RESILIENCE FACTORS IN LOW-INCOME FAMILIES WITH AN AUTISTIC CHILD

By

Alicia Horak

Submitted in partial fulfilment of the requirements for the degree of

Master of Arts in Clinical Psychology

In the

Faculty of Health Sciences

At the

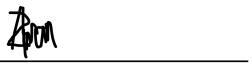
Nelson Mandela Metropolitan University

2017

Supervisor: Mrs Lisa Currin

Declaration

I, Alicia Horak, s215109759, hereby declare that the treatise for the degree of Magister Artium in Clinical Psychology to be awarded is my own work and that it has not previously been submitted for assessment or completion of any postgraduate qualification to another University or for another qualification.



Alicia Horak

Abstract

Autism Spectrum Disorder (ASD) encompasses a group of life-long neurodevelopmental disorders. It is an enormous challenge to care for someone with ASD. The majority of people with ASD will need life-long support from family members and will not be able to function independently in society. This places emotional and financial strain on a family. There are many low-income families in South Africa with autistic children who cannot afford specialised intervention. It has been estimated that 135 000 autistic children are not getting the specialized education they need. Despite not receiving the needed support, there are many low-income families who remain resilient after their child is diagnosed.

This study aimed to explore how these low-income families remain resilient. Qualitative data was gathered using in-depth, semi-structured interviews conducted in English and Afrikaans; depending on the participant's language of preference. Six participants were recruited with the help of professionals in a local community in Cape Town, Western Cape. The data obtained was transcribed and analysed through thematic analysis. Lincoln and Guba's model (Krefting, 1990) was used to determine the trustworthiness of the data. The three themes that emerged from the study were (1) parents' response to the diagnosis of their child, (2) the resources parents found helpful in their immediate environment and (3) the specific coping skills that parents use to remain resilient. Walsh's family resilience framework as well as the Resiliency Model of Family Stress, Adjustment and Adaptation (The Resiliency Model) of McCubbin and McCubbin were used to understand how participants adjusted to their circumstance and remained resilient. This study provides a more in-depth understanding of the resilience factors of families with a child with ASD in a resource-limited setting in the Western Cape.

Keywords: Autism, Autism Spectrum Disorder, Low-income Families, Parents, Resilience.

Acknowledgments

I hereby wish to extend my gratitude to the following people who made this treatise possible.

Mrs Currin, thank you very much for guiding and advising me with regards to this study. Thank you also for being willing to correspond with me from Port Elizabeth to Cape Town and for working hard with me to finish this study in time. Without your time and effort I would not have been able to complete this study.

Thank you also to my dear friend and classmate, Rozanne van Wyk, for helping me with the logistics and admin of handing in my treatise. I also sincerely appreciate your love, support and encouragement the past 2 years.

Cornelius Zeeman, thank you for being a loving and caring husband and a major source of support in my life – especially the past two years. I cannot in words say thank you enough for your encouragement, love and patience.

My family and friends, who patiently listened to my hardships and worries of the past two years. Your faith in me has been constant and helped me to keep believing in myself.

Gail Klopper, who helped with the analysis of my data, thank you for your wisdom and time.

Khanyiso Jonas and Grazelde Meyer – thank you for the effort you put into transcribing my interviews for me.

Thank you very much for each and every participant of this study. Without your willingness to share your stories this study would not have been possible. Thank you for your honesty.

To God, my heavenly father, You carried me every step of the way and once again proved to me that with Your strength I can do anything and You will always support me.

Contents

Declaration 2
Abstract 3
Acknowledgments 4
List of Tables 8
List of Figures 9
Chapter 1: Introduction to and Motivation for the Study 10
Introduction 10
Defining Autism Spectrum Disorder 10
Genetics of Autism Spectrum Disorder 11
Treatment of Autism Spectrum Disorder 12
Motivation for the Study 12
Primary Aim of the Research 14
Delineation of Chapters 14
Conclusion 14
Chapter 2: Autism and Resilience in Families 15
Introduction 15
History of the Concept of Resilience 15
Family Resilience Research in South-Africa 17
Research Review of the Impact of Caring for a Child with ASD on the Family System 19
Research Review on Resilience in Families Coping with Autism Spectrum Disorder 24
Research highlighting a focus on low-income families 28
Research highlighting further qualitative research 31
Conclusion 32
Chapter 3: Walsh's Family Resilience Framework and the Resiliency Model of Family Stress, Adjustment and Adaptation 33
Introduction 33
Resilience 33
Walsh's Family Resilience Framework 34
Family belief systems 34
Organisational patterns 35
Communication processes 36
The Resiliency Model of Family Stress, Adjustment and Adaptation 37
Adjustment 38
Adaptation 40

Conclusion 43
Chapter 4: Research Design and Methodology 44
Introduction 44
Problem Formulation and Research Aim 44
Aim and Objectives 44
Significance of the Research 45
Research Methodology 45
Research design 45
Sampling and research participants 46
Data collection 47
Procedure 48
Data Analysis 49
Trustworthiness of the Data 51
Ethical Considerations 52
Informed consent and voluntary participation 53
Privacy and confidentiality 53
Beneficence and non-maleficence 54
Maintenance, dissemination and keeping of records 54
Debriefing of research participants 55
Conclusion 55
Chapter 5: Results and Discussion 56
Introduction 56
Biographical description of the sample 56
Parents' response to the diagnosis of ASD 59
Self-education and research 60
Recognition of the symptoms of ASD 62
Anticipation of learning problems 64
Parents described the availability of resources 65
Resources within the close family circle 65
Resources in community 68
Parents developed their own coping strategies 70
Develop relaxation strategies 70
Develop a strong faith base 72
Develop a specific environment 74
Conclusion 77

Chapter 6: Conclusion, Limitations and Recommendations 79
Introduction 79
Conclusions from this Study 79
Objective One: To explore and describe how low-income families cope with the everyday stressors of living with a child with Autism Spectrum Disorder 80
Objective Two: To explore and describe the specific characteristics which enable these families to remain resilient 82
Objective Three: To explore and describe the resources utilised by low-income families raising an autistic child 83
Limitations of the study 85
Value of the study 86
Recommendations 87
Conclusion 89
References 91
Appendix A: Cover Letter 99
Appendix B: Informed Consent Form 101
Appendix C: Biographical Questionnaire 104
Appendix D: Interview Schedule 107

List of Tables

Table 1 Biographical Information of Adult Participants 48

Table 2 Summary of Themes 49

List of Figures

Figure 1 Resiliency Model of Family Stress, Adjustment and Adaptation 36

Figure 2 Adaptation Phase of Families in this study 75

Chapter 1: Introduction to and Motivation for the Study

Introduction

Chapter one introduces the present research on resilience in low-income families living with a child diagnosed with Autism Spectrum Disorder (ASD). Attention is given to the context of the research and the motivation for this study. This chapter also defines ASD and explores the aetiology and treatment of ASD.

Defining Autism Spectrum Disorder

According to the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DMS-5) (American Psychiatric Association, 2013) the essential features of Autism Spectrum Disorder (ASD) are persistent impairment in reciprocal social communication and social interaction and restricted, repetitive patterns of behaviour, interests, or activities. These symptoms are present from early childhood and limit or impair everyday functioning. The stage at which functional impairment becomes apparent will vary according to characteristics of the individual and his or her environment (APA, 2013). Core diagnostic features are evident in the developmental phase, but intervention, compensation and current supports may mask difficulties in at least some contexts. Manifestations of the disorder also vary greatly depending on the severity of the autism condition, developmental level and chronological age and therefore the term *spectrum* (APA, 2013).

Verbal and non-verbal deficits in communication have various manifestations. Many individuals have language deficits, ranging from complete lack of speech through language delays, poor comprehension of speech, echoed speech, or stilted and overly literal language (APA, 2013). Deficits in social-emotional reciprocity are clearly evident in young children who may show little or no initiation of social interaction and no sharing of emotions. Reduced or absent eye-contact, gestures, facial expressions and body orientation is also

common. An early feature of ASD is impaired joint attention as manifested by a lack of pointing, showing or bringing objects to share interest with others (APA, 2013).

The clinical presentation of ASD is complicated by various comorbid conditions like Attention Deficit Hyperactivity Disorder (ADHD), sensory difficulties, epilepsy and intellectual disability. Approximately 50% of children of ASD also meet criteria for ADHD (Malcolm-Smith, Hoogenhout, Ing, Thomas & de Vries, 2013).

ASD is further complicated as deficits vary markedly across the spectrum in their precise nature and intensity. It is very challenging to accurately identify and characterise individuals with Autism Spectrum Disorder and to manage it appropriately (Malcolm-Smith et al., 2013).

Genetics of Autism Spectrum Disorder

The main areas of evidence that support a genetic aetiology of ASD are twin studies and family studies comparing the rate of autism in first degree relatives versus the population (Geschwind, 2011). As monozygotic twins share 100% of their genetic material and dizygotic twins share 50% and both share in utero environment with their twin, higher disease co-occurrence in monozygotic twins than dizygotic twins supports a genetic aetiology of ASD. This is what is observed in every twin study in ASD, overall consistent with heritability estimates of about 70–80% (Geschwind, 2011).

Studies in families show that first-degree relatives of ASD individuals have a markedly increased risk for ASD relative to the population, consistent with a strong familial, or genetic, effect observed in twins. First-degree relatives of individuals with ASD have an increase in behavioural or cognitive features associated with autism, such as social or language dysfunction, even if in lesser forms, when compared with the population prevalence (Geschwind, 2011; Folstein & Rosen-Shiedley, 2001).

Treatment of Autism Spectrum Disorder

Parents of children with ASD often use a variety of treatments simultaneously. Interventions with foundations in behavioural interventions are most investigated and often seen as first-line treatments for ASD (Mire, Raff, Brewton & Goin-Kochel, 2015). Behaviourally based interventions target skills across multiple domains, including communication, socialization and motor skills. An internet-based survey of parents with children with ASD found that 53.6% of the sample used ABA (Applied Behaviour Analysis)-based therapies (Mire et al., 2015). According to Autismlink (2016), ABA is based on the theory of B.F Skinner and uses immediate and positive consequences to reward positive behaviour.

A wide variety of biomedical or Complementary and Alternative Medicine (CAM) are also indicated for ASD with more than 70% of parents having tried at least one CAM (Mire et al., 2015). Symptoms targeted by these treatments vary, but the general aim is to create biological changes or improve sensory or other experiences (like through animal therapy) (Mire et al., 2015).

Psychotropic medications (i.e., antipsychotics, mood stabilisers, stimulants, antidepressants) are frequently prescribed for children with ASD, though core symptoms may be only weakly related to psychotropic use (Mire et al., 2015). No drug currently has been identified to ameliorate core symptoms of ASD but rather to target associated symptoms (Mire et al., 2015).

Motivation for the Study

It is seen, worldwide, as an enormous challenge to care for someone with ASD (Bekhet, Johnson & Zauszniewski, 2012). Approximately 85% of individuals with ASD have cognitive limitations which limit their ability to live alone and will thus need some form of care from parents or family members throughout their lives (Karst & van Hecke, 2012). It is

estimated in the United States that it can cost a family 3-5 million dollars more to raise an autistic child than to raise a neurotypical child (Malcolm-Smith et al., 2013). In South Africa it has been estimated that it costs a family about R3 million to raise an autistic child (SNAP Education, 2012). According to SNAP Education (2012) this cost can be reduced to R1 million through early interventions. With early intervention more children on the autism spectrum can be enrolled in mainstream schools and more children with ASD can be educated to a point where they might be able to enter a workplace (SNAP Education, 2012). According to Statistics South Africa (2014), 4.75 million households in South Africa lived below the poverty line in 2011, with poverty more than twice as high in rural areas.

There is limited information regarding the incidence, prevalence and impact of ASD in South Africa (Malcolm-Smith et al., 2013). In the Western Cape, 10 children are diagnosed per week with ASD at the Red Cross Children's Hospital, Lentegeur and Tygerberg Hospitals (Bateman, 2013). There are only 9 schools in South Africa which are specifically tailored for ASD and it is thus estimated that 135 000 autistic children are not getting the specialised education they need (Bateman, 2013). According to Russel et al. (2015) an increasing awareness of ASD has led to evolving demand for services, but research guiding health service provision is limited.

Because of the few available services, especially in disadvantaged communities, and the lack of financial resources, a diagnosis of ASD is often nothing more than "bad news" for families of low socio-economic status (Malcolm-Smith et al., 2013). This poses the question: how do these families stay resilient after receiving the "bad news"?

There are many different demanding and overwhelming aspects of caring for someone with ASD and therefore family members' mental health is often affected (Bekhet et al., 2012). One child with ASD needs the same amount of attention as six neurotypical children (Bateman, 2013). Learning how to be resilient despite these overwhelming challenges can

help families overcome the stress and burden associated with caring for someone with ASD (Bekhet, Johnson & Zauszniewski, 2012). According to Karst and van Hecke (2012) the impairments associated with ASD not only affect the individual, but also family members, caregivers and teachers. Very limited research has been done on interventions to help people with ASD and their families (Karst & van Hecke, 2012). A study on the resilience factors of these families can provide help to other families who experience the same crisis.

Primary Aim of the Research

The main aim of this study was to explore and describe how low-income families with a child on the autism spectrum remain resilient. Specific objectives were identified and are discussed in Chapter 4.

Delineation of Chapters

Chapter 1: Introduction to and Motivation for the Study

Chapter 2: Autism and Resilience in Families

Chapter 3: Theoretical Framework

Chapter 4: Research Methodology

Chapter 5: Results and Discussion

Chapter 6: Conclusion, Limitations and Recommendations

Conclusion

In this chapter the context and rationale for the study was discussed. ASD was defined and the genetic aetiology and treatment of the disorder was discussed. In the next chapter the literature regarding resilience in families with a child with ASD will be reviewed.

Chapter 2: Autism and Resilience in Families

Introduction

The context and the motivation for the current study were described in the previous chapter. ASD was defined and the genetic aetiology and treatment of the disorder was discussed. It was highlighted that it is an enormous challenge to care for someone with ASD and that there are few available resources to low-income families. This chapter will firstly review the history of the concept of resilience and family resilience research in South Africa. Secondly, the existing literature confirming the challenges of caring for a child with ASD will be reviewed. Furthermore resilience research for families with a family member with ASD will also be reviewed. Existing literature recommending further research with low-income families are reviewed as well as studies motivating for qualitative research.

History of the Concept of Resilience

Positive, strengthening and adaptive outcomes in response to adversity have a long and renounced history. The term resilience has been used broadly for centuries, but it is only in the past several decades that resilience has gained currency as a psychological concept. The term began to appear in the 1970's in developmental literature on chronic adversity. Much of the research on human development at the time was focused on the aetiology of psychopathology (Bonanno & Diminich, 2013). The focus, however, began to shift due to research by developmental psychologists, psychiatrists and other mental health professionals documenting the large number of children, who, despite adversity, emerge as functional and capable individuals (Bonanno & Diminich, 2013).

Many studies have been conducted aimed at identifying the protective factors which enabled children and adults to bounce back from adversity (Patterson, 2002). Researchers in disciplines other than psychology were noting similar competent functioning following risk exposure. Antonovsky (Patterson, 2002), a medical sociologist introduced the concept of

salutogenesis to describe the high functioning of many survivors of the Holocaust. McCubbin (McCubbin & McCubbin, 1996) and his colleagues in explaining the variability in military families' response to war, noticed that some families adapt successfully and others do not. The disciplines of public health, medical sociology, psychology and family science converged at the same point asking the same question – how do some stay healthy in the face of risk and others do not? (Patterson, 2002).

At first, resilience research was focused on defining resilience and identifying the factors that were associated with positive outcomes (Bonanno & Diminich, 2013). Identifying the differences between those who did well and those who did not do well was paramount.

Research confirmed that there were in fact great consistencies across contexts regarding resources, individual qualities and relationships as predictors of resilience outcomes (Bonanno & Diminich, 2013). The focus of resilience later expanded to more than just the identification of resilience factors, to an understanding of the specific processes that lead to resilience (Bonanno & Diminich, 2013). Over the years, resilience became more than just a list of protective factors, but rather a process of coping and adjustment, using the individual's own resources and enhancing their own existing resilience qualities (Hanekom & Brown-Baatjies, 2008).

Walsh (2003) took a systems-orientated view of resilience and focused on identifying the strengths and potentials that families hold that help them cope with life's demands and stressors. Walsh (2003) defined resilience as the ability of a system to remain intact in spite of adversity and to return to the same level of pre-morbid functioning as before the crisis or to surpass the premorbid level of functioning (Brown-Baatjies, Fouche & Greeff, 2008). A systems-oriented view of resilience brought the family to the forefront of research and the study of resilience became increasingly viewed as a family level construct (Walsh, 2003). A family-resilience approach aims at identifying those aspects that contribute to healthy family

functioning, rather than family deficits. To be considered family resilience, the outcome of interest should be at the family system level, where a minimum of two family members are involved (Patterson, 2002). Family resilience encompasses a number of common ideas. Resilience is believed to come to the fore when families are faced with hardships. Inherent in the concept of resilience is fortitude – "bouncing back" after "falling down" (Greeff & van der Walt, 2010).

There is no universal list of key, effective protective and recovery factors, but a review of recent research recognises recurrent and prominent attributes among resilient families (Black & Lobo, 2008). These factors include: a positive outlook, spirituality, family member accord, flexibility, communication, financial management, time together, mutual recreational interest, routines and rituals and social support (Black & Lobo, 2008). These factors have been shown to not only compensate for risk factors, but to promote family harmony, balance, and security (Black & Lobo, 2008). The family serves as a bridge between the individual and other community contexts and is often central in the processes evident when resilience occurs. Families often fulfil important functions of nurturance and socialisation, economic support and membership/sense of belonging which provides personal and social identity and provides meaning to life (Patterson, 2002).

Family Resilience Research in South-Africa

Over the past few decades interest in the field of positive psychology gained momentum in South Africa and South African research into individual resilience progressed to investigations into the concept of family resilience. Greeff (2007), from the University of Stellenbosch, has made considerable contributions to South African research publications on family resilience in various vulnerable families, such as families in which a parent has died (Greeff, & Joubert, 2007), poor single-parent families (Greeff & Fillis, 2009), and families with an autistic child (Greeff & van der Walt, 2010).

Dass-Brailsford (2005) conducted a study to explore the resilience factors amongst a socially disadvantaged group of black youth in Durban, South Africa. Three sets of factors were identified as having helped participants remain resilient and to, specifically, gain academic achievement. First were individual characteristics of the participants, secondly family support and role models and lastly, support from the community and schools. The study aligned with a trend towards focusing on those factors that reduce risk and increase coping, which is a step in the right direction and reflective of a discipline that values and respects the healthy aspects of human development and enhances the coping skills of those that are less resilient. It is an approach that focuses on strength. Interventions should always strive to facilitate a resilient response in victims (Dass-Brailsford, 2005).

De Villiers and van den Berg (2012) implemented a resiliency programme for children and found that intrapersonal characteristics (such as emotional regulation and self-appraisal) of resilience increased significantly after implementation of the programme. The study was conducted due to concern that South African children are exposed to many risk factors that pose a threat to their well-being. These risks include familial conflict, poverty, exposure to high levels of community violence, educational stressors (a lack of resources, poorly trained educators, a lack of support services) and the HIV pandemic. The lack of psychological and psychiatric services at primary, secondary and tertiary levels further exacerbates the situation for South African children. The study indicated that interventions should be developed to empower children with the necessary resilience resources to deal with adversity (De Villiers & van den Berg, 2012).

Brown and Robinson's (2012) study regarding the resilience factors in remarried families indicated results which could inform and improve interventions and psycho-education regarding how remarried families adapt and remain resilient. The study contributed

to the growing body of research regarding resilience in families in South Africa and highlights the importance of family resilience studies in South Africa.

A South African study on resilience factors in families with a child with ADHD indicated the advantages of a family resilience framework (Brown, Howcroft & Muthen, 2010). The study indicates that it is becoming more important to recognise existing strengths and to understand those processes that enable families to endure change and to rebound as a strengthened unit from life's challenges (Brown et al., 2010).

In South Africa, research which specifically contributes to the understanding of the resiliency process in families, or which identifies those resiliency factors that play an essential recovery role in families faced with stress, is limited (Brown et al., 2010). Although South African research on specifically *family* resilience is limited, the awareness and interest into the field is growing. From the available South African studies, it has been concluded that South African families do have the capacity to preserve family stability and harmony and have the capacity to restore the family's functioning following crises (Brown et al., 2010). This indicates that South African families are resilient (Greeff & Human, 2004; Greeff & Van der Merwe, 2004). The value of a proactive, health-focused orientation should not be underestimated in a developing country, such as South Africa, where resources are limited (Brown et al., 2010).

The family resilience perspective has much to offer the family science discipline. A focus on resilience draws greater attention to family success and competence. The knowledge derived from family resilience studies can be used in practical settings (Patterson, 2002).

Research Review of the Impact of Caring for a Child with ASD on the Family System

According to Patterson (2002) family resilience studies should focus on families who experience significant risk. The processes by which families succeed or fail will be more evident if we examine more extreme situations of risk exposure, rather than the more

normative challenges of daily life. Furthermore, it is only under conditions of significant risk that resilience as a process is operative. Such studies will reveal which family relational processes are protective across a range of risk exposures and which are unique to specific adversities.

Families where a child has been diagnosed with ASD can be said to be under conditions of significant risk. These families face various challenges which are unique to them. These challenges are life-long and impact various aspects of family life such as vocational, personal, social and financial. A diagnosis of ASD should be considered a family problem and not just a problem of the individual diagnosed (Hanekom & Brown-Baatjies, 2008). The family context is therefore of critical importance (Walsh, 2003).

A study by Kheir et al. (2012) conducted in Qatar confirms the impact of having a child with autism on the lives of the caregivers. Parents reported poor physical and mental health, limited access to resources, marital conflict, restrictions of activities for the family and increased stress. A study on the quality of life of Iranian mothers with a child with ASD had similar results (Kousha, Attar & Shoar, 2016). The study found that mothers are at higher risk for experiencing greater distress, lower psychological well-being, anxiety and depressive symptoms. The study emphasises the importance of recognising and addressing caregiver's mental health status and quality of life (Kousha et al., 2016).

Tint and Weiss (2016) state that many families of individuals with ASD are required to reassess their life priorities, commitments and relationships to meet the needs of their family member with ASD. Many family caregivers reduce their work hours while facing high unexpected costs due to care for their family member (Tint & Weiss, 2016). Many individuals with ASD, due to their ongoing troubled behaviour, need constant monitoring, which limits the family's ability to socialise, contributing to their sense of social isolation. There is also often a lack of understanding from the general public regarding the symptoms

and behaviour associated with someone with ASD. There is considerable research indicating the significant social, financial, physical, emotional and financial stressors these families face (Tint & Weiss, 2016). The influence of someone with ASD can also extend beyond the parents to siblings and other family members (Tint & Weiss, 2016).

A study by Lee et al. (2009) found that parents of children with higher functioning ASD may still experience substantial stress, which has a negative impact on mental and physical health. The study indicated that the parents who participated felt that income, which would allow access to professionals, plays a significant role in buffering stress. The researchers indicate that future research should include low-income families with higher functioning ASD children to explore how income affects quality of life and how this relationship is observed across a broad range of socio-economic status.

Mothers of children with ASD report higher levels of stress and depression than mothers of children with developmental delays (Weitlauf, Vehorn, Taylor & Warren, 2014). Understanding and addressing this increased distress is particularly important since caregivers of very young children with ASD are often placed in the difficult roles of advocates, service coordinators, and interventionists for their children. Given the well-documented challenges of raising children with ASD, research identifying factors that worsen or alleviate the clinically significant distress surrounding diagnosis may help families adapt during this critical time (Weitlauf et al., 2014).

O'Brien (2007) confirmed that having a child diagnosed with ASD is experienced as an ambiguous loss for parents. The inherent ambiguity of autism, related to the lack of knowledge surrounding its aetiology, symptoms, treatment, and outcome, suggests that parents whose children are diagnosed with ASD experience conflicting realities and emotions. Coming to terms with the discrepancies between their initial expectations for their child and the altered look that is required for the family to function well after a child receives

an ASD diagnosis, is a process that few families can be expected to negotiate easily. An autism diagnosis is not a time-constrained situation, but one in which parents must live with the contradiction inherent in recognising the irreversible nature of their child's condition while maintaining a long-term commitment to the child's upbringing (O'Brien, 2007). Therefore, families of children with ASD can be expected to experience ambiguity and loss over many years and need support in their efforts to live with the emotions that often emerge at each new phase of the child's development (O'Brien, 2007). This study highlights the immense challenges families are confronted with when having to come to terms with an ASD diagnosis.

Smith and Anderson (2014) highlights the permanency of caring for a family member with ASD in a study on the roles and needs of families of adolescents with ASD. The researchers highlight the significant, multiple roles that families play in the lives of their children and the fact that parents continue to be primary caregivers for their child with ASD well into adulthood. Parents need to be involved to help their child transition into adulthood. The adolescent with ASD will need guidance with regards to work options, support groups, developing specific skills and emotional support. Parents of adolescents with ASD have intense daily lives marked by ongoing, chronic stress from a variety of sources such as unpredictable, challenging behaviours from their child, financial strain, exposure to bullying and difficulties associated with the adolescent phase. Most of these difficulties are chronic and not easily remediated and therefore education (building an understanding of their child) and support is of paramount importance for these parents (Smith & Anderson, 2014).

The above-mentioned indication of the required life-long parental care for children with ASD is also highlighted by Pozo and Sarria (2015). These authors conducted a study to explore whether parents of adult children with ASD are in better mental and physical health than parents of young children with ASD. The results of their study indicated that parental

stress is always present, independent of the age of their child with ASD, but anxiety and depression may be lower in parents of adolescents or adults compared with parents of younger children. The reason for the improvement in emotional health of parents of adolescents or adults with ASD, is that they present with less behavioural problems than young children with ASD and the parents have the benefit of cumulative experience. However, older parental age was associated with poorer well-being as increasing age poses new demands and concerns. Thus, despite improvements in their child's symptoms and extended parenting experience, parents of adolescents or adults with ASD continue assuming multiple responsibilities and may experience negative consequences as a result of their own ageing process. The need to care more for themselves as they age and increasing concerns regarding the future of their child with ASD, when they die or become too elderly to care, may compromise their psychological well-being. Interventions aimed at supporting families of adults with ASD should be prioritised by health care systems (Pozo & Sarria, 2015).

According to Whitehead, Dorstyn and Ward (2015) there is extensive research confirming that caregivers of children with ASD are at increased risk of developing mental illness such as depression or anxiety. These authors conducted a study with female caregivers with a child with ASD regarding their adjustment to their child's diagnosis. The results indicated that caregivers who assumed that their psychosocial circumstances were out of their control and who engaged in avoidant coping (disengagement, self-blame, denial, emotional venting) had poorer mental health. Emotional and behavioural challenges characteristic of ASD, as well as a lack of resources, worsened caregivers' mental health. In comparison, action-orientated strategies relieved distress of caregivers. These action-orientated strategies will be discussed in greater detail in the following section. Further research is indicated to explore the variables that would protect caregivers' mental health.

Research Review on Resilience in Families Coping with Autism Spectrum Disorder

As discussed in the preceding section, families caring for a child with ASD are faced with a myriad of challenges. Insight into a family's coping mechanisms, adjustment and adaptation that allows resilience can be very useful. Unfortunately, very little research has been conducted in South Africa on the resilience of families coping with a member who has ASD. An overview of international family resilience literature that has emerged regarding families with ASD will follow. The few studies that have been conducted, which focused on the resilience in families from higher socio-economic status, will also be reviewed. These studies indicate the needed exploration of resilience factors in families from lower socio-economic status. Furthermore, studies indicating further qualitative research will also be reviewed.

Cridland, Jones, Magee and Caputi (2014), provide directions for future family-focused ASD research. This article highlights that many studies focus on the challenges of families living with a member with ASD. However, they emphasise that a comprehensive understanding of the challenges for families also warrants investigation into coping and support mechanisms. The authors indicate a range of areas that would benefit from further research, such as resilience, family connectedness and spiritual development, appreciation of life and enrichment of relationships. According to the authors' systematic review, resilience is apparent in families who make active efforts to spend time with each other, balance needs of the family member with ASD with needs of other family members, maintain healthy routines, hold shared values, find meaning in challenging circumstances, have flexible roles, utilise support services, openly communicate and have proactive approaches to challenges. They argue that exploring resilience factors such as the afore-mentioned, increases information that can be used in clinical support settings. Clinical support services are a type of formal social support that increases well-being, knowledge about the disorder, family

functioning and resilience (Cridland et al., 2014). Strengths-based approaches (implemented in clinical support services) help families utilise their own resources and recognise their own capacities for resilience (Cridland et al., 2014).

The study referred to in the previous section by Whitehead et al. (2015) indicated that caregivers who took proactive steps (planning, acceptance, positive reframing) to identify and resolve their distress related to their children (with ASD) and who accessed social networks reported resilience. These caregivers' mental health was better than caregivers who did not seek help and had no hope for possible relief of their circumstances. The implication of this study was that caregiver resilience protects caregivers against the development of pervasive mental disorders due to a perceived inability to cope. Exploring how caregivers remain resilient and incorporating this in interventions with parents is indicated for future research (Whitehead at al., 2015).

A study by Pastor-Cerezuela, Fernandez-Andres, Tarraga-Minguez and Navarro-Pena (2015) conducted in Spain compared parental stress of parents in children with typical development and parents of children with ASD. The results indicated that parental stress in the ASD group was clinically significant and higher than in the comparison group. Another objective of the study was to analyse the relationship between parental stress in the ASD group and the parental characteristics of resilience. The results indicated that the ASD families involved in the study showed adaptive management and even a positive contribution to the family dynamic, which indicates good resilience levels, despite challenges. Parents who perceived themselves as more resilient to adversity reported less stress associated with depressive symptoms and with their feelings of competence about their role as parents.

In the case of the parents of children with ASD, this pattern of resilience is, evidently, quite important in facing and dealing effectively with day-to-day life with a child with ASD (Pastor-Cerezuela et al., 2015). Furthermore, those parents of children with ASD who

perceived themselves as more resilient to adversity reported two parental characteristics closely related to two indicators of resilience: optimism and self-efficacy. The researchers of this study thus propose the design of interventions to increase positive cognitions or cognitive appraisal that helps families to learn how to be resilient. They suggest that enhancing resilience among family members of children with autism may be beneficial to both the parents and the children. Further studies on resilience factors in families with a child with ASD is recommended (Pastor-Cerezuela et al., 2015).

Foo, Hui Yap and Sung (2014) presented an in-depth analysis of the lived experiences of Singaporean parent-caregivers with a child diagnosed with ASD who exhibits challenging behaviours. The results indicated that what helped caregivers to go on with their lives was a sense of responsibility to care for and protect their child, their duty to support their spouse and ensure that their child's behaviour does not inconvenience others. The caregivers reported that over the years they developed a sense of self-respect in their resourcefulness and capability in caring for their child. This study illustrated that clinical practice and future research would benefit from a family resilience framework in understanding the effects on parents having a child with ASD and challenging behaviours (Foo, Hui Yap & Sung, 2014).

The possible buffering effects of psychological resilience on stress, anxiety and depression associated with parenting a child with an ASD were investigated amongst parents in Australia by Bitsika, Sharpley and Bell (2013). The study confirmed that parental anxiety and depression is elevated above the norm for parents of a child with ASD. This study further indicated that no matter how stressed the parents of children with ASD may feel, their ability to surmount the emotional and physical demands of parenting their children will be, at least, partially determined by their psychological resilience. These findings note the need for further research into specific resilience factors which could provide avenues for intervention and training of parents (Bitsika, Sharpley & Bell, 2013).

Canadian parents in sixteen families of children with Autism Spectrum Disorders or Down Syndrome participated in a qualitative study examining family belief systems by King et al. (2009). As a result of their experiences with their children, families reported becoming more certain about what matters. Families adopted perspectives of optimism, acceptance, and appreciation, and of striving to change the environment or to meet their children's needs as best as possible. These perspectives provided families with a sense of hope, meaning, and control over their situations. The findings indicate the strengths and resilience of families in the face of life's adversities. Insight into parents' perspectives can increase sensitivity and improve practitioner responses to family needs (King et al., 2009).

A study by Bekhet, Johnson and Zauszniewski (2012) conducted in the United States of America examined the effects of caregiver burden and positive cognitions on resourcefulness in persons caring for someone with ASD. The results of the study indicated that positive cognitions had mediating effects on the relationship between caregiver burden and resourcefulness. Caregivers are thus better able to be resourceful when they have positive thoughts. Resilience may help caregivers not only to survive the day-to-day burdens of caring for a person with ASD but also to thrive, that is, to grow into stronger, more flexible, and healthier persons. The findings provide direction for the development of interventions to strengthen positive thinking and help caregivers of persons with ASD cope with the burden of caregiving (Bekhet et al., 2012).

A review of the literature of existing studies regarding resilience in families with a family member with ASD, was conducted by the same authors (Bekhet et al., 2012) and the following resilience factors were found in studies: self-efficacy, acceptance, a sense of coherence, optimism, positive family functioning and enrichment. The results of the review also indicated that families who exhibited resilience factors could cope better with caring for

a child with ASD (Bekhet et al., 2012). The authors highlight the importance of research on resilience factors and the implications of such research.

Research highlighting a focus on low-income families

Patterson (2002) indicated that further research on family resilience should have a focus on families who not only face a significant stressor, but who also have additional stressors related to their ecological context. According to this author a family's ability to be resilient in the face of a stressor is not only related to their internal relational processes, but also to risks or opportunities in the social systems in their environment. Families who live in neighbourhoods characterised by violence, crime and poverty are at greater risk of not being able to maintain their core functions. Risk processes such as marital conflict, child abuse or substance abuse are more likely to emerge under these poor social circumstances. The absence of needed community resources to support families in fulfilling their core functions further undermines family resilience. A society's norms and values as well as resources available in the community determines the degree to which families are able to acquire and develop new capabilities when challenged (Patterson, 2002).

Patterson (2002) indicates that, based on the above-mentioned argument, families in limited-resourced communities need to be a focus of family resilience studies.

In a study conducted by Bayat (2007) in Chicago, USA, resilience factors were explored in families of children with autism. Specific resilience processes were identified such as: making positive meaning of disability, mobilisation of resources, becoming united and closer as a family, finding greater appreciation of life in general and gaining spiritual strength. One of the limitations of the study was the demographic profile of participants, as 63% of the families were middle- to upper-class white families. Further research was recommended with a more representative sample. Bayat (2007) also recommended research with qualitative methodologies like face-to-face interviews which might provide deeper analysis.

Fewster and Gurayah (2015) conducted a study on the experiences and coping strategies of parents of children with ASD. The participants were parents whose children attended a stimulation clinic, which provides stimulation for children with ASD in the form of programmes, in KwaZulu-Natal in South Africa. The themes that emerged about parents' experiences and coping strategies were used in the article to guide practitioners when dealing with parents of children with ASD. The indications were that health practitioners need to recognise parents' vulnerability while providing knowledge in an honest manner, acknowledging parents' concern and considering their mental well-being, and providing practical and productive feedback to face society and reduce the effects of stigma. The study indicated that further research is necessary with rural and less resourced communities within South Africa. It was acknowledged that these populations would most likely have different lived experiences and ways of coping than parents in better resourced communities (Fewster & Gurayah, 2015).

A study by Tilahun et al. (2016) conducted in Ethiopia with low-income caregivers of children with ASD indicated that these caregivers experience stigma related to their child's diagnosis and that they specifically worry about being treated differently and they feel ashamed of their child's diagnosis and make an effort to keep it a secret. In this study, caregivers mentioned a range of biomedical or supernatural factors as a cause of their child's condition. Examples of these perceptions are that spirit possession, punishment from God or head injury, birth complications, or epilepsy is the cause for the condition. The majority of caregivers indicated an unmet need for educational provision and treatment for their child. The researchers conclude that in response to the stigma in low resource settings, there is a need for interventions to improve public awareness of ASD in these communities. Professionals need to be empathetic to the needs and conditions of caregivers' beliefs and provide psycho-education in a sensitive manner. This study indicated further research in low

resource communities regarding caregivers' needs, perceptions, weaknesses and strengths (Tilahun et al., 2016).

A review of research by Samadi and McConkey (2011) indicated that most research on ASD has been conducted in affluent English-speaking countries which have extensive professional support services. These researchers conducted a series of investigations in Iran to identify how support services can be developed in this developing country. It was further identified by Samadi and McConkey that further local research in different countries is essential if international understanding of ASD is to be advanced. Internationally the emphasis has to be on empowering families and making them more resilient. Certainly in less developed countries with their dearth of professional services, self-help becomes the major strategy for on-going parental support, but awareness about how this can be fostered is poorly promoted. Meeting the needs of families in rural communities requires particular attention (Samadi & McConkey, 2011).

A study conducted by Greeff and van der Walt (2010) identified resilience factors in families with a child that has been diagnosed with ASD. The participants were families in the Western Cape whose children attended a special school for autistic learners. The following resilience factors were identified: higher socio-economic status, social support, open and predictable patterns of communication, a supportive family environment including flexibility and commitment, family hardiness, internal and external coping strategies, a positive outlook on life and family belief systems (Greeff & van der Walt, 2010). It was recommended that further research be undertaken to identify resilience factors in families from lower socio-economic backgrounds that do not have access to educational services specialized for autistic children (Greeff & van der Walt, 2010).

Although research has been done about the resilience factors of families with a child on the autistic spectrum, no South-African studies were found pertaining specifically to low-income families.

Research highlighting further qualitative research

Hanekom and Brown-Baatjies (2008) conducted a study exploring how South African families adjust and adapt when living with a child that has been diagnosed with ASD. The majority of the families who participated were from Port Elizabeth and the majority of parents had completed further education on a tertiary level. The following resilience factors were identified: family hardiness, problem-solving communication, social support, spousal relationship and family time, togetherness and routine (Hanekom & Brown-Baatjies, 2008). Hanekom and Brown-Baatjies (2008) recommended further research on the topic of resilience in families living with a child with ASD in the South African context. It was also suggested that in future research the researcher should make contact with participants on a personal level. It was specifically recommended that the researcher make contact through an extended parent-teacher meeting with parents to ask them face-to-face for their assistance with the study. A further recommendation was that a qualitative study should be done to provide the population an opportunity to comment on their personal experience (Hanekom & Brown-Baatjies, 2008).

Heer, Rose, Larkin and Singhal (2015) explored the experiences and context of caring for a child with ASD in India. Mothers were interviewed and indicated that advice from family members and support from extended family and friends made a big difference in the quality of their lives. Belonging to a support group encouraged understanding of the disorder and provided a sense of belonging and empowerment. Acceptance of their child and their autism were crucial aspects of parents' narratives and played an important role in helping them cope effectively with their child's difficulties. It was noted in the study that the Indian

mothers appeared to hold more Western views about ASD and demonstrated less adherence to traditional understandings. The researchers stated that this was unexpected and reinforces the value of qualitative approaches in allowing new insights to arise which may otherwise be overlooked.

Patterson (2002) also encouraged family resilience research to include qualitative methods as family meaning-making processes are so important to family resilience. Given the subjectivity of meanings, qualitative methods would help clarify how these processes unfold and the content of these meanings.

Conclusion

This chapter highlighted the importance of further research on resilience factors in South African families faced with significant challenges. Existing literature regarding family resilience in South Africa was reviewed and it was concluded that there are few existing studies, but interest in the field is growing. Research regarding the challenges families with a child with ASD face was reviewed. A review was done of existing research regarding resilience in families with a child with ASD. It was indicated that a focus on families from lower socio-economic communities is needed to represent the entire population in a developing country such as South Africa. There are also studies indicating a much needed focus on qualitative research for a deeper understanding of personal experiences within families.

In the following chapter the concept of family resilience will be defined. The two theoretical frameworks used in this study will be discussed.

Chapter 3: Walsh's Family Resilience Framework and the Resiliency Model of Family Stress, Adjustment and Adaptation

Introduction

The previous chapter discussed the literature regarding resilience factors in families with a child with ASD. The literature suggested that families with a child with ASD face significant stressors. However, certain resilience factors have been identified in these families, but a gap has been identified in the literature regarding a focus on specifically low-income families.

This chapter defines the concept of resilience and the meaning of, specifically, *family* resilience in this study. In family resilience literature there are two theoretical frameworks which are being used in the field of family resilience studies. Both of these frameworks [Walsh's Family Resilience Framework and the Resiliency Model of Family Stress, Adjustment and Adaptation (The Resiliency Model)] will be used as theoretical frameworks in this study and will be discussed below.

Resilience

The concept of resilience has become an important concept in theory and research about mental health (Walsh, 2003). MacPhee, Lunkenheimer and Riggs (2015) defines resilience as adaptive self-stabilisation and self-organisation following disturbances to a system caused by significant adversity. In other words, when a stressor is overwhelming, severe or chronic it poses a threat to the family system's regulatory capacity and complicates the establishment of new equilibrium (MacPhee et al., 2015). Thus, the process of maintaining functioning or thriving in the face of significant adversity constitutes resilience.

According to Walsh (2003) resilience refers to a family's strengths and resources which enable them to respond successfully to adversities. Family resilience refers to a family's ability to adapt after a crisis is experienced. A basic view in this systemic approach is that

serious crises affect the entire family system. A family resilience perspective recognises parental strengths and potential, alongside limitations. Furthermore, it looks beyond the parent-child dyad and considers broader influences on the relative network, such as sibling relationships, couple relationships and extended family ties. The family resilience approach changes the view of troubled families as damaged and beyond repair to viewing them as challenged by adversities, but with the potential for growth and healing in all members (Walsh 2003).

Walsh's Family Resilience Framework

Walsh (2003) developed a theoretical framework of family resilience and based his work on the premise that any serious crisis would have an impact on the whole family (Walsh, 2003). Walsh's family resilience framework can be used as a conceptual map to identify key processes that families use to deal with stress and vulnerability and to be resilient in spite of prolonged adversity (Walsh, 2003). Key processes to resilience can be identified within the following three domains of family functioning: *family belief systems, organising patterns* and *communication processes* (Walsh, 2003). Each of these processes will be discussed in greater detail below.

Family belief systems

Family belief systems powerfully influence how we view a crisis, our suffering and our opinions. Shared perspectives of reality develop through social and family interaction and organise family processes and approaches to crises situations. Any adversity experienced by a family forces the family to draw on their meaning of a crises and they would respond in the same manner as they naturally respond to crises situations. The way a family makes meaning of adversity has the potential to disrupt a family (Walsh, 2003).

Resilience is fostered by shared, facilitative beliefs that increase options for problem resolution, healing and growth. Families characterised by resilience will approach adversity

as a shared challenge and keep in mind that they are not alone. Well-functioning families has the ability to normalise and contextualise distress. These families enlarge their perspectives and view their perspectives and reactions to distress as understandable in light of difficult circumstances. The tendency to blame, shame and catastrophize is removed in viewing their situation. Families do best when they gain a sense of coherence by rephrasing their own perspectives to view a crisis as a challenge that is comprehensible (Walsh, 2003).

Part of a family's belief systems which helps them to be resilient is fostering positive outlooks. In moments of distress and crises it is paramount to rekindle hopes and dreams in order to see possibilities. Walsh indicated that optimism should be learned and helplessness and pessimism unlearned. Walsh however highlighted the importance of reinforcing a positive outlook by successful experiences and a nurturing community context. Many families feel tapped in impoverished communities and lose hope – the despair robs them from meaning, purpose and a sense of future possibility (Walsh, 2003).

Organisational patterns

The way in which families organise themselves to meet the challenges they face, is an important determining factor for resilience. The first factor which Walsh highlighted as encouraging the development of healthy family patterns is flexibility. This refers to a family's ability to bounce back after a stressor or to bounce forward which means to change to meet new challenges. Families need to be willing to review relationships and reorganise patterns of interaction to fit new conditions. Families often need help in navigating new terrain and in undergoing structural reorganisation. Firm, yet flexible authoritative leadership is most effective for family functioning and the well-being of children during stressful times.

Resilience is further strengthened by mutual support, collaboration and commitment to withstand troubled times together. At the same time family members need to respect each other's individual differences, separateness and boundaries. Family members may have quite

varied reactions to the same event or may need more/less time to process the experience (Walsh, 2003).

Furthermore, kin and social networks are vital lifelines in times of trouble, offering practical and emotional support. The significance of role models and mentors for resilience of at-risk youth is well documented. Involvement of the family in church congregations and community groups can also contribute to resilience. This helps families who are more isolated to become more involved in the community and to rely on outside support. Multi-systemic approaches facilitate both family and community resilience (Walsh, 2003).

Communication processes

Communication processes foster resilience by bringing clarity to crisis situations, encouraging open emotional expression and fostering collaborative problem-solving. Clarifying and sharing crucial information about crisis situations and future expectations facilitate meaning-making. Family members may have bits and pieces of information or hearsay and as a result start to fill in the blanks – often with their worst fears. Clarifying and sharing honestly help in all family members' understanding and decision-making (Walsh, 2003).

Open communication supported by a climate of trust, empathy and tolerance for differences enables members to share a wide range of feelings that can be aroused by crisis events. Shared acknowledgement of the reality and circumstances of a painful loss fosters healing whereas denial and cover-up – especially in stigmatised circumstances such as suicide can impede recovery and lead to estrangement. It often happens that families (with good intentions) avoid and hide threatening or painful topics as they wish to protect children or elderly. However, anxiety about the unspeakable can generate catastrophic fears (Walsh, 2003).

Furthermore, collaborative problem-solving and conflict management are essential for family resilience. This involves negotiation of differences with fairness and reciprocity over time so that family members accommodate one another. Resilient families set clear goals and priorities and take concrete steps to achieve them. Failures are viewed as learning experiences and successes as building blocks. Families become more resourceful when they are able to shift from crisis-reactive mode to a more proactive stance, thriving toward a better future. Each family needs to find their own pathway through adversity which fits their situation, strengths and weaknesses, resources and culture (Walsh, 2003).

The Resiliency Model of Family Stress, Adjustment and Adaptation

Another framework which is important in the field of family resilience is the Resiliency Model of Family Stress, Adjustment and Adaptation (The Resiliency Model) of McCubbin and McCubbin (1996) (McCubbin, Thompson & McCubbin, 2001). This framework is used very often in family resilience studies and is also relevant for this study. The Resiliency Model emphasised the importance of including the concepts of ethnicity, culture and diversity in family structure in the understanding of family stress and family resilience. The acknowledgement that ethnicity, culture and diversity in family structure are important in the understanding of family stress and family resilience opens the door for employing the model in the South African context (Brown-Baatjies, Fouché & Greeff, 2008). The model has also been applied in a number of studies in the South African context (Greeff & Human 2004; Greeff & Fillis, 2009; Greeff & Van der Merwe, 2004; Greeff & Joubert, 2007).

The model explores why certain families adjust to their circumstances and are resilient and why others are not. The model works from the basis of the following five assumptions: families experience hardships as a natural part of life, families develop abilities that will benefit the individual development of strengths in family members, these abilities are unique to the family and will help the family to overcome a crisis, families will get support from

others in the community and their unique culture will be a part of their support system, when facing a crisis a family will work hard to restore the order in the family (McCubbin & McCubbin, 1996). This model offers a contextual framework for understanding family resilience as it recognises that the family system exists within the context of its larger social environment of nature, community, society, nation, and the world. The model looks at two interrelated phases – adjustment and adaptation (see figure 1), which will be explored separately (Brown-Baatjies, Fouché & Greeff, 2008).

Adjustment

Adjustment is the small changes the family makes directly after a crisis to try and prevent disruption for the family by a stressor (van Breda, 2001). A stressor is a demand placed on the family and produces change, or has the potential to produce change. The extent to which the family adjusts depends on several interacting elements that will determine the outcome of the situation (van Breda, 2001).

Firstly the *stressor* (A) has an impact on the family's *vulnerability* (V) which is shaped by the accumulation of stressors. A family's vulnerability is shaped by other stressors on the family such as financial strain, being overworked or difficulties related to the specific developmental phase of the family members (van Breda, 2001).

The family's vulnerability (V) again interacts with the family's typology which is determined by *established patterns of functioning* (T). These factors again interact with the family's *resistance resources* (B) which is their abilities and capabilities to manage the stressor in such a way that prevents breakdown in the family system. Resistance resources (B) are also the family's promotion and maintenance of harmony and balance. Resistance resources are employed in an effort to avoid a crisis, reduce disharmony and imbalance in the family system, and avoid resultant substantial changes or deterioration in family functioning. This in turn interacts with the family's *appraisal* (C) – the family's definition of the problem

being minor or a catastrophe. The family's appraisal interacts with the family's *problem solving and coping strategies* (PSC). Family problem solving and coping strategies include the development of constructive problem solving communication in order to maintain and restore family harmony and balance. All the aforementioned components (A, V, T B, C, PSC) interact with one another in order to determine the family's response to the stressor and its accompanying hardships (van Breda, 2001).

The outcome of the family adaptation process can be positive (*bonadaptation*) or negative (*maladaptation*). Bonadaptation essentially implies that the family is able to stabilize, achieve harmony and balance, promote the individual development of its members, and achieve a sense of congruence despite being faced with major changes in the patterns of family functioning. Maladaptation refers to unsuccessful adaptation where families sacrifice personal growth and development and the family's overall sense of well-being, trust, and sense of order becomes very low (Brown-Baatjies, Fouché & Greeff, 2008).

If the stressor is not too severe and the family is not too vulnerable, and/or has a helpful pattern of functioning, a positive stressor appraisal, resources and good problem-solving and coping skills; the family may survive the crisis and emerge in a state of *bonadjustment*. However if the stressor is very severe, intense or chronic, the demands placed on the family may be too great to be managed by minor adjustments. Families need to make more drastic second order change. These families will likely experience a state of *maladjustment* and this leads to the adaptation phase. When the family moves into a state of crisis, it typically marks the beginning of the adaptation phase of the Resiliency Model where families are forced to restructure their patterns of functioning in order to deal with the crisis and restore harmony and balance to the family system (van Breda, 2001).

Adaptation

Adaptation is the family's way of positively or negatively adapting to changed circumstances. The adaptation phase typically denotes the post-crisis and adaptation-oriented factors and resiliency processes that are essential in the relational process of family adaptation. It is concerned with the family's hardiness and ability to bounce back after a time of crisis or hardship. The adaptation phase aims to restore harmony and balance to the family system, with specific reference to its interpersonal relationships, the development, well-being and spirituality of the unit and its individual members (McCubbin & McCubbin, 1996).

The family's experience of the crisis is exacerbated by the concurrent pile-up of demands (AA). The AA factor interacts with the family's newly instituted patterns of functioning (TT), the modified or revitalized established patterns of functioning, and retained and restored patterns of functioning (T) (Brown-Baatjies et al., 2008).

Families at risk are characterised by disharmony, which is fostered by the inadequacy of the family's established pattern of functioning (T). These retained patterns of functioning (T) as well as new patterns of functioning (TT) interact with the family's appraisal processes (CC), resources (BB – social, family and community support) and problem solving and coping (PSC) ability to produce the outcome of family adaptation (XX). These relational processes and interactions take place over time with the overall goal of achieving harmony, balance and *bonadaptation* in the family system and between the family system and the larger community and society (Brown-Baatjies et al, 2008).

The family's appraisal/judgment processes in crisis situations consists of five levels of appraisal, namely, schema – family's shared values and beliefs (CCCCC), coherence – sense of order and predictability (CCCC), paradigms – shared expectations (CCC), situational appraisal (CC) and stressor appraisal – definition of stressor (C) (van Breda, 2001).

As an outcome, families can achieve bonadaptation or maladaptation. Positive adaptation implies that the family is able to stabilise, promote the individual development of its members and achieve a sense of congruence, despite being faced with major changes in the patterns of family functioning. Maladaptation refers to unsuccessful adaptation where the family sacrifices personal growth and development and the family's overall sense of trust, well-being and sense of order becomes very low (van Breda, 2001).

Maladaptation brings about the cyclical nature of the model where the family would go through the process of adjustment and adaptation again. Successful adaptation is thus seen as the outcome of the family resilience process (McCubbin & McCubbin, 1996). Figure 1 provides a visual representation of the model.

Figure 2. Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1996)

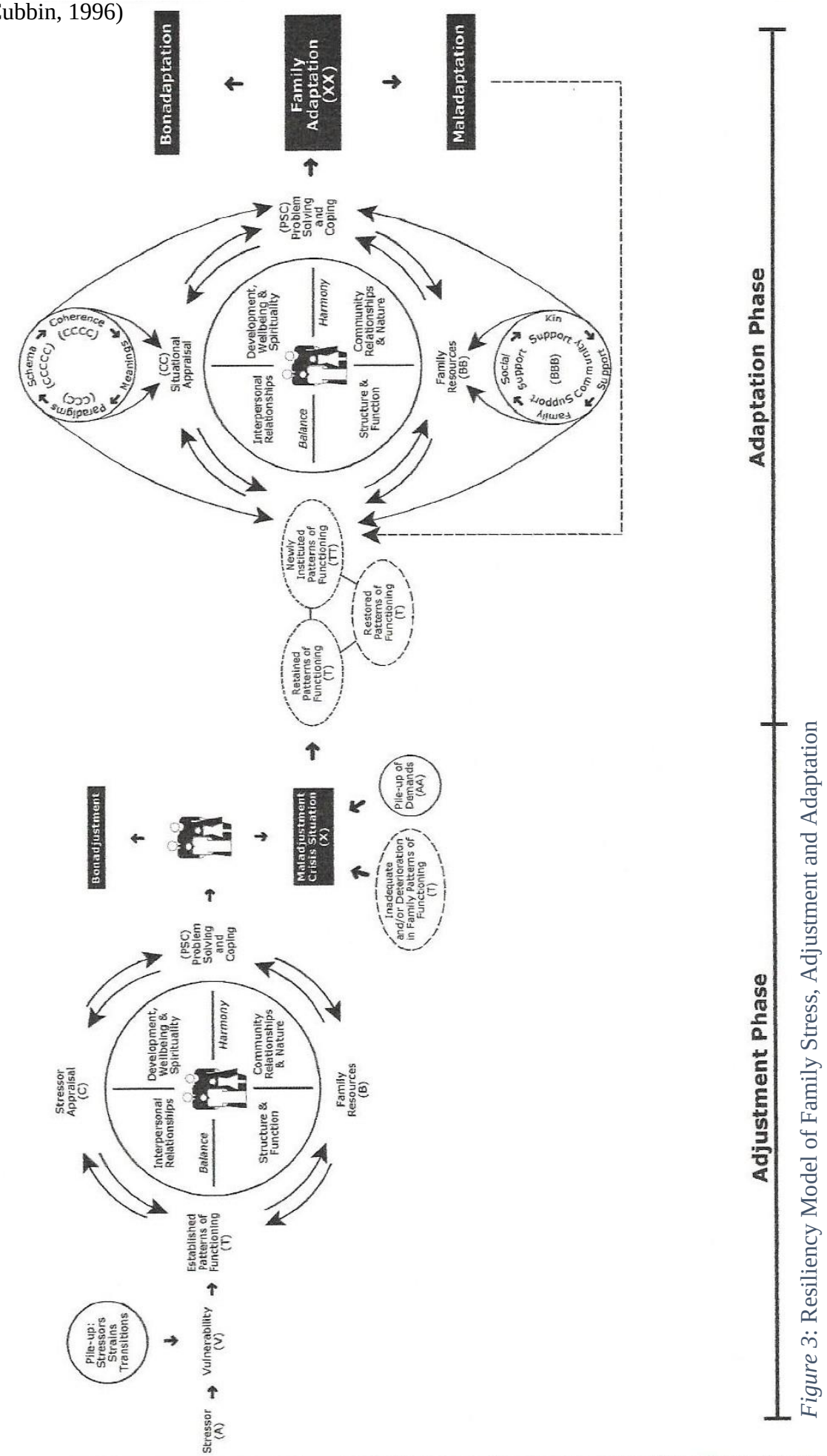


Figure 3: Resiliency Model of Family Stress, Adjustment and Adaptation

Conclusion

In this chapter the theoretical framework for the study was reviewed. The concept of resilience, specifically family resilience was defined.

The abovementioned frameworks will be used to understand family resilience in this study. There will be a focus on how these families adjusted and adapted to their circumstances and cope with the everyday stressors of living with a child on the autistic spectrum.

The next chapter will describe the research methodology of the study.

Chapter 4: Research Design and Methodology

Introduction

The previous chapter described the theoretical frameworks which were used in this study to understand how low-income families with a child with ASD remain resilient. This chapter describes the research design and method used to gather data for this study. An outline of the research aims is provided as well as an indication of the significance of the research. The use of a qualitative research design is justified. It further explains how participants were selected to participate in the study, how data was collected and how data was analysed using thematic analysis. In conclusion the applicable ethical issues are discussed.

Problem Formulation and Research Aim

Individuals with ASD have difficulties across several developmental areas including language and communication, social interaction and repetitive and stereotyped behaviour (Bateman, 2013). Eighty five percent of individuals with ASD have cognitive limitations and will thus need some form of care throughout their lives (Bateman, 2013). There are not enough schools in South Africa that are equipped to care for children with ASD (Bateman, 2013) and families with a lower socio-economic status cannot afford to send their children to specialized schools. There are thus many autistic children who attend public schools and whose caretakers do not have any support. In spite of adverse conditions, many families remain resilient and their autistic child attends a mainstream school. It is necessary to explore how these families remain resilient to inform and support other families who struggle to cope, particularly those who have limited financial resources.

Aim and Objectives

The aim of this study was to explore and describe how low-income families with an autistic child remain resilient. Specific objectives related to the study were as follows:

- To explore and describe how low-income families cope with the everyday demands of living with a child with Autism Spectrum Disorder.
- To explore and describe the specific characteristics which enable these families to remain resilient.
- To explore and describe the resources utilised by low-income families raising a child on the autistic spectrum.

Significance of the Research

The findings from the proposed research study contributed to the understanding of resiliency qualities of families where a family member has a chronic condition. It has contributed specifically to the field of research on resilience in families, particularly low income families, raising a child with ASD.

Research Methodology

Research design

Qualitative research aims to describe the point of view of participants and by doing that endeavours to provide a better understanding of patterns of meaning (Biggerstaff & Thompson, 2008). According to Biggerstaff and Thompson (2008), qualitative research methods give the researcher the opportunity to form an understanding of what it means to participants to live with a specific condition or to be in a specific situation. With qualitative research the purpose of data gathering is to provide evidence of the experience it is investigating. Research about people's experiences implies depth and methods of data gathering, such as short questionnaires or scales, cannot capture the richness and depth of personal experience (Polkinghorne, 2005).

In this study, qualitative research was best suited to gain in-depth knowledge of the families' resilience factors. It allowed for a focus on meaning and an understanding of how

the participants understand and experience their lives. A comprehensive understanding of the participants' specific contexts was appropriate and achieved through qualitative research methods. Qualitative methods further allowed the researcher to engage with participants according to their unique styles and personalities.

Sampling and research participants

A specific low-income community was identified in the city of Cape Town in the Western Cape, South Africa. Purposive sampling, which involves selecting people from whom the researcher can substantially learn about the experience (Polkinghorne, 2005) was utilised to find participants to be included in the sample. The participants of this study were parents who have a child with Autism Spectrum Disorder. Professionals within the community assisted with the identification of participants who met the following criteria:

1. A mother or a father, or both, who have a child with Autism Spectrum Disorder.
2. Low socio-economic status and no access to specialized intervention for their child.
3. The parent can converse comfortably in English or Afrikaans as a first or second language.

Professionals contacted the parents on behalf of the researcher to enquire about their willingness to participate in the study. Once parents agreed the researcher contacted the parents and arranged a suitable date and time to have an interview. The researcher interviewed participants until data saturation and six families in total were interviewed. Data saturation was reached when themes elicited during interviews became similar. Four out of the six interviews were conducted with four mothers, one interview was conducted with both parents present and one interview with one father. The children with ASD of these parents ranged in age from 9 – 11 years of age.

Data collection

The data was collected through semi-structured interviews. According to Barribal and While (1994) it is beneficial to use semi-structured interviews when investigating people's beliefs and experiences. Semi-structured interviews was thought appropriate for eliciting unique experiences, feelings and opinions and for addressing sensitive topics such as ASD.

Semi-structured interviews were conducted with participants and no other parties were present during the interviews. The researcher engaged with the participants by asking questions in an unbiased manner and by listening intently to responses. Biggerstaff and Thompson (2008) recommended the use of a prompt sheet with a few main themes for discussion as guidance during interviews. They emphasize that a prompt sheet should not be prescriptive and should not override what the participant wants to talk about.

The researcher compiled an interview schedule to guide interviews (Appendix D). However, the use of this did not lead participants according to any predetermined ideas. The participants' train of thought was followed and no pressure was asserted on the participant to discuss specific matters.

Before conducting the semi-structured interviews, the researcher explained the research and process to follow to participants. Following this explanation, the participants signed a consent form (Appendix B) and then completed a biographical questionnaire (Appendix C). The questionnaire was completed with the participants. The researcher asked the questions and as participants answered the researcher filled in the answers on the questionnaire. The information gathered in the questionnaires was used to describe the sample group in the study.

Interviews were initiated with the following open-ended question: "What will you say helps you and your family to cope with the everyday stressors of living with a child with Autism Spectrum Disorder?" (Refer to Appendix D).

After the question was asked, certain methods were used to gain as much information as possible and to encourage participants to share their experiences. One of these methods is probing, which requires the researcher to ask certain questions to encourage the participant to share more. Examples of such questions are: “Tell me more about this?”, “What resources or qualities did you use to cope with the challenges of caring for your child?” (Refer to Appendix D). Another method is paraphrasing, where the researcher repeats what the participant said with the goal of summarizing what has been said. An example is: “So what you just said is a, b and c. Is there anything you would like to add?” (Refer to Appendix D).

The interviews were recorded digitally using a digital voice recorder in order to record the data verbatim. Using a digital voice recorder was deemed to be less intrusive than note taking and therefore less disturbing to the interview process. The reason for using a digital voice recorder was also clearly explained to the participants prior to the interview process and consent to record the interview was requested and obtained from all participants.

Procedure

The research proposal was submitted to the Faculty Postgraduate Studies Committee (FPGSC) and Research Ethics Committee: Human (REC-H) at the Nelson Mandela Metropolitan University (NMMU) to request permission to conduct the study. Only upon approval from the respective committees, did the researcher proceed with the research study.

The first step in gathering the data for this study was to contact professionals within the identified community. Once professionals were identified, they were asked to identify parents of children with ASD. Thereafter the parents of these children were contacted by the professional. The purpose of the research was explained to them telephonically and they were asked whether they are willing to participate. The researcher arranged an appropriate time and place with each participant for individual interviews. There are no incentives

involved for participating in the study and the participants were aware that they would not receive anything in return for participating in the interview.

Each participant was presented with a letter (Appendix A) describing the research as well as a consent form (Appendix B) and biographical questionnaire (Appendix C). The interviews took place at a private, mutually agreed upon place which was comfortable for the participant and the issue of confidentiality was discussed with the participant. The researcher assisted each participant with the completion of the consent form and biographical questionnaire and answered any questions that the participants had. The participants indicated as part of the questionnaire whether they wanted feedback after completion of the study. All the participants indicated that they would like feedback and they were assured that a summary of the research outcomes would be sent to them after completion. It was agreed that the researcher will contact them telephonically once the study is completed to arrange the best method of feedback to each participant according to their needs. Feedback will either be emailed, printed copies can be posted or verbal feedback will be provided telephonically.

Data Analysis

The qualitative data was analysed through the use of thematic analysis. According to Braun and Clark (2006) thematic analysis is an easy method to learn and use. It is also a flexible method that can be used across theories and research questions. With the use of thematic analysis a large amount of data can be summarized and key findings can be identified (Braun & Clark, 2006).

Thematic analysis requires the identifying, analysing and reporting of patterns in a data set (Braun & Clark, 2006). The researcher plays an active role by identifying themes, deciding which themes are important for the research question and then reporting on those themes.

Thematic analysis was thought the best method of data analysis for this study as it allowed the researcher to report on the realistic experiences of participants. It allowed a rich and detailed understanding of families' experiences and coping strategies which enabled them to be resilient. The data in this study needed to be examined in order to answer a specific research question and therefore a deductive approach was taken to analyse the data. The data was organised in such a manner to elicit and interpret certain patterns within the data sets (Braun & Clark, 2006).

The six steps of thematic analyses as explained by Braun and Clark (2006) were followed:

1. **Becoming familiar with the data**: After the interviews were transcribed, the researcher repeatedly read the data and became familiar with the data. By doing this, the researcher became comfortable with the content of the data.
2. **Formulation of codes**: Once familiar with the content of the entire data set, the researcher started to organise the data into initial groups/codes. The researcher thus identified characteristics in the data which seemed interesting and started to organise the data according to each identified code.
3. **Identifying themes**: The researcher then organized the identified codes under suitable themes. The researcher thus analysed the codes and decided how certain codes could be combined to form an overarching theme. A thematic "map" of the data was thus generated.
4. **Revising themes**: After themes were identified, the researcher checked that the themes made sense in relation to the codes and the original data. Themes identified by the researcher were collated with themes found by an independent coder to ensure reliability.

5. **Naming and describing themes**: Specifications of each theme were made and names and definitions for each theme were formulated. The data was thus reviewed and refined to ensure clear definitions and names for each theme.

6. **Producing the report** – The report is the summary of the thematic analysis and provides the themes as well as examples as proof of the themes. The researcher selected clear and compelling examples and did a final analysis of the selected excerpts and related the analysis back to the research question and literature. The researcher told the story of the data and an argument was conducted in relation to the research question.

After the abovementioned analyses were followed, a scholarly report of the analysis was produced.

Trustworthiness of the Data

Lincoln and Guba's (Krefting, 1990) Model of Trustworthiness proposes four criteria that should be considered by qualitative researchers in order to establish the trustworthiness of the data.

The first criterion is credibility, also referred to as truth value. This refers to whether the researcher is confident of the truth of the findings. The researcher needs to ensure that the findings of the study present such accurate descriptions of the participants' experience that others who share that experience would immediately recognize the descriptors (Krefting, 1990). To ensure credibility of the research, the researcher accommodated the participants by meeting at a time and place convenient for the participant. In doing this, the researcher ensured that each participant was comfortable and at ease during the interview to guarantee honest feedback from participants regarding their personal experiences. Furthermore, an independent coder was used to ensure that the themes elicited from the data were truthful.

The second criterion is transferability, also referred to as applicability, which is the degree to which the findings can be applied to other contexts or within other groups. Guba argued that in qualitative research, the researcher has addressed this appropriately if sufficient descriptive data is presented to allow comparison (Krefting, 1990). The researcher thus ensured a full and descriptive analysis of the data and participants in order to evaluate the generalizability of the results to other contexts. Similarities between participants were highlighted to describe a specific sample group to whom the results can be generalised. From the starting point, the research question also indicated who the participants of this study would be.

The third criterion is dependability, also referred to as consistency, which refers to whether the findings would be consistent if the research was repeated within the same context. In terms of qualitative research, dependability refers to traceable variability which is variability that can be attributed to identified sources. Such sources might be participant fatigue or changes in the participant's life. In this study, specific participant criteria were thus carefully described with as much detail as possible. The research design, procedure and setting were also carefully described.

Neutrality is the fourth and last criterion and refers to the degree to which the findings are a result solely of the participants and not of other motivations or perspectives (Krefting, 1990). Detailed records were kept of all the steps of the research project to ensure objectivity. An independent coder was also employed to recheck the thematic analysis and to counter any possibility of researcher bias.

Ethical Considerations

The research study was conducted after approval was received from the Faculty Postgraduate Studies Committee (FPGSC) and Research Ethics Committee: Human (REC-H) at the Nelson Mandela Metropolitan University (NMMU).

Informed consent and voluntary participation

The South African Department of Health provides a clear procedure for conducting research. They indicate that a psychologist must enter into an agreement with every participant and set out the nature of the research and the responsibilities of each party. This must be explained to participants in a language that is reasonably understandable to them. The researcher is expected to emphasize the voluntary nature of research and the freedom of participants to withdraw from the study at any time (South African Department of Health, 2006).

The goal and purpose of the study was explained to the participants in English or Afrikaans, depending on which language they were most comfortable with. The participants were informed about their right to voluntarily consent or decline to participate and to withdraw from the study at any time. The researcher presented the participants with a formal letter informing them of the purpose of the study and a letter asking for their informed consent. An opportunity was provided for participants to pose questions to the researcher. The purpose of the use of a digital audio recording device was explained to participants and they were required to give their informed written consent in this regard. Generalised feedback regarding the outcome of the research study will be made available to all the participants after the completion of this document.

Privacy and confidentiality

The participants were assured that their privacy and right to confidentiality would be upheld at all times. The data is being stored in a safe place and only the researcher has access to the data. Anonymity was ensured as it was not expected of participants to provide their names and information provided during the interviews was dealt with confidentially. Privacy was emphasized during interviews to ensure that participants felt safe and were willing to share their personal experiences. Differences in culture, beliefs, perceptions and language

between the researcher and participants were taken into account and respected. This was done by the researcher being fully present during interviews, listening intently and maintaining a non-judgmental stance.

Beneficence and non-maleficence

The general ethical principles of do good (beneficence) and do no harm (non-maleficence) were adhered to during this study. The study was considered of minimal risk to participants as it is embedded in positive psychology with the focus on resilience factors to assist families to adapt to difficult circumstances.

In addition, safeguards were established before starting the study should participants experience discomfort during the study. This was done by asking participants if they had an established support system to rely on for support should they feel unsettled after an interview. All participants mentioned relevant support systems to fall back on should it become necessary, but were also provided with the researcher's contact details should they need further assistance to reach appropriate sources of support in the community. During the interview sessions, the researcher engaged participants with respect and warmth to ensure that participants had a positive experience and felt at ease.

Maintenance, dissemination and keeping of records

The research data was safely stored throughout the research process by the researcher for analysis. The data is currently being stored in a password protected database by the researcher, who has sole access to the database. Confidentiality of the data is ensured in the storing of data by excluding participants' names.

As recommended by the Ethical rules of conduct for practitioners registered under the Health Professions Act (HPCSA, 2011, p. 27), the data will be kept for a period of five years following the date of collection.

Debriefing of research participants

All the research participants indicated through the biographical questionnaire that they would like feedback with regard to the outcome of the research study. A summary report with general feedback regarding the results of the study will be made available to the participants. The participants will be contacted telephonically or via email with feedback.

Conclusion

This chapter discussed the research methodology and procedure pertaining to this study. The research aims and significance of the research justified the use of a qualitative research design. Purposive sampling was used to select participants for the study and data was collected through in-depth semi-structured interviews. Data was analysed using thematic analysis.

The trustworthiness of the data was ensured following Lincoln and Guba's Model of Trustworthiness. Various ethical principles adhered to during the study, which ensured the safety and well-being of participants, were discussed.

The next chapter will provide a detailed discussion of the results of the thematic analysis.

Chapter 5: Results and Discussion

Introduction

The previous chapter discussed the research design and methodology used in the current study. This chapter describes the results and a discussion of the data that was collected through the semi-structured interviews. The results will be presented in such a manner that the research aims are met, namely, to explore and describe how low-income families cope with the everyday stressors of living with a child with Autism Spectrum Disorder, the specific characteristics which enable these families to remain resilient and to explore and describe the resources utilised by these families. Data was gathered by means of 6 interviews with parents who have a child with ASD. Three main themes and several subthemes emerged from the data which will be explored in depth in this chapter.

Biographical description of the sample

Before the semi-structured interviews were started, a biographical questionnaire was completed with parents. The following table presents the information obtained from the biographical questionnaires:

Table 1

Biographical Information of Adult Participants

Variable	**Classification**	**n**	**%**
Gender	Male	2	33
	Female	4	66
Age	30 – 40 years	1	16
	40 – 50 years	3	50
	50 – 60 years	2	33
Religion/church denomination	Dutch Reformed church (*NG church)*	4	66
	Lutheran Church	1	16
	None	1	16
Marital status	Single	1	16
	Married	5	83

Amount of family members	2	1	16
	2 – 5	5	83
Age of child's diagnosis	0 – 4 years	1	16
	5 – 6 years	5	83
Work status	Unemployed	0	0
	Employed, contract	1	16
	Employed, permanent	5	83
Amount of family members with an income	1	1	16
	2	5	83
Home Language	Afrikaans	3	50
	English	2	33
	IsiXhosa	1	16

Half of the participants spoke Afrikaans as a first language and interviews were therefore conducted with these participants in Afrikaans. Two of the participants were English speaking and only one was IsiXhosa speaking. Although this participant could speak and understand English as a second-language, it should be mentioned that language might have made it difficult for her to express herself.

Table 2

Summary of Themes

Themes	**Sub-themes**	**Categories**
1. Parents' response to the diagnosis of ASD	1.1 Self-education and research	• Read about the symptoms • Understanding their child • Awareness beforehand / pre-warned made diagnosis easier to accept
	1.2 Recognition of the symptoms of ASD	• Delayed developmental

			milestones • Poor sleeping habits • Poor social interaction
	1.3	Anticipation of learning problems	• Disruptive in school • Slow learning • Need for excessive repetition when learning
2. Parents described the availability of resources	2.1	Resources within the close family circle	• Spousal support • Grandparents • Other family members / close family friends
	2.2	Resources in community	• Doctors at clinics / day hospitals explained diagnosis • Teachers are particularly helpful and understanding • Colleagues listened and gave the benefit of their experience with similar children
3. Parents developed their own coping strategies	3.1	Develop relaxation strategies	• Reading, TV, sleep • Visiting friends and family • Connecting with other parents • Spending time away – taking a “break”
	3.2	Develop a strong faith base	• Child is ‘special’ – a God-given gift • God only gives what he knows one can deal with

			• God sees the bigger picture • Positive cognitions about the future
	3.3	Develop a specific environment	• Strict boundaries and day and night routines • Plan spousal schedules to ensure care • Accepting the child and going on as normal as possible

As can be seen from Table 2, three overarching themes were identified. The first theme was related to how parents responded to the ASD diagnosis of their child – and how their responses helped them to cope. The second theme indicated what resources parents found helpful in their immediate environment. The third main theme describes the specific coping skills that parents use to remain resilient. Walsh's family resilience framework as well as the Resiliency Model of Family Stress, Adjustment and Adaptation (The Resiliency Model) of McCubbin and McCubbin, both previously discussed, will be used to understand how participants of this study adjusted to their circumstance and remained resilient. The main themes and sub-themes will be discussed in detail below.

Parents' response to the diagnosis of ASD

The study found that all the parents interviewed indicated the role their initial response played in the process of adaptation and eventually resilience. When analysed within the context of the Resiliency Model of McCubbin and McCubbin (1996) (see figure 1), it seems that parents' initial response was perhaps old patterns of functioning (T - looking for answers) as well as new patterns of functioning (TT – consulting new resources) interacting

with the families' problem-solving and coping (PSC) abilities. One problem-solving strategy which families used in response to the stressor (diagnosis of child) was self-education and research. Parents also found it helpful to recognise the symptoms and anticipate learning problems. These three sub-themes will be discussed below.

Self-education and research

According to the Resiliency Model a family's old and new patterns of functioning interact with the family's problem solving and coping (PSC) ability to produce the outcome of family adaptation. The study indicated that parents used a pattern of problem-solving which entailed doing their own research about the stressor – which was their child's diagnosis of ASD. Parents found it helpful to read about the symptoms of ASD and in that way gained an understanding of their child's difficulties. Below are some quotations taken from the interviews to illustrate this finding:

- "Because knowledge is power. So, for us, I think from the get-go, it was a matter of, 'okay, we don't know what this is right… let's go research it'. And then somebody gives us another term and then we go and research it and gradually we just started educating ourselves. Uhm… to find out exactly what it is that we're dealing with." (Mother of a 7 year old boy)
- "I mean, like if you don't know… anything in the world… in life… if you don't know anything; you find out what's wrong. I've looked at web pages about support groups and that, but *ja*, I've done the research. It was helpful." (Father of an 8 year old boy)

Parents indicated how the knowledge of what ASD is and what the symptoms are helped them to build an understanding of their child's inner world. Understanding what the diagnosis is and what it means helped parents to go on as they now had answers. One mother of a 10 year old boy reported:

- "At that time I… before… I didn't know what's happening. What's going on to him… but now I know what's going on. So I'm not worried like before." Another parent of a 7 year old boy indicated "Also for us to understand you know… what the child is going through – a child that cannot verbalise what he's going through or what he's experiencing."

This finding is supported by Heer, Rose, Larkin and Singhal (2015) who found that Indian mothers reported that an understanding of ASD helped them significantly to accept their child.

Furthermore, parents indicated that having an awareness of their child's difficulties before a diagnosis was made was helpful to "soften the blow". Parents indicated that by the time a formal diagnosis was made, they were already aware that their child was different and suspected that something was wrong. Parents indicated how they noticed from a young age that their children had difficulties:

- "I must honestly say that initially the baby was okay, although I noticed all the sensitive stuff. So I was a bit concerned. So I've… always felt that he was possibly on the spectrum and the family as well because he had very obsessive behaviour and you know the thing of sequencing everything. Everything is in lines, in patterns." (Mother of 7 year old boy)
- "And even as a small, small baby. I mean he was probably… I don't know… six months. We started seeing repetitive behaviours. He would roll his head before he goes to sleep – something he still does. So from that point onwards, I already had a suspicion of what was coming. So, I did the research… figured out by myself that he fits the typical profile of Autism spectrum. And then subsequently the doctor diagnosed him. So it was almost like we were forewarned. So it was

an impact, but it wasn't that much of an impact because we knew." (Mother of 7 year old boy)

The study thus highlighted the importance of self-education and research for low-income families to truly understand and accept the child's diagnosis. It became clear that parents were active in their initial response to the child's difficulties and their initial reactions entailed certain behaviour. Although certain parents eventually consulted professionals in the community as will be seen later, it seems that part of the initial response for parents was doing their own research and developing their own understanding.

Pastor-Cerezuela et al. (2015) indicated that parents of children with ASD who perceived themselves as more resilient to adversity reported two parental characteristics closely related to two indicators of resilience: optimism and self-efficiency. It thus seems that parents who are self-efficient are more resilient. This study also highlights self-efficiency as an important characteristic for resilient parents. The finding in this study that low-income families' self-efficiency helped them to educate themselves and develop their own understanding is a specific and new finding which has not been indicated by other literature.

Recognition of the symptoms of ASD

Parents indicated that what helped them initially was recognising the most prominent symptoms of ASD in their children. Parents realised that their children did not reach their developmental milestones at the expected time. Most of the parents indicated delayed developmental milestones as one of the first ways in which they realised that their children had a difficulty. They reported that it was helpful to be able to link the delayed milestones to a disorder – a reason that made sense. Below is one of the reports that a parent gave regarding delayed developmental milestones.

- "By one year I noticed he was struggling to walk *mos*. When he was turning 2 years he supposed *mos* to start to talk. But he didn't start up until 3 years. Then

he start to mention my name…and other people. Then afterwards I noticed this child… when he's turn 4 years, he still struggle to talk. Then I notice there's something wrong." (Mother of 10 year old boy)

Parents also indicated that they noticed poor sleeping habits and that this is another symptom which made sense in terms of ASD. A mother of a 9 year old boy reported the following:

- "He remains busy, he doesn't switch off. That's all that… it can get very frustrating on the long run. How can I say… he doesn't sleep… he's not like a normal child who will sleep from 2 to 5 o'clock. He doesn't clock out. He is awake this morning at 7 and then tonight at 11 or whatever time he goes to sleep. If we go to sleep at 8, then he goes to sleep, but then he fidgets for an hour or 2 and then his father needs to say to him 'shh go to bed'."

Another symptom which was highlighted by many parents as a prominent symptom immediately recognised, is poor social interaction. The father of an 8 year old boy and the mother of an 11 year old girl reported the following:

- "What he used to do before pre-school was like just sit and play by… not really playing, but you know, just lining his cars up and that's how it should stay. And even though there were children playing in the road, he would just look at them, stare… not interact at all. So, he was just like, all by himself."
- "And like they also say, she is now also emotionally a bit behind her friends. She struggles to make friends. That is one of… And she gets attached to a teacher and then at the end of a year, it's horrible. The next year to get a new teacher... And she can't make a friend. And this year she has a friend, next year she's in a different class, different new children. She struggles to make a new friend."

Throughout interviews it was apparent that parents could clearly recognise the symptoms of ASD in their children's behaviour and habits. Recognising these symptoms was part of parents' initial response and helped parents in the initial phase of adaptation. O'Brien (2007) confirmed that coming to terms with the discrepancies between their initial expectations for their child and the reality that follows after an ASD diagnosis, is a process that few families can be expected to negotiate easily. Going through the process of understanding the child's presentation and coming to terms with the diagnosis is a big challenge. It is therefore very significant that parents in this study report that from the very start just being able to link symptoms to a diagnosis was extremely helpful in coming to terms with their child's difficulties.

Anticipation of learning problems

Most parents in the study indicated that anticipating academic difficulties for their children after the diagnosis was part of their initial response. They prepared themselves for difficulties lying ahead and indicated that it was helpful to anticipate challenges. Most parents indicated that they had to learn to not become anxious about their child's slow progress, but rather to meet their child where he/she is at. Part of this was either to be patient and understanding of slow progress, or to help their child study by excessive repetition. For example, parents indicated the following responses to learning difficulties.

- "I mean his attention span is so short. 'Cause like… it's difficult, we would just stop because he doesn't want to concentrate or do anything; and just leave him and let him be and then try at a later stage again." (Father of 8 year old boy)
- "We received homework. I bought these books: Oxford… So I bought those books extra. It's an Oxford book, the she practiced mathematics. My entire afternoon goes just to her and it works. It works. We have to repeat." (Mother of 11 year old girl)

Some parents also indicated that they realised from early on that their child will be disruptive in school and this will be part of the academic challenges. The mother of an 11 year old girl reports:

- "It upset the friends in class, because she never sat still. When teacher said here is this task you have to do this, then she would get up and walk around in the class. Then the friends would complain and say teacher she is not doing her work".

Anticipating academic difficulties was thus part of what parents did initially in their response to the stressor. This aligns with the outline of the adaptation phase of the Resiliency Model. It seems that parents' retained and newly instituted patterns of functioning interacted with their paradigms - shared expectations (CCC) during the initial phase and contributed to their resilience.

Parents described the availability of resources

Parents were able to describe what resources helped them to remain resilient in light of a significant stressor. All the parents who participated in the study were of lower socio-economic status and although they do not have access to specialised resources, they were able to reflect on the resources in their immediate environment that were helpful.

Resources within the close family circle

Foo et al. (2014) presented an in-depth analysis of the lived experiences of caregivers of children with ASD. The results indicated that what kept caregivers going was a sense of responsibility to care for and protect their child and their duty to support their spouse. In this study, parents also indicated that spousal support was very important within the immediate circle. They specifically described that "taking turns" in caring for the child is something they found paramount in their lives. Below are quotations from three parents describing this:

- "To be honest we just like made turns and said like… Well… I told my wife, 'Okay, yesterday it was my turn, now…' And even there were times like we had to try to do it together. But there were times like… when we rotated. We say, 'Now it's your turn and then you...' You don't have the energy every day for it." (Father of 8 year old boy)
- "I think both parents should be involved and should play a role. And my husband as you know… He is very supportive and he is more than happy to give me a break, by doing you know… An activity with him or taking him out you know." (Mother of 7 year old boy)
- "The two of us who basically take turns … like tonight I am going again and then he is with his father. There is always someone between the two of us who will take care of him." (Mother of 10 year old boy)

Furthermore parents indicated significant support from family members such as grandparents or aunts/uncles. This is another finding which aligns with the Resiliency Model of McCubbin and McCubbin (McCubbin, Thompson & McCubbin, 2001). The model indicates that the family's patterns of functioning (TT) interacts with the family's resources (BB – social, family and community support). In this study, support from family and close friends is indicated as helpful in the process of adapting to the stressor. The mother of an 8 year old boy reported:

- "And my sister, when he was younger… she support me to train him to walk… She go to take him to the crèche. Because I was working security that time. I come later. It was busy."
- "And my brother-in-law …. He goes and fetches him from the bus. He goes to my sister in Ceres and she understands a lot. Then she again looks after him for a weekend. You need to get someone close to you, close to him. This someone can

only be a family member. Who has the same courage and patience. And then you can perhaps leave him for a weekend to give yourself a break. You know that can also be a big help. And that's also one of the things that can carry you through." (Father of a 10 year old boy)

As illustrated by the quotations below, half of the participants indicated the significant supportive role of their own mothers or mothers-in-law:

- "And my mother in-law… we're actually grateful that she's at home now she helped a lot. She looks after him; honestly it helps a lot." (Father of an 8 year old boy)
- The support that we're getting from my mom is absolutely invaluable. I don't think that we would've coped as well as we did and I also don't think he would've coped as well as he did" (Mother of 8 year old boy)
- "My mother was really, when she was still young and really difficult, then my mother would look after her, and that really helped." (Mother of 11 year old girl)

As seen in the statements above, participants in the study highlighted how the assistance of family members helped them to remain resilient. They specified that grandparents or aunts/uncles helped to take care of the child and sometimes look after their child when they are unable to or need a break. They describe how the understanding of family members is crucial for the family, to be able to provide that support. It was clear that participants are very appreciative of their family's support and understanding.

This finding is supported by Bayat (2007) who highlighted becoming united and closer as a family as a specific resiliency process for families with an autistic child. Greeff and van der Walt (2010) identified resilience factors in families with a child that has been diagnosed with ASD and, amongst others, a supportive family environment including flexibility and commitment was highlighted. Both of the last-mentioned studies were conducted with

specifically middle- to upper-class white families – the first-mentioned in the USA and the last-mentioned locally in the Western Cape. Both studies recommended that further research be undertaken to identify resilience factors in families from lower socio-economic backgrounds. It is thus necessary to highlight that this study, conducted with lower-income families report the same resiliency process of a supportive family environment.

Resources in community

Parents also highlighted the significance of resources within the community. They particularly referred to consultations with medical officers at their local clinics/day hospitals. Participants indicated that this was a valuable source of information and it is often where they found answers to their questions. The mother of a 10 year old boy reported:

- "I go to the Day Hospital, they say it's too early, I must wait."

She described that this helped to contain her anxiety about her son's delayed developmental progress. Another mother of an 11 year old girl reported:

- "We went to the doctor. Thank you for him as well. He gave us information."

It thus seems that some parents found the doctors' explanations very helpful.

All of the participants indicated how helpful and supportive the mainstream schools are where their children are enrolled. Parents described the structure of the class environments and teachers' patience and understanding as extremely helpful. They also reported that the time the child is at school is time where they can recuperate and find new energy for their child. For many of the parents the school was also a source of information and teachers also often helped to explain the diagnosis to parents.

- "And the teacher left her. Thank you to that teacher. I am so thankful for that teacher. She just said it's okay, don't worry. Even if she didn't do the tasks, it's okay." (Parent of an 11 year old daughter)

- "I think the environment is very…*ja*, the school is very supportive. It's very conducive. They're very strict as well in terms of discipline in the class." (Mother of an 8 year old boy)

Furthermore parents reported the following:

- "And then they teach him how to speak English and then he learn quickly…how to speak English. Then they say you must not worry because there's a school psychologist. They *gonna* test him then they *gonna* tell me the results. Then I come here by 2013 they tell me no he's got Autism." (Mother of 10 year old boy)
- "And that… Is the only break that we really get and that really helps us. The school where he goes really helps us. It's nice to leave him there at the school that the teacher sit with him for a bit. It's really the only break we have in a day." (Father of 10 year old boy)

Furthermore, other resources parents report to be helpful are colleagues who listen and give the benefit of their experience with similar children. For example, the mother of an 8 year old boy reported the following:

- "Colleagues who have exactly the same type of children or similar… So one always listens to what this one has to say, perhaps it's helpful, and then you try it at home."

It seems that this form of social support within the immediate community is also highlighted as important by some parents as part of the family adaptation process (BBB – see figure 1).

This finding is supported by Cridland et al. (2014) who indicated that parents who utilise support services are more resilient. They described the support and information parents receive from services in the community as crucial for remaining resilient. Current literature

thus supports the finding in the current study of the importance of resources in the immediate community.

Parents developed their own coping strategies

The third theme that was apparent in this study was that parents developed their own coping strategies. Samadi and McConkey (2011) highlighted the importance of self-help strategies to empower families in less-developed countries and make them more resilient. There is a dearth of literature on the self-help strategies low-income families with an autistic child employ to remain resilient. This finding in the current study thus contributes significantly to the literature regarding self-help strategies of this population group. Parents in this study made reference to various relaxation strategies, they made reference to their beliefs and structure in the home environment. These findings relate to situational appraisals (CC) and problem solving and coping (PSC) strategies interacting with the family's patterns of functioning in the Resiliency Model. The subthemes will be explored in detail below.

Develop relaxation strategies

Parents in this study reported on various relaxation strategies which they find help them to remain resilient among very difficult circumstances. They highlighted the importance of taking care of themselves as they are aware of the stress of taking care of a child with ASD. Some parents reported certain activities to distract themselves and give them a "break" from the worry and stress. Examples of these types of activities are reading, watching television or sleeping to provide their body with needed rest and relaxation. The mother of a 10 year old boy reported:

- "I just… I just sleep. Or… I just watched the television. Sometimes just take a book and read".

Parents also referred to spending time with friends and family as a way to relax. The last-mentioned parent also reported the following,

- "If I finish to clean the house and go to talk with other people then I'm fine".

She highlighted that it is helpful to distract herself by speaking to others about other matters. This parent also specifically said:

- "Sometimes I phone my sisters… just forget about that."

A father of a 10 year old boy also reported on the need to speak to others:

- "I spoke to my friend. Now, my friend, we are very good friends. I take this now as an example. He knows my son, he knows me very well. He knows the situation. You see, someone on the outside can observe very well, someone who is close to you like a friend."

Another parent reported specifically on the value of connecting with other parents who are going through something similar. For her it is helpful to speak to other parents about their experiences and to know that she is not alone. She reported:

- "By connecting with other parents… by just knowing that you're not the only one going through this… I think there was a lot of comfort in that for us. It was nice being able to speak about these things freely." (Mother of 8 year old boy)

Furthermore, parents highlighted the need to sometimes have time away from their child. Whether that entails taking a holiday or just being at work and not focusing on the child, either way it was indicated by parents that they need time to recuperate. Some parents leave their child with a family member for a period to give them time to build their strength again. One of the mothers of a 10 year old boy said:

- "But if I'm there at work I just feel free, because I talk with my colleagues, I talk about other *stuff*, because they don't know what is a Autism, especially us Africans."

Another mother of an 8 year old boy said:

- "And when you are doing things, the mind is distracted. But I think for me being busy was really… it helped a lot."

She thus highlights how important it is to give her mind "a break". This parent also referred to having time with her husband alone is very good to relax and recuperate:

- "So what we try to do is we try to create little pockets of time… Where we go out and have a coffee or we go out and just go have a drink or…"

Cridland et al. (2014) reported that resilience is apparent in families who make active efforts to spend time with each other. This is thus also found in the current study. The implication is that parents prioritise their own mental health as well and they have certain things in place for themselves. This is an important finding as a study by Kheir et al. (2012) conducted in Qatar confirms the impact of having a child with autism on the lives of the car-egivers. Parents reported poor physical and mental health and increased stress. A study on the quality of life of Iranian mothers with a child with ASD had similar results. The study emphasises the importance of recognising and addressing caregiver's mental health status and quality of life (Kousha et al., 2016). The finding in the current study that parents have certain "habits" that improve their mental wellbeing is a significant contribution to the literature on resilience.

Develop a strong faith base

Parents also reported that having a strong faith base is an important factor in their view on their own resilience. What they believe about their child and their current circumstances helps them to maintain a positive outlook. This finding is supported by Walsh's family resilience framework, which highlights the family belief system as one of the three domains of functioning and a key component in the process of resilience (Walsh, 2003). Walsh (2003) also highlighted positive outlooks as crucial in maintaining resilience. This finding also fits in the Resiliency Model of McCubbin and McCubbin. A family's appraisal/judgment of crisis

situations consists of, amongst others, shared values and beliefs (CCCC), situational appraisal (CC) and stressor appraisal – definition of stressor (C) (van Breda, 2001). In the current study the belief systems of parents fits in the situational appraisal (CC) and stressor appraisal (C) of the Resiliency Model.

Many of the participants indicated that they view their child as "special" or "God-given". Parents indicated how they view and understand their child within the framework of their religion. The parents seem to hold positive beliefs about their children. One of the mothers of an 11 year old daughter said:

- "I know now that because she is such a miracle, we were okay with it…"

Furthermore, the father of a 10 year old boy described the following:

- "As the time goes along you start to see he is given to you and he is here, and one needs to accept that because he was given to you… So he is a gift in his own way. Which actually makes it special is that he is different. That makes him special."

Parents also indicated that they believe that God will only give them what He knows they can deal with. For many of the parents their faith shaped their beliefs about their child and their own abilities. Research participants' indication that specifically religious belief is a resiliency factor, is consistent with Walsh's (2003) assertion that families struggling to find meaning when a young child is diagnosed with a chronic condition could search for meaning through their spiritual beliefs and practices. The following quotations demonstrate this finding:

- "He came through someone, you know. Someone gave it to you and that someone is now the Higher Being as we know it in our faith. Through that it is now… you have to be thankful for that. If you cannot accept that then you are unthankful for what the Father has given you. The Father will not give you

something that you cannot handle. We might not see it now, but as we go along we will see the bigger picture." (Father of an 8 year old boy)

- "My religion – I would not have received something if I could not handle it. I really believe that God would not have given me something that I cannot handle." (Mother of 11 year old girl)

The positive beliefs of parents and the manner in which they make sense of their child's diagnosis is an important resilience factor for parents in this study. This finding is supported in the literature. For example, Bekhet et al. (2012) conducted a study which indicated that positive cognitions had mediating effects on the relationship between caregiver burden and resourcefulness. Caregivers are thus better able to be resourceful when they have positive thoughts. This finding is supported by the finding in the current study of the significance of parents' positive thoughts. For example, one of the parents indicated the following regarding his own thought processes:

> Every day when I get up I tell myself "Ai my son, when are you going to get better." Maybe you will get better tomorrow and that gives me new courage. It motivates me. No he will get better. He will get calmer, at a later stage. It says to me, *ag*, I can hold out and go on until… You know, that hope and courage for the future it stays there (Father of 10 year old boy).

The families of this study thus demonstrated their hope for the future, which is recognised by Walsh (2003) as a key resilience factor in the process of adaptation.

Develop a specific environment

Parents also indicated that creating a specific environment for their child was a very important coping mechanism for them as a family. Having a set routine and strict boundaries in the family helps the family to remain resilient. This finding fits in McCubbin and McCubbin's Resiliency Model as it indicates the families' sense of coherence and

predictability (CCCC). This sense of coherence and predictability is part of the family's appraisal processes (CC) and is key in the process of adaptation which will lead to resilience. The current study highlights how low-income families' implementation of coherence and predictability lead them to resiliency.

All of the participants in this study indicated the importance of having a set routine for their child with ASD. They reported on the necessity to have predictability in the household to contain their child. The following quotations illustrate this finding:

- "And with us 'what's next' is like a catch phrase in our house, because we need to constantly know what's next. So we are very successful with preparation, for instance. So if something needs to happen, or we need to go out somewhere, or we need to go away, or I need to go away for work or whatever the case may be… That preparation starts way before the actual event. So that critical maintaining of routine. Everything happens according to the clock." (Mother of an 8 year old boy)
- "Yes, you can definitely not change her things. What happens every day needs to be the same. We had to learn that certain things will not change and we need to respect that. For example, she is very shy. When she is in the bathroom you may not bother her. We are three women in the house, me and her and older sister. When older sister is there she comes in where I am busy and starts to talk... but not the other one. She is private." (Mother of 11 year old daughter)
- "We definitely have to let him know exactly what we're doing, what we're going to be doing otherwise there's definitely *goggas* that jump out. The other thing that he is very specific about is night times. We haven't gone out a lot at night for years now, because even as a small baby he totally go *bonkers* in the car if we were riding at night. So that's something that we've, *ja*… I feel you know, we've

felt that we must make compromise for some things." (Mother of 11 year old boy)

Parents also indicated that they need to plan their own routines very carefully to ensure that there is always someone to care for the child so that the routine can stay in place. Again the spousal support and flexibility in spousal relationship is highlighted.

- "Yes it is actually quite difficult because my wife works and I work. So there isn't really a space and time related. We try and see who is now available. You know, if she works 3 or 4 nights in a row then I just have to make myself available." (Father of 10 year old boy)

This finding of the importance of routine is supported in the literature. According to Cridland et al. (2014), to maintain healthy routines and have flexible roles is very important to remain resilient.

Parents also indicated the importance of accepting the child and going on as normal as possible. They reported that it is their sense of responsibility which helped them to move to acceptance. Most parents reported that they realised that they have to adapt to help their child and part of that is accepting the circumstances. The participants reported that they accept their child and continue with their lives as best they can. They highlighted continuing with life as "normal" as possible. The following quotations illustrate acceptance and normalisation as part of parents appraisal processes (CC):

- "We have that responsibility. No-one else is going to do it. We as parents will have to do it. You don't really have a choice. So what will you do now? What you have to do is you need to accept and adapt to your child." (Father of 10 year old boy)
- "And I mean, *ja*… if it is what it is. Parents just need to accept it man. Don't… like don't deny it and don't hide it. Don't keep your child away from life and the

community. Don't do that. Accept, make peace with it and let them interact. So to be honest about it and open and just kind of go on with life." (Father of 8 year old boy)

- "I have to do that. There's no other way for you to do that but to get up and to go and to do. So we involve him you know… in our daily lives as much as we possibly can. And just sit with him… just ask about 'how was school' and that's it." (Mother of 8 year old boy)

King et al. (2009) found that families of children with ASD adopted perspectives of optimism, acceptance, and appreciation and strived to meet their children's needs as well as possible. These perspectives provided families with a sense of hope, meaning, and control over their situations. This study indicates that the current finding is supported by the literature. The families that participated in this study all held on to perspectives which gave them a sense of hope and control over their lives. They ascribe their abilities to remain resilient to the fact that they have accepted their children and they now focus on living normal lives.

Conclusion

This chapter described the results that were obtained from interviews with 6 participants. Three main themes emerged from these interviews. The first theme was related to parents' response to the diagnosis of their child and how their responses helped them to continue with their lives after receiving such difficult news. The second theme indicated what resources parents found helpful in their immediate environment. The third main theme described the specific coping skills that parents use to remain resilient. The themes and subthemes of this study were substantiated by other research studies and some new information was found in this sample pertaining to low-income families' self-education and research as part of their

initial response, as well as certain relaxation strategies as part of the family's own way of coping.

Walsh's Family Resilience Framework as well as the Resiliency Model of Family Stress, Adjustment and Adaptation (The Resiliency Model) of McCubbin and McCubbin was used to conceptualise the resiliency factors of these families. The findings of this study align with the adaptation phase of the Resiliency Model which leads to bonadaptation. Families in this study indicated how their old and new patterns of functioning (T and TT) interacted with their situational appraisal processes (CC), problem-solving and coping skills (PSC) and family resources (BB) to guide them to resilience.

In the next chapter, conclusions will be drawn from the results, the limitations of the study will be discussed and recommendations for future research will be made.

Chapter 6: Conclusion, Limitations and Recommendations

Introduction

In the previous chapter the results from the interviews were introduced and discussed. In this chapter conclusions will be drawn from this results. The limitations of the current study as well as recommendations for future research will also be discussed. Recommendations for future interventions and research regarding resilience factors of families with a child with ASD will be included.

Conclusions from this Study

Over the past few decades resilience studies have gained interest in South Africa. It has been indicated by South African literature that focusing on those factors that reduce risk and increase coping, is a step in the right direction and reflective of a discipline that values and respects the healthy aspects of human development and enhances the coping skills of those that are less resilient. It is an approach that focuses on strength (Dass-Brailsford, 2005). The value of a proactive, health-focused orientation should not be underestimated in a developing country such as South Africa where resources are limited (Brown et al., 2010). The current study is set against the background of family resilience studies and contributes to the field of family resilience literature.

The current South African research regarding resilience factors in families with a child with ASD, all highlight the importance of a focus on low-income families (Malcolm-Smith et al., 2013). Currently there is a gap in the literature for studies within a lower socio-economic population group specifically pertaining to ASD (Patterson, 2002; Fewster & Gurayah, 2015; Tilahun et al., 2016; Samadi & McConkey, 2011; Greef & van der Walt, 2010). Various South African studies (De Villiers & van den Berg, 2012; Brown and Robinson, 2012; Brown et al., 2010; Patterson, 2002; Greef & van der Walt, 2010) have recommended that further research be undertaken to identify resilience factors in families from lower socio-economic

backgrounds that do not have access to educational services specialized for children with autism. The current study thus answers this call.

The aim of this study was to explore and describe how low-income families with an autistic child remain resilient. Specific objectives related to the study were as follows:

- To explore and describe how low-income families cope with the everyday stressors of living with a child with Autism Spectrum Disorder.
- To explore and describe the specific characteristics which enable these families to remain resilient.
- To explore and describe the resources utilised by low-income families raising an autistic child.

Walsh's (2003) Family Resilience Framework as well as the Resiliency Model of Family Stress, Adjustment and Adaptation (The Resiliency Model) of McCubbin and McCubbin (1996), was used to understand how participants of this study adjusted to their circumstance and remained resilient.

Data for this study was collected using semi-structured interviews conducted with 6 participants in a low-income community in Cape Town, South Africa. A qualitative research design using semi-structured interviews was deemed most appropriate to obtain an in-depth understanding of the families' resilience factors.

Even though the sample group were not homogenous in their personal particulars, they had shared ideas regarding their own resilience factors. These predominant ideas were divided into themes and subthemes and used to answer the aim and objectives of this study. Below follows a detailed discussion of each answered objective:

Objective One: To explore and describe how low-income families cope with the everyday stressors of living with a child with Autism Spectrum Disorder

The study found that families that participated in this study have certain behaviours/habits and understandings which help them to cope with the everyday stressors of living with a child with ASD. Parents reported that having an understanding of their child's difficulties and inner world helps them to have patience and tailor their parenting and responses accordingly. The parents in this study described how they did their own research and educated themselves with regards to their child and the diagnosis of ASD. This helped them to form an understanding and improve their knowledge regarding the symptoms of ASD and what they can anticipate going forward.

Furthermore parents indicated that they developed their own coping strategies to help them on a day-to-day basis. Part of these coping strategies are developing a specific environment by setting strict boundaries and rules in the household. All of the participants highlighted the importance of having a strict routine and predictability for their child. They described the importance of meeting the child where he/she is at and working with what you have. The married participants described how important it is for them as a couple to plan their schedules according to the child's routine to ensure that the child will be cared for without disruption of routine.

Parents in this study also highlighted the importance of accepting their child and going on with life as normally as possible. It is very important for these parents to involve the child in their lives and to provide the child with a normal childhood, rather than exclude the child.

Another coping strategy parents reported on were relaxation strategies. Parents highlighted the importance of taking care of themselves as they are aware of the stress of taking care of a child with ASD. Some parents reported certain activities to distract themselves and give them a "break" from the worry and stress. Examples of these types of activities included reading, watching television or sleeping to provide their body with needed

rest and relaxation. Parents also referred to spending time with friends and family as a means of relaxation.

Furthermore, parents highlighted the need to sometimes have time away from their child. Whether that entails taking a holiday or just being at work and not focusing on the child, it was indicated by parents that they need time to recuperate. Some parents leave their child with a family member for a period to give them time to build their strength again.

Objective Two: To explore and describe the specific characteristics which enable these families to remain resilient

Participants in this study reported on their specific appraisal of their circumstances and parents shared a specific outlook which helped them to remain resilient. What they believe about their child and their current circumstances helps them to maintain a positive outlook. Many of the participants indicated that they view their child as "special" or "God-given". Parents indicated how they view and understand their child within the framework of their religion. The parents seem to hold positive beliefs about their children.

Parents also indicated that they believe that God will only give them what He knows they can deal with. For many of the parents their faith shaped their beliefs about their child and their own abilities.

The positives beliefs of parents and the manner in which they make sense of their child's diagnosis is an important resilience factor for parents in this study. Positive cognitions is thus a shared characteristic of the parents in this study.

Another characteristic belonging to the families of this study, is self-efficacy. Parents were self-efficient in their approach to understanding their children. They reported on their ability to do their own research and self-educate. Parents were active in their initial response to the child's difficulties and their initial reactions entailed certain behaviour. Although certain parents eventually consulted professionals in the community as will be seen later, it

seems that part of the initial response for parents was doing their own research and developing their own understanding.

Objective Three: To explore and describe the resources utilised by low-income families raising an autistic child

The participants of this study identified support they received from various sources. All the parents that participated in the study were of lower socio-economic status and although they do not have access to specialised resources, they were able to reflect on the resources in their immediate environment that were helpful.

In this study, parents indicated that spousal support was very important within the immediate circle. They specifically described that "taking turns" in caring for the child is something they find paramount in their lives. Furthermore, parents indicated significant support from family members such as grandparents or aunts/uncles, specifically mentioning the significant supportive role of their own mothers or mothers-in-law. Participants in the study highlighted how the help of family members helped them to remain resilient. They specified that grandparents or aunts/uncles helped to take care of the child and sometimes look after their child when they are unable to, or need a break. They describe how the understanding of family members is crucial for the family to be able to provide that support. It is clear that participants are very appreciative of their family's support and understanding.

Parents also highlighted the significance of resources within the immediate community. They particularly referred to consultations with medical officers at their local clinics/day hospitals. Participants indicated that this was a valuable source of information and it is often where they found answers to their questions.

All of the participants indicated how helpful and supportive the mainstream schools are where their children are enrolled. Parents described the structure of the class environments and teachers' patience and understanding as extremely helpful. They also reported that the

time the child is at school is time where they can recuperate and find new energy for their child. For many of the parents the school was also a source of information and teachers often helped to explain the diagnosis to parents. Furthermore, other resources parents report helpful are colleagues who listen and give the benefit of their experience with similar children.

In this study it was thus found that parents have various support systems, characteristics and behaviours which help them to remain resilient. The parents in this study view themselves as self-efficient and foster positive cognitions. From the start of their child's difficulties they focused on gathering as much information as possible and they made sure they were prepared for what lay ahead. Parents in this study have limited access to resources, but they made sure that they utilise the resources in their community that they have access to, such as day hospitals/clinics and schools. Furthermore parents were willing to rely on family and spouses for support.

The Resiliency Model of McCubbin and McCubbin was used to conceptualise the findings of this study and it indicated that parents successfully went through the adaptation phase to bonadaptation – resilience. Parents' old and new patterns of functioning (T and TT) interacted with their coping and problem solving skills (PSC), their resources (BB) as well as their appraisal/judgment of the situation (C). This process led them to resilience. The process is illustration below in figure 2 based on McCubbin and McCubbin's Resiliency Model (McCubbin & McCubbin, 1996).

Figure 2. Adaptation Phase of Families in this study

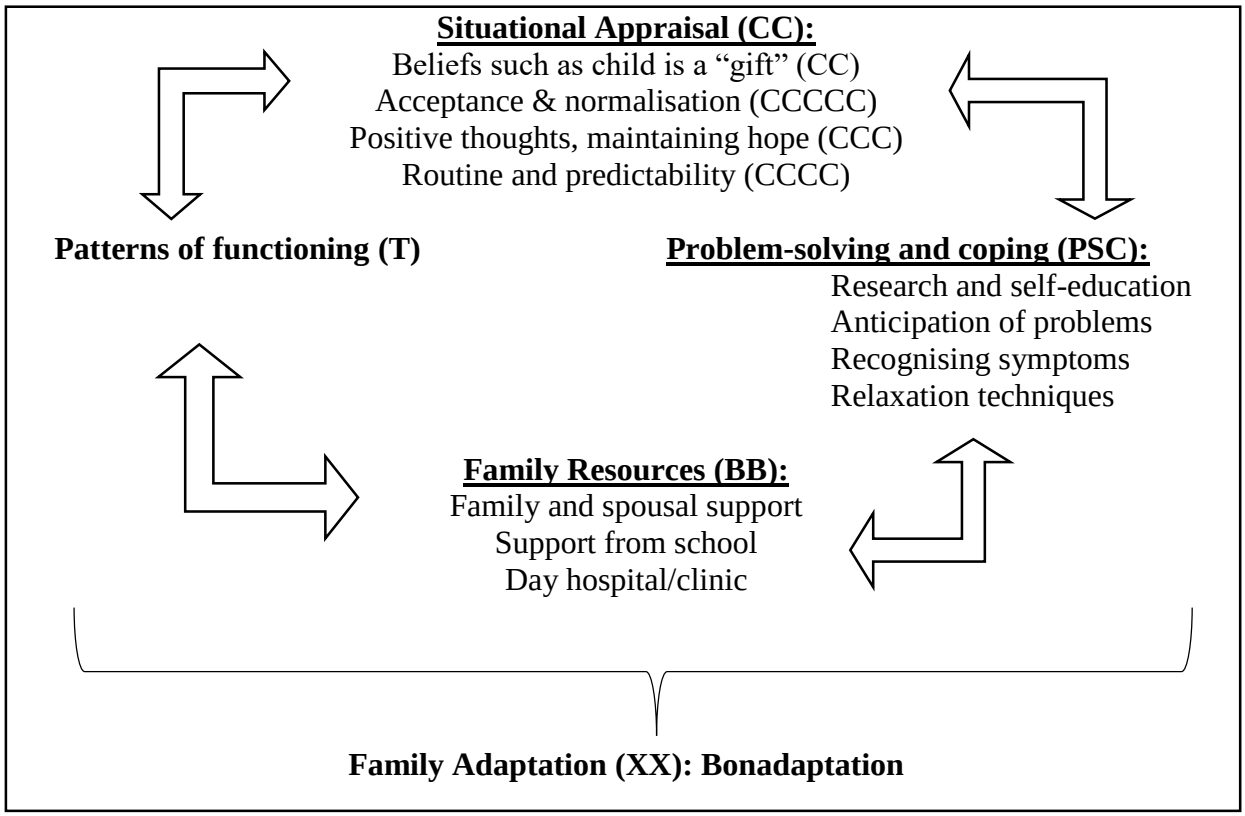


Figure 2: Adaptation phase of families in this study

Limitations of the study

The study presents with some limitations. Parents who participated in the study were overwhelmingly female (66%), married (83%) and permanently employed (83%). This restricts generalization, and future studies should recruit a more diverse group of parents. Specifically, recruitment of more male caregivers and/or fathers will allow researchers to understand how gender differences may relate to caretaking of children with ASD and how males and females may differ in their perceptions and coping mechanisms. Spousal support was also specifically mentioned as a major part of parents' support system. It thus seems that parents that participated in the study had the benefit of a partner who helped with the caretaking of children.

Furthermore it was difficult to find South African literature to corroborate the findings of this study, as only two other studies have been conducted in South Africa regarding the

coping and resilience of families with a child with ASD (Fewster & Gurayah, 2015 and Greeff & van der Walt, 2010). Both these studies were conducted with families of higher socio-economic status and indicated that further research is necessary with rural and less resourced communities within South Africa. The results of the current study can thus not be compared to the results of these studies.

Another limitation of the study was that most parents experienced their child with ASD as functioning better presently than shortly after the diagnosis. It was thus required of them to think back to more difficult times, which holds the potential for recall bias.

Value of the study

The current study contributed to the body of research regarding resilience factors in families who face a significant stressor. It also contributes to the field of research regarding ASD and the challenges that come with this diagnosis. Due to the significant stress placed on the entire family to have a family member with ASD, the resilience factors of these families need to be investigated. It is necessary to explore how families manage to be resilient while living with significant challenges. The value of this study is that it specifically investigated the resilience factors of low-income families. In light of the lack of resources families of low socio-economic status have, it needs to be explored how they are able to remain resilient. The information gathered in this study is of value to other, similar families.

This study provided a more in-depth understanding of the many different resilience factors that enable families to remain resilient in a resource-limited setting in the Western Cape. The qualitative nature of the research yielded a number of resilience factors, which quantitative measures would not necessarily have uncovered. It was found that a theoretical framework such as the Resiliency Model of McCubbin and McCubbin is useful to understand how the factors identified by participants led them to resilience.

Recommendations

This study has highlighted the importance of a focus on low-income families where they have restricted access to resources and limited information to identify how these families are resilient. Existing research regarding, specifically, families where the stressor is having a child with ASD, are mainly conducted with families of higher socio-economic status. However, in contexts – such as the context of this research – where families do not have access to resources, they are often affected severely by their child's diagnosis. In these contexts, it is of paramount importance to develop guidelines which take these unique limitations and context-specific needs into consideration. This study highlighted various resilience factors which take the unique needs of these resource-limited settings into consideration. The study followed a strength-based approach in order to portray families as challenged, rather than destroyed, and to highlight the success of families in managing distress. The findings of this study can be seen together with existing findings regarding resilience factors of families with a child with ASD and can highlight the applicability to low socio-economic settings.

Further research should focus on the unique challenges families in low socio-economic areas need to face due to limited resources. It is often suggested to parents of children with ASD to seek specialised intervention and guidance for their child. However, low-income families cannot afford specialised care for their child. Parents do however, have access to primary health care facilities such as clinics and day hospitals. Although parents reported the information and support from professionals at these settings helpful, it was not highlighted as their main source of support and guidance. It appeared that parents opted to conduct their own research and developed their own coping strategies. It could thus be helpful to these families if professionals at the primary health care level could be empowered to provide parents with detailed information and guidance. It is essential to assist families in these

settings with the development of skills to manage their child at home. The self-help strategies which parents in this study indicated could be conveyed to health care professionals which they can again convey to other parents who are confronted with this stressor.

It is recommended that future research focus on a community's specific strengths and resources. For example, participants in this study reported that they found it very helpful to do their own research and educate themselves regarding their child's diagnosis. Future research should explore how families do research, what sources they use and what type of information they find specifically useful. If they report making use of the media and internet-based resources, the benefit is that these resources are easily accessible and available to most individuals. It should be explored whether the resources that this community use is specific to this community or whether there are other communities that also find it useful. The correct use and interpretation of resources used for self-education should be emphasised so that parents do not interpret information in a way that worsens their view on the situation. Different communities might use different sources to self-educate and it is recommended to explore whether a community's use of resources are unique to that community. In that way the information regarding resources can be made public to other communities to help them gain an understanding of their child's diagnosis.

Furthermore, parents of this study indicated that their specific beliefs regarding their child and the diagnosis helped them to be resilient. For most parents their beliefs were centred on their religion, however, they did not report the church as particularly helpful. They reported that it was difficult to take their child to church, nevertheless, parents in this study held onto their faith in difficult times. It would be useful to explore whether other communities find the church, as an institution, very helpful or whether participants of a certain religion rely more on their faith than others.

Lastly, recommendations can be made related to the methodological limitations of this study. Future researchers should use larger representative samples to obtain a variety of families to improve the generalizability of the results. Future research should also aim to include more male caregivers in the sample to gain an understanding of possible gender differences in the view on resilience factors in the family. Including siblings of children living with ASD as research participants could be useful to obtain a holistic perspective of family resilience processes.

Conclusion

As seen in the literature review discussed in chapter 2, there are a number of studies available regarding the resilience factors of families with a child diagnosed with ASD. These studies are, however, mostly based on findings from higher socio-economic communities where the families have access to resources in terms of specialised interventions for their child. In resource-limited settings, which predominate in communities in South Africa, these resilience factors might not be applicable. It is thus necessary to explore and describe the resilience factors of families in communities where they do not have access to specialised care for their child. Understanding these families' strengths can be helpful to guide other low-income families to resilience.

The objectives of this study were to explore and describe how low-income families cope with the everyday stressors of living with a child with ASD; to explore and describe the specific characteristics which enable these families to remain resilient and to explore and describe the resources utilised by these families. Semi-structured interviews were conducted to gather data for this study as an in-depth qualitative research design was deemed best to gain insight into families' resilience factors.

Through obtaining an in-depth understanding of families' resilience factors, recommendations can be made to other families of lower socio-economic status to guide

them to resilience. Families who participated in this study repeatedly demonstrated their ability to withstand commonly identified stressors related to caring for a child with ASD. The sample thus provided hope to other parents for the future, which is a key resiliency factor identified by Walsh (2003).

The results of this study can also be made known to professionals at local day hospitals/clinics where parents often go in search of answers. These professionals can use the information gained in this study to guide parents after their child's diagnosis as many of these families do not have the finances to follow through on recommendations to seek specialist help. Recommendations were also made regarding future research on this topic.

This chapter included the limitations of the current study, but also indicated the value of the study within the current body of research, especially taking into consideration the limited amount of research available in resource-limited settings in South Africa.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, D.C., United States of America: American Psychiatric Association.

Autismlink. (2016). Retrieved July 10, 2016 from the world wide web, *www.autismlink.com/pages/autism_therapy*

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*(9), 702-714. doi: 10.1111/j.1365-2788.2007.00960

Barriball, K. L., & While, L. (1994). Collecting data using a semi-structured interview: a discussion paper. *Journal of Advanced Nursing, 19,* 328-335. Retrieved from http://web.ebscohost.com.ez.sun.ac.za/ehost/pdfviewer/pdfviewer?vid=6&hid=21&sid=37291f27-6876-4009-ac7e-b3860fcc6b8b%40sessionmgr13

Bateman, C. (2013). Autism – mitigating a global epidemic. *The South African Medical Journal, 103*(5), 276-277. doi: 10.7196/SAMJ.6915

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012). Resilience in family members of persons with autism spectrum disorder: a review of the literature. *Issues in Mental Health Nursing 33,* 650-656. doi: 10.3109/01612840.2012.671441

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012). The effects on resilience of caregivers of persons with autism spectrum disorder: the role of positive cognitions. *Journal of the American Psychiatric Nurses Association, 18*(6), 337-344. doi: 10.1177/1078390312467056

Bitsika, V., Sharpley, C. F., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal of Developmental Physical Disability,25,* 533-543. doi: 10.1007/s10882-013-9333-5

Biggerstaff, D. L., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): a qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology, 5*(3), 173-183. Retrieved from http://dx.doi.org/10.1080/14780880802314304

Black, K., & Lobo, M. (2008). A conceptual review of family resilience factors. *Journal of Family Nursing, 14*(1), 33-55. doi: 10.1177/1074840707312237

Bonanno, G. A., & Diminich, E. D. (2013). Annual research review: positive adjustment to adversity trajectories of minimal-impact resilience and emergent resilience. *Journal of Child Psychology and Psychiatry, 54*(4), 378-401. doi: 10.1111/jcpp.12021

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

Brown-Baatjies, O., Fouché, P., & Greeff, A. (2008). The development and relevance of the Resiliency Model of Family Stress, Adjustment and Adaptation. *Acta Academica, 40*(1), 78-126. Retrieved from https://www.researchgate.net/publication/283672121_The_development_and_relevance_of_the_Resiliency_Model_of_Family_Stress_Adjustment_and_Adaptation

Brown, O., Howcroft, G., & Muthen, T. (2010). Resilience in families living with a child diagnosed with hyperactivity/attention deficit disorder. *South African Journal of Psychology, 40*(3), 338-350. doi: 10.1177/008124631004000312

Brown, O., & Robinson, J. (2012). Resilience in remarried families. *South African Journal of Psychology, 42*(1), 114-126. doi: 10.1177/008124631204200112

Cridland, E. K., Jones, S. C., Magee C. A., & Caputi, P. C. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism 18*(3), 213-222. doi: 10.1177/1362361312472261

Dass-Brailsford, P. (2005). Exploring resiliency: Academic achievement among disadvantaged black youth in South Africa. *South African Journal of Psychology, 35*(3), 574-591. Retrieved from: http://melissainstitute.com/documents/ExplorationinResiliency.pdf

De Villiers, M., & van den Berg, H. (2012). The implementation and evaluation of a resiliency programme for children. *South African Journal of Psychology, 42*(1), 93-102. Retrieved from: http://0-sap.sagepub.com.wam.seals.ac.za/content/42/1/93.full.pdf+html

Fewster, D. L., & Gurayah, T. (2015). First port of call: facing the parents of autism spectrum disorder. *South African Family Practice 57*(1), 31-34. doi: 10.1080/20786190.2014.995917

Foo, M., Hui Yap, P. M. E., & Sung, M. (2014). The experience of Singaporean caregivers with a child diagnosed with autism spectrum disorder and challenging behaviours. *Qualitative Social Work, 14*(5), 634-650. doi: 0.1177/1473325014558662

Geschwind, D. H. (2011). Genetics of Autism Spectrum Disorders. *Trends Cognitive Science, 15*(9), 409-416. doi: 10.1016/j.tics.2011.07.003

Greeff, A. P., & Fillis, A. J. (2009). Resiliency in poor single-parent families. *Families in Society: The Journal of Contemporary Social Services, 90,* 279-285. doi: 10.1606/1044-3894.3902

Greeff, A. P., & Human, B. (2004). Resilience in **f**amilies in **w**hich a **p**arent has **d**ied**.** *American Journal of Family Therapy, 32*, 27-42. doi: 10.1080/01926180490255765

Greeff, A. P., & Joubert, A. (2007). Spirituality and resilience in families in which a parent has died. *Psychological Reports, 100*, 897-900. doi: 10.2466/pr0.100.3.897-900

Greeff, A. P., & van der Walt, KJ. (2010). Resilience in families with an autistic child. *Education and Training in Autism and Developmental Disabilities, 45*(3), 347-355. Retrieved from http://www.jstor.org/stable/23880109

Hanekom, L., & Brown-Baatjies, O. (2008). *Resilience in families with a child living with autism spectrum disorder*. (Unpublished master's thesis). Nelson Mandela Metropolitan University, Port Elizabeth, South Africa.

Health Professions Council of South Africa. (2011). *Ethical rules of conduct for practitioners registered under the Health Professions Act, 1974.* Retrieved from http://www.hpcsa.co.za/downloads/ethical_rules/ethical_rules_of_conduct_2011.pdf

Heer, K., Rose, J., Larkin, M., & Singhal N. (2015). The experiences of mothers caring for a child with developmental disabilities: a cross cultural perspective. *International Journal of Human Rights in Health Care, 8*(4), 218-232. doi: 10.1108/IJHRH-06-2014-0011

Karst, J. S., van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: a review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review, 15*, 247–277. doi: 10.1007/s10567-012-0119-6

Kheir, N., Ghoneim, O., Sandridge, A. L., Al-Ismail, I., Hayder, S., & Al-Rawi, F. (2012). Quality of life of caregivers of children with Autism in Qatar. *Autism, 16*(3), 293-298. doi: 10.1177/1362361311433648

King, G., Baxter, D., Rosenbaum, P., Zwaigenbaum, L., & Bates, A. (2009). Belief systems of families of children with autism spectrum disorder or Down syndrome. *Focus on Autism and Other Developmental Disabilities, 24*(1), 50-64. doi: 10.1177/1088357608329173

Kousha, M., Attar, A. H., & Shoar, Z. (2016). Anxiety, depression and quality of life in Iranian mothers of children with autism spectrum disorder. *Journal of Child Health Care, 20*(3), 405-414. doi: 10.1177/1367493515598644

Lee, G. K., Lopata, C., Volker, M. A., Thomeer M. L., Nida, R. E., Toomey, J. A., Chow, S. A., Smerbeck, A. M. (2009). Health-related quality of life of parents of children with high-functioning autism spectrum disorders. *Focus on Autism and Other Developmental Disorders, 24*(4), 227-239. doi: 10.1177/1088357609347371

MacPhee, D., Lunkenheimer, E., & Riggs, N. (2015). Resilience as regulation of developmental and family processes. *Family Relations, 64*(1), 153-175. doi: 10.1111/fare.12100

Malcolm-Smith, S., Hoogenhout, M., Ing, N., Thomas, K.GF., & de Vries, P. (2013). Autism spectrum disorders – global challenges and local opportunities. *Journal of Child and Adolescent Mental Health, 25*(1), 1-5. Retrieved from http://dx.doi.org/10.2989/17280583.2013.767804

McCubbin, M. A., & McCubbin, H. I. (1996). Resiliency in families: A conceptual model of family adjustment and adaptation in response to stress and crises. In H. I. McCubbin, A. I. Thompson & M. A. McCubbin (Reds.), *Family assessment: Resiliency, coping and adaptation – Inventories of research and practice* (pp. 1-64). Madison, WI: University of Wisconsin System.

McCubbin, H.I., Thompson, A.I., & McCubbin, M.A. (2001). *Family measures: Stress, coping and resiliency - Inventories for research and practice.* Hawaii: Kamehameha Schools.

Mire, S. S., Raff, N. S., Brewton C. M., & Goin-Kochel, R. P. (2015). Age-related trends in treatment use for children with autism spectrum disorder. *Research in Autism*

Spectrum Disorders, 15-16, 29-41. Retrieved from http://dx.doi.org/10.1016/j.rasd.2015.03.001

O'Brien, M. (2007). Ambiguous loss in families of children with autism spectrum disorders. *Family Relations, 56*(2), 135-146. Retrieved from http://www.jstor.org/stable/4541656

Pastor-Cerezuela, G., Fernandez-Andres, M. I., Tarraga-Minguez, P., & Navarro-Pena, J. M. (2015). Parental stress and ASD: Relationship with austism spectrum severity, IQ, and resilience. *Hammil Institute of Disabilities*, 1-12. doi: 10.1177/1088357615583471

Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family, 64*, 349-360. Retrieved from http://www.hbftpartnership.com/documents/uploadResources/Integrating_family_resilience_and_stress_theory-Patterson2002.pdf

Polkinghorne, D. E. (2005). Language and meaning: data collection in qualitative research. *Journal of Counselling Psychology, 52*(2), 137-145. doi: 10.1037/0022-0167.52.2.137

Pozo, P., & Sarria, E. (2015). Still stressed but feeling better: well-being in autism spectrum disorder families as children become adults. *Autism, 19*(7), 805-813. doi: 10.1177/1362361315583191

Russel, A. J., et al. (2015). The mental health of individuals referred for assessment of autism spectrum disorder in adulthood: a clinic report. *Autism, 20*(5), 623-627. doi: 10.1177/1362361315604271

Samadi, S. A., & McConkey, R. (2011). Autism in developing countries: lessons from Iran. *Autism Research and Treatment*, 1-11. doi: 10.1155/2011/145359

Schanen, N. C. (2006). Epigenetics of autism spectrum disorders. *Human Molecular Genetics, 15*(2), 138-150. doi: 10.1093/hmg/ddl213

Smith, L. E., & Anderson, K. A. A. (2014). The roles and needs of families of adolescents with ASD. *Remedial and Special Education, 35*(2), 114-122. doi: 10.1177/0741932513514616

SNAP Education. (2012). Autism poses huge financial threat. Retrieved from http://www.snap.org.za/snapforautism.org.za/2-uncategorised/41-autism-poses-huge-financial-threat

South African Department of Health, Ethical Rules of Conduct For Practitioners Registered Under the Health Professions Act (Act No. 56 of 1974), Form 223, Annexure 12. (2006). *Rules of conduct pertaining specifically to the profession of psychology* (Report No. 29079) Government Gazette, retrieved from http://www.hpcsa.co.za/downloads/conduct_ethics/rules/ethical_rules_psychology.pdf

Statistics South-Africa. (2014). *Poverty Trends in South Africa: an examination of absolute poverty between 2006 and 2011* (report number 03-10-06). Retrieved from http://beta2.statssa.gov.za/publications/Report-03-10-06/Report-03-10-06March2014.pdf

Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., Hoekstra, R. A. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. *BMC Health Services Research, 16*(152), 1-12. doi: 10.1186/s12913-016-1383-9

Tint, A., & Weiss, J. A. (2016). Family well-being of individuals with autism spectrum disorder: a scoping review. *Autism, 20*(3), 262-275. doi: 10.1177/1362361315580442

Van Breda, A. (2001). Resilience theory: a literature review. *South African Military Health Service, Military Psychological Institute, Social Work Research & Development.* Report nr: MPI/R/104/12/1/4.

Walsh, F. (2003). Family resilience: a framework for clinical practice. *Family Process, 42*(1), 1-18. Retrieved from http://web.ebscohost.com.ez.sun.ac.za/ehost/pdfviewer/pdfviewer?vid=13&hid=21&sid=37291f27-6876-4009-ac7e-b3860fcc6b8b%40sessionmgr13

Weitlauf, A. S., Vehorn, A. C., Taylor, J. L., & Warren, Z. E. (2014). Relationship satisfaction, parenting distress and depression in mothers of children with autism. *Autism, 18*(2), 194-198. doi: 10.1177/1362361312458039

Whitehead, K., Dorstyn D., & Ward, L. (2015). Psychological adjustment in families affected by autism spectrum disorder. *Journal of Developmental Physical Disability, 27*, 703-717. doi: 10.1007/s10882-015-9446-0

Appendix A: Cover Letter

P O Box 77000. Nelson Mandela
Metropolitan University
Port Elizabeth. 6031. South Africa. www.nmmu.ac.za

UCLIN PSYCHOLOGY CLINIC

TEL: (041) 504 2330
FAX: (041) 583 5324
e-mail:215109759@nmmu.ac.za

Dear Participant

My name is Alicia Horak and I am studying towards my Masters degree in Clinical Psychology at Nelson Mandela Metropolitan University. I am currently completing a study about resilience factors in families with an autistic child. I would like to ask you to participate in my study.

The information for this study will be gathered through a biographical questionnaire and a semi-structured interview. The interview process should take approximately an hour and will be digitally recorded.

The interview process will be confidential and participation in this study is completely voluntary. The results will be presented in the form of a written treatise and will be made available to participants should they be interested. Your identity will remain completely confidential and you are not required to write your name on any questionnaire. It is however vital that you answer as honestly as possible.

If you decide to participate in the study, you will be asked to give written informed consent. Please sign your initials against each section to indicate that you understand and agree to the conditions of the research study.

Please feel free to ask any questions that may not have been answered.

Your assistance in this study will be greatly appreciated. Please do not hesitate to contact me on 041 504 2330 if you require any information regarding the study.

Thanking you

_____	_____
Alicia Horak	Lisa Currin
Researcher	Supervisor

Appendix B: Informed Consent Form

NELSON MANDELA METROPOLITAN UNIVERSITY

INFORMATION AND INFORMED CONSENT FORM

RESEARCHER'S DETAILS	
Title of the research project	Resilience Factors in Low-Income Families with an Autistic Child.
Reference number	
Principal investigator	Alicia Horak
Address	Nelson Mandela Metropolitan University Department of Psychology Port Elizabeth
Postal Code	6000
Contact telephone number **(private numbers not advisable)**	041 504 2354

A. DECLARATION BY OR ON BEHALF OF PARTICIPANT		**Initial**
I, the participant and the undersigned	(full names)	
ID number		
OR		
I, in my capacity as	(parent or guardian)	
of the participant	(full names)	
ID number		
Address (of participant)		

A.1 HEREBY CONFIRM AS FOLLOWS:		**Initial**
I, the participant, was invited to participate in the above-mentioned research project		
that is being undertaken by	Alicia Horak	
from	Department of Psychology	
of the Nelson Mandela Metropolitan University.		

THE FOLLOWING ASPECTS HAVE BEEN EXPLAINED TO ME, THE PARTICIPANT:	**Initial**

2.1	**Aim:**	This research aims to explore the resilience factors of families with Autistic children.			
2.2	**Procedures:**	I understand that I need to complete the consent form, biographical questionnaire and participate in the interview process. If however I do not participate all the questionnaires will be returned to Alicia Horak.			
2.3	**Risks:**	There are no risks attached to this research and I am free to withdraw from the study at any stage without any negative consequences.			
2.4	**Possible benefits:**	As a result of my participation in this study, results may be utilised by a variety of professionals in order to alleviate the stressors these families face. Results may be used in order to assist families with coping with the demands of caring for an autistic child.			
2.5	**Confidentiality:**	My identity will not be revealed in any discussion, description or scientific publications by the investigators.			
2.6	**Access to findings:**	Any new information or benefit that develops during the course of the study will be shared as follows: The results will be made available to participants should they be interested and will be presented in the form of a written treatise.			
2.6	**Voluntary participation / refusal / discontinuation:**	My participation is voluntary	**YES**	**NO**	
		My decision whether or not to participate will in no way affect my present or future care / employment / lifestyle	**TRUE**	**FALSE**	

THE INFORMATION ABOVE WAS EXPLAINED TO ME/THE PARTICIPANT BY:									**Initial**
Alicia Horak									
in	**Afrikaans**		**English**		**Xhosa**		**Other**		
and I am in command of this language.									
I was given the opportunity to ask questions and all these questions were answered satisfactorily.									

4.	No pressure was exerted on me to consent to participation and I understand that I may withdraw at any stage without penalisation.	

5.	Participation in this study will not result in any additional cost to myself.	

A.2 I HEREBY VOLUNTARILY CONSENT TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT:

Signed/confirmed at	on	20
Signature or right thumb print of participant	Signature of witness: Full name of witness:	

STATEMENT BY OR ON BEHALF OF INVESTIGATOR(S)			
	I, Alicia Horak **declare that:**		
1.	**I have explained the information given in this document to** …… **He/she was encouraged and given ample time to ask me any questions.**		
2.	**This conversation was conducted in** ……..		
Signed/confirmed at		Date: ……	

Appendix C: Biographical Questionnaire

This questionnaire is confidential and your information will remain anonymous. Please mark the applicable box, or fill in the space provided:

1. Area where you live:……
2. Age: ……..
3. Gender: ……
4. Religion/church you and your family belong to (optional):……
5. Marital status

   (Married/Living together/Single/Estranged/Divorced/Widow/Widower):…….
6. Number of nuclear family members:……..
7. How many children (under 18) live in your home?

1	2	3	4	5	6	7	8	9	10

8. How many adults live in your home?

1	2	3	4	5	6	7	8	9	10

9. How many non-family members live with you?

1	2	3	4	5	6	7	8	9	10

10. Family composition:

Family member	Relation to family	Age	Gender
Adult 1			
Adult 2			
Adult 3			

Adult 4			
Adult 5			
Child 1			
Child 2			
Child 3			
Child 4			
Child 5			

11. What is your home language?

Setswana	English	Afrikaans	IsiXhosa	Sesotho	French	Ander

12. When was your child diagnosed with Autism Spectrum Disorder?

.....

.....

13. Your work status (Permanent/Part-time/Unemployed):…….....

Please proved details about your work (e.g. Permanent/Temporary, type of work)

……..…

……..……

….....

14. Highest standard/grade completed at school?

None	Sub A Gr. 1	Sub B Gr. 2	Std 1 Gr.3	Std 2 Gr. 4	Std 3 Gr. 5	
Std 4 Gr. 6	Std 5 Gr. 7	Std 6 Gr. 8	Std 7 Gr. 9	Std 8 Gr. 10	Std 9 Gr. 11	Std 10 Gr. 12

15. Did you achieve any other qualification?

Yes	No

If "yes", please provide details: …….....

16. What is the family's main source of income?

…….....

17. Would you like to receive general feedback regarding the results of this study?

Yes	
No	

If yes, please provide a contact number:_____

Thank you again for your participation!

Appendix D: Interview Schedule

Semi-structured, open-ended question:

"What will you say helps you and your family to cope with the everyday stressors of living with a child with Autism Spectrum Disorder?"

After the question is asked certain methods will be used to gain as much information as possible and to encourage participants to share their experiences.

"Probing" questions:

"Tell me more about this?"

"What resources or qualities do you use to cope with the challenges of caring for your child?"

"What do you use in your family and outside of your family to help you through difficult times?"

"If other people look at your family and see that you are struggling, what would they say you use to help you through tough times?"

"What would your family say helps you?"

Paraphrasing:

"So what you just said is a, b and c. Is there anything you would like to add?"