. I do like "[ASD child] do not do that" and yeah then he knows.</i>
Mother E	<i>Uhm, you know, I think because they require so much attention you automatically have a good relationship with them and a strong bond.</i>
Mother F	<i>He is probably more close to me than the dad, but I think it is because I am more involved with his everyday things than his dad.</i>

5.1.2.5 Impact on Siblings

Out of the six mothers who had neurotypical children, all reported having noticed the child with Autism Spectrum Disorder to have had a negative impact on the relationships with their siblings. Mother B and Mother G stated that their typical child used to have a difficult time when the child with Autism Spectrum Disorder was around, and both reported that it only lasted for about “six months” until the siblings’ emotional intelligence improved and subsequently became much more supportive toward their sibling.

“They went through probably like a six month period where he was really hurting her where he would bite her and pull her hair out of her head. I do not know what happened. I think he noticed that she was needy and he was needy, and he did not like the fact that there was a bit of competition between them, but that has passed, thank the Lord, because that was the toughest time, because then you do not know how to cope.”

“I have been extremely, extremely blessed. Really blessed! They are amazing with him, my daughter particularly; she has done her own research. If I have ever gone on courses, she would ask if she can go with. She is very, very informed and supportive.” - Mother G

“My daughter at the age of 12 battled with him a bit. It was the only time for about six months, and my heart stopped. I thought “she has got to be there for him forever” and now she is unbelievable. She took him to the movies yesterday and the day before.”

“Our relationship definitely changed as she took the back step. Definitely! I’m very..., but when she was small, when she was small, I’m keeping up your whole battery here, but when she was in Grade 2 they gave her a father-daughter weekend, and she said no, no, no, no, ‘I don’t think Dad will leave my brother’ which was bizarre. I was worried about her because she did come second, not because we wanted it like that, but you can imagine [pause] I think it was hard for her.” Mother B

Similar to Mother G and B, Mother A described the relationship between the siblings as complicated, especially the relationship between her child with Autism Spectrum Disorder and his middle sister; however, this did not only last for six months but also for the entire time. She mentioned that her autistic son created “*havoc in the relationship*” she has had with her middle child and reported to have “*lost her*”. She reported that it got worse when the middle sister's father passed away as she reportedly said, “*it should have been you instead because it is your fault that we never*

had a mom". Mother A mentioned that her middle child found it extremely difficult to have an autistic sibling who demanded so much of their mother's time. Mother A stated that her middle child often *"locked herself in the bathroom several times and ended up sleeping there because she was too scared for him"* as he is extremely aggressive towards her and would bite her and shoot her with the windbuks by accident. Mother A described this to be a *"terrible time in their lives"*.

Mother C and D stated that there is no relationship between the child with Autism Spectrum Disorder and their sibling as avoidance by the typical children is their preferred way of coping. Although Mother C mentioned that, her typical child would often present with anger towards her child with Autism Spectrum Disorder and could never understand why she had to get another child but has finally come to terms with it and now understands and accept his brother with Autism Spectrum Disorder. The neurotypical child of Mother D has reportedly *"pushed away"* her brother with Autism Spectrum Disorder and *"she does not realise when he is there, and she does not realise when he is gone"*. Similar to a study conducted by Giallo and Gavidia-Payne (2006) who have found emotional symptoms, adjustment difficulties and peer problems amongst the sibling, the participants in this study have reported similar experiences and explained that the siblings prefer visiting others instead of inviting friends to their home. Mother D reported that her daughter has *"never brought any friends home to visit"* as she was *"scared he will throw a tantrum"*. Mother E reported that the eldest child *"carries some of the responsibilities of the disabled child"* and furthermore believes that *"the other kids easily feel neglected because the disabled child requires so much attention and exhausts you"*. She stated that her typical children, during their adolescent years, experienced *"a lot of shame because they are too embarrassed to invite friends home because their friends will not understand the behaviours and so it is a very, very difficult time"*. The embarrassment and awkwardness siblings experience correspond with the findings of a study conducted by Orsmond and Seltzer (2007) who have found siblings between the age of 7 and 20 years to feel ashamed of their autistic brother or sister.

Although having a sibling diagnosed with Autism Spectrum Disorder can be very challenging and anxiety provoking, the mothers also reported the existence of positive interactions between child and sibling. According to Mandeleco and Webb (2015), the siblings' experiences are subject to several types of influences that could have negative and positive outcomes. Increased empathy, helpfulness, self-regulation, self-control and social interactions are all examples of positive effects that the child with Autism Spectrum Disorder can have on his/her siblings (Mandeleco and Webb, 2015).

Some siblings have gained an appreciation for their brother with Autism Spectrum Disorder; adding to a positive experience. Some of the siblings also reportedly have good, supportive relationships with their autistic brother and often take on their responsibilities to assist their parents with the management of the child's behaviour. These results correspond with the results obtained in a study conducted by the Autism Society (2011) which has indicated that siblings feel pressured to make up for their autistic sibling's deficits and feel obligated to care for the autistic child when the parents are no longer able to do so. Adverse effects on the siblings include sibling rivalry, depression and anxiety, family conflict, and a decrease in socialisation (Mandeleco and Webb, 2015).

5.1.2.6 Preference for social isolation

Mother A, D, E and G reported having withdrawn from social activities and gatherings with family and friends due to their ASD child's disruptive and unexpected behaviour, as well as the reason for others not being understanding and supportive of their child's disability. Parents reported that the lack of social support increases their levels of stress and causes a wide variety of mixed emotions. These results correspond with results obtained from a study conducted by Hoffman (2012) who has found that families felt less supported by others (i.e. friends and family) when these individuals did not understand the struggles and challenges parents face when raising a child with Autism Spectrum Disorder; resulting in isolation from others.

Participant	Quotes verifying preference of isolation
Mother A	<ul style="list-style-type: none"> ▪ <i>... the biggest thing of all is that you lose your friends because when you go visit other people, everyone will tell you how naughty this child is and how he needs proper hiding and things like 'just give me this child for a week, and you will see a difference'...</i> ▪ <i>It got so bad to the extent that I didn't even go anywhere up until 2 years ago.</i> ▪ <i>I am very lonely. I have no friends! None!</i> ▪ <i>To raise a child with ASD is extremely lonely and your support system is just this big because grandparents get older and my mom and dad never looked after him because they could not. He was too fidgety and busy.</i>
Mother D	<ul style="list-style-type: none"> ▪ <i>There are no people coming to us. We do not have friends, we do not have a lot of family, and when family members come to visit, you have to make sure [ASD child's] iPad is charged, and everything is done because the little ones do not understand him</i>

Mother E	<ul style="list-style-type: none"> ▪ <i>...you have to go to a place by yourself, or others in the family have to go out by themselves because many times it is the easier way out to withdraw instead of going out to places</i>
Mother G	<ul style="list-style-type: none"> ▪ <i>I just got to the point in my life where I made the conscious decision that If I had to go somewhere and fight with him, then I am not going and if that makes you feel uncomfortable then I am sorry. I do not invite those over that are going to feel uncomfortable.</i>

5.1.2.7 Lack of support from extended families and friends

All participants reported to have encountered other challenges such as minimal support from extended families and friends, which influence their psychological well-being. Most of the participants partaking in this study have reported having little to no contact with their extended families and, despite their desire to feel supported, receive no support from either extended families or friends. Findings from literature (Hoffmann, 2012; Jardine, 2008) indicate otherwise as results by other studies indicate that mothers reported receiving much support from their peers and extended families that contribute to a parent's well-being and coping.

Mother A reported not feeling supported by her extended family as they often judge her son for “*faking his disability*” due to not truly understanding what ASD entails. She reported that most of the men in her extended family claim that her child is just a “*spoilt brat*” who “*should have gotten more hidings as a child*”. She mentioned it to be merely impossible to defend her child and create insight, as others perceive her as always “*defending him*” and “*covering his wrongdoings*”. Mother C reported similar experiences; however, she stated that her family had made efforts to understand the child's behaviour which improved the relationships in the family and subsequently helped her to care for her child. Nowadays, the extended family asks about her child when she is visiting without him and often wants to know how he is doing, adding that this causes her to feel “*happy*” and “*grateful*”.

Mother D reported not to have received any support from her extended family and hardly ever sees them. She further reported, despite having the desire for support from her extended family, that “*everyone goes on with their own lives*” as they do not know what it is like to live with a child with Autism Spectrum Disorder. In the same way, Mother G reported not to have seen her family for quite a while and have “*lost all*” of her friends as everyone seems to be “*uncomfortable with her*”.

child" to the extent where he does not get invited to his cousins and peers' birthday parties. Mother B, conversely, reported having an "absolutely amazing" support system that loves and appreciates her child. She stated, "His grandfather is one of his other best friends. My brother is like his other. No, [pause] we have an extended family from heaven, and that helps because other parents do not have that. Some parents have grandparents who have never looked after the child".

It emerged that parents experienced less stress when their extended families and friends looked beyond their child's strange behaviour and attempted to engage with the child to establish a relationship. Some mothers reported withdrawing from socialising with extended family members as others often interfere with the parent's way of managing the child's behaviour and discipline of the child, without understanding the condition. This finding is supported in research by Meirsschaut, Roeyers & Warreyn (2010) who suggest that Autism Spectrum Disorder can be a source of conflict between family and extended family regarding parenting styles and preferred methods of discipline. Similarly, Cosser (2005) mentioned that parents experienced higher levels of stress when the extended family was critical of the parents' parenting style.

5.2 FINANCIAL IMPACT

The financial cost of raising a child with Autism Spectrum Disorder was described by all participants to be a significant stressor due to the high costs related to caring for a child with Autism Spectrum Disorder. The results obtained from the data indicate the immense financial difficulties experienced by families as a result of caring for a child with ASD and emphasises the need for financial support. Themes that emerged from the data will be discussed in the following section to create insight into the costs related to the care of someone with Autism Spectrum Disorder and to establish the financial needs of the parents. In this study, similar to findings by Balfour (2007), results revealed that raising a child with Autism Spectrum Disorder required more monetary resources than a typical child; causing a burden to the parents due to the cost of their child's basic needs.

"It is very stressful. Financially definitely! Financially it is huge, because everything that they need is expensive and because his dad left when he was nine months old, he did not support me at all. So I was a single mom for a really long time until I married [current husband]. Financially he almost broke me a few times." - **Mother G**

"Having a child with autism is more expensive because it is forever." – **Mother B**

“Definitely yes but it depends on what you want to do, you know. I could take him to a cheaper school. I could let him eat anything [laughs]... I think because I started there, I have just been maintaining that. So I know my Woolies bill is ten grand (R10 000) a month, but it is choice. I could buy from Spar, I guess. I mean kids eat from Spar; they're not going to die.” – Mother F

“It is definitely more expensive to raise an ASD child. There are no two ways about it. Definitely, because it is such a specialised thing, and unfortunately the medical aid and the physiotherapists and the government knows that, and there's no, I mean, if you compare, a lot of people go to Australia and other countries because it is more inclusive and they don't nail them because they've got special needs.” – Mother G

Emerson (2003) has also found families with an intellectually disabled child to be economically disadvantaged when compared to families who do not have a child with an intellectual disability. There is a great need for financial counselling and planning by professionals to reach out to struggling families of children with Autism Spectrum Disorder for assistance. Sharpe and Baker (2012) explained the need for reduced fees or pro bono work from professionals to assist families from lower social classes with caring for the needs of their child with Autism Spectrum Disorder. The assistance from such professionals could be valuable for parents and alleviate the financial strain they experience.

5.2.1 The expense of the child's basic needs and necessities

The financial strain of living with a child with Autism Spectrum Disorder was found to be of significance as their basic needs, and ongoing care entails tremendous costs. All mothers reported costs related to a child's basic needs that contribute to their financial strain and reported these to be extremely costly with reference made to the high costs related to school placement and transport; the cost of sanitary needs (nappies); specific dietary requirements; the cost of caretakers and tutors.

Expense: Schooling and Transport

Most participants, except for the two mothers who have two children over the age of 18 years, have reported paying R5 000 – R5 600 per month for their child's school fees, despite the difficulties and challenges faced to find a school who could accommodate their child's needs. Mother C reported that *“it is financially draining to raise a child with autism”* and that it starts *“with the expense of school costs”*. She reported paying R5 300 for her child's schooling, excluding transportation cost.

This fee seems very expensive when compared to Mother A who used to pay “R1 500 per month” towards her child’s schooling (all therapies included) when he was in a special needs primary school (approximately ten years ago).

Mother F and G reported paying fees towards aftercare as well as transportation to and from the school as both are working mothers who are unavailable to attend to their children and, therefore, has to pay a private driver to transport their children to school and after-school activities.

[Interrupts] Okay, well his school fees...his schooling is only until half-past 12 in the afternoon, so the school fees are R5 500 a month... Then obviously, because it is a half day, you still need to get someone to get him at home. So it is transport which is over a grand (R1000) a month. –

Mother G

Mother F explained that they used to pay “R1 500” per month towards transport, however, since changing schools and with the new school not having any transport, they will have to make use of a private driver which is more expensive; “R5 600 per month” and furthermore reported that although it is very costly, it is a “choice” she had to make.

Transport at his previous school used to be R1 500 per month. Having a private driver, which we will have to get now when he goes to the new school, will be about R5 600 a month. - **Mother F**

Mother D reported that she took her child to a residence over the weekends and mentioned that he attends holiday schooling as the family often goes away during the holidays and is unable to take him with. She stated that the fees towards boarding and holiday schooling are costly as one weekend at the specialised facility cost “R5 000 per weekend”. She reported paying a total of “R9 000 per month” for her child to board at the specialised centre for children and young adults with special needs. She said that her child only stays at the residence for about two weekends per month and he is at home for the other two weekends, but then she has to pay R800 per weekend to hire a facilitator to assist with his needs when he is at home. She further mentioned paying “R800 per week” towards the holiday school which accommodates her child during school holidays.

The costs related to schooling and caretaking was found to be the most expensive in this domain; corresponding with results obtained from a study by Lavelle et al., (2014) who has found school costs and caretaker costs to be the highest and much higher amongst those with Autism Spectrum Disorder when compared to others’ who does not consist of a disability.

All parents reported paying about R4 500 to R5 600 per month towards their child's school fees, not including aftercare, transport or holiday schooling, which is much higher than the average fee of Model C mainstream schooling in South Africa. According to an article by Brand South Africa (2015), parents pay a monthly fee of about R 8000 to R20 000 per year; almost half of the fee that parents of children with Autism Spectrum Disorder pay. Government special needs schools are more affordable as school fees range from R1 000 to R2 000 per month; however, parents are often refused by these schools due to no availability or due to the extreme severity of their child's behaviour. The limited special schools available in the context of South Africa contributes to the high levels of stress experienced by parents as they are forced to pay expensive fees to have their child placed in a school or keep their child at home. The latter calls for an all-inclusive mainstream school environment that is safe and accepting for those with special needs, especially in the context of South Africa.

Expense: Tutor and Caretakers

Mother A reported that her son, who is high functioning, had a tutor, from primary school until the end of his tertiary studies to assist him with academically related tasks. She said the cost became very costly when he reached his final year at tertiary level as the professional tutor cost them “R15 000 per month” and, therefore, had to get someone more affordable. Mother A reported that, nowadays, she “pays R8 000” towards the tutor as each session costs R400 per hour.

“...and another thing that is expensive is their care such as tutors which cost a lot! So he (referring to child with Autism Spectrum Disorder) has BCom Accounting. He finished that last year and he did very well because it was numbers and he is very good with numbers and this year he had to do his STR and [sigh] his first month's bill of the tutor was R 15000, for a month, because we pay R400 per hour and remember, when you do your STR's you have to get accountants because you can't use a third or fourth year student to help because they are too busy and it is a high-level thing. So we had to get an accountant or a CA, and she was very accommodating and only asked R400 an hour!”

Mother A also had a caretaker who used to care for her child during his early childhood years. She said: “So at the school, he had a tutor and when he got home, he had Johannes who could walk after him. It was Johannes's job. He followed [ASD child] all over and made sure that he was safe”. Mother B, similarly, also had a facilitator who could assist her child with his homework in the

afternoons as he was not willing to work while in his mother's presence; she would "*stand around the corner and he would just sit*".

"Yeah from about eight years I would have someone go in the day and sit with him a little bit, and she would do homework with him in the afternoon, and then I always had someone come and do homework with him at least two, three times a week and I don't know what that cost. I cannot remember." – Mother B

Mother C, F and G also reported having caretakers at home who assist their children with their needs and activities. Mother C reported paying the caretaker "*R150 per day*" whereas Mother F has two caretakers, one for the week and one for the weekend; paying "*three point five per month*" (R3 500) towards the caretaker who comes in on weekends. Mother G reported paying "*about two, three thousand Rands a month*" (R2000 – R3000 per month) for someone to take care of her child in the afternoon until she arrives home from work.

The cost of tutors and caretakers is very high as fees range from R 150 per day to R15 000 per month; depending on the services provided and duration worked. According to Lavelle et al., (2014) the most severe level of ASD was associated with \$21 313 (R319 695) higher costs towards caregiving when compared to a neurotypical child who does not have a diagnosis of Autism Spectrum Disorder.

Expense: Sanitary care (nappies)

Many of the participants said that there are other fees related to raising a child with Autism Spectrum Disorder that others do not necessarily consider, but should, as it is a substantial expense. Mothers F, E, C, and D have found nappies to be a significant expense which adds to the financial burden due to their children having a difficult time to become fully toilet trained.

Oh, yes definitely, very expensive! To get used to a toilet routine, [ASD child] was potty-trained in the end but only after 12 and nappies are very expensive. – Mother E

His nappies were a big expense! It was easily R1000 a month because it was all pull-ups. When he turned ten, we took him off the nappies. It was a big thing, but many of the autistic children are still on nappies. It works out like R700 to R800 because you have to buy pull-ups and then when they get too big for the pull-ups then you have to buy adult nappies, and that is even more expensive –
Mother D

Well, he started at, but he was never really fully...uhm...trained, so there still had to be routine where I take him every hour. I mean a packet of Medicare with about ten nappies in it, is about R300. So he goes through that in a week, so we choose to take him every hour instead. - Mother F

Yes, he is still on nappies, and it is still a challenge today... For nappies, let me say R 100 or R 200 per week. It depends, remember, sometimes he has a runny tummy, so then he uses more, so yeah, about R 200 per week (R800 per month). – Mother C

A new finding surfacing in this study was the expense of diapers, barely considered in other studies; however, carries tremendous costs. These costs are often overlooked due to every child, whether autistic or not, use diapers; however, the costs towards diapers are much higher amongst children with Autism Spectrum Disorder as most children with Autism Spectrum Disorder have difficulty in reaching continence. For example, one of the mothers whose autistic son is 12 years old is still using diapers; and contributes to his mother's high level of strain experienced as she currently pays about "R800 per month" and has been buying diapers for the last 12 years.

Expense: Clothing

Mothers A and G reported clothing to be another expense out of their pockets which can become costly, especially when having to buy the appropriate clothing for their children. Both mothers reported that their ASD children, who suffer from hypersensitivity, are sensitive to certain garments and do not like wearing a specific type of clothing because of the fabric. The sensitivity to some clothing adds to parents' expenses as they have to buy clothing which mostly consists of expensive material in order to satisfy the child and prevent them from continually removing pieces of clothing in public. Mother A said, *"for instance, he cannot tie his shoelaces, so his shoes are only the slip in shoes with no laces and it is more expensive"*. She further stated that her son's formal wear for work could not be made from *"wool because it scratches him so it must be a soft or Suede material and those are very expensive"*. Correspondingly, Mother A said her child *"does not like things that cannot breathe"* and reported that her child prefers wearing *"cotton"* clothing. Her son suffers from eczema as well and, therefore, *"if he has some material that does not have a breathing or airy material then he feels itchy and irritable, but generally, he is not as bad as other kids I know."*

5.2.2 Expense of Remediation

It was noted in the data that all parents started with early interventions soon after their child's diagnosis of Autism Spectrum Disorder with the hope of alleviating challenging symptoms;

however, for those who can afford remediation, these often include expensive interventions and treatments adding to the parent's expenses per month. Another expense, medication, was found to be very high as children with Autism Spectrum Disorder should take various treatments for their symptoms every month.

He got exposed to equestrian therapy, water therapy, sensory therapy, I took him to Germany for stem cell implants and my dad took him to the USA for oxygen therapy, he got physiotherapy, speech therapy, occupational therapy, deep pressure therapy and you name it. - Mother A

Expense: Medication

All participants have reported their children to be on some medication; whether it is for comorbid conditions, or vitamins needed to assist their child in gaining essential nutrients, everyone reported a high cost related to the treatment of their child's symptoms. For example, mother A reported that her son takes “*Omega 3, folic acid, vitamin B3 injection and Vitamin B12*”. With medical aids not funding all treatment costs, it increases parents' expenses, especially in the case of raising a child with Autism Spectrum Disorder.

He drinks one and a half mg Risperdal in the mornings. Do you know how much that is? It is a very high dosage. He drinks 400g Tegretol, 250g Velbitrin. Now Tegretol and Velbitrin are both mood stabilisers. Then he drinks Epilim which is an anti-depressant because of 70% of children with autism struggle with depression. – Mother A

It definitely influenced my finances! Medical aid does not see autism as an (unclear audio), and that chronic medication cannot be used for that. So Juadon, for example, a behavioural medication, they pay. He drinks 20mg, 40mg, and 60mg. They pay the 20's and the 40's but not the 60's because you have already got 60mg for the day. So they do not pay that at all, and their excess on Juadon is another R400 since July, and there is not a generic version. – Mother D

Mother E, on the other hand, reported paying only R270 per month for her child's Epilepsy treatment as they “*do not have the finances for any other special treatment or interventions*”. Mother G reported that her child is only taking Concerta which costs “*almost R1000 per month*”. Mother C pays “R650 per month” for her child's medication, and Mother F stated that her child's medication adds up to a total of “*R2 000 per month*”.

Overall, the monthly cost of these expenses appeared to be high for most of the mothers and resemble findings obtained by Lavelle et al., (2014) who reported that children with Autism Spectrum Disorder had \$3020 more health care costs compared to those who do not have ASD. Parents reported to pay up to R2 000 per month for their child's medication, and once their medical aids are exhausted, they have to pay these expenses out of their pockets; highlighting the financial burden parents are forced to accept. As stated by Sharpe and Barker (2011, p. 248), the costs related to children with Autism Spectrum Disorder are not limited to cost of interventions as the parents of a child with Autism Spectrum Disorder face greater "*outlays of time and money*". Specialised care, for example, is extremely costly due to the care required for a more extended period when compared to neurotypical children.

Expense: Interventions/ Therapies

Other costs related to the treatment of the child's symptoms and behaviour is costs related to consultation fees of professional health specialists and therapeutic interventions. Mothers F, C, D, and A said they take their child to a psychiatrist, at least once every six months, for a review of their child's behaviour and symptoms so treatment could be adjusted accordingly. Mother F reported paying about R2 000 per psychiatric consultation, whereas Mother A pays R2 800 per consultation. Mother C and D pay between R450 and R650 per consultation.

Mother F, A, B, and D reported to pay for speech therapy as well; however, Mother D reported that her child's speech therapy sessions are divided into two separate sessions due to her child's short attention span.

Now he is with [speech therapists name], the speech therapist, and because we are now out of the medical savings, I am paying the therapy cash, and that is about R 375 per session, and he has two sessions per week, so each month that is about two point something (R 3000 to be exact). – Mother F

He had speech therapy up until the age of 14. At that time, speech therapy was R680 a session, and he went twice a week. – Mother A

I swear by speech therapy! That he has had from a baby as well. I am paying for speech therapy again now because the students at the varsity needed people, but that is R242 a lesson times 4 (R968) per month. – Mother B

Yes and because his attention is so short, his speech therapy gets divided into two half-hour session because he cannot get therapy for an hour. Uhm I think it is R240 for half an hour or otherwise, it is four hundred and something for an hour session...Yeah, you can work on R450 per week. So it is about R2000... - Mother D

Speech therapy [consider], uhm, I am very blessed that I know the lady, so she gives me a good discount, but I mean for one session for half an hour is R260 which is really cheap compared to others. So, that will be once a week every week. So, that will be about R800 a month (R1040 a month). – Mother G

Mother G further complained about the speech therapist suggesting three sessions per week required; however, due to not being able to pay for three sessions a week, she only takes her child once a week.

He goes for speech, he goes for OT (occupational therapy), and he goes for physio. All of those once a week and he is supposed to go more than once a week for speech. They recommended that he goes three times a week. How? I cannot afford it. - Mother G

Other costs related to treatment and interventions were that of physiotherapy; occupational therapy; dietician; and music therapy. Mother A reported that her child had to go for physiotherapy "*for a very long time because he has a very low muscle tone and his body posture is very, very, weak*". She further stated that her child attended Occupational Therapy, twice a week, which cost her R 480 per session. Mother G reported that her son also attends Occupational therapy once a week and costs R490 per session. Mother B reported that her son visits the dietician which costs "*R2 400 for the first visit, and then it is every visit that is five hundred and something after that*" but she reported that she no longer takes her child to see the dietician as they seem to know what foods are appropriate and which are not. She reported, "*I don't really take him at the moment because we know what we are doing*". Additionally, she stated that her son used to attend musical therapy, which she "*swears by*" but was not able to recall the costs.

In summary, costs towards traditional ASD-related therapies such as physiotherapy, speech therapy, equestrian therapy, occupational therapy, and music therapy were found to be very high; however, Lavelle et al., (2014) have not found these therapies to be higher in those with Autism Spectrum Disorder.

The use of more than one intervention can carry tremendous costs, as consultation fees to visit health professionals are expensive, especially for those from the lower social class in South Africa. According to Sharpe and Baker (2007), as mentioned before, children with Autism Spectrum Disorder are required to work with a trained therapist for about 30 – 40 hours per week and can cost up to \$30 000 (ZAR 450 000), annually. These high costs relate to experienced professionals providing one-on-one sessions in order to improve the child's developmental functioning. Participants reported to be paying a minimum of R 450 and up to R2 800 per psychiatric consultation. The cost of speech therapy ranges from R240 to R680 per session. Occupational therapy and physiotherapy were found to cost parents about R480 – R500 per session.

5.2.3 Other Expenses

Other expenses in this study refer to expenses related to the improvement of autistic children's level of functioning and activities the children attend to assist with the development of an ASD child's social skills, behavioural skills, and communication skills. For example, Mother A bought her son a monkey pet to enable the child to develop an understanding of others' needs and to create insight into what it entails to understand another. Mother A reported that she wanted to increase her son's insight and allow her child with the opportunity to care for another; while increasing his self-awareness and independence through having responsibilities.

This monkey was R30 000, and as a parent, you obviously want the best for your child, and you see the positive things that can come from this like this monkey. I can see how this can have a good influence on him. He has to give her (referring to the pet monkey) a bottle, her nappy, he must give her food, he must bath her twice, or three times a week, he must teach her manners, he must clean the monkey's cage. - Mother A

Mother A also bought her son a specialised computer for “R45 000” as he loves technology and working with numbers, and, therefore, got her son the computer to assist him with daily tasks, work-related tasks and accounting as he obtained a degree in BCom Accounting. She reported that her son loves technology and therefore decided to buy him a computer that enables voice-to-text typing and calculating sums in a less complicated way.

Mother B reported that she takes her child to the gym, four days a week, to help him with his physical health and sensory muscle stimulation, as well as to improve his self-esteem. She reported getting her son a personal trainer and pays “R 4700 per month” for his gym contract.

Mother A, B, C and F pay for swimming lessons and equestrian therapy as their children love swimming and believe that swimming allows the children to improve their developmental functioning. Mother A said: *"I took him for swimming lessons because it forced him to listen or else, he would drown. When he was on the horse, he had to concentrate otherwise he would fall off. So he had to go for equestrian therapy because it taught him to listen as well"*. Mother B stated that she pays R400 a month for her child's swimming lessons, whereas Mother F pays *"close to R2 000"* per months as it includes transport fees, to and from the swim school. Mother C reported paying *"R1 100 per month"* for her child's swimming lessons. Mother F reported that the horse riding costs her *"about R2 500 per month"*; also including transport fees as she is unable to take him for his lessons.

5.2.4 Financial support from the state

Two of the mothers reported to have received financial support from South Africa Social Security Agency (SASSA) and complained of the R1 500 they receive every month, not being nearly enough to cover the cost of the child's basic needs. Mother A, C, D, F, and G reported to have not received any disability grant/care dependency grant from SASSA due to various reasons such as the child's age not meeting the requirements; the income of the parents being too high; and the use of medical aid funds that automatically disqualifies parents from receiving a social grant. Mother A and F reported that they claim the expenses from TAX at the end of each financial year.

"...we do tax returns which also help, uhm, so whatever you spend, you are supposed to keep a record of, and then you can claim. I think they pay 30% or 40% off the total." – Mother F

"He studied BCom Accounting and then he said to me that everything I spend on him could be deducted from the taxes and then we did that last year and we got R 32000 back from the taxes."

– Mother A

Mother G annoyingly explained that she does not qualify for a grant as she applied for a grant but got told that she *"earns too much money"*, although she used to collect the grant each month for some time.

"...you get told that you earn too much money, but yet, your salary does not even cover."

– Mother G

The cost of living with a child with Autism Spectrum Disorder is extremely high, and those who do receive a disability grant from SASSA, receive about R1 500 in total per month and mentioned that it is not enough. Some parents reported to have received financial support through tax benefits and reported that these were very helpful; however, only three of the mothers interviewed in this study were aware of this, as others were not familiar with the tax benefits offered by SARS.

Parents of children with Autism Spectrum Disorder, living in New Zealand, receiving a child disability allowance of about \$47.64 and is non-taxable (Ministry of Social Development, 2019). This fee is used to reimburse families for ongoing regular costs associated with having a child with a disability. These costs may cover doctor visits and prescriptions, transportations costs; and counselling costs. Parents who required extra support could apply to organisations such as Halberg Trust, the Variety Club, and New Zealand Lotteries Commission for assistance with vehicle modification, specialised equipment, and sporting activities. In Australia, payments of about \$1000 per month (R10 000), per child, is provided to the primary caregiver of children who have a disability such as Autism Spectrum Disorder (Autism Awareness Australia, 2018). If care is provided for children over the age of 16 years, the care allowance is \$127.10 (R1270) every two weeks. These funds provided by the governments may improve the child's development while enhancing the parent's well-being as they no longer experience high financial strains and, therefore, adequate support from the government is crucial for the health of children with Autism Spectrum Disorder, as well as their families.

5.2.5 Challenge of exhausted medical aids

Despite ASD being an extremely costly disorder with various treatment options and medications prescribed to those diagnosed with ASD, mothers A, B, D, F, and G reported not to have received any sufficient support from their medical aid funds as their medical aids do not always cover necessary remediation. Mother D and F reported that their medical aid fund becomes exhausted by "the end of May each year" which does not assist in any way as they have to carry the costs and pay out of their pockets for the remaining months of the year. Mother E reported that she is unable to afford any medical aid but has had supportive family opening a trust fund which allows them to seek treatment from professionals; however, the trust fund is created for medication, and doctor visits only as other specialised treatments are "too expensive".

“Very, very expensive! His medication is R 3800 per month out of my pocket because medical aid does not cover the medication”. - Mother A

Similarly to the findings of this research study, researchers have found that most medical aids do not cover the necessary treatments required, which cause parents to pay for treatments out of their pockets. According to Sharpe and Barker (2011), health insurance does not pay for behavioural or other types of therapy for Autism Spectrum Disorder; corresponding to the results obtained in this study as mothers complained of medical aid funds not contributing to the cost of such interventions. Young, Ruble and McGrew (2009) stated that the ability of many families to earn a living reduces when they experience challenges to access services such as denial of medical insurance coverage, exacerbating their overall emotional burden. The family’s access and availability to these resources may depend on several external and internal factors, such as culture and socio-economic status, should be investigated in future research.

5.3 ADVICE TO OTHERS

Parents were asked whether they had any suggestions or advice for those living with children with Autism Spectrum Disorder, as well as professionals working with families and children on the spectrum and all parents thought it would be essential to raise their opinions based on their own experience. Therefore, two main themes stood out; advice to other parents raising a child with Autism Spectrum Disorder, and advice to professionals.

5.3.1 Advice to other parents

	QUOTES VERIFYING ADVICE TO OTHER PARENTS
Mother A	There is actually so much that I can say, but the biggest thing is to love them as they are and do not try to change them, change your home so that they can function within. It does not help you want to change them because you are going to kill them.
Mother B	Discipline. Keep your marriage together. Take your child out! Insist that he goes out. Do not care about what other people do.
Mother C	Support, support, support! Support is very important.
Mother D	It takes a lot of patience and holding on, and some days you will just feel like you cannot go anymore, but someone once told me that it gets better as they grow older and it’s true because then he goes off the nappies and now he’s on a different level.

Mother E	I will say that God's grace can be enough, and you have to find strength and wisdom at the feet of the Lord. So, your own quiet time with the Lord is very important and amazing because what you find at the Lord, you don't get at other people.
Mother F	I think for me it is not to compare your child to other kids because they are all different and just focus on your child's strength. Because if you [interrupts self] yeah I think many people struggle badly because this one is talking and this one is not and so on...I do not know it is just other advice that I would like to give, do not become a prisoner to your house because people tend to judge, I mean I do not visit people, but I go to places. So, just focus on your child and what you like doing with him and try to highlight that. That is what I do. I just focus on the things that he can do and ignore the stuff that he cannot do.
Mother G	My advice would be that you have to change yourself because you are not going to change your child. So once you have made peace with the fact that you are not going to change that child for anything in the world, then you can make peace. You have to, and if I say change I do not mean normal, I mean you have to laugh. You have to laugh. If you do not have a sense of humour about the silly things that they do and the tantrums that they have, you are going to be miserable later.

5.3.2 *Advice to professionals*

	QUOTES VERIFYING SUPPORT TO PROFESSIONALS
Mother A	In my opinion, I feel that in this area, the schools are very, very bad in their service of parental guidance. There is supposed to be a weekly or monthly parental guidance sessions just for an hour per week or so where the parents can come and because you get so lonely and things that happen around you, you think it is just you.
Mother B	Be very careful about how you give feedback.
Mother C	[deepens voice] Joh, joh, joh! Professionals have to be professional in that context they must be professional. No matter what. No matter what. Even if you do not like me, then refer me to someone else that is better than you in terms of maybe explaining this situation for me.

Mother E	You know I think compassion and empathy for people, especially parents because you constantly get bad news and just saying to a parent that walk in that this is wrong and that is wrong, and nothing is going to come right actually only upsets parents further. Another thing, it is probably not always easy, but it is so difficult for a parent to go with the child to a consultation room because then he is already draining and unmanageable.
Mother F	You have to listen; the family knows the child better. Unfortunately, it is not what it is in the books [laughs], and I do not know, it is not an umbrella approach. You just have to tailor it to that family.
Mother G	[Thinking] hmmm that is a difficult one. [Considers] I would just say... [Pause]...try and be a little bit sensitive. Do not give so much advice all the time because sometimes it comes across that they are being critical and I do not think that it is their intention; you know what I mean? They bombard you with information about what you should do and should not do and like sometimes we are doing the best that we can, you know, and it is okay!

CHAPTER SIX

SHORTCOMINGS, RECOMMENDATIONS AND CONCLUSION

6.1 Limitations

This study is only a small qualitative study consisting of the experiences of seven families; therefore, this study does not represent generalisations to a larger population. Further research should be conducted to establish this. The researcher has worked with some of the parents in the past, and this might have influenced their response to some of the questions asked throughout the semi-structured interviews. This study only involves mothers which is another limitation. Mothers were the only research respondents as they were the primary caregivers of the children. Some fathers were either not available, uninterested, or did not have the time to meet with the researcher as they had very busy schedules; possibly also emphasising the fathers' absence and involvement in their child's life as indicated in this study. A methodological shortcoming was that of not using a focus group as a data collection method as this method may have helped the participants not feel isolated; a sub theme identified in this study.

6.2 Strengths of the study

There is limited information regarding the experiences of family members who have been impacted by an Autism Spectrum Disorder diagnosis with the primary focus being on the financial cost of raising a child with such a disorder. This study contributes and expands on the existing knowledge. This study represents the experiences of seven families who reflected on their own psychological and financial experiences and needs when having to raise a child with Autism Spectrum Disorder. This study provides value and means to current and future families with similar experiences. This study can motivate professionals to have a deeper understanding of what these families go through and may result in working more effectively with the families so they can get the help they need. This study offers guidance, advice, suggestions and resources for families to assist in the coping process.

6.3 Recommendations

This study has underpinned needs for further research on several key topics. A study exploring the extent to which government disability grants benefit the families of children with ASD; the extent to which siblings of children with ASD influences the child's condition; and the experiences of mothers compared to the experiences of fathers would be useful. It would be recommended that an

experimental study be conducted in order to explore the long-term effects of chronic stress as well as the physiology of stress with specific focus on the “fight or flight” response and the hormonal system, as these were important themes surfacing from the study.

The challenges of finding appropriate school placement and the effect of the public judgment on parents who raise a child with ASD, as well as further exploration relating to the extent to which the financial strain influences the family are all areas requiring attention. Future research could also explore the cultural differences and socio-economic differences that influence a parent’s financial burden as this study is limited by its inability to capture the cultural differences between families. Recommendations to professionals as emphasised by the mothers in this study indicate the need for a comfortable, understanding, empathetic environment where parents are informed about appropriate treatment options in such a way that they feel supported and satisfied with the service received. Professionals and schools could have frequent guidance sessions in order to inform those, who are unfamiliar with the disorder, with more information. It is important for professionals to listen to the parents’ complaints, have compassion, and adopt a supportive approach when working with ASD children and their families.

6.4 Reflexivity of the researcher

Having worked in the field of Autism Spectrum Disorder for two years, this study had a meaningful purpose for the researcher. As a special needs teacher at a school for children with Autism Spectrum Disorder, part of the responsibilities has been to provide support to parents and families who have been affected by Autism Spectrum Disorder. During the time spent at the special needs school in Pretoria, the researcher became aware of the extreme challenges parents and families of children with ASD experience on a daily basis. These challenges ranged from emotional disturbances and lack of support, to financial difficulties and schooling problems. During the interviews, as predicted in the beginning of this study, the researcher came to realise that the families involved in this study had faced many challenges over the years and the great need for support is an aspect that stood out significantly.

Reflexivity refers to the ongoing process of self-reflection, which is adopted and used in qualitative research in order to generate awareness about one’s actions, feelings and perceptions (Anderson, 2008). Gilgun (2006) suggests that reflexivity aims to improve transparency in the researcher’s role and subsequently provide the researcher with the opportunity to apply necessary changes to ensure

credibility of the research findings. With the use of introspection, the researcher could gain insight into existing assumptions and biases and subsequently realised that not all parents with ASD children had negative experiences but that some also had many positive experiences. For example, although most parents reported many hardships involved, most parents reported that their child has had a positive influence on their lives as well.

The results of this study indicate that families who felt unsupported by professionals, the government, and other family members seemed to be at greater risk for mental health problems whereas those who felt much supported by others, appeared to have coped better and subsequently feel better about their situation. It was shocking to discover how little support these parents receive. The challenges experienced by these families and their children were a personal field of interest for the researcher and subsequently informed the topic of this research project. Since working in the field of Autism Spectrum Disorder for a few years, the researcher realised that these parents have great needs, and therefore, came to the decision to investigate this phenomenon further.

In this study, themes were extracted relating to the mothers' experiences of raising a child with Autism Spectrum Disorder and theories were applied to describe how these families' lives were influenced and how they managed to cope with these stressful experiences. According to Anderson (2008), the researcher should listen and pay close attention to the emotional interactions that evolves during the interviews and these findings should be noted and presented in the data collected. During the interviews, the researcher was provided with the opportunity to reflect on respondent's experiences whilst probing further to obtain clarity from the information provided. The researcher had the opportunity to formulate interpretations based on the respondents verbatim whereas participants have the power to challenge the researcher in various ways, for example, by refusing consent, redirecting or avoiding questions, and by confronting the researcher. All of the women provided written consent to participate in the study and they were open and willing to share personal experiences with the researcher while the researcher listened with empathy. The researcher treated all participants fairly and respectfully whilst allowing them the opportunity to tell their story.

Although this study highlights many similarities between the parents' experiences, it was noted that respondents had very different, positive and negative, individual experiences and the researcher have gained valuable insights into the experiences and challenges of these strong mothers; emphasising the need to study this phenomenon further. It was appalling to hear how parents struggle financially

when having to care for a child with Autism Spectrum Disorder and this made the researcher realise how easily one can overlook the needs of parents whilst only focusing on the ASD child. The researcher believes that more consideration should be given to parents and families who live with an ASD child due to the paucity of literature in the South African context. Throughout this process, the researcher has learned a lot whilst enhancing her skills as a researcher by gaining insight into conducting qualitative research through semi-structured interviews and by applying the conservation of resources theory, the cognitive appraisal theory, and the family systems theory. The researcher has gained a number of insights about parenting, coping, and raising a child with Autism Spectrum Disorder with minimal resources.

Overall, respondents enjoyed using the opportunity to talk about their ASD child whilst feeling supported by the researcher who was truly interested in their story. The researcher has learned a lot throughout this research study and, therefore, her approach to working with any parent, especially parents of children with special needs, will be adjusted in such a way that parents always feel accepted, understood, and supported.

6.5 Trustworthiness and credibility

In qualitative research, it is pivotal to enhance the trustworthiness and credibility of the research by recognising personal subjectivity and biases, consider how it may influence the findings, and use strategies to ensure that it does not influence the findings in any way (Wagner, Kawulich, & Garner, 2012). The fundamental principles of reliability and validity are embraced in qualitative research through the concepts of credibility, transferability, and dependability. Credibility, also known as internal validity in qualitative research methodology, refers to the confidence that can be placed into the truthfulness of the research findings by the use of research strategies such as reflexivity, triangulation, member checking, and time sampling (Anney, 2014). In this research study, credibility is ensured by giving participants the power to choose whether they want to partake in this to guarantee that data collected only involved participants who genuinely wanted to partake in the study (Shenton, 2004). The researcher has attended supervision which allowed the researcher to reflect on own thoughts and experiences whilst the supervisor provided guidance and challenged any possible biases.

According to Anney (2014), “transferability refers to the degree to which the results of qualitative research can be transferred to other contexts with other respondents”. A comprehensive review of

literature regarding the financial and psychological costs of raising a child with ASD were conducted and discussed to provide adequate context for the study. More so, the researcher reported common themes and subthemes generated by transcribing the verbatim of participants to provide evidence for the findings that are presented in this study. Dependability refers to “the stability of findings over time” (Bitsch, 2005) and refers to the evaluation of the quality of processes such as data collection, data analysis and reporting of results. The researcher achieved dependability through the development of consistent procedures for conducting the interviews by following a supervisor reviewed interview schedule to maintain uniformity. The researcher also made use of consistent procedures for analysing the data collected. A comprehensive research design and data collection was included in this study to allow for possible replication in the future.

CONCLUSION

It appears that there are various psychological and financial needs of parents raising a child with Autism Spectrum Disorder. As stated in the aim at the beginning of this study; this study succeeded in demonstrating that there are definite psychological and financial challenges involved in raising a child with Autism Spectrum Disorder. It succeeded in proving that raising a child with Autism Spectrum Disorder is financially more costly than expected as it entails life-long costs. The aim was achieved with semi-structured interviews with seven mothers in Gauteng. Thematic analysis of the transcriptions was used to generate themes and subthemes.

The findings in the study reflect that parental stress begins before the diagnosis is made and increases upon receiving the diagnosis. Participants experience various emotions throughout the process of caring for a child with Autism Spectrum Disorder. Significant feelings were found to be that of guilt, stress, denial, anxiety, depression, frustration, confusion, shock, and fatigue; similar to the process of grief. Challenges parents experience is found to be the lack of social support and social isolation; increasing their levels of stress. Raising a child with Autism Spectrum Disorder has been found to have a significant impact on parental well-being as well as the siblings, extended families, and peers. The impact on family life was significant as families have to adjust and adapt which leads to further repercussions; affecting the families’ finances, careers, and lifestyles. Although raising a child with Autism Spectrum Disorder is found to be very challenging, many parents reported that their child had a positive influence on them as well as the child taught them patience, acceptance, and unconditional love.

The financial strain, on the other hand, was found to be tremendous as medical aids and support from the government does not cover the costs related to caring for a child with ASD. What emerged from this study are the high costs of the child's schooling, treatment, sanitary care, and high costs towards caretakers and tutors. In addition, all parents complained of medical aids not covering the child's treatment costs and those who received a disability grant reported it to be not merely enough.

Professionals, educators and other parents of children with Autism Spectrum Disorder should consider the results of this study to increase awareness and support for families and subsequently enhance their quality of life. Future research may focus on understanding the extent to which these financial challenges influence the family from diagnosis of the child to the present. The total cost and financial needs of raising a child with Autism Spectrum Disorder should be compared to those who raise typical children to identify the differences between the two. Future research should focus on the different experiences of mothers compared to fathers when raising a child with ASD. It is the hope of the researcher that this research project will improve the insight of parents living with a child with Autism Spectrum Disorder and create awareness to professionals about the importance of emotional support, financial support, and understanding.

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APPENDICES

APPENDIX A: ETHICAL CLEARANCE



05 June 2017

Ms Anouska Geldenhuys (217045051)
School of Applied Human Sciences – Psychology
Howard College Campus

Dear Ms Geldenhuys,

Protocol reference number: HSS/0529/017M

Project title: The financial and psychological cost of raising a child diagnosed with an Autism Spectrum Disorder (ASD)

Approval Notification – Expedited Application

In response to your application received on 12 May 2017, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL**.


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 and Methods must be reviewed and approved through the 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 discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully


.....
Dr Shenuka Singh (Chair)

/ms

Cc Supervisor: NC Memela
Cc Academic Leader Research: Dr J Steyn
Cc School Administrator: Ms Ayanda Ntuli

Humanities & Social Sciences Research Ethics Committee

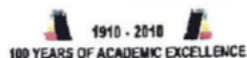
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Founding Campuses:  Edgewood  Howard College  Medical School  Pietermaritzburg  Westville

APPENDIX B: INFORMED CONSENT



CONSENT TO PARTICIPATE IN RESEARCH

THE FINANCIAL AND PSYCHOLOGICAL COST OF RAISING A CHILD WITH AUTISM SPECTRUM DISORDER (ASD)

Dear Participant

Firstly, I would like to thank you for taking the time to read this letter. My name is Anouska Geldenhuys, and I am currently a Masters student at the University of KwaZulu-Natal in Durban. My research supervisor is Zethu Memela, in the school of Applied Human sciences, Discipline of Psychology. I would like to invite you to consider participating in my research project: The financial and psychological cost of raising a child with Autism Spectrum Disorder. You have been chosen with the help of Pathways Pretoria as an ideal candidate due to your direct experience of having a child with an Autism Spectrum Disorder.

1. PURPOSE OF THE STUDY

The aim and purpose of this study is to generate understanding of the impact on family dynamics, challenges experienced by family members, and the financial effect raising a child with Autism Spectrum Disorder (ASD). I would like to gain deeper understanding of how a family is influenced by the Autistic child.

2. PROCEDURES

Data will be collected through semi-structured interviews, with the purposes of obtaining a clear understanding of the lives and experiences of the participants. If you agree to participate in this study you as the parent/caregiver will have to be willing and available to be interviewed for an hour.

3. POTENTIAL RISKS AND DISCOMFORTS

The researcher aims to contribute to the general well-being of people. Your right will not be abused or violated for the purpose of gaining information and knowledge. Should the interviewer feel it is necessary, she will refer the participant for counselling at Lifeline Pretoria, Itsoseng clinic or SADAG.

Contact details:

- **Itsoseng Clinic:** University of Pretoria (Mamelodi Campus)
Corner of Hans Strijdom Avenue and Hinterland Street, Mamelodi East Department of Psychology: Administration building, Ground Floor, Room D120. For appointments contact Mr. Rico Visser on:
Telephone: 012 842 3515
Fax: 086 518 3871 Email: Itsoseng.clinic@up.ac.za Clinic
Hours: Mondays to Thursdays from 9:00 to 16:00 (Services are free of charge)
- **Lifeline Pretoria:** 012 342 2222 Address: 71 Watermeyer St, Val-De-Grace, Pretoria.
- **SADAG:** 011 234 4837

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR SOCIETY

There will be no financial benefits for participants. However, the findings of this study might help you as well as other parents/caregivers who are dealing with the same challenges. Your input in this study is valuable as it has the potential to provide State Departments with a rich image of what it is like to be in the family/support system of ASD. Your contribution can raise awareness to State Departments regarding the financial impact of raising a child with ASD.

5. CONFIDENTIALITY

Interview questions might include items that require personal responses. Therefore, this letter serves to assure you that all responses will be completely anonymous and at no point in the study will you be named. Confidentiality will be maintained by using numbers/codes instead of names for participants. Confidentiality will be maintained by means of keeping all information (audio recordings and handwritten notes) locked away. All audio recording will be deleted after the completion of the study.

6. PARTICIPATION AND WITHDRAWAL

Your participation in this study is completely voluntary. No participant should feel coerced in any way, and a decision to not participate will not result in any form of disadvantage. Subjects are free to withdraw from the study at any stage and for any reason. You may also refuse to answer any questions you don't want to answer and still remain in the study.

Should you require clarification of further information regarding the study, please do not hesitate to contact me on the contact details provided below.

<u>Contact details of Researcher</u> Anouska Geldenhuys 082 064 6404 Anou2@hotmail.co.za Student: 217045051 UKZN: Howard College	<u>Contact Details of Supervisor</u> N.C Memela 031 260 7428 memelan@ukzn.ac.za	<u>Contact details of Research Office</u> Phumelele Ximba Administrative Officer 031 260 3587 XIMBAP@ukzn.ac.za
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PARTICIPANT DECLARATION

I (Full names of participant) hereby confirm that I understand the contents of this document and the nature of this research project, and I consent to participating in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire.

I hereby provide consent to:

- Audio-record my interview YES/NO

Signature of Respondent

Date

Signature of Researcher

Date

APPENDIX C: INTERVIEW QUESTIONS

Demographic Information Sheet

Parent/Caregiver: _____

Age: _____

Race: _____

Marital Status: _____

Child with disability:

Age: _____

Description of Disability:

Semi-structured Interview Questions

I will be asking semi-structured interview questions which will touch on the following themes:

- A. The child's condition and level of functioning
- B. Family relationships
- C. Relationships with partner/spouse
- D. Impact on siblings
- E. Mental Health of the parent
- F. Support Systems
- G. Emotions and behaviour control in the family
- H. Treatment needs of the ASD child
- I. Financial impact

In addition to above themes, I would like to make enquiries about the following questions:

1. What advice would you give to other families who have a child with Autism Spectrum Disorder?
2. What advice would you give to professionals who work with families who have children with Autism Spectrum Disorder?
3. Other: Please discuss any other relevant information you feel comfortable disclosing that could be helpful in gaining a better understanding of the experiences of families who have a child diagnosed with Autism Spectrum Disorder.

APPENDIX D: EXAMPLE OF TRANSCRIPTION

Transcription – Mother G

Interview Transcription: Interview 007 on 12 July 2017

Key:

R = Researcher

P = Participant

R: Briefly, we are just going to start talking about what it is like having a child with Autism Spectrum Disorder. So before we start with that I would like to go into the child's condition and level of functioning. What does he do and what is the behaviour that is so strange compared to other children and things like that.

P: Okay, He is 10 years old and he, he is non-verbal, so it is challenging, and he is on Concerta because he is very, very busy and he does not concentrate at all. He goes to a special needs school. Uhm and he basically, I cannot say he is high functioning. He has areas that are higher than others are, but he is not a high function autistic, as he does not have one thing that he does particularly well. Uhm he has a great love for people, which is some people, will say aah then he cannot be Autistic because he loves people so much but that is not true because the way that he loves them is inappropriate. It is extreme.

R: Like no boundaries?

P: Yeah, no boundaries. No sense of danger. Strangers are his best friends. So uhm, but Ja he doesn't dress himself yet. He can do basic pulling up his pants if you help him with those things and he feeds himself and he is toilet trained.

R: Oh so he is potty-trained?

P: Ya he goes to the toilet.

R: Yeah and does he display any repetitive behaviour?

P: You know what's funny with him which is not typical is that he never had it and the older he is getting I'm seeing more say OCD type of behaviour like certain things if he puts his shoes in

the cupboard they must be in the cupboard a certain way and he'll throw them in and in and in the whole time until he gets them in the way that he wants and it is not a typical way so you can't help him, because you would think left and right must be next to each other. No it's not like that. They must go in in God only knows which way and until they look that way, he will throw them in the cupboard 7 times over until they in the way that they must be. So he has...now that he is getting older, he has things like he will draw the curtains and then he will draw them again and again and again and like okay the curtains are fine, but they not fine.

R: And when did you realise the strange behaviour? When did you realise there's something different with [REDACTED] (ASD Child)?

P: With [REDACTED] (ASD Child) it was young.

R: Hmmmm....

P: He wasn't diagnosed with Autistic Spectrum Disorder until quite later, a lot later, but with him basically 6 months he wasn't sitting and that was to me a que that he couldn't sit. And they said that he was very stuck in my womb so he could just be delayed and then they said he had water on his brain and then I ended up with a great neurologist and then he said to be no we have to test him for many syndromes and then he went through the whole genetic counselling and only now recently has he been diagnosed on the autistic spectrum.

R: Oh... so in the beginning you were very unclear what it was.... [Interrupted]

P: he was undiagnosed yes.

R: So when he got diagnosed with Autism Spectrum Disorder, sitting there and they tell you that this is the diagnosis of your child. What does it feel like?

P: I must be honest for me the experience was different to most parents I think because at this stage he's been diagnosed with many things that were actually terrible. So many syndromes that they've thought he had. They originally thought he had Angelman syndrome and then he developed too quickly for that and he didn't....Angelman Syndrome is damage on the chromosome 15 and he had no damaged chromosomes. So with every diagnosis that he had and all the drama that we had gone through the autism was almost a relief to me, you know. It sounds

strange but the water on the brain and all that stuff and the shunts...that didn't have to happen. So the autism to me was almost a bit of a relief.

R: Hmm... And you knew what Autism Spectrum Disorder was all about when they told you?

P: [shakes head] yeah

R: so you knew exactly what intervention was needed to help your child and... [Interrupted]

P: I think also being in the special needs industry, being in the school that I was, was a blessing for me when they said it is autism. I was like "aah it's okay". It's not okay, but it's okay. I've seen a lot worse.

R: hmmm...some parents don't really understand what's going on and... [Interrupted]

P: and also you know you think that you've got the worst situation ever because it's all you know but for me having seen children with feeding tubes and children with, you know, far worse disabilities... I was just grateful.

R: yes, and what does it feel like to have a child who cannot communicate with you?

P: Communication is probably the toughest part, because for him he thinks he is communicating. He suffers a lot from dyspraxia so he thinks that he is verbalising, and he will move his mouth, everything so there is a lot of frustration, and that is where most of his and my frustration comes from, you know. He will move his mouth and he will say things and then he will look at you like ok well are you going to respond and then I will, but then it is not always what he wants. So, that is where I think he's biggest frustration comes from and he really wants to talk so it's difficult.

R: Okay, but he can communicate if he wants something to eat. Can he communicate that to you not verbally, but by showing?

P: Yes, he can show. He is very good at communicating in that way.

[Interruption]

P: sorry

R: No, it is fine

P: yeah I will say communication is my biggest [pause] and his biggest frustration.

R: yes, because it is a big challenge. You know you can't really understand your child or you can but not as easy as you would like to. It is quite difficult. Uhm...What I wanted to ask you is how soon after the diagnosis did your child receive treatment?

P: uhm...

R: like medication and all those kind of things?

P: Basically the first year already, because uhm [interruption at her office] basically the First year already, because he was diagnosed with something else within the first year. So I immediately took him for OT and physio and those kinds of things. So I started intervention quite early. Uhm [pause] and I was also very hard on him actually if I think about it I was very tough with him. I expected a lot from him and I pushed him a lot, but uhm medication wise and Concerta wise it was only quite recently he went to see a psychiatrist which I was very against, because I was like "my child don't need a psychiatrist", but it was actually a good thing because she put him on Concerta and it made a big difference.

R: So it seems like it's working?

P: oh yes definitely.

R: Would you say the diagnosis...sorry you wanted to say something?

P: [shakes head] no

R: Would you say the diagnosis of him being autistic, do you think, in a way, it strengthened your relationship with him, or did it make it a bit weaker. How did it influence the relationship between you two?

P: uhm... I'm a very different parent to most [laughs] so I don't know...I don't know...like for me it never really also, because we struggled so much to find a diagnosis it never really mattered to me. It got to the point where I was exhausted financially. I practically lost everything, because it was expensive every time they did those genetic tests. I even sent blood tests to Germany and overseas for testing so desperate to find a diagnosis and what was wrong that I got to the point

where I was like, you know what, is there an operation to fix it... No there isn't... So just stop it, stop the problem and the poking and all as it does not really matter. I'm not having more kids, so it doesn't matter. That's just where I got to. So like I said, the autistic thing...ugh...I was like, another diagnosis here we go. I just believe in giving him whatever blocks he gives me; I build onto them.

R: okay...yes

P: and that's just been my attitude.

R: I think it's a good thing also in order to help him improve or reach things that he needs to...like milestones or not really milestones as he passed that already, but I think it is needed for a child to have that support from his mother.

P: Ya and I just take like where is he at with dressing, where is he at with cognitive abilities and then I just build on that, you know. As long as he is constantly improving then I'm happy and he is. I must say I'm very blessed that he is constantly improving.

R: Well that's good. So you can see improvement. Even if it's little, I mean, any improvement is good improvement. So that's good. How did the diagnosis or how does it influence you emotionally and physically or what impact does it have emotionally and physically to have a child with autism or on the spectrum?

P: It's draining. It's very draining, because they do not stop needing you ever and it is different for me. I think people are confused, because they seem to think that if your child has special needs and their in a wheelchair and they can't walk and things like that it is more draining, but I can't say that one is more draining than the other, because with children that are autistic or on the spectrum they are demanding. They are very demanding. They've got very demanding personalities. You know, they are very strong, and they have got very strong personalities in general. So, because [REDACTED] (ASD Child) demands my attention all the time, he's not a child that will just go and play, I must be with him. He needs me to see him. He doesn't need me, and I don't need to hold his hand, but I must be there, and I must look all the time what he is doing. So it's that constant...he constantly wants that one-on-one attention.

R: Yes, yes.

P: and if there's other people around or I'm not doing what he wants me to do then he plays up. So if it's now time for me to sit down and watch TV then the food can burn, the house can burn down it doesn't matter if I'm now sitting and watching TV then it's a problem, because you know they are very routine driven. If the routine is out, then there's trouble. Then the whole house has to suffer. So from that point of view it's very emotional draining, because sometimes you just want to lose it. You just want to scream, because you cannot now do the routine, because life happens and if you throw that routine out then it's a problem.

R: yes and the family relationships, what is the family like?

P: Hmmm...It's difficult. It is difficult [pause], because he is so demanding. He has a habit of screaming when he doesn't get his own way. He gets like this high pitch scream and he will scream and scream and if that doesn't work, he will make donkey noises. He goes [eeeh-aaah...eeeh-aaaah] the whole time. And then he won't stop. You can carry on, you can put him in his room, you can smack him, you can bribe him it doesn't matter he will carry on. So, it's difficult, because either mommy or daddy will eventually give in, because even though you know you shouldn't it's just to make the child keep quiet.

R: That's so difficult.

[Interruption in office]

R: how does it influence your relationship with your partner to have a child with Autism Spectrum Disorder?

P: It's tough on interpersonal relationships, because you do find you know the difficult thing for any parent is that there is no line between what's behavioural and 'what is just plain naughty', because it's difficult. Sometimes you know people will say "ugh he just needs a hiding, or he needs discipline or whatever, but there are so many factors sensory influences that people don't take into account. So I think that is where it's difficult to find a balance between when is he actually just being damn naughty or when is it his autism, because there is no define line and that is where it becomes difficult, even for my partner, because it'll be like you know he will be acting up and then I'll be like "aren't you going to discipline him" and then he's like ok, but the

other day when I discipline him it was a problem [laughs] so must I discipline him or mustn't I discipline him?

R: [laughs] so he is so confused and doesn't know what to do [laughs]

P: I'm like bl*ksem him. then the next time he will discipline him and then I will say "juseee, but that is unnecessary you know" and then he will say "but you said I must bliksem him when he is being naughty" and then I'm like "yes, but you need to take into account that he has been in the shops for the whole day so the lights have been...". So that's where it becomes hard to handle.

R: And [REDACTED] (ASD Child)'s father is he still present in his life?

P: No

R: Oh okay

P: His...my, my husband at the moment is his dad, but he is not his biological father. His biological father left when he was 9 months old. Well actually I kicked him out, because he decided that drugs was an easier option and he couldn't cope. After [REDACTED] (ASD Child) was diagnosed or there was a problem then he couldn't cope. So he started drinking, using drugs such as cat.... [Interruption]

R: Would you say the difficult behaviour or the challenging behaviour [REDACTED] (ASD Child) displayed made it difficult for you and his biological father where his father couldn't cope with it?

P: Ja he couldn't deal with it.

R: would you say it's from a point of being scared or just not... [Interrupted]

P: I think he just couldn't deal with it and I started throwing myself into books and looking and meeting people and phoning physiotherapists and getting as much information as possible and he just was like "there's no point, don't do it", you know.

R: and you say that [REDACTED] (ASD Child) has a brother?

P: Ya

R: and it's only the two of them?

P: no he has got a brother and a sister. His sister is 14 and his brother is 12.

R: oh okay. So he is the youngest and how does it influence or do the siblings know about his diagnosis of being autistic?

P: yes

R: and how do they react or respond to his behaviour?

P: I've been extremely, extremely blessed. Really blessed. They are amazing with him, my daughter particularly; she has done her own research. If I've ever gone on courses she would ask can she go with? She is very, very informed.

R: That is really good, because usually the siblings tend to.... [Interrupted]

P: like they went through their time where...I think...I don't know what happened and we still don't know what happened. They went through probably like a 6-month period where he was really hurting her where he would bite her and pull her hair out of her head. I don't know what happened. I think it was a...she was very clingy to me at that particular stage of her life, because she was just going into being a teenager and so I think he noticed that she was needy and he was needy and he didn't like the fact that there was a bit of competition between them, but that has passed thank the Lord, because that was the toughest time, because then you don't know how to cope.

R: Yoh, I can imagine.

P: You know, and I mean he was rough. He bit her open and it was very, very bad.

R: How does it influence your relationship with your other children with him needing attention all the time? Does it influence your relationship with the other children at all?

P: It does, because I often feel like...you know...his sister is also just personality wise a very high maintenance child with regards to the fact that she wants my attention all the time. So between the two of them I'll often make a joke and say I can't even go to the toilet, because literally she'll sit on the one side of me and he'll sit on the other and then I'm on the toilet and I'm like can't you

two not just get out, you know [laughs]. I have to have both of them on the toilet with me all the time or I'll be in the shower and then she will come jump in the shower with me and if he sees she's in the shower with me then he must also come jump in the shower with me. So from that point of view it is changing and then my other son, because he doesn't demand attention, he gets it. He is like "shame mommy having [REDACTED] (ASD Child) at home is very tough". [Laughs] Then I feel like he gives back and they like make time for him. It's difficult, because I feel like I need to make individual time for each one of them. Whereas [REDACTED] (ASD Child) and Tristan don't really allow for that, you know. But I think you have that in every family.

R: Yes definitely. I think it happens all over and not just....

P: [interrupts] I think what's crushing everyone is also not being able to make the allowance you know, because he was like for example maybe...like last night is a good example. They each had a bowl of chips and then he scoffed his down, because he likes chips and he does it on purpose and he watches how much his brother and sister has got left so he finishes his before they finish theirs so he can go to them and grab theirs. So the I'm like you are not going to take theirs, you had yours so sit down it's finished. You have to have manners and then he will cry and perform and then eventually one of them will be like "you know what I can't do it, just take it". So that's one of the difficulties where you don't want the family to give in, because he has to learn, but for sanity sake eventually, because he can carry on. We have left him ones before when he didn't get his own way and it can be a 5-hour stunt when he is in the mood.

R: [surprised] Wow!

P: 5 hours!

R: 5 hours. Wow that is even more draining.

P: Yeah so then you just give him what he wants. It was winter, it was now and then he wanted to swim, and we were like you can't swim it's cold and he was like no I can, what's the problem, I can. So we were like you are not swimming! 5 hours that child cried...5 hours! So eventually I was like you know what, it's fine. Ripped all his clothes off and I was like "bye" here is your pool now get in and so he got in the pool and he swam. [Laughs]

R: Got to do what you got to do [laughs].

P: I said if social welfare had to come here now.... [Laughs]

R: You can't help it, what can you do. And what is it like going out as a family, going somewhere into the public. Is it challenging to take an autistic child to a public area?

P: It is. It's very challenging especially because my husband is such an introvert. He is very introverted and quiet, and he doesn't want everybody to look at him and talk to him so with a childlike [ASD child] it's not going to happen. You get attention whether you want it or not and the thing is [ASD child] is an extrovert so if he is not getting the attention, he will get it. So we've always got people staring and I'm over it. It doesn't worry me, and it hasn't worry me for probably the best part of 3 years already, but like I've said I'm a different mom to most moms. Uhm in my career as a special needs teacher I have experienced that 90% I would say of the school where I was parents don't take their kids out. They don't and they would rather leave them, because it's easier and also you think you doing them a major favour and then they actually don't enjoy where they are going. It's out of their routine, they don't like it, but I force [REDACTED] (ASD Child). So I'm like "you just have to suck it up we are going to the shop and that's it".

R: Which can also be a good thing because he can get use to different environments.

P: Yes and I do. We take him out with us. Obviously, we try to do things that he likes, and we try to do things that.... I'm not going to take him to a fancy restaurant, but I will take him to Spur, you know. Like it or not and if people don't like it then go sit somewhere else. Maybe we'll have another Spur incident [laughs].

R: [laughs] hopefully not. Would you say that it made your life or if it did, in what way did it make your life more stressful to have a child on the spectrum?

P: It is very stressful. Financially definitely! Financially it's huge, because everything that they need is expensive and because his dad left when he was 9 months old, he didn't support me at all financially. So I was a single mom for a really long time until I married [current husband].

R: Recently?

P: Ya recently so I ya.

R: That must have been very difficult though.

P: Financially he almost broke me a few times.

R: Yes and did you have support from outside family members?

P: [considers] I cannot say my family didn't support me, because they did, but not in the way I needed it to be. You know the thing is that everybody thinks they have an answer, everybody thinks...I've always said that once you have a child that's autistic then you meet the most intelligent people. I don't know where they come from, but it's a miracle. All of a sudden, the world is full of intelligence and everybody has an opinion on what you should do and what's wrong with him and how long it's going to take, and he is going to grow out of it and...

R: Everyone's doctors all of a sudden

P: I'm telling you! Even when you walk in the mall and people are like AAH SHAME is he autistic? You must do this you must do that and I'm just like thank you, thank you very much. You get phone numbers of Avril Elizabeth Home from people that you don't even ask for.

R: Really?

P: hmmm. People are strange.

R: Yes that is very strange. I haven't heard about that before.

P: Yea people are very nice especially because he is so friendly I think it gives...because he is so friendly people think because he approaches them and he hugs them and stuff, now we friends so now I can give you my opinion and I can tell you where he should be and which home you should put him and refer you to a doctor.

R: Yes and the extended family or outside family or the bigger family, what is the relationship like between them and [REDACTED] (ASD Child)?

P: I don't really see my family at all, because he wasn't invited to many birthday parties. So, I will find out that my family have gone to a cousin's birthday party and then he wasn't invited so then...even friends. I lost quite a few friends, but they weren't really friends, because they would invite me and say "if it's possible can you find someone to look after [ASD child], because we really want to spend time with you" or "we don't want any incidences, because my gran is not

going to handle it well". They try and tell you nice excuses of why you shouldn't bring him so those people I just left. So basically, I don't have good relationships with my extended family and if I say hi and Bye that is where it ends. I don't do the family visits, because it makes them uncomfortable and I'm not going to go...I just got to the point in my life and in [REDACTED] (ASD Child)'s life where I made the conscious decision that If I had to go somewhere and fight with him, then I'm not going and if that makes you feel uncomfortable then I'm sorry. Don't take it personal it's not about you, but I'm not going to fight with him on the weekend. I fight with him to brush his teeth, I fight with him to brush his hair, I fight with him to get dressed, and I fight with him to do everything so when it comes to visiting people I'm not going to visit you if my child is not welcome. If you cannot handle the fact that he is different or the house isn't child friendly or whatever the case is, then fine. You can either come to me where he is in his comfort zone or we don't see each other. That's just how...

R: [interrupts] and do they come to you if you do invite them over?

P: Ya, only the ones that I invite and I'm selective now. I don't invite those that are going to feel uncomfortable. Even my mom, bless her heart, she can only handle him in small increments, because she gets nervous when he's around other people. So if she's at my house or we at her house it's fine, but when he's around other people she gets...[impersonating mom] he is going to grab her glasses, he is going to upset...and then she plants those ideas in his head and then he hears her and then he laughs and then he will do it. So I try to tell her don't instigate the behaviour, because he wasn't thinking about pulling her glasses off, but now he is you know and then she gets nervous and I can see it in her body language and everything. So I try not to put her in that position.

R: I think also people think that no these kids won't understand, and I can say anything, because he won't understand, but I think they much smarter than we think they are.

P: I think they much more intelligent than most people. I really do. It's really interesting if you consider that there's a link or they trying to prove that there's a link between autism and people who are registered with Mensa which is the most intelligent people. Like Albert Einstein was thought to be Autistic looking back at his behaviour and that's quite an interesting study. I mean especially with [REDACTED] (ASD Child) like when he went to 2 professors who diagnosed him, and

they said his brain is too fast. That's why Concerta is helping him. His brain is way too fast for him. It's too fast for him. He can't keep up with his thoughts and stuff so that is actually amazing if you think about it. One of the professors said please bring him later on in life as he would love to test him, but for now he is too young, because he said to me: "I promise to you this child is a genius". It's just that everything is too fast for him to file.

R: hmm...and he can't express himself clearly so you might think that he is not a genius, but you never know. You've covered most of the questions in the psychological impact section. Uhm so now looking at the financial impact, you said that you believe that it does have a huge impact on the finances. Would you say that it is more expensive to raise a child with autism or with special needs compared to neuro-typical children?

P: Definitely. There is no 2 ways about it. Definitely, because it is such a specialised thing and unfortunately the medical aid and the physiotherapists and the government knows that and there's no, I mean, if you compare, a lot of people go to Australia and other countries because it is more inclusive and they don't nail them because they've got special needs. You know special needs being in South Africa, I mean if you just look at the equipment that children need from perspective of wheelchairs and standing frames you're looking at R75 000 for a thing like that and when it comes to autism they will not need that, but special schools, in special schools you know how much you pay for a special needs school and it's generally half day. So there's no help. Then you try to get a government grant and you get told that you earn too much money, but yet your salary doesn't even cover. The top plan on discovery gives you like a R1000 a month for therapies, but if you work it out a physio session is R490 for half an hour, so you can keep your R1000. It doesn't help.

R: What I've realised with doing this study is that the medical aid doesn't really cover anything regarding a child with disabilities.

P: No they don't. They really don't. You go on the top plan and then they turn a certain age and then they classify them as an adult, and they charge you adult fees. I mean I know a lady who has twins with Cerebral Palsy. Ones in a wheelchair and one isn't, but he walks with a standing frame and they now 21 and their medical aid now, so imagine they are paying R24000 a month for medical aid for the whole family to be on medical aid and it doesn't cover. They need, the twins

need to go for physiotherapy, they go to bio kinetics, they go to occupational therapy and they go to speech therapy. So you cover times 2, 4 therapies a week. What is the medical aid covering for R24 000 a month?

R: So you're not receiving any financial support from the government at all?

P: No. I did try and apply because I use to get a SASSA grant which that R1500 really makes a big difference. It really does. It covers his Concerta and so, but uhm [sigh] they say I earn too much money, so they stopped. As soon as you earn over a certain amount of money then they won't give you which is actually a pity because we could still use it.

R: Yes, yes. Can we talk a bit about the expenses that you have to cover each month regarding [REDACTED] (ASD Child) and if possible if you could estimate the medication, what it cost you a month and...

P: [interrupts] Okay, well his school fees...his schooling is only until half past 12 in the afternoon, so the school fees are R5 500 a month. Then his Concerta is almost R1000 it's like eight hundred and something rand a month. So then you are looking at already, my maths isn't very good, but it comes to about 6 grand. And then obviously because it's half day he still needs to get someone to get him at home. So it's transport which is over a grand (R1000) a month. And then you are looking at someone to look after him until you get home so then you need a helper or a caregiver uhm which is probably looking at about two three thousand rand a month (R2000-R3000) on top of that. So that's no clothes, no food, that's no physio, no devices because he needs a tablet at the moment so that he can communicate because at school they use tablets and he does really well with his tablet at school, but I don't have one at home. So, you know, those type of things cost a lot of money and then like I said those expenses alone it's not physio, it's no OT (occupational therapy), no speech.

R: Is he going for speech therapy?

P: He goes for speech; he goes for OT (occupational therapy) and he goes for physio.

R: Is that every month, the speech therapy, well all three of those?

P: All of those once a week and he is supposed to go more than once a week for speech. They recommended that he goes 3x a week. How? I can't afford it.

R: So what does it cost you a session for speech therapy for instance?

P: Speech therapy [consider] uhm I'm very blessed that I know the lady so she gives me a good discount, but I mean for one session for half an hour it's R260 which is really cheap compared...

R: [interrupts] compared to the others. So that will be once a week every week. So that will be about R800 a month (R1040 a month). And then with the OT?

P: OT is R490

R: and he sees her once a week also?

P: Ya and the physio. So you can imagine, I think [REDACTED] (ASD Child) alone cost me close to R20 000 a month without food.

R: Joh, and yeah that's specific food again that he has to eat or...

P: [interrupts] well I'm blessed that he doesn't. He eats anything and everything.

R: and he is comfortable in wearing any clothes and not sensitive to specific clothes?

P: hmmm...he doesn't like things that don't breathe. Like you know that kind of material that doesn't have, like he likes cotton and, I don't know how to explain it. You get like that material that's got no... But it affects his eczema because he suffers from eczema on his legs. So if he has some material that doesn't have a breathing or airy material then he feels itchy and irritable, but generally he is not as bad as other kids I know. Like labels don't bother him and those types of things. I'm very blessed.

R: That's nice yes. And any other...is he seeing a psychiatrist?

P: No...

R: Okay not at the moment. Usually they see them only once a year anyway.

P: Ja and I think maybe when the hormones kick in and he gets older, then maybe that would be something I would have to look at again, but for now since I've seen her the one time and she recommended Concerta and it's been fine.

R: and audiology, dietician, nothing like that?

P: No.

R: Transport...we talked about that, school fees [reading through list of possible expenses]. Is he going for horse riding, swimming, music therapy?

P: No. He was going for swimming. I think in summer he will start again because it's very calming and I think autistic children generally tend to love water. [REDACTED] (ASD Child) really loves swimming so I will definitely take him back.

R: Hmmm so just a last few questions. What advice would you give other families who have a child with autism?

P: My advice would be that you have to change yourself because you are not going to change your child. So once you've made peace with the fact that you are not going to change that child for anything in the world then you can make peace. You have to, and if I say change, I don't mean normal, I mean you have to laugh. You have to laugh. If you don't have a sense of humour about the silly things that they do and the tantrums that they have, you're going to be miserable later. So if you cannot find a place... I'm...I have a very different attitude. I laugh a lot. I laugh about the things he does, I laugh about his tantrums maybe not to his face, but sometimes we laugh. I mean if you don't have a sense of humour then you know...I mean the one day he ate a tampon in the shop and I didn't realise that he could open my bag and I was still carrying him and he [laughs] and I know when he gives people things he goes hmm,hmm,hmm [impersonating child] and I saw this nice guy, I saw this hot guy and I was still thinking 'aah Wow he is good looking' and he walked past me and then the next thing I heard, I heard [REDACTED] (ASD Child) going hmm hmm hmm. So I'm like what is he giving someone? I thought he grabbed something off the shelf because he likes to just randomly grab things off the shelf and give it to people, you know. Like you can have this packet of chips my mom will pay for it, you know. So I turn him around and I'm like what are you giving this man and then he turned around and I see this good looking

guy and I'm like Oh hello [talking to guy] and then I look down and then he goes I won't be needing this and he had eaten the top of the paper of so it was like a mushroom...[phone rings] sorry let me just take this quickly....So uhm Ya, there was this tampon that looked like a mushroom and I mean I could have been mortified, but...

R: [interrupts] but you ended up laughing about it because it is funny.

P: yes. You have to find a sense of humour.

R: yes definitely. And when you look at giving advice to professionals working with families like doctors, psychologists. What would you like to say to those people when working with these families?

P: [thinking] hmmm that's a difficult one. [Considers] I would just say... [Pause]...try and be a little bit sensitive. Don't give so much advice all the time because sometimes it comes across that they are being critical and I don't think that it's their intention, you know what I mean? They bombard you with information of what you should do and shouldn't do and like sometimes we are doing the best that we can, you know, and it's okay!

R: Definitely! Anything else that you would like to mention? I think we've covered most of the things, more than most of the things and it will definitely contribute to my study.

P: Good! I hope so, there is nothing else really.

R: So that is it. Then we are done... [Recording ends]

APPENDIX E: REFERRAL MECHANISMS

Anouska Geldenhuys (217045051)

Referral mechanisms for further support for the participants

- Itsoseng Clinic – University of Pretoria (Mamelodi Campus)
Corner of Hans Strijdom Avenue and Hinterland Street, Mamelodi East
Department of Psychology: Administration building, Ground Floor, Room D120.
For appointments, contact Mr. Rico Visser on:
Telephone: 012 842 3515
Fax: 086 518 3871
Email: Itsoseng.clinic@up.ac.za
Clinic Hours: Mondays to Thursdays from 9:00 to 16:00
(Services are free of charge)
- UNISA: Centre for Applied Psychology
Unisa Main Campus, Pretoria
Theo van Wijk Building
Fifth Floor Room 5-152
Asanda Nogquala
Tel: 012 4292590 (office hours)
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