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THE ROLE OF RESILIENCE AND SOCIO-ECONOMIC STATUS IN THE PARENTING OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN SOUTH AFRICA

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Declaration:

A research project submitted in partial fulfillment of the requirements for the degree of MA in Psychology by Coursework and Dissertation, in the Faculty of Humanities, University of the Witwatersrand, Johannesburg. 05 May 2015.

I declare that this research project is my own, unaided work. It has not been submitted before for any other degree or examination at this or any other university.

_____ _____

Signature Date

Abstract

The purpose of this study was to understand the role of resilience and socio-economic status (SES) in the parenting of children with Autism Spectrum Disorders (ASD) in 3 South Africa cities (Johannesburg, Pretoria and Durban). This study also intended to understand the extent to which SES moderated the relationship between resilience and parental daily stresses. A total of 102 parents of children with ASD completed three measures (Family Resilience Assessment Scale, Parental Daily Hassles Scale and Hollingshead Two Factor Index). Pearson's correlation revealed significant moderate correlations between parental daily hassles (frequency and intensity scales), Family Resilience Assessment Scale, and SES. A regression analysis illustrated that the parent's gender was a significant contributor in the daily hassles of parents (Frequency and Intensity). A t-test analysis revealed a statistically significant difference between fathers and mothers in favour of the latter on Parental Daily Hassles Frequency and Intensity. A stepwise regression illustrated that SES moderated the relationship between Resilience and Parental Hassles (Intensity). The family's SES levels had a significant impact in the resilience levels of the parents such that lower SES parents were faced with more micro level challenges that impacted in their parenting.

Key words: Autism Spectrum Disorder, Parental Daily Hassles (frequency and Intensity), Family Resilience, Socio-Economic Status

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Dedication

I dedicate this work to my son Bukhona Simelane whom I love dearly. Through him I understand more about ASD.

Contents

Declaration: i

Abstract ii

Acknowledgements iii

Dedication iii

List of Tables viii

List of Figures ix

List of Acronyms x

CHAPTER 1 1

INTRODUCTION 1

1.1.Statement of the Problem 1

1.2.Rationale 2

1.3.Research Questions 5

1.4.Aims of the study 5

1.5.Overview of the Research Study 5

CHAPTER 2 6

LITERATURE REVIEW 6

2.1 Introduction 6

2.2 Autism in South Africa 6

2.3 Definition 7

2.3.1 Communication Impairment 9

2.3.2 Social Impairment 10

2.4 Aetiology of Autism Disorder 10

2.5 Comorbid Disorders 12

2.6. Parental Challenges 13
2.7. Parent-Child Interaction Model 15
2.8. Resilience 17
2.8.1. Family Resilience Framework 18
2.8.2. Family Belief System 20
2.8.3. Organisation Patterns 20
2.8.4. Communication and Problem Solving 21
2.9. Socio-Economic Status 22
CHAPTER 3 26
METHODS 26
3. Introduction 26
3.1. Research Design 26
3.2. Sampling 26
3.3 Demographic 28
3.4. Measures 29
3.4.1. Family Resilience Assessment Scale (FRAS) 29
3.4.2. Parenting Daily Hassles (PDH) 31
3.4.3. Demographical Information: The Hollingshead Two Factor Index (1975) 32
3.5. Procedure 32
3.6. Data Analysis 33
3.7 Ethical Considerations 34
3.8 Reflexivity 35
CHAPTER 4 38
RESULTS 38
4.1 Introduction 38

4.4.2 Standard Multiple Regression PDHI 49

4.5.1 Stepwise Regression PDHI 51

4.5.2 Stepwise Regression Parental Daily Hassle Frequency Scale 53

CHAPTER 5 57

DISCUSSION 57

5.1 Introduction 57

5.2. Differences in Daily Hassles of Mothers and Fathers 57

5.3 Correlation Analysis 58

5.5. The Predictors of Parental Daily Hassle 59

5.2 Limitations 60

5.3 Implications 61

5.2. Recommendations 61

5.3 Conclusion 62

References 63

Appendices 78

Appendices 78

A- Ethics Approval letter 78

B- Medical Clearance Ethics Approval 79

C- Gauteng Department of Education Approval Letter 80

D- Gauteng Province letter of Approval 81

E- Gauteng Department of Education Research Approval Letter 82

F- Information Sheet 83

G- Information Sheet (continued) 84

H- Consent Form 85

I- Emthonjeni Centre (Referral Letter) 86

J- Participant Background Information Sheet 87

K- Participant Background Information 88

L- Family Resilience Assessment Scale 89

M- Family Resilience Assessment Scale (Continued) 90

N- Family Resilience Assessment Scale (Continued) 91

O- Family Resilience Assessment Scale (Continued) 92

P-Family Resilience Assessment Scale (Continued) 93

Q- Family Resilience Assessment Scale (Continued) 94

R- Family Resilience Assessment Scale (Continued) 95

S- Family Resilience Assessment Scale (Continued) 96

T- Family Resilience Assessment Scale (Continued) 97

U- Parental Daily Hassle Scale 98

V- Principal's Approval Letter (Browns School) 99

W- Principal's Approval Letter (Unica School) 100

X- Principal's Approval Letter (Johannesburg Hospital School) 101

W- Principal's Approval Letter (The Key School) 102

X- Action In Autism Approval Letter 103

List of Tables

Table 1 Demographic Information 28
Table 2 Comparison of Male and Female Participants 43
Table 3 Correlation Matrix 45
Table 4 Standard Regression PDHF 47
Table 5 Standard Regression PDHF 48
Table 6 Standard Regression PDHI 49
Table 7 Standard Regression PDHI 50
Table 8 Stepwise Regression PDHI 51
Table 9 Stepwise Regression PDHF 53

List of Figures

Figure 1 Model of Stress in Parent-Child Interaction by (Mash & Johnston, 1990) 16
Figure 2 Framework of Family Resilience by Walsh (2003) 19
Figure 3 Socio-Economic Status and Sex of Parent 40
Figure 4 Socio-Economic Status and Marital Status 41
Figure 5 Socio- Economic Status by Race 42

List of Acronyms

A- ASD	-	Autism Spectrum Disorder
B- SES	-	Socio-Economic Status
C- FRAS	-	Family Resilience Scale
D- FCPS	-	Family Communication and Problem Solving Sub-scale
E- USER	-	Utilisation of Social and Economic Resources Sub-scale
F- MPO	-	Maintaining a Positive Outlook Sub-scale
G- FCON	-	Family Connectedness Sub-scale
H- FSPI	-	Family Spirituality Sub-scale
I- AMMA	-	Ability to Make Meaning of Adversity Sub-scale
J- PDH	-	Parental Daily Hassles Scale
K- PDHF	-	Parental Daily Hassles Frequency Sub-scale
L- PDHI	-	Parental Daily Hassles Scale Intensity Sub-scale
M- MARITALSTAT	-	Marital Status

CHAPTER 1

INTRODUCTION

1.1.Statement of the Problem

Raising a child with Autism Spectrum Disorder (ASD) is a physically, emotionally and financially costly experience (Bitsika, Sharpley & Bell 2013; Markoulakis, Fletcher & Bryden 2012; Lee et al., 2009). Other challenges associated with having a child with ASD include high therapy and education costs. Some parents are unable to deal with these challenges. Many parents respond with shock when faced with the reality of their child's diagnosis of autism (Heiman, 2002). After a diagnosis is obtained, parents and sometimes other members of the family may show elevated stress levels (Bitsika et al., 2013; Rolland & Walsh, 2006; Siman-Tov & Kaniel, 2011). In some families, this experience may affect the quality of life to the extent that the family's functioning deteriorates. Greeff and Van der Walt (2010) mentioned that the presence of a child with ASD may have adverse effects on various domains of family life, including the marital relationship, sibling relationships and adjustments as well as normal family routines. Family daily routines are often determined by the needs of the child and are changed accordingly in order to accommodate the daily demands of the child (Greef & van der Walt, 2010). Children with ASD often require twenty-four hour care and some parents are unable to provide this (De Grace, 2004). Many families often need help when undergoing changes such as dealing with the presence of a child with ASD. In the aftermath of a major family transition such as having a child with ASD, families usually find it difficult to return to the previous level of functioning (Walsh, 2003).

Limited studies have explored the interaction of resilience and socio-economic status combined, relation to particularly in parent's experience of daily hassles in raising children with ASD. Daily hassles are related to child behaviours and parenting daily duties that are challenging to parents. While Greef and Van der Walt (2010) investigated resilience in the parenting of children with ASD, the findings of the study were confined to middle class contexts. This study explored beyond middle class families, as it included all levels of SES families with ASD children.

Parents of children with ASD from disadvantaged families often battle to find diagnosis early for their children and some children from disadvantaged backgrounds are kept away from the public because of a lack of understanding of the disorder (Newschaffer et al., 2007). This problem is directly linked to finances and a lack of necessary information about the child's condition (Mandel et al., 2007). Circumstances have limited these families from finding a diagnosis as well as proper care for their children (Dawson, 2011).

Research has found that high resilient families who are raising children with ASD coped with challenges associated with the child's disorder and generally adapted better when compared to families of typical children (Simon, Murphy, & Smith, 2005). It is against this backdrop that this study was undertaken in order to understand the role of resilience in the parenting of children with ASD in different SES families in South Africa. This study proposed that the family's SES would moderate the relationship between resilience and parental daily hassles, such that a change in SES will moderate the relationship between resilience and parenting daily hassles.

1.2.Rationale

Siblings and families of children with ASD experience more than the usual care giving demands. The demands are diverse, some parents have reported experiencing unpleasant attitudes from practitioners and school educators in reaction to the child (Gerstein, Crnic, Blacher, & Baker, 2009). A number of studies have suggested that resilience could be a buffer in the parenting of children with ASD (Greef & Van der Walt, 2010; Lee et al., 2009; Twoy, Connolly & Novak, 2007).

While there is no consensus on the causes of ASD, different researchers have provided different causal models. Some of these models include genetic factors, auto immune factors and vitamin D deficiencies (Bakare & Munir, 2011). There is limited knowledge around ASD among the general populace and various categories of health workers and these are some of the challenges that parents are unable to cope with (Bakare & Munir, 2011).

Research suggests that having resilience during challenging periods as a process of bouncing back could be a useful factor and may assist families and parents who are in crisis to return to a pre-existing norm (Walsh, 2003). Walsh defines resilience as the ability to withstand and rebound from disruptive life challenges. It has been found that the entire family contributes to resilience in their unique and individual personal qualities (Simon et al., 2005). Resilient families are able to deal with life challenges if they show strong focus in communication, finances and strong family ties (Simon et al., 2005). According to Heiman (2002), parents of children with special needs such as ASD were able to act in a resilient way by drawing support from family members, professionals and friends.

Studies have shown that family bonds promote family resilience during periods of adversity (Greef, Vansteenwegen & Gillard, 2012). A balance between demands faced by a family and courage in dealing with challenges has been found to mean success in adaptation (Greef et al., 2012). Families who have a supportive environment and a higher degree of cohesion are more likely to adapt to the presence of an autistic child (Greef & van der Walt, 2010). Thus, family resilience is the path a family undertakes as it adjusts and prospers in the face of adversities (Hawley & De Haan, 1996). Family resilience therefore looks far beyond parent-child relationships; it also involves the influence of extended family networks, siblings and social relations (Walsh, 2003). The premise of the family resilience perspective is that serious crisis and challenges have an adverse impact on the family as a whole (Walsh, 2003). Each member of the family plays a role in contributing to family resilience. Parents contribute through their personality traits and their coping mechanisms and children may contribute through their cognitive and emotional development (Simon et al., 2005). Mothers of children with ASD have been found to experience more than normal levels of depression and anxiety in parenting, as compared to fathers (Bitsika et al., 2013). An additional factor explained in Walsh (2003) was the family's financial security. This factor if disregarded could have damaging effects in the family since a serious illness or chronic disorder such as ASD can strain the family's finances.

The family's SES background has a fundamental role in the care giving process. Previous studies have suggested that the parent's education levels and family income are a determinant of SES

and have a positive relationship with the family's success in adaptation and the development of a child with ASD or general disabilities (Greef et al., 2012).

The American Psychology Association conceptualised SES as the individual's or group's social/class standing which is often measured as a combination of occupation, education and income (APA, 2014). SES has been shown to associate with children's well-being and development. Low parental education has been found to correlate with lower levels of IQ and school achievement later in childhood.

The poor cannot afford to seek care when ill and the distribution of health is in favour of the rich. The costs associated with raising a child with ASD are exorbitant. The lifetime costs of caring for a child with ASD ranges from 1.4 to 3.5 million dollars (Lord & Bishop, 2010). The average public health expenditure of a child with ASD is 85% to 550% higher than that of a typical child, and is estimated at 4.7 million dollars (Newschaffer et al., 2007). The cost of raising a child with ASD in South Africa is approximately 3 million rands, and if interventions are received earlier such costs could be reduced to 1 million rands (Brink, 2012). The average monthly income of a South African is estimated at 5 802 rands per month (Stats SA, 2014) and the monthly fees for privately owned schools which cater for ASD children range from approximately 6 000 rands per month. These schools are only available in large cities. Accessing better education is difficult and expensive for parents in the lower SES stratum. This particular study explored the role that resilience and SES play in the parenting of children with ASD. South African studies on resilience have largely focused on the middle to higher SES groups. Thus there is a need to understand resilience in the low SES context and to explore whether parenting of children with ASD in these groups is indeed affected by SES status.

It is essential to acknowledge that this study does not purport that caring for a child with ASD is a negative experience for parents and families. The essential focus of this study was to understand how these families overcome the daily parenting challenges and to further understand the role resilience and SES has in these families.

1.3.Research Questions

The following research questions were a guide for this research study

1.1.1. Is there a difference between parental daily hassles (Frequency and Intensity) of female participants and male participants?

1.1.2. Is there a relationship between parental daily hassles (Frequency and Intensity), resilience and SES?

1.1.3. What is the best predictor of parental daily hassles (Frequency and Intensity) between the patents' SES and Resilience levels?

1.1.4. What moderation effect does SES have on the relationship between resilience and parental daily hassles (Frequency and Intensity)?

1.4.Aims of the study

The aim of this study was to explore the role of resilience and SES in the parenting of children with ASD among South African parents. The study also explored the extent to which SES of the parent moderated the relationship between resilience and parenting daily hassles for parents with children diagnosed with ASD in South Africa.

1.5.Overview of the Research Study

This research study comprises five chapters. Chapter two reviews the literature, chapter three discusses the method applied in this research study. The analysis and the results are presented in chapter four. Finally chapter five provides the discussion section, the limitations, implication of the study and conclusion.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter provides a review of literature on the topic of daily stresses experienced by parents of children with ASD. The literature further focuses on the role of resilience and SES in parenting children with ASD. Given that there are limited studies conducted in South Africa and in the African continent on the topic of ASD, the literature is largely drawn from studies conducted beyond the African continent.

2.2 Autism in South Africa

ASD is a relatively new disorder in South Africa. The first diagnosis of autism in South Africa was in 1970, before this diagnosis children with ASD were regarded as mentally retarded (Venter, Opt-Hof, Coetzee, Walt & Rietief, 1984). The first diagnosis in South Africa was obtained 27 years after the initial discovery of the disorder by Kanner in 1943. Not much research in the area of ASD has been done in South Africa thus there are still many challenges that the country is undergoing in dealing with ASD. Challenges such as the scarcity of professionals who are qualified to diagnose the disorder, schooling for children with ASD and the general knowledge of the disorder in the general populace are the commonly mentioned challenges in previous research studies (Pillay & Lockart, 2001; Roberts, 2007; Dabrowska & Pisula, 2010). According to Mubaiwa (2008) the prevalence of ASD in South Africa mirrors that of Europe and America of 10-20 per 10 000.

The issue of proper education for children with autism is yet to be addressed in the country. The majority of children with ASD attend segregated schools and there is currently no transition plan for integration into mainstream schools (Molteno, Molteno, Finchilescu & Dawes, 2001). A study by Ysell et al. (2007) on parents' perceptions in South Africa and United States reported a

desire from parents for the inclusion of children with disabilities in mainstream schools as a necessity for their children. Roberts (2007) stated that the education authorities in South Africa do not fully support the idea of integrating children with ASD into mainstream schools. The study further highlighted that mainstream teachers have limited knowledge in teaching children with ASD (Roberts, 2007). Challenges of this nature have created difficulty in rolling out programmes of including children with ASD in mainstream schools. The shortage of teachers specialising in ASD in government schools poses a challenge to parents who are unable to send their children to alternative schools. Schools which cater for ASD children in South Africa may not be accessible to all parents due to affordability and accessibility. These constraints disfavour ASD children from disadvantaged backgrounds as some children may end up starting school late and some may even be institutionalised (Holroyd, Brown, Wikler & Simon, 1975).

2.3 Definition

The term ‘autism’ is taken from a Greek term ‘autos’ meaning ‘self’. Children with ASD experience difficulties in social and communication interactions, as a result most of them tend to keep to themselves. ASD has been found to occur more in boys than in girls, with a ratio of 4:1 males to females (Faras, Al Ateeqi & Tidmarsh, 2010). The prevalence of the disorder has increased significantly over the past decade. This increase could be associated with better diagnostic tools and public awareness (Faras et al., 2010). The criterion used for diagnosing ASD has also changed over the years.

The first *Diagnostics and Statistical Manual* (DSM I and II) did not have a term or a disorder called autism. The closest term to the diagnosis of autism at the time of the DSM I was Schizophrenic Reaction Childhood (McPartland, Reichow & Vokmar, 2012). Further research produced new knowledge in the early 1980’s thus the DSM III introduced Pervasive Developmental Disorders with three categories, which were Childhood Onset PDD, Infantile Autism and Atypical Autism (McPartland et al., 2012).

The diagnostic criteria for autism have continued to advance. The introduction of the DSM 5 in (2013) brought about major changes. A fundamental change is the combining of all diagnosis found in the DSM IV TR into a single diagnosis, ASD (Frazier et al., 2012). The criterion for diagnosis in the DSM 5 was tested in real clinical settings to ensure a more accurate approach in the diagnosis of ASD (McPartland et al., 2012). The DSM 5 proposes the following for the diagnosis of ASD, impairment in social interaction and communication, repetitive mannerisms, behaviour and activities.

The symptoms should be present from early development and should cause clinically significant impairment in social functioning. The disorder should not be the result of intellectual disability though it is common that autism and intellectual disability co-occur (MacPartland et al., 2012). The DSM 5 has introduced three severity levels of ASD.

In level one, individuals require support because of their deficit in social communication which in turn causes noticeable difficulties when switching between activities. Level two individuals are regarded as individuals who 'require substantial support'. Individuals in level three require even greater support as these individuals do not only have difficulty in social function they are also very limited in initiating social interactions. Research in the field of ASD over the years has produced improved knowledge in the subject of ASD.

The introduction of the DSM 5 will reduce the numbers of people who receive ASD diagnosis significantly compared to the DSM IV. Different studies have found that people who received diagnoses using DSM IV TR declined by up to 55% (Worley & Matson, 2012; MacPartland et al., 2012). It is hoped that the introduction of the DSM 5 will bring about more accuracy in diagnosing ASD as it provides clearer diagnosis criterion (MacPartland et al., 2012). This suggests that ASD is still a relatively new disorder and more studies are being conducted to improve the diagnosis as well as the body of knowledge that exists.

2.3.1 Communication Impairment

It is mentioned that some children with ASD are non-verbal and if speech is present they suffer from 'theory of mind'. Theory of mind is defined as the inability to process information such as central coherence and executive functioning which can be classified as cognitive problems (Leyfer et al., 2006). It further states that individuals with ASD fail to attribute mental state of themselves and of others. Wimmer and Perner (1983) developed the unexpected test of false which tests the mental state and examines the child's understanding of true, mistaken and false belief (Sprung, 2003). About 80% of children with ASD failed the unexpected test of false. The unexpected test of false assumes that children acquire developmental ability of understanding reality by the age of four. For example, children who failed this test were unable to follow a sequence of events when tested. The assessment is conducted by using two dolls, and one doll has an incongruous belief of the other doll's location. The child is then asked to predict the other doll's location, and most ASD children fail to correctly predict the location.

ASD individuals who suffer from these cognitive problems may be unable to define their mental state and unable to experience daily life experiences (Leyfer et al., 2006). One of the triad of ASD is communication or linguistic disorders. Some common language deficits in children with ASD are the idiosyncratic use of language, use of unusual or made up words (neologism), imitation of words that are not appropriate to current production (echolalia), reversal of second person nouns, inappropriate intonation and poor syntax (Adams, Gouvousis, Van Lue & Waldron, 2004). Some researchers have compared language disorders in children with ASD with that of children with developmental delays (Loveland & Landry, 1986; Lovaas, 1977). The language of an ASD child is more severe when compared to that of a delayed child. Further to this, ASD children from an early age fail to develop early communicative gestures such as pointing at an object and this challenge has been identified as one of the core issues which pose problems in their future speech language development (Adams et al., 2004). Language deficits in children with ASD create a further challenge in their reciprocal conversations and subsequently leading to other related problems such as social skills (Adams et al., 2004).

2.3.2 Social Impairment

Poor language, lack of eye contact, and misunderstanding of social cues like body language, gestures and facial expression may lead children with ASD to experience difficulties in interacting socially with others. These reasons mentioned may cause ASD children to withdraw from others, become aggressive and sometimes behave inappropriately (Adams et al., 2004). Lack of social skills impact on the global development of the child, for example poor social skills deprives the child with the benefits of positive support and opportunities found in healthy peer relationships (Disalvo & Oswald, 2002). Furthermore, poor social skills have been found to increase the likelihood for children with ASD to develop maladaptive behaviours later in their lives (Disalvo & Oswald, 2002).

The study further mentioned that ASD children do not experience complete failure but lack the flexibility and the spontaneity of applying social reciprocity (Disalvo & Oswald, 2002). It is also mentioned that the main problem is the actual acquiring of these skills, even when they desired to interact with others; their skills are usually not adequate for them to interact (Disalvo & Oswald, 2002). Previous research has suggested that children with ASD may be taught these social skills through applied behavioural principles. These studies mentioned that through adult modelling and peer teaching, children could be taught to orient to another person, make eye contact, and vocalise a response towards that individual (Disalvo & Oswald, 2002; Mc Eachin, Smith & Lovaas, 1993). The weakness of these interventions is that, when modelled by adults the natural context of children's social interactions is usually ignored. Peer modelling also has some shortcomings which includes the premature and actual absence of relevant modelling skills required in order to be able to transfer these skills (Disalvo & Oswald, 2002).

2.4 Aetiology of Autism Disorder

Since the discovery of the disorder by Kanner in 1943 the causes of ASD are still not adequately defined. Kanner (1943) suggested that the disorder is caused by an unknown inborn defect. Kanner suggested that parents of ASD children came from highly intelligent backgrounds, there

were patterns of obsessiveness in the family, most parents were professionals and finally he stated that most of these parents had limited genuine concern in people. In his discovery he stated that there were few warm hearted mothers and fathers. While some researchers (Bettelheim, 1967) agreed with Kanner's findings other studies discovered biological and prenatal causes of the disorder (Folstein & Piven, 1991). There are a few anecdotal risk factors that have been listed as possible causes of the disorder by the United Kingdom Research Council (UKRC). These include exposures before and/or after birth to drugs, vaccines, infections, heavy metal, epilepsy, mental deficiencies, depression, anxiety and gastrointestinal tract. One of the listed risk factors, Measles Mumps and Rubella (MMR) occupied many research journals after a paper released by Dr Andrew Wakefield in 1998. Incident cases of autism after the introduction of MMR vaccine increased after Dr Wakefield's paper in 1998, this suggested that receiving an MMR vaccine was associated with the development of autism (UKRC, 2001). However, MMR as a cause for ASD has been disproved in many recent studies which found no evidence that MMR caused ASD, and the paper by Wakefield was retracted (Maglione et al., 2014; Baird et al., 2008)

An association of high mercury (Hg) exposure and ASD has also been reported. A study by Bradstreet, Geier, Kartzinel, Adams and Geier (2003) found that 221 children with ASD had high urinary mercury concentration when compared to a control group of 18 typical children. This study also found that vaccinated children with ASD showed higher urinary mercury concentration compared to the normal group (Bradstreet et al., 2003). This study however failed to determine whether these high levels in mercury (Hg) are due to higher exposure to (Hg) or failure to excrete mercury in the system or a combination of the two reasons (Bradstreet et al., 2003).

The increase of industrial areas may be one of the causes of the high levels of Hg in the air and water. It is mentioned that Hg is released into the air and water from natural resources such as coal burning and manufacturing facilities. It is thus spread in the air and in the entire environment, through the food chain and is then consumed by humans through absorption in animal tissues such as fish (Geier, Kern & Geier, 2010). There are different other processes which may increase the exposure of Hg in humans. Some drugs which are easily accessible over

the counter for example, certain skin bleaching creams, some contraceptives, other lens solutions and some dental fillings contain inorganic forms of Hg (Geier et al., 2010). About 6% of women of child rearing age were found with high concentration levels of Hg in their system (Geier et al., 2010). The foetus is known to be susceptible to high levels of Hg which may disrupt the neurodevelopmental process and renal impairment from the foetus thus leading to the development of ASD (Geier et al., 2010).

Different studies have mentioned an association between heredity and ASD. Jick and Kaye (2003) mentioned that a substantial amount of ASD is due to the characteristics of the parents as the cause. Studies have suggested a recurrence sibling risk of about 2-14% probability for a sibling to develop autism given that one sibling has ASD (Hertz-Picciotto et al., 2006). Twin studies have found a 40-60% concordance for autism in monozygotic (identical) as compared with dizygotic (fraternal) twins. These findings meant that in the identical set of twins if one twin met the criteria for ASD diagnosis the other twin was 40-60% likely to meet the criteria (Geier et al., 2010; Hertz-Picciotto et al., 2006).

2.5 Comorbid Disorders

A study conducted in the United States of America (USA) by Leyfer et al. (2006) on a sample of 109 children from ages 5-17 assessed the presence of comorbid disorders in children with ASD. It was found that 32% had phobias of needles and crowds, 37% had Obsessive Compulsive Disorders (OCD), 31% had Attention Deficiency Hyperactivity Disorder (ADHD) and 10% had Depression. Leyfer et al. (2006) mentioned that comorbid disorders are not easily detected and the rates of these comorbid disorders are usually not known. Simonoff, Pickles, Chandler, Loucas and Baird (2008) found even higher rates of comorbid psychiatric disorders. This study sampled 112 children between the ages of 10-14 years old and found that 70% of the children had one comorbid psychiatric disorder with ASD and 42 % had two comorbid disorders. The highest comorbid disorder was social anxiety 29% followed by ADHD and Oppositional Defiant Disorders 28% (Simonoff et al., 2008).

Intellectual Disorders (ID) have been found to co-vary with ASD (Matson & Shoemaker, 2009). ID is characterised by challenging behaviours, social cognitive and adaptive skills deficits. It is mentioned that about 40% of persons with ID have ASD, and 70% of persons with ASD have ID (Matson & Shoemaker, 2009). The rates of ASD and ID are about 50-70% of all ASD cases (Matson & Shoemaker, 2009).

Depression has been found to co-occur with ASD. The prevalence of depression in children with ASD has been reported to vary from 1.4 % to 38 % (Matson & Shoemaker, 2009; Magnuson & Constantino, 2011). Depression in children requires that parents take more than normal care giving duties of the child. Depression has long term outcomes and may put a person with ASD at a risk of committing suicide, non-compliance and aggression (Matson & Shoemaker, 2009; Magnuson & Constantino, 2011).

Gastrointestinal (GI) problems have been found to be common in children with ASD. Chronic constipation, diarrhoea is said to occur in 46-85% of children with ASD. Other studies have mentioned lower rates of 17-24% (Myers & Johnson, 2007). GI problems in children with ASD may contribute to the severity of the disorder. Pains associated with GI may likely to frustrate the child and thus leading to other problems such as reduced concentration, increase aggression mostly in those children who are unable to communicate their needs (Adams et al., 2011).

About 11%-39% of children with ASD suffer from seizures. It is mentioned that when mental retardation is present the prevalence of seizures in the child escalates to 42% (Myers & Johnson, 2007).

2.6. Parental Challenges

Parents and siblings play a key role in the effective treatment of ASD. The presence of ASD in a family brings about severe stress and to some degree depression may be experienced (Myers & Johnson, 2007). Families of children with ASD experience myriads of challenges in caring for their children. Most parents mentioned that they recognised that the child was different as early

as age two years and some parents reported that they recognised the differences in the child even before the age of two (Hutton & Caron, 2005). Parents mentioned that they recognized that there were differences in the child through observing certain delayed milestones in the child for example, child not babbling.

One other key concern parents mentioned is the difficulties in obtaining necessary services. They indicated that they were initially informed by practitioners that nothing was wrong with the child and subsequently sent home without examination. However parental instincts prevailed and most parents persisted until they received the care they were seeking (Hutton & Caron, 2005). The period surrounding the diagnosis of the child and the initiation of intervention services brings about a challenge in parenting children with ASD and these challenges have been found to elevate stress levels in parents (Hastings, 2003; Davis & Carter, 2008). Parents have also mentioned that the public and other family members demonstrated disapproval of the child's behaviour causing the parent anxiety and stress (Dabrowska & Pisula, 2010).

Parenting is a challenging experience and being a parent of a child with ASD could be even more demanding and may also pose a threat to the psychosocial well-being of parents (Higgins, Bailey & Pearce, 2005). To most parents the behaviour of the child is more of a salient stressor than the child's disorder (Hastings, 2003). Children with ASD experience regulatory problems such as eating problems and sleeping problems. These regulatory problems may be stressful to the parent and may preclude a normal family life (Higgins et al., 2005). Problems such as externalising behaviours are common in children with ASD. These problems include tantrums, aggression and hyperactivity (Boonen et al., 2014; Hastings, 2003). Externalizing problems have been found to affect parents' psychological wellbeing and contribute to levels of stress (Boonen et al., 2014). Other factors that have been found to bring about challenges to parents are the severity of the disorder and the child's competencies. Parents of children with high incompetence such as not achieving age expected social and emotional milestones, showed higher parenting stress levels (Hastings, 2003).

Studies have compared parenting challenges in mothers and fathers of children with ASD and have yielded different research results. Other studies have found that stress levels in mothers and

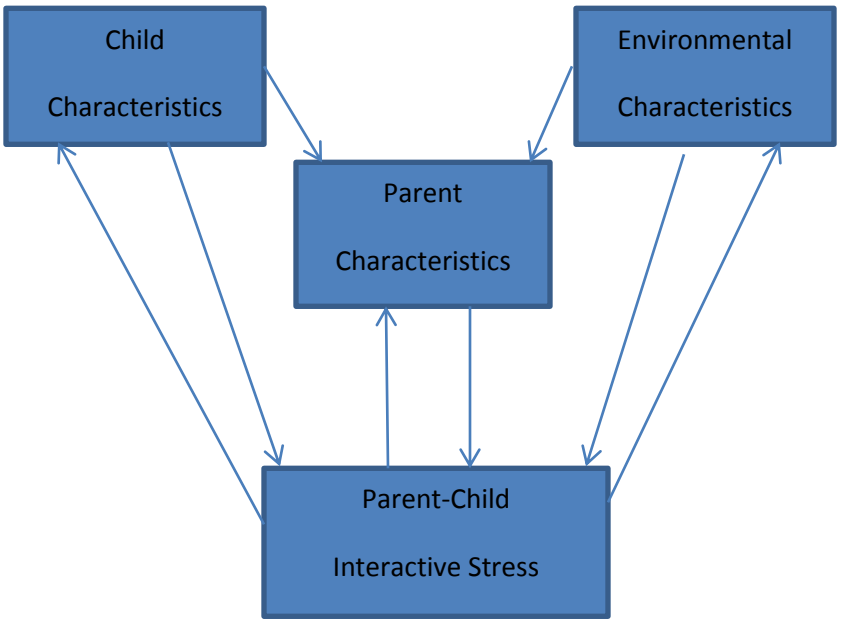
fathers of children with ASD were comparable (Hastings, 2003; Davis & Carter; 2008). Mothers were more affected by the child's behaviour as compared to fathers. These findings may be due to reasons such as fathers being less involved in the daily responsibilities of the child as compared to mothers. Higgins et al. (2005) found a relationship between the mother's stress levels and the educational progress of the child. In addition to these findings, mothers of children with ASD reported less marital satisfaction when compared with mothers of children with downs syndrome and typically developing children (Higgins et al., 2005). Above all, both fathers and mothers presented equal levels of stress and depressive symptoms when the child is young and upon receiving the child's diagnosis of ASD (Davis & Carter, 2008; Hastings, 2003).

2.7. Parent-Child Interaction Model

Mash and Johnston (1990) developed a model which illustrates factors that are related to parenting stress. This model uses a direct pathway (see figure 1) for the influences of the child, parent and the environment and it is recursive (Mash & Johnston, 1990). This implies that stress in the parent child model is seen as having an impact on the three aspects. The three aspects of the model out of a broader paradigm of parenting stress include the parent's characteristics, characteristics of the child and environmental characteristics. The model by Mash and Johnston (1990) was chosen for this study as it has been applied previously to families of hyperactive children and abused children. Similarities exist in behavioural problems of children with hyperactivity, abused children and children with ASD. These children may experience behavioural, cognitive, social and academic problems and are faced with a possibility of failing to adapt later in their lives (Barkely, 1998 ; Mash & Johnston, 1990; Sternberg et al., 1993).

Parent's characteristics include the parent's psychological resources such as the affective state, personality and the general health of the parent (Mash & Johnston, 1990). This model illustrates that some characteristics may prevent stressful situations or may exaggerate them. A model by Bluth et al. (2013) for couples raising children with ASD supported this statement. The model illustrated that parents could prevent stressful situations by applying behaviour called mindfulness.

Figure 1 ***Model of Stress in Parent-Child Interaction by Mash & Johnston, 1990***



The definition of mindfulness is "paying attention in a particular way, on purpose, in the present moment and nonjudgmentally" (Bluth et al., 2013, p 204). The assumption is that humans are not aware of the moment and if mindfulness is not activated as a conscious state they may be faced with the consequences that may lead to possible future suffering (Bluth et al., 2013). For example, parents may apply automatic processing by telling a hyperactive child to slow down. These responses may become automatic and without any conscious cognitive effort (Mash & Johnston, 1990).

The child's characteristics include temperament, cognition and regulatory problems (Davies & Carter, 2008; Bluth et al., 2013; Mash & Johnston, 1990). These characteristics can promote the negative control orientated parent child interactions. Behaviours such as aggression and property destruction change the parents' behaviour (Davies & Carter, 2008; Mash & Johnston, 1990). This was supported by a study conducted (Anderson, Lytton & Romney, 1986; Brunk &

Henggeler, 1984; Mash, 1984), this study found that children's behavioural problems may bring about a predictable type of parental control.

Environmental characteristics include major life events, poverty, social isolation and daily hassles. These have been found to have negative effects on parent child interactions (Mash & Johnston, 1990). Macro level factors such as poverty have been acknowledged as factors having a negative impact on child problems and ASD outcomes (Cuccaro et al., 1996; Mash & Johnston, 1990; Mandell, Novak & Zubritsky, 2005; Marcus et al., 2001; Schopler, 2005).

2.8. Resilience

The term 'resilience' stems from early psychiatric literature that studied children who appeared to be invulnerable to adverse life events (Earvolino-Ramirez, 2007). The terms 'invincible' and 'invulnerable' were used interchangeably in the early literature (Anthony, 1974). Walsh (2003) defined resilience as the ability to bounce back from adversities and cope successfully.

Early literature referred to resilience as a personality trait until in the recent studies where it has been redefined as a dynamic, modifiable process (Earvolino-Ramirez, 2007). Individuals respond to different circumstances differently. How an individual responds in one particular situation may not determine a similar response in a different situation. It is mentioned that resilient individuals have common characteristics called protective factors and these factors are attributes that are needed in order to allow the process of resilience to occur (Earvolino-Ramirez, 2007). Resilience is a process of going through the worst time and bringing out the best in an individual. Often, challenges have been seen to yield learning, transformation and yield an individual to a better life direction (Walsh, 2003).

Walsh (2006) extended the concept of resilience to family resilience. The premise of the framework was that families and couples also need strength and support in crisis situations. The concept of family resilience focused on shifting families from a point of being damaged towards

being challenged (Walsh, 2003). It is mentioned that while some families are discouraged by crisis or persistent stresses, others emerge strengthened and more resourceful (Walsh, 2003).

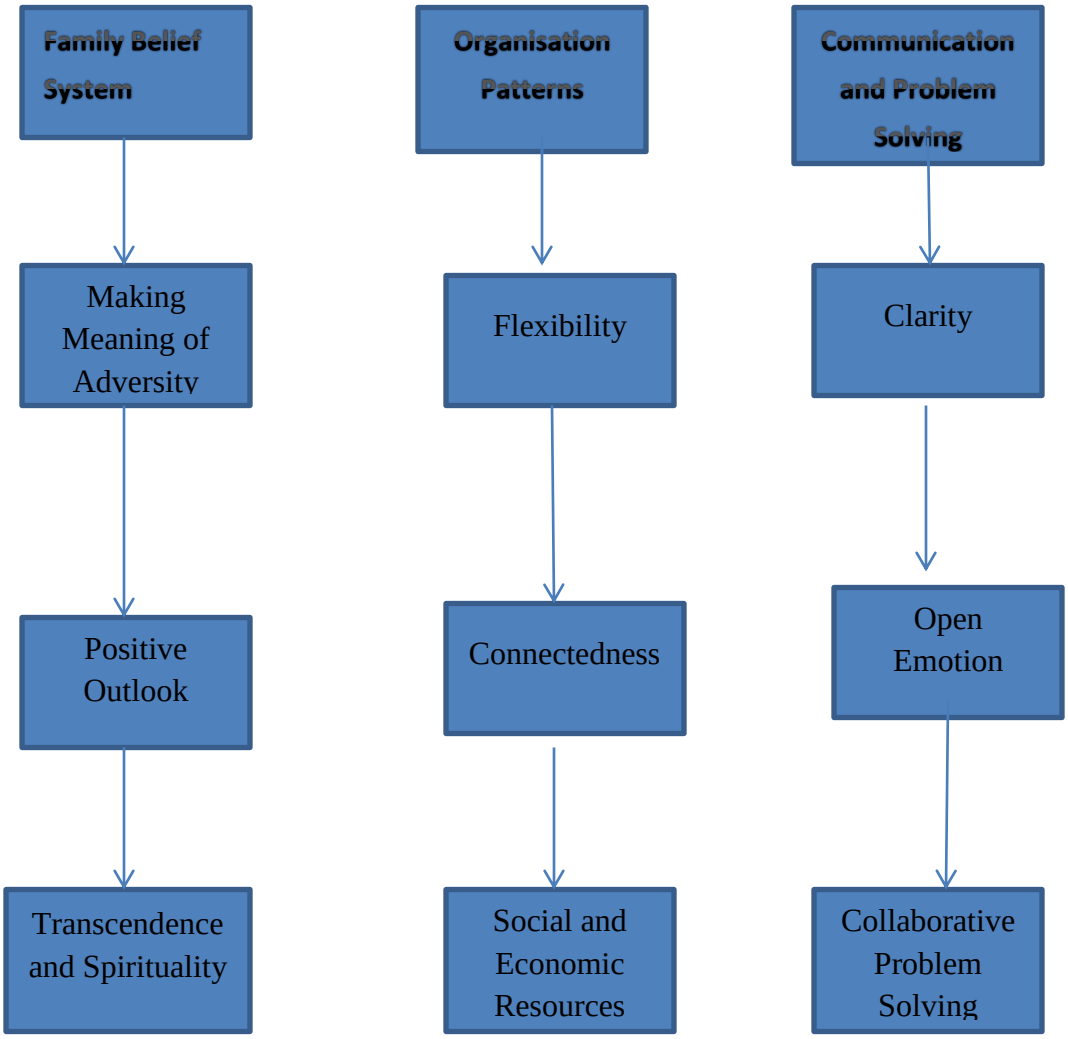
Families of children with ASD are faced with a variety of challenges. Despite these challenges a number of families have shown evidence of resilience (Bayat, 2007). Some families have become advocates of their children's condition. Such actions of advocacy are qualities and components that qualify an individual or family to be considered as resilient (Bayat, 2007).

2.8.1. Family Resilience Framework

The family resilience framework by Walsh (2003) was developed to assist families beyond managing stressful conditions but also in shouldering or surviving during periods of ordeals.

Parents of children with ASD come from all walks of life and they have different backgrounds and beliefs. Thus, a framework of resilience embraces these differences. It is grounded on a principle that there is no single model that fits all situations (Walsh, 2003). The framework further acknowledges that every family has potential to recover and grow out of adverse difficult situations (Walsh, 2003). This framework was developed through drawing findings from different research studies. It is divided into three different domains (family beliefs, organisation patterns and communication) as core pillars of the framework which will be discussed in detail below. There are a total of nine underlying sub-constructs to this theory.

Figure 2 ***Framework of Family Resilience by Walsh (2003)***



2.8.2. Family Belief System

The family's belief system shapes and influences how an event is approached. The family's view of reality and its socialisation organises family processes and approaches to crisis situations (Walsh 2003).

Making meaning of adversity: Some cultures apply an individualistic approach in problem solving and others a collective approach. Families who work collectively are able to better deal with challenges when compared to individualistic families. Research suggests that most families do better when they are helped to gain a sense of cohesion (Walsh, 2003).

Positive Outlook: Families who live in impoverished conditions may eventually lose hope about life in general. This despair robs them of meaning, purpose and a sense of future possibility (Walsh, 2003). Families who are hopeful have been found to deal better with family challenges and rise above them. Walsh mentioned that when challenges overwhelm families it is "essential to rekindle hopes and dreams in order to see possibilities, tap into potential resources and strive to overcome them" (Walsh, 2003, p 8).

Transcendence and Spirituality: An individual's faith, congregation affiliation, and religion have been found to be other sources of resilience. Religion and faith however are not the only sources where people find spiritual connection. Some people find spiritual connection through nature, music and art (Walsh, 2003). Beliefs, rituals and ceremonies provide strength, comfort, meaning and purpose to families who are undergoing challenging periods (Walsh, 2013).

2.8.3. Organisation Patterns

In order to deal with challenges, families need to adapt and organise themselves in different ways to deal with the demands of a crisis situation. This part discusses the family's flexible structure, connectedness and the social and economic situation of the family.

Flexibility: Becvar and Becvar (2000) defined flexibility as the capacity to change when necessary. The presence of a child with autism changes the face of the family. Families often need help in dealing with child's disorder and to construct a new family structure. Sixbey (2005) mentioned the importance of a stable and flexible family environment. Stability assists the family with continuity and dependability and all members in the family feel it. Stability provides predictability and consistency in family rules (Sixbey, 2005). Structure and stability could be achieved through applying authoritative leadership, and leadership style promotes flexibility (Becvaar & Becvaar, 2000; Sixbey, 2005). Thus, applying flexibility could assist families in bouncing back to the family's pre-existing state.

Connectedness: Togetherness and unity are necessary for families to deal with adverse life challenges. Having a crisis or a child with autism can shatter family cohesion if members are unable to turn to one another (Walsh, 2003). Families with resilience are able to harness affected family connections when faced with challenges. This reunion builds broken bonds and assists family members to deal with a crisis situation (Sixbey, 2005).

Social and economic resources: Family and community networks are important lifelines for families who are undergoing challenges. Families who are isolated could benefit from reconnecting with their communities and other family members in times of troubles (Walsh, 2003). Scarcity of resources such as economic strains may compound the adverse crisis. For an example a family may find costs associated with the child's therapy unattainable and thus worsen the crisis situation (Walsh, 2003).

2.8.4. Communication and Problem Solving

It is possible for parents of children with ASD to lack knowledge of the disorder before the child's diagnosis stage. Therefore communicating about the disorder may bring them closer to a problem solving stage. For this reason, family communication brings about clarity to a crisis during periods of despair (Walsh, 2003). Three components of communication and problem solving will be discussed below, namely clarity, open emotion and collaboration.

Clarity: Walsh (2003) discusses clarity as a means of sharing crucial information amongst family members. Clarity also assists in filling in missing information and clarifying hearsays on the topic being discussed. Families may also use clarity to share information about the crisis situation in the family for example a family facing a crisis of having a child with ASD may empower one another with information about what to expect in the future in order to make meaningful decisions about the child.

Open emotion: By sharing emotions families can deal with the challenge of having a child with ASD. For an example one parent may respond to the situation by using humour when others are saddened by the situation. It is important for families to control their emotions whenever there is a crisis in the family. Families should take caution during emotional periods because high emotions are likely to bring about conflicts in the family (Walsh, 2003).

Collaborative problem solving: Conflicts are common in all families. Solving problems is often not a simple process to most families. Effective families recognize that problems exist and work on better ways to solve them. Families that are resilient are able to involve one another and brainstorm on the potential ways they can approach problems (Sixbey, 2005). Family members negotiate possible decisions with fairness and accommodate one another. This helps them open new possibilities and shift from being in a crisis to a proactive position. Collaborative problem solving assists families in prioritizing and taking concrete steps towards achieving desired goals and also to learn from their own experiences (Walsh, 2003).

2.9. Socio-Economic Status

While previous studies have found no etiological associations between ASD and SES, there is however a growing body of knowledge which acknowledges that the family's SES may have a negative impact on the outcome of a child with ASD (Dawson, 2011; Mandel et al., 2005). SES indicators have an association with children's verbal skills and cognitive development (Bradley & Corwyn, 2002). A study by Greef and van Der Walt, (2010) on resilience in families of

children with ASD found that SES of families appeared to play a role in the family's adaptation. Middle SES families were found to adapt better in raising a child with ASD. The more resources people have the less likely they experience diseases since they have the ability to devote more of their resources to their health (King & Bearman, 2011). Thus other studies have found that higher SES families are able to cope better with a child with ASD when compared to lower SES families (Greef & van Der Walt, 2010). It is also important to emphasize that underprivileged families are unable to access diagnosis early and timeously (Dawson, 2011; Mandel et al., 2005). For example, public health facilities are difficult to navigate and the costs of private health care facilities are not easily accessible to all, especially to those affected by psychological and mental illnesses (Pretorius & Ahmed, 2001; Dawson, 2011). Such challenges in the South African context could have negative implications for children with ASD. About 50% of South Africans live in poverty and lack proper facilities in their communities (Dawson, 2011).

Also, a shortage of professionals in the psychiatry field may have negative outcomes in ASD in South Africa. According to Pillay and Lockhart (2001) South Africa provides one child psychiatrist to a population of 1 million children. Mandel et al., (2005, 2009) found that a parent's income and place of residence as well as pediatricians that the child has seen is associated with the age at which the child receives a diagnosis of ASD. Children from poor families and rural areas where there are limited health facilities have been found to receive diagnosis much later when compared to their counterparts (Mandel et al., 2005, 2009). One study found that children from rural areas received their diagnosis 0.4 months later when compared to children from urban areas and children from poor households received diagnosis 0.9 months later when compared to children from middle or upper income groups (Mandel et al., 2005, 2009). Such differences in SES pose challenges in parents as well as the development of a child.

Some studies have shown that parenting behaviour is not only influenced by SES, some parents show no difference in parenting even after taking into account SES (Emmen et al., 2013). Hasnain & Akter (2014) found that children with ASD were mostly common in low SES families, and only a small percentage of autistic children among these families attended school. A study by Smith (1999) observed that children with autism who receive early behavioural

intervention presented with improved cognition and adaptive behaviour. Lower SES parents may not be able to access these interventions due costs.

According to the family stress model (Conger & Donnella, 2007), economic pressures increase the risk of parental emotional distress which may lead to increased marital conflict and this process negatively affects parenting. This model states that when child rearing is threatened, it places the child's development in serious jeopardy (Conger & Donnella, 2007). Ataguba, Akazali and Mcintyre (2011) mention that the poor face many factors which are recognised as social determinants of ill health. This is the case also in South Africa, according to the National Health Insurance Green Paper, (2011) majority of South Africans do not have access to the available expensive health care systems. The problem of limited access to health care may impact negatively in the interventions, therapy and medication for children with autism from lower SES families.

The aim of this research study was to understand the role of resilience and SES in the parenting of children with ASD in South Africa. The literature has shown that there are many challenges in South Africa experienced by parents of children with ASD. The family's social status may have a negative impact in the development of a child with ASD. It was also mentioned in the literature that the costs of raising a child with ASD could be as high as 3 million rands. This amount incorporates therapy, education, special diets and other medical costs associated with ASD. These challenges escalate even beyond the household level to impact the country at large. The majority of South Africans do not have access to the health care system. There are limited professionals in the country specializing in the child psychiatry field. The daunting experience of waiting in long lines for a psychiatrist may be stressful to parents and children.

Most parents report that the child's behavior is the most salient stressor. Mothers tend to experience more parental challenges compared to fathers. This is likely because mothers are generally more involved in the child's daily experiences than fathers. The parent-child model by Mash and Johnston (1990), states that the parent, the child and the environment are factors related to parental stress. The parent's characteristics such as the parent's general health, the child's characteristics such as cognition and the environmental characteristics such as poverty all have an impact in parental stress. However some families are able to deal better with raising a

child with ASD than others. Walsh (2003) developed a framework which can be used to understand and assist families manage challenging situations such as raising a child with ASD. Family resilience framework is divided into family beliefs, organisation pattern and communication. The pillars of family resilience shape and influence how families approach challenges, adapt and organise themselves in dealing with challenges and how families communicate about the problem. Previous research in South Africa found that resilience may be a buffer in the parenting of children with ASD. More research is required to understand how parents of children with ASD particularly from lower SES stratum cope with daily parenting hassles.

It is mentioned in the literature parents of children with ASD are faced with challenges which are beyond normal care giving challenges (Davies & Carter, 2008).These parental daily hassles can be defined as strains and stresses accompanying child rearing, they become overwhelming to some parents and may lead to feelings of depression and anxiety (Rutgers et al., 2007). Apart from the burden of costs associated with raising a child with ASD parents are faced with issues of isolation and the acceptance of the child in the community which may also lead to frustration as well as feelings of anger in some parents (Rutgers et al., 2007). Thus family resilience may assist families in approaching parental stresses associated with rearing a child with ASD; in that it can assist families survive stressful conditions. Based on the framework of family resilience, families can be taught to approach challenging situations such as daily parenting stresses by drawing on the resources that they already have, such as the belief system of the family (Walsh, 2003). The framework further stated that families could benefit from other members of the community by forming networks and reconnecting with other family members during times of crisis. Finally the family resilience network states that how families approach problems could be another way of reducing challenges. Thus collaborations in problem solving situation may assist open new ways of thinking and better approaches towards challenges (Walsh, 2003).

CHAPTER 3

METHODS

3. Introduction

This chapter discusses the methods employed in this study. It discusses the research approach and design employed. Further to this, the chapter discusses the sampling techniques of the study. This section also discusses the measures used and the procedure followed to collect and analyse data in the study.

3.1. Research Design

The study employed a quantitative approach. This approach was used to examine the relationship between resilience, SES and parenting daily hassles in the parenting of autistic children. A cross sectional survey design was applied. A cross sectional design collects data about a particular population of interest. In the current study parents of children with ASD were studied (Neuman, 2011). Data was collected by means of questionnaires from a sample of parents with children diagnosed with ASD in three South African cities i.e. Gauteng, Pretoria and Durban.

3.2. Sampling

A non-probability purposive sampling technique was adopted to create a representative sample. In order to locate a specific population (parents of children with ASD) a purposive sample was applied and thereafter a snowball sampling was adopted. Due to the limited number of diagnosed cases of autism in South Africa which are closely related with the shortage of professionals who are qualified to diagnose the disorder, a snowball sampling was adopted (Pillay & Lockhart, 2001; Mandel et al., 2005). Three cities, in two different provinces were identified for the sampling of the study i.e. Johannesburg, Pretoria and Durban. The cities were identified in terms of accessibility for the researcher and also that they were well developed in terms of schooling

facilities and availability of practitioners who were qualified to diagnose ASD. Participants were referred to the researcher by other participating parents or organisations. Whilst autism is not a new phenomenon, it is however still not clearly understood in some communities and thus it is probable that a limited amount of diagnosed cases have been reported in low SES families.

Approximately 300 questionnaires were distributed to organisations, hospitals and schools. The study sampled 102 parents from the respective selected research centres. The sample included 18 males and 84 females. There were 4 schools, 2 hospitals and 1 not for profit organisation approached to request access to conduct research. In total there were 7 sites namely: - Unica School (n=12), The Key school (n= 7), Action in Autism (n=32), Johannesburg Hospital School (n=21), Browns School (n= 18) and Chris Hani Baragwanath Hospital (n=12). The total sample was (n=102).

The schools, hospitals organisations were identified due to specialisation in children with ASD. Due to low numbers of questionnaires returned, principals were approached to redistribute questionnaires during parents' meetings and school functions where parents were present. Criteria for inclusion were: nuclear families that included a mother and father, two mothers or two fathers. About 26 questionnaires were received from Chris Hani Baragwanath Hospital and Browns school. This number was not sufficient for a study to be conducted thus the criteria was extended to include single parents of children with ASD.

3.3 Demographic

Table 1 ***Demographic Information***

Variable	N	Percentage %	Mean	Mode	Standard Deviation
Parent Age	102 (22-64 years)		39.01	35	7.56
Child Age	102 (1-18 years)		7.68	5	3.64
Race					
Black	81	80	-		-
White	12	12			
Indian	6	6	-		-
Coloured	3	3	-		-
M Status					
Married	54	53	-		-
Single	35	34	-		-
Widowed	3	3	-		-
Separated/Divorced	5	5	-		-
Living with partner	5	5	-		-
Gender					
Male	18	18	-		-
Female	84	82	-		-

Participant's demographic information is presented according to the participant's age, race, marital status and gender (see table 1). There were 102 parents who participated and the mean age was 39.01 and standard deviation of 7.56. Over half participants (53%) were married and 5% indicated that they were living with partners. The female gender was predominant in the sample (82.4%) and male gender was (18%).

3.4. Measures

The following measures were used to collect data:

Independent variables were Family Resilience Assessment Scale (FRAS) and the Hollingshead Two Factor Index (SES). Dependant variables were measured using parental Daily Hassle Scale (Frequency and Intensity Scale). All questionnaires were available in English.

3.4.1. Family Resilience Assessment Scale (FRAS)

The Family Resilience Assessment Scale (FRAS) was developed by Sixbey in 2005 to measure the degree of resilience that a family exhibits. This scale is based on Walsh's (2003) Family Resilience Model. The scale has a cronbach alpha of $\alpha = 0.96$ as reported by Sixbey (2005). A study on parental stress in families of children with ASD found a strong negative correlation between FRAS, parental stress and parental distress (Plumb, 2011). This suggests that as family resilience increases, parental stress and distress decreases. This scale meets the criteria to be used in this study since it has been previously used in parents of children with ASD (Plumb, 2011).

The scale has 66 items and one open ended question. For this current study the open ended question was not used. The scale uses a 4-point Likert scale; from strongly agree to strongly disagree. A higher score indicates higher level of resilience and a low score indicates low level of resilience. Internal reliability found for the total FRAS in the current study was $\propto = 0.95$.

The FRAS has six subscales namely:

(1) Family Communication and Problem Solving (FCPS), Internal reliability for the subscale found in this study was $\alpha = 0.95$

(2) Utilizing Social and Economic Resources (USER). Internal reliability for this subscale for the study was $\alpha = 0.76$.

(3) Maintaining a Positive Outlook (MPO scale), internal reliability for this sub scale in this study was $\alpha = 0.77$.

(4) Family Connectedness (FCON). The scale has 6 items, and 4 items are reversed with a range of 18-12. Internal Reliability for this sub scale for this study was $\alpha = 0.46$. FCON scale had a low reliability rate and this may be based on the reversed items in this scale. Other studies have reported a low reliability in this scale, this may attributed to the reversed items in the scales (Plumb, 2011; Sixbey, 2005).

(5) Family Spirituality (FSPI), internal reliability found for this sub scale in this study was $\alpha = 0.82$.

(6) Ability to Make Meaning of Adversity (AMMA), internal reliability for this subscale in this study was $\alpha = 0.62$).

The scale has an American version with a cronbach alpha of 0.96 (Sixbey, 2005) and a Turkish version with Cronbach alpha of 0.92 (Kaya & Arici, 2012). A correlation coefficient of the two versions was found to be 0.99 (Kaya & Arici, 2012). The researcher has not come across any South African study that has used the scale but it has been used in international studies (Buchanan, 2008; Openshaw, 2011; Plumb, 2011). Plumb (2001) found a Cronbach alpha of 0.76 in a study measuring the impact of social support and family resilience on parental stress in families of children diagnosed with ASD.

The FRAS scale has good validity as tested by Family Assessment Device 1 with Cronbach 0.91, Family Assessment Device 2 with Cronbach 0.85 and Personal Meaning Index with Cronbach 0.85 (Sixbey, 2005). Family assessment device is based on McMaster's Model of Family Functioning (Epstein, Baldwin & Bishop, 2007). The FDA is used to screen family functioning and to describe the structure, organisational properties and the patterns of transactions among family members (1983). The Personal Meaning Index (PMI) is a 16 item measure which was developed to measure the existential belief that life is meaningful (Reker, 2005).

3.4.2. Parenting Daily Hassles (PDH)

The 20-item Parenting Daily Hassles (PDH) measure has items that are related to child behaviours and parenting tasks that can be demanding or challenging for parents (Crnic & Greeberrg, 1990). The items on the scale represent the typical hassles that may occur on a normal parenting day (Almand, 2002). According to Gerstein et al. (2009) the findings of the (PDH) revealed that, the degree and the level to which daily parenting stress is experienced differs significantly from mothers as compared to fathers over time. The researcher has not come across any South African study that has used the scale but it has been used in non-American samples such as Taiwan and reliability was found to be 0.86 (Chen & Luster, 2002).

This scale has two, separate Likert scales. The first scale measured the frequency of parenting hassles and the second scale measure the intensity of parenting hassles (Crnic & Greenberg, 1990). Rutgers et al. (2007) studied attachment of parents and children with ASD, nonclinical and mental retardation, a cronbach of $\alpha = 0.86$ was found. The two scales are highly correlated, r = 0.78 (Crnic & Greenberg, 1990).

The frequency scale uses a 4 point Likert scale from 1- never to 4- constantly, a high score indicates more consistently occurring hassles. Reliability of the frequency scale has been found to be 0.81 (Crnic & Greenberg, 1990). Internal reliability found for the parental daily hassle frequency scale for the current study was $\alpha = 0.91$.

The Intensity scale uses a 5 point Likert scale from 1- low to- 5 high, a higher score indicates more intense hassles. Items on the scale include (1) ‘continually clearing up messes of toys or food’ and (13) ‘having to change your plans because of an unpredicted child need’. Reliability of the intensity scale has been found to be Cronbach $\alpha = 0.91$ (Crnic & Greenberg, 1990). Internal reliability found for the parental daily hassles scales for the current study was $\alpha = 0.90$

3.4.3. Demographical Information: The Hollingshead Two Factor Index (1975)

Participants were asked to complete a demographic questionnaire for the purpose of obtaining biographical data. The questionnaire was designed according to the Hollingshead Two Factor Index based on education and occupation of the breadwinner in the household.

The demographical information include the following information: age of parent, age of child, length of time since diagnosis, occupation, education level, sex, race, home language, marital status. According to the Hollingshead index, occupation has 7 categories from 1- higher executive to 7- unskilled labourers. Education also has 7 categories from 1- less than 7^{th} grade to 7- university graduate professional.

The score on occupation is multiplied by 7 and the score on education is multiplied by 4. The two scores are added together and a higher score signifies an index of lower social position. The Hollingshead factor index has been chosen for this study for two reasons, namely; (1) It is less challenging to complete and (2) it uses the parent's level of education which is a predictor of the child's development (Southwood, 2010). Participants were categorised in three SES groups namely higher SES (34-40), medium SES (41-55), lower SES (55-66).

This index was developed in America however several South African studies have used the index and found it to be a relevant measure of SES in the South African context (Barbarin, 1999; Gonasillan, Bornman & Harty, 2013). Barbarin and Ritcher (1999) reported a correlation between the Household Economic Social Status Index (HESSI) which is a South African developed measure of social index and the Hollingshead Index.

3.5. Procedure

Upon receipt of ethical clearance from the medical research office, permitting the study to commence, research questionnaires were distributed to the respective schools, hospitals and organisations participating in the study. The research pack consisted of a consent form,

information sheet, ethical clearance and survey questionnaires. The research pack was sent via the school to interested participating parents. The researcher visited the schools bi-weekly to determine if any surveys had been returned. Chris Hani Baragwanath Hospital was visited once a month over 2 months as per the hospitals scheduled group meetings for parents of children with ASD. At Chris Hani Baragwanath research questionnaires were completed on site. Thus, anonymity could not be guaranteed to participants because some participants were assisted by the researcher to complete the questionnaires.

There was a low return response from participants and majority of parents did not complete the questionnaires. Permission to join weekly parental meetings was granted by the school principal to the researcher to continue with the distribution of questionnaires. After reaching the targeted sample of at least 100 questionnaires the data collection process ended and the process of cleaning the data commenced.

3.6. Data Analysis

In order to analyse the data all responses from the survey questionnaires were transferred and entered on an excel file. After this process was completed all the information from the excel file was transferred to Statistical Package for Social Scientists (SPSS) system for analysis. Some participants did not complete some items on the questionnaire and there were missing data. A list wise deletion approach was adopted for missing data.

An independent samples t- test was conducted to test differences in parents daily hassle scores between a group of mothers and fathers. Independent samples t- tests were conducted in order to test for mean differences between two different groups of participants (Pallant, 2013).

In order to determine if a relationship existed between variables a correlation matrix was conducted on all variables. Correlation analyses were conducted to describe the strength and direction of a linear relationship between variables (Pallant, 2013).

Finally a stepwise regression analysis was conducted in order to find predictors of parental daily hassles in the parenting of children with ASD. A stepwise regression is an analysis conducted by entering a list of variable and allowing the software to select which variable it will enter and in which particular order (Pallant, 2013). In this study a stepwise regression was conducted in order to determine if SES moderated the relationship between resilience and parental daily hassles. Variables entered in the model were SES, Resilience, and dependent variables Parental Daily Hassles.

3.7 Ethical Considerations

This study had multiple ethical considerations. Firstly, permission was obtained from the University of the Witwatersrand (Medical Ethics Committee) prior to commencement of the study. Secondly, permission to conduct the study was obtained from the participating schools. Because some schools participating in the study are registered under the Gauteng Department of Education, permission to access the schools and to conduct the study was also requested from the relevant department. Permission to conduct research at Action in Autism was requested from the chairperson of the board. Finally, permission to conduct research at the Chris Hani Baragwanath Hospital was requested from the University of the Witwatersrand medical ethics committee and the Hospital's CEO.

Participants were asked to read the information sheet with details of the study. After reading the information sheet, those interested in participating were asked to complete the informed consent. It was communicated to the participants that neither they nor their children will benefit directly from the study. Participants were also informed that they retained the right to withdraw from the study at any particular moment without being prejudiced.

Participants were however guaranteed confidentiality. A code name was allocated to each participant for example (#01, #02 etc.) to ensure confidentiality. All information pertaining to the study was kept in a locked cabinet. The information pertaining to the study is kept for a period of three years, after this period all information will be destroyed. Participants, schools and

organisations were informed that the researcher may provide a concise summary of the finding on request. Schools, organisations and hospitals which requested that the findings of the study be made available to them will be provided with a summary of the study. However, no participants thus far have asked for the findings of the study.

Parents of children with ASD are faced with unique challenges and some studies have mentioned anxiety and distress in the parenting of such children (Davis & Carter, 2008; Hastings, 2003). Thus, the researcher also acknowledged that participating in such a study may evoke distress for parents exercise to parents. Prior referral arrangements were made with Emthonjeni Centre located at the University of the Witwatersrand to refer parents who may experience emotional distress during the process of completing questionnaires at a minimal cost.

3.8 Reflexivity

For some researchers the process of reflexivity may only be seen as significant to a qualitative approach of research. As a result many quantitative researchers avoid or still do not see the relevance of including a reflection section in their studies (Ryan & Golden, 2006). However, there are many advantages that are produced by the practice of reflexivity, such as good research outcomes and also enhancement and growth in favor of the researcher (Lamb & Huttlinger, 1989). As a parent of a child with ASD, I felt it necessary to include this section. I have also chosen to include this section in this study based on the following statement by Guillemin and Gillam, (2004).

> "Our research interests and the research questions we pose, as well as the questions we discard, reveal something about who we are" (p 274)

Throughout the process of this study I have engaged with this statement because the questions I have encountered during fieldwork whilst collecting data for this study. I was asked by the majority of participants "why did I choose to conduct a study of this nature"? In the initial stages of my interaction with participants I found the question difficult and opted to avoid answering it. Coming across such questions opened up a new way of thinking for me as a researcher. I started

pondering upon how was I to approach such question. I soon realized that the question was unavoidable. My role as a researcher was to find knowledge not to influence it. I needed to step back and look at my role as a researcher and find ways better approach to the question. As I could not divulge that I am a parent of a child with ASD I answered the question as follows “this topic is very important to me and I am researching it in order to produce as much knowledge as I can around the topic in order to contribute to a body of knowledge that exists”.

One important aspect that I was interested in was to understand how parents from disadvantaged backgrounds coped with the costs associated with raising a child with ASD. I have personally experienced the daunting process of consulting different specialists without obtaining a diagnosis for my boy. After a lot of expenses on therapies I felt the need to understand how a parent who was less privileged would cope in raising a child with ASD. Most of all, I needed to understand how the child’s development might be affected due to limited financial resources in the household.

Through conducting this study I have gained immense knowledge and information on the topic of ASD in the South African context. The first discovery was that the South African government has created special grants for children and parents who were less privileged. Parents may only access these grants in two different formats. Firstly, parents may access funding support from the South African Government upon obtaining an ASD diagnosis of the child. Secondly, if the parent was not employed and was personally looking after a child diagnosed with ASD, they may be eligible to apply for financial assistance. Through these grants, parents who were less advantaged may be able to cater for the needs of their children.

The second discovery was that, the South African government has opened schools that will cater specifically for the educational needs of children diagnosed with ASD. However, there are too few schools available for the children who have been diagnosed. For example a school that I engaged with in Johannesburg (Johannesburg General Hospital School) had a long waiting list of parents who needed a place for the schooling of their children. More research is needed to understand the fate of those children not yet diagnosed.

As a final comment, embarking on a personal topic is an emotional process. There were moments in the field where I felt overwhelmed with emotions. These emotions were aroused by

parents who were misinformed, lacked knowledge and sometimes who were frustrated by the process of trying to gain services or even obtaining a child's diagnosis. Some of the struggles that these parents were experiencing were struggles that I personally related with and experienced. Most of these parents' were very keen to take part in the study with a hope that they may find answers or information to ease their frustration. The disappointment in their faces was obvious when informed that this was a research study that may not benefit them directly but conducted for the purpose of finding new knowledge and contributing to the body of knowledge that exists in the topic of parental daily hassles in raising a child with ASD.

CHAPTER 4

RESULTS

4.1 Introduction

This chapter presents the results of the research study on the role of resilience and SES in the parenting of children with ASD in South Africa. In order to answer the first research question i.e. is there a difference between parental daily hassles of mothers and fathers? An independent samples t-test was conducted. The second research question asked i. e. Is there a relationship that exists between the variables of interest, parental daily hassles (Intensity and Frequency), family resilience and SES? A correlation analysis was conducted. The third research was i.e. what is the best predictor of Parental Daily Hassles (Intensity and Frequency) in the parenting of children with ASD? A multiple regression analysis was conducted. A stepwise regression analysis was conducted as a final analysis to answer the following question: - What moderation effect does SES have on the relationship between resilience and parental daily hassles (Frequency and Intensity) in determining the moderating effect of SES between Resilience and Parental Daly Hassles.

In Table 2 below the various descriptive statistics are presented for both the independent and dependent scales of the measure. For both the dependent variables majority of the sample had responded on these scales. For the PDHF scale the mean score was 44.00 (n = 70, SD = 12.10), while the mean score for the PDHI was 48.44 (n = 68, SD = 16.07). The range for the PDHI was larger than that of the PDHF by 11 points. On the independent scales the highest response rate was observed on the SES *(*n = 102, M = 50.87, SD = 9.28), and the lowest was on the FRAS (n=64). The highest range was observed on the FRAS of 81 points and a large variance as depicted by the standard deviation of 19.98 (n = 64, M = 126.95, SD = 19.98) and the lowest range was observed on the AMMA scale of 5 points (n = 100, M = 4.97, SD = 1.35). FCPS (n = 78, M = 48.85, SD = 10.89), USER (n = 89, M = 18.96, SD = 3.68), MPO (n = 96, M = 10.60, SD = 2.36), FSPI (n = 94, M = 8.04, SD = 2.64).

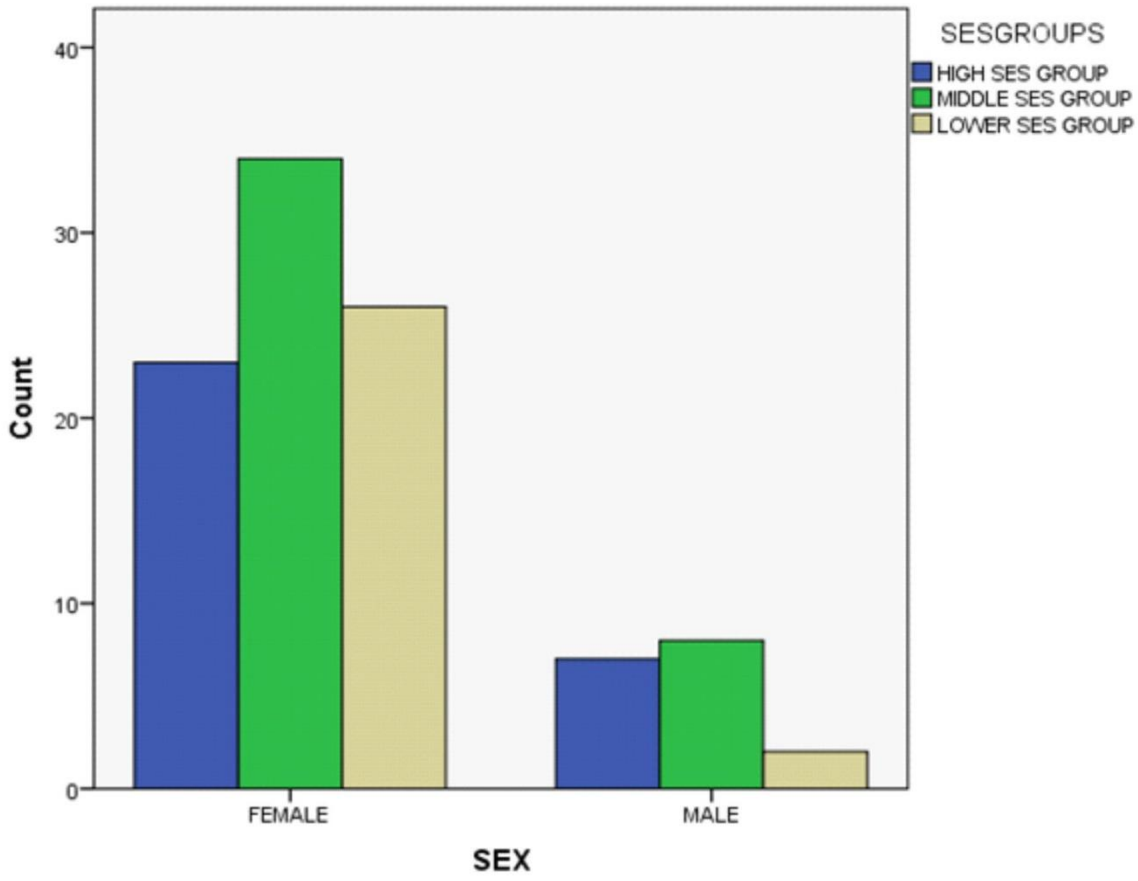
Descriptive Table of Variables

Variables	N	Min	Max	Mean	Std Dev
PDHF	70	20	71	44.00	12.10
PDHI	68	20	82	48.44	16.07
FCPS	78	27	83	48.85	10.89
USER	89	8	28	18.96	3.68
MPO	96	6	15	10.60	2.36
FCON	93	7	19	12.91	2.23
FSPI	94	4	16	8.04	2.64
AMMA	100	3	8	4.97	1.35
RFAMILYRESILIENCE	64	82	163	126.95	19.98
SOCIO-ECONOMIC STATUS	102	34	66	50.87	9.282

Table 2: **Descriptive Table of Variables**

Figure 3 below illustrates that the majority of female participants were from lower SES families when compared to male participants. Participants who scored (55-66) were grouped in lower SES, participants scoring 41-55 were grouped in the middle SES group and a score from 34-40 was the higher SES group. About 31% of females in this study reported a lower SES status when compared to 11.8% male participants. In addition, the majority of male participants were from higher SES families when compared to 27.7% female participants. About 41% of female participants reported they were from middle-income families compared to 47.1% males who reported that they were from middle income SES families.

Figure 3 ***Socio-Economic Status and Sex of Parent***



Respondents varied in their marital statuses, figure 4 below illustrates that the majority of parents in the study were married and about 80% were from high SES group. About 3% of single parents were in the high SES group and only 1 % of parents who reported that they were separated or divorced were in the higher SES group.

In the group that reported that they were living with partners, 13% was in the high SES group. Of the parents who reported that they lost their spouses, about 7.1% of them were in the middle SES category.

Figure 4 ***Socio-Economic Status and Marital Status***

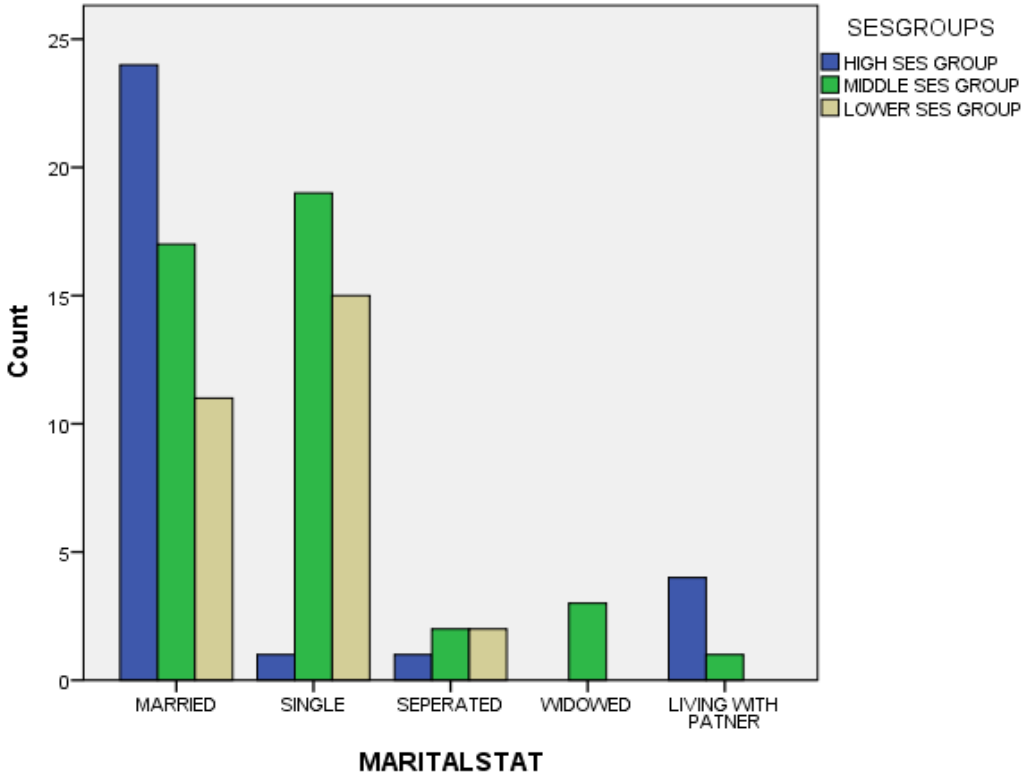


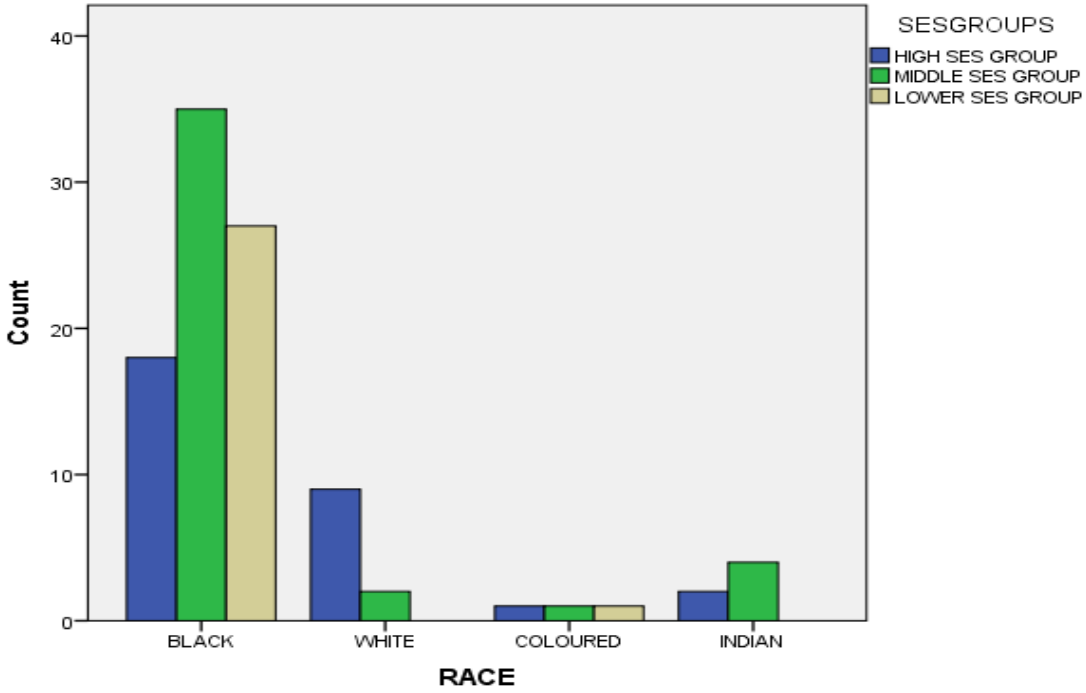
Figure 5 below represents a comparison of race and SES of parents with ASD in the current study.

The majority of black participants in this study were in the middle category of SES. Participants from white families were majority in the higher SES category.

The coloured group[1] was equally spread in all SES categories. Indian participants were mostly represented in the middle SES category.

[1] The term coloured stems from the previous South African apartheid government meaning people of mixed ancestry (Christopher, 2001)

Figure 5 ***Socio- Economic Status by Race***



4.2 Research Question 1 – Independent Samples T- Test

The first research question asked whether there a difference between parental daily hassles (frequency and intensity) of female and male participants?

To answer question 1, an Independent Samples T- Test was conducted. The following assumptions for conducting a t-test were considered. The dependent variable in this study was Parental Daily Hassles (Frequency and Intensity) and it was measured at an interval level. The homogeneity of variance as presented by the Levene's test was assumed $p = 0.063$ (see table 3). The Levene's test makes an assumption that the sample was obtained from a population of equal variance (Pallant, 2013).

A t- test analysis revealed that there were significant differences in the scores of males and females. A comparison of PDHF scores of fathers (M= 36.714; SD= 8.39) and mothers (M= 45.821; SD=12.25), t (68) = 2.623, p = 0.011 as indicated by the independent t-test is higher in

mothers than fathers. The magnitude of the differences in means was large (mean difference = 9.107, *CI*: 2.178-16.035) and the effects size was (d = 0.867).

A comparison of PDHI scores of mothers and fathers was also analyzed. These scores illustrated differences between mothers and fathers in the levels of parental intensity in the parenting of children with ASD. There was a significant difference in the scores of females (M= 51.33; SD= 15.76) and males (M=38.20; SD=13.00), t (66) = 2.952, p = 0.004 (see table 3). Mothers had higher scores when compared to fathers. The magnitude of the differences in means was large (mean difference = 13.1396, *CI*: 4.25-22.027) and the effect size was large (d = 0.908).

Table 3 ***Comparison of Male and Female Participants***

Variable	Variance	F	SIG	t	df	SIG(2-t)	M Diff	CI L	CI U
PDHF	**ASSUMED**	**3.569**	**.063**	**2.623**	**68**	**.011**	**9.10714**	**2.17882**	**16.03547**
	NOT ASSUMED			**3.278**	**28.617**	**.003**	**9.10714**	**3.42087**	**14.79341**
PDHI	**ASSUMED**	**1.891**	**.174**	**2.952**	**66**	**.004**	**13.1396**	**4.25191**	**22.02734**
	NOT ASSUMED			**3.289**	**26.826**	**.003**	**13.1396**	**4.94061**	**21.33864**

4.3 Research Question 2 - Correlation Analysis

The second question asked whether there is a relationship between parental daily hassles (Frequency and Intensity), resilience and SES.

In order to answer question 2, a Pearson's product moment correlation was conducted to understand the relationship between Parental Daily Hassles (Frequency and Intensity), Resilience and SES. Based on a scatter plot line, linearity between variables of interest was observed.

A Pearson's *r* correlation analysis was computed to assess the relationship between Parental Daily Hassles Frequency, Parental Daily Hassles Intensity, Family Resilience Total Scale, Family Communication and Problem Solving, Utilizing Social and Economic Resources, Maintaining a Positive Outlook, Family Spirituality, and Ability to Make Meaning of Adversities.

A positive relationship between SES and family connectedness was observed $r = 0.323$, this relationship was statistically significant $p = 0.001$. Other correlations were below 0.3, however some of the variables reached statistical significance. There was a positive relationship between Parental Daily Hassles Intensity and Family Resilience, $r = 0.185$, n= 50, $p > 0.05$. A relationship between Parental Daily Hassles Frequency and Family Resilience revealed a positive relationship between these variables, $r = 0.081$, n= 51, $p > 0.05$. Parental Daily Hassle and Family Connectedness showed a positive weak relationship of, $r = 0.203$, n = 68, $p > 0.05$ (see table 4 below). Parental Daily Hassles showed a positive correlation with SES $r = 0.072$ and parental daily hassles Intensity $r = 0.16$. There was a negative relationship between FSPI and SES $r = -0.217$, $p = 0.005$. This relationship suggests that if family spirituality increases then the SES of the household will decrease and vice versa. Another weak negative relationship was observed between FSPI and PDHI $r = -0.012$.This particular relationship suggests that if family spirituality reduces then parental daily stress (Intensity) will increase and vice versa.

Table 4 ***Correlation Matrix***

VARIABLES	FRAS	FCPS	USER	MPO	FCON	FSPI	AMMA	SES	PDHF	PDHI
FRAS	**1**	**.960****	**.642****	**.831****	**0.149**	**.449****	**.735****	**-0.031**	**0.081**	**0.185**
FCPS	**.960****	**1**	**.462****	**.824****	**0.168**	**0.18**	**.700****	**-0.042**	**0.087**	**0.17**
USER	**.642****	**.462****	**1**	**.341****	**-0.046**	**.303****	**0.205**	**-.273***	**0.121**	**0.125**
MPO	**.831****	**.824****	**.341****	**1**	**0.106**	**.245***	**.622****	**-0.085**	**0.1**	**0.163**
FCON	**0.149**	**0.168**	**-0.046**	**0.106**	**1**	**-0.121**	**0.159**	**.323****	**0.203**	**0.16**
FSPI	**.449****	**0.18**	**.303****	**.245***	**-0.121**	**1**	**.213***	**-.217***	**0.013**	**-0.012**
AMMA	**.735****	**.700****	**0.205**	**.622****	**0.159**	**.213***	**1**	**0.058**	**0.028**	**0.067**
SES	**-0.031**	**-0.042**	**-.273***	**-0.085**	**.323****	**-.217***	**0.058**	**1**	**0.072**	**0.16**
PDHF	**0.081**	**0.087**	**0.121**	**0.1**	**0.203**	**0.013**	**0.028**	**0.072**	**1**	**.928****
PDHI	**0.185**	**0.17**	**0.125**	**0.163**	**0.16**	**-0.012**	**0.067**	**0.16**	**.928****	**1**

** Sig 0.001

* Sig 0.005

Family Resilience (FRAS) , Family Communication and Problem Solving (FCPS), Utilizing Social and Economic Resources (USER), Maintaining a Positive Outlook Subscale (MPO), Family Spirituality (FSPI), Ability to Make Meaning of Adversity (AMMA), , Parental Daily Hassles Frequency (PDHF), Parental Daily Hassle Intensity (PDHI) and SES.

4.4 Research Question 3 – Regression Analysis

The third question asked, what was the best predictor of parental daily hassles (Frequency and Intensity)?

In order to answer this question a standard regression analysis was conducted (See table 5 and 6). The variables of interest were Family Resilience, SES and Parental Daily Hassle. According to Stevens (1996), about 15 participants are required in social science research per predictor for a reliable equation. In this study there were 102 participants and 8 variables of interest therefore the sample for this study was adequate to conduct multiple regression.

In the following tables (5, 6) and tables (7, 8) below two multiple regression analysis are shown. The following variables were entered in the equation (Family Resilience, Family Communication and Problem Solving, Utilising Social and Economic Resources, Maintaining a Positive Outlook, Family Connectedness, Family Spirituality, Ability to Make Meaning and Adversity, Child Age, Sex, Race, Marital Status and SES) to predict Parental Daily hassles (Intensity and Frequency), preliminary analysis was conducted to ensure that the sample size was not violated.

Table 5 ***Standard Regression PDHF***

Model		Unstandardised (B)	Standardised (B)	t	Sig	CI-low	CI-upper
1	(Constant)	37.722		2.080	.045	.973	74.471
	FRAS	-.661	-.990	-.760	.452	-2.423	1.101
	FCPSSUBSCALE	.609	.486	.537	.595	-1.689	2.906
	USERUBSCALE	1.414	.360	1.044	.303	-1.330	4.159
	MPOSUBSCALE	1.924	.382	1.306	.200	-1.061	4.910
	FCONSUBSCALE	2.022	.365	1.862	.071	-.179	4.223
	FSPISUBSCALE	.986	.176	.740	.464	-1.714	3.687
	AMMASUBSCALE	-1.210	-.121	-.451	.655	-6.649	4.228
	CHILD AGE	-.417	-.123	-.847	.402	-1.414	.580
	SEX	-12.615	-.399	-2.688	.011	-22.124	-3.107
	RACE	3.070	.239	1.414	.166	-1.329	7.469
	MARITALSTAT	-1.823	-.154	-1.114	.272	-5.138	1.492
	SESGROUPS	1.555	.094	.597	.554	-3.725	6.836

Family Resilience (FRAS) , Family Communication and Problem Solving (FCPS), Utilizing Social and Economic Resources (USER), Maintaining a Positive Outlook Subscale (MPO), Family Spirituality (FSPI), Ability to Make Meaning of Adversity (AMMA), , Parental Daily Hassles Frequency (PDHF), Parental Daily Hassle Intensity (PDHI) and SES.

In the first model, predicting Parental Daily Hassles (frequency) as shown in (table 5 and 6). The total variance explained by the model was 39.5%, F (12, 37) = 2.015, p = 0.051. The model was not significant however the sex of the parent showed statistical significance (*beta* = -0.399, p = 0.011) (see table 5).

Table 6 ***Standard Regression PDHF***

MODEL	DESCRIPTION	R SQUARE	SUM OF SQUARE	DF	MEAN SQUARE	F	SIG
1	REGRESSION	0.395	3160.348	12	263.362	2.015	0.051
	RESIDUAL		4835.572	37	130.691		
	TOTAL		7995.920	49			

4.4.2 Standard Multiple Regression PDHI

Table 7 ***Standard Regression PDHI***

		UNSTANDARDISED	STANDARDISED			95.0% CI	
	MODEL	**B**	**B**	**T**	**SIG**	**CI-LOW**	**CI-UP**
1	**(Constant)**	**31.747**		**1.362**	**.182**	**-15.543**	**79.037**
	FRAS	**-1.132**	**-1.325**	**-1.008**	**.320**	**-3.411**	**1.147**
	FCPSSUBSCALE	**1.152**	**.717**	**.807**	**.425**	**-1.745**	**4.049**
	USERUBSCALE	**2.443**	**.527**	**1.420**	**.164**	**-1.045**	**5.932**
	MPOSUBSCALE	**2.933**	**.450**	**1.550**	**.130**	**-.906**	**6.773**
	FCONSUBSCALE	**2.596**	**.385**	**1.866**	**.070**	**-.226**	**5.418**
	FSPISUBSCALE	**1.788**	**.251**	**1.041**	**.305**	**-1.694**	**5.271**
	AMMASUBSCALE	**-.745**	**-.058**	**-.249**	**.805**	**-6.825**	**5.334**
	CHILD AGE	**-.462**	**-.106**	**-.737**	**.466**	**-1.734**	**.809**
	SEX	**-14.541**	**-.355**	**-2.429**	**.020**	**-26.683**	**-2.399**
	RACE	**1.105**	**.066**	**.409**	**.685**	**-4.373**	**6.582**
	MARITALSTAT	**-3.126**	**-.194**	**-1.375**	**.178**	**-7.737**	**1.485**
	SESGROUPS	**4.786**	**.223**	**1.402**	**.170**	**-2.139**	**11.712**

Family Resilience (FRAS) , Family Communication and Problem Solving (FCPS), Utilizing Social and Economic Resources (USER), Maintaining a Positive Outlook Subscale (MPO), Family Spirituality (FSPI), Ability to Make Meaning of Adversity (AMMA), , Parental Daily Hassles Frequency (PDHF), Parental Daily Hassle Intensity (PDHI) and SES.

In the second model predicting Parental Daily Hassles Scale (PDHI), the total variance explained by the model was 39.9% F (12, 36) = 1.988, p = 0.56. In this model also, sex was statistically significant (*beta* = -0.355, p =0.20).

Table 8 ***Standard Regression PDHI***

MODEL	DESCRIPTION	R SQUARE	SUM OF SQUARE	DF	MEAN SQUARE	F	SIG
1	**REGRESSION**	**0.399**	**5327.66**	**12**	**443.972**	**1.988**	**0.056**
	RESIDUAL		**8040.175**	**36**	**223.338**		
	TOTAL		**13367.832**	**48**			

A multiple regression did not reveal significance in both (Intensity and Frequency). As a result, a stepwise regression analysis was conducted to understand the contribution of each variable in Parental Daily Hassles (Intensity and Frequency). Table 9 lists all the model predicting Parental Daily Hassles (Intensity) and table 10 lists the models predicting (Frequency). In a stepwise regression a list of variables are provided, in this study the following variables were entered in the equation (Family Resilience, Family Communication and Problem Solving, Utilising Social and Economic Resources, Maintaining a Positive Outlook, Family Connectedness, Family Spirituality, Ability to Make Meaning and Adversity, Child Age, Sex, Race, Marital Status and SES) to predict Parental Daily hassles (Intensity and Frequency).

4.5.1 Stepwise Regression PDHI

Table 9 ***Stepwise Regression PDHI***

MODEL		DF	MEAN SQUARE	F	SIG
1	Regression	12	443.972	1.988	.056[b]
	Residual	36	223.338		
	Total	48			
2	Regression	11	483.078	2.219	.035[c]
	Residual	37	217.675		
	Total	48			
3	Regression	10	528.059	2.481	.021[d]
	Residual	38	212.822		
	Total	48			
4	Regression	9	570.356	2.701	.015[e]
	Residual	39	211.144		
	Total	48			
5	Regression	8	604.414	2.833	.014[f]
	Residual	40	213.313		
	Total	48			
6	Regression	7	649.576	3.019	.012[g]
	Residual	41	215.142		
	Total	48			
7	Regression	6	733.845	3.438	.007[h]
	Residual	42	213.447		
	Total	48			
8	Regression	5	845.896	3.980	.005[i]
	Residual	43	212.520		
	Total	48			
9	Regression	4	972.042	4.512	.004[j]
	Residual	44	215.447		
	Total	48			
10	Regression	3	1117.757	5.023	.004[k]
	Residual	45	222.546		
	Total	48			

In table 8 above a stepwise regression predicting parental daily hassles (Intensity) is shown. Model 1 was not statistically significant however, Model 2 was statistically significant F (11, 37) = 2.219, p = 0.035. In model 2, family connectedness was statistically significant (beta = 0.403; p = 0.041). Sex was also statistically significant in this model (*beta* = -0.355, p =0.020). Model 3 was statistically significant F (10, 38) = 2.481, p = 0.021. Three variables were statistically significant sex (*beta* = -0.342, p =0.018), family connectedness (*beta* = 0.418, p = 0.029) and Utilising Social and Economic resources scale (*beta* = 0.620, p = 0.039). Model 4 was statistically significant F (9, 39) = 2.701, p = 0.015. Three variables were statistically significant, sex (*beta* = -0.342, p = 0.013), Family connectedness (*bet*a = 0.418, p = 0.025) and Utilising Social Resources (*beta* = 0.620, p = 0.043).

Model 5 was statistically significant F = (8, 40), p = 0.014. Two variables were statistically significant family connectedness (*beta* = 0.292, p = 0.049) and sex *(beta* = -0.374, p = 0.009). Model 6 was statistically significant F = (7, 41) = 3.019, p = 0.014. Sex was statistically significant in this model *(beta* = -0.378, p = 0.009). Model 7 was statistically significant F = (6, 42) = 3.438, p = 0.014. Sex was statistically significant (*beta* = -0.382, p = 0.008). Model 8 was statistically significant F = (5, 43), p = 0.005. Sex was statistically significant (*beta* = -0.366, p = 0.010). Model 9 was statistically significant F = (4, 44), p = 0.005. Two variables were statistically significant family connectedness (*beta* = 0.278, p = 0.040) and sex *(beta* = -0.426, p = 0.002). Model 10 was statistically significant F = (3, 45) = 5.023, p = 0.004. Sex was statistically significant (*beta* = -0.403, p = 0.003).

4.5 Stepwise Regression Parental Daily Hassle Frequency Scale

Table 10 ***Stepwise Regression PDHF***

MODEL	DF	MEAN SQUARE	F	SIG
Regression	12	263.362	2.015	.051[b]
Residual	37	130.691		
Total	49			
Regression	11	284.888	2.227	.033[c]
Residual	38	127.951		
Total	49			
Regression	10	308.874	2.455	.022[d]
Residual	39	125.825		
Total	49			
Regression	9	339.656	2.751	.013[e]
Residual	40	123.475		
Total	49			
Regression	8	375.499	3.084	.008[f]
Residual	41	121.754		
Total	49			
Regression	7	414.692	3.420	.006[g]
Residual	42	121.264		
Total	49			
Regression	6	462.115	3.804	.004[h]
Residual	43	121.470		
Total	49			
Regression	5	526.956	4.325	.003[i]
Residual	44	121.844		
Total	49			
Regression	4	626.932	5.140	.002[j]
Residual	45	121.960		
Total	49			
Regression	3	823.823	6.860	.001[k]
Residual	46	120.097		
Total	49			

In table 9 below a stepwise regression predicting parental daily hassles (frequency) is shown. Model 1 was not statistically significant however model 2 was statistically significant F (11, 38) = 2.217, p = 0.033. Family connectedness was statistically significant (*beta* = 0.401; p =

0.029). Sex was also statistically significant in this model (*beta* = -0.408, p =0.008). Model 3 was statistically significant *F* (10, 39) = 2.455, *p* = 0.022. Sex was also statistically significant in this model (*beta* = -0.436, *p* =0.003). Model 4 was statistically significant *F* (9, 40) = 2.751, *p* = 0.013. Two variables were statistically significant, sex (*beta* = -0.449, *p* = 0.002) and Family connectedness (*bet*a = 0.348, p = 0.015). Model 5 was statistically significant *F* = (8, 41), *p* = 0.008. Three variables were statistically significant, family connectedness (*beta* = 0.335, p = 0.017), sex *(beta* = -0.448, p = 0.002) and race (*beta* = 0.299, *p* = 0.038). Model 6 was statistically significant *F* = (7, 42) = 3.420, *p* = 0.006. Three variables were statistically significant, family connectedness (*beta* = 0.357, p = 0.010), sex *(beta* = -0.475, *p* = 0.001) and race (*beta* = 0.320, *p* = 0.024). Model 7 was statistically significant *F* = (6, 43) = 3.438, *p* = 0.004. Three variables were statistically significant, family connectedness (*beta* = 0.352, *p* = 0.011), sex *(beta* = -0.468, *p* = 0.001) and race (*beta* = 0.355, *p* = 0.011). Model 8 was statistically significant *F* = (5, 44), p = 0.003. Three variables were statistically significant, family connectedness (*beta* = 0.321, *p* = 0.017), sex *(beta* = -0.474, *p* = 0.001) and race (*beta* = 0.376, *p* = 0.007). Model 9 was statistically significant *F* = (4, 45) = 5.140, *p* = 0.002. Three variables were statistically significant, family connectedness (*beta* = 0.286, *p* = 0.027), sex *(beta* = -0.453, p = 0.001) and race (*beta* = 0.341, *p* = 0.010). Model 10 was statistically significant *F* = (3, 46) = 6.860, *p* = 0.001. Three variables were statistically significant, family connectedness (*beta* = 0.292, p = 0.022), sex *(beta* = -0.448, *p* = 0.001) and race (*beta* = 0.335, p = 0.011).

4.5. Research Question 4 – Stepwise Regression

What moderation effect does SES have on the relationship between resilience and parental daily hassles (Frequency and Intensity)?

In order to answer this question a stepwise regression was conducted. In order to understand if SES moderated the relationship between Resilience and Parental Daily Hassles (Frequency and Intensity) a stepwise regression was conducted. A stepwise regression analysis predicting Parental Daily Hassle Frequency in Table 11 illustrated that the parents' SES did not make a

significant contribution in family resilience and its subscales. There were 8 models and all models did not reach statistical significance (see table 11)

Table 11 ***Stepwise Regressions PDHF and and SES***

MODEL		DF	MEAN SQUARE	F	SIG
1	Regression	8	199.447	1.278	.282[b]
	Residual	41	156.106		
	Total	49			
2	Regression	7	222.795	1.454	.210[c]
	Residual	42	153.246		
	Total	49			
3	Regression	6	214.816	1.377	.246[d]
	Residual	43	155.977		
	Total	49			
4	Regression	5	201.073	1.266	.296[e]
	Residual	44	158.876		
	Total	49			
5	Regression	4	223.622	1.417	.244[f]
	Residual	45	157.810		
	Total	49			
6	Regression	3	269.243	1.723	.175[g]
	Residual	46	156.265		
	Total	49			
7	Regression	2	324.351	2.075	.137[h]
	Residual	47	156.324		
	Total	49			
8	Regression	1	474.212	3.026	.088[i]
	Residual	48	156.702		
	Total	49			

Table 12 ***Stepwise Regression PDHI SES***

MODEL		DF	MEAN SQUARE	F	SIG
1	Regression	8	421.534	1.687	.132[b]
	Residual	40	249.889		
	Total	48			
2	Regression	7	481.473	1.975	.082[c]
	Residual	41	243.842		
	Total	48			
3	Regression	6	462.286	1.833	.116[d]
	Residual	42	252.241		
	Total	48			
4	Regression	5	515.879	2.056	.090[e]
	Residual	43	250.894		
	Total	48			
5	Regression	4	577.794	2.299	.074[f]
	Residual	44	251.288		
	Total	48			
6	Regression	3	751.484	3.043	.038[g]
	Residual	45	246.964		
	Total	48			
7	Regression	2	967.399	3.892	.027[h]
	Residual	46	248.544		
	Total	48			

In a stepwise regression Predicting Parental Daily Hassles (Intensity) shown in table 12 below there were 7 models and only model 6 and model 7 were statistically significant. The model 6 was statistically significant F (3, 45) = 3.043, p = 0.038. SES was statistically significant (p = 0.043, beta = 0.296). The model explained R square = 0.169 (16.9%) of the variance in parental daily hassles frequency. The model 7 was statistically significant F = (2, 46) = 3.892, p = 0.027. SES was statistically significant (p = 0.019, *beta* = 0.336). The model explained R square = 0.145 (14.5%) of the variance in parental daily hassles frequency

CHAPTER 5

DISCUSSION

5.1 Introduction

The objective of this study was to understand the role of resilience and Socio-Economic Status (SES) in the parenting of children with Autism Spectrum Disorder (ASD) in South Africa. The discussion of the results will be structured in terms of the guiding research questions. Research questions in this study followed this order: First an analysis of differences between mothers and fathers' parental daily hassles was discussed. Secondly, the relationship between the main variables in the study namely:- Family Resilience, Parental Daily Hassles Frequency (PDHF), Parental Daily Hassle Intensity (PDHI), and the subscales of Family Resilience Assessment Scale (FRAS) namely:- Family Communication and Problem Solving (FCPS), Utilizing Social and Economic Resources (USER), Maintaining a Positive Outlook Subscale (MPO), Family Spirituality (FSPI), Ability to Make Meaning of Adversity (AMA), and SES was discussed. A final discussion was a prediction of Parental Hassles (Intensity and Frequency). Finally, the study limitations and implications of the study are discussed.

5.2. Differences in Daily Hassles of Mothers and Fathers

An independent samples t- test analysis was conducted to measure the level of parental daily hassles, the findings illustrated that there were significant differences in parents' daily hassles for both Frequency and Intensity scales. The frequency scale measured the frequency a parental hassle occurs, for example how often a parent cleans after the child such as cleaning after a mess of toys or food. Intensity measured the intensity of a particular hassle in the parents' stress levels. In this study mothers reported higher mean scores when compared with male counterparts for Intensity and Frequency. These finding could be attributed to the reasons that mothers naturally and historically are the main care givers regardless of the child's condition and this involvement may be even greater if the child has a disorder such as ASD. As suggested in Higgins et al.

(2005) mothers tend to be more involved in the child's daily responsibilities when compared to fathers. This does not necessarily suggest that fathers are not involved or less responsible in the activities of the child. Fathers are not directly involved with daily activities that are directly related to the care of the child. Furthermore fathers have different coping strategies compared to mothers which may reduce their levels of stress (Hastings et al., 2005). It is also worth noting that majority of female participants were from low income families (see figure 3). The environment may have a negative effect in the parenting as well as the stress levels of the parent (Mash & Johnston, 1990). The impact of the environment in terms of the parents' SES and the development of the child are discussed later in the discussion. The impact of the environment in terms of the availability of resources and the development of the child are also discussed later in the discussion.

5.3 Correlation Analysis

Although the variables in the study showed a significant correlation, the relationship was weak. Parental daily hassles (Intensity) had a positive relationship with family resilience and its sub scales. This relationship suggests that increased parental daily hassles intensity correlates with increased family resilience. Parental daily hassles (Frequency) also showed a positive relationship correlation with family resilience and its subscale. There was however a notable low negative relationship between family's spirituality (sub scale of family resilience) and parental daily hassles (Intensity). This relationship suggests that if family spirituality increased then parental daily hassles will decrease and vice versa. Also, family spirituality showed a negative relationship with the family's SES. Walsh (2003) suggests that family beliefs, ceremonies and rituals provide strength, comfort and meaning to families when undergoing challenging situation. Reports of the effectiveness of spirituality in families of children diagnosed with ASD have been previously documented (Plumb, 2011). There is however opposing views in the role of spirituality, some researchers have reported that the activity of taking a child to religious services could be a stressful exercise whilst some studies have reported that religious acts have a positive effect on the well-being of the parents (Baker-Ericzenel, Brookman-Frazee & Stanmer, 2005; Plumb, 2011; Tarekeshwar & Pargament, 2001; Ekas, Whitman & Shivers, 2009)

5.5. The Predictors of Parental Daily Hassle

In this study Parental Daily challenges differ between mothers and fathers. The regression analysis in this study illustrated that the parent's sex was the most predictor of parental daily hassles (Frequency and Intensity). These finding are in line with other research findings on parent's sex (Hastings, 2003; Higgins et al., 2005; Davies & Carter, 2008). After running a stepwise regression Family Connectedness, Utilising Social and Economic Resources and race were significant contributors in Parental Daily Hassles (Frequency and Intensity) of raising a child with ASD. It has been stated in the literature that unity and togetherness are one of the necessary resources required to deal with a crisis. This study is in line with the model of resilience by Walsh (2003). Furthermore the model states that scarcity of resources such as the ability to meet necessary therapy costs may worsen the crisis of raising a child with ASD (Walsh, 2003). Graph 3 illustrates that most families in this study were from low SES backgrounds. The majority of low SES families in this study were black South Africans which may be categorised as previously disadvantaged. Poverty and scarcity of resources has been mentioned to have negative effects on the parent (Mash & Johnston, 1990; Walsh, 2003). These findings are also in line with the study by Emmen et al. (2013) lower SES was found to be related with distress and less positive parenting.

Not all families undergo stress when faced with raising a child with ASD. Some parents and families are able to withstand adverse and difficult conditions. Such families are said to be resilient. According to Walsh (2003) every family has a potential to recover from an ordeal and grow from adverse situation. Families in this study were from different SES backgrounds and racial groups. The framework of family resilience suggests that each family's belief system will influence how it will approach a crisis situation. It further suggests that whatever approaches a family has towards dealing with adverse crisis situations such as raising a child within ASD. African families tend to take a collective approach in dealing with situations whereas westernised families take an individualistic approach. Walsh (2003) mentioned that families could be taught to develop a sense of cohesion in dealing with crisis situations. Meaning that, families with an individualistic problem solving approach may be taught skills and a sense of collective behaviours which may reduce the burden of dealing with a crisis in isolation. The

family's SES backgrounds contributes in its resilience levels, lower SES families are said to despair in crisis positions such as dealing with a child with ASD. This despair may have negative effects in finding future possibilities of a better life (Walsh, 2003).

In the regression model predicting parental daily hassles (Intensity) SES was statistically significant in all models (model 1-7). This suggests that SES moderated the relationship between resilience and parental daily hassles (Intensity). Thus, a family's SES has an impact in the parent's resilience levels and the intensity of daily hassles of parents with children with ASD. These findings are in line with previous studies stating that the family's SES status may have an impact in the development of the child with ASD (Dawson, 2011; Mandell, 2005). Families from low SES families face challenges such as difficulties in accessing early diagnosis for their children (Mandell et al., 2005). If diagnosis is delayed then interventions will be delayed which may have long lasting financial and developmental challenges in the family and the child with ASD.

5.2 Limitations

There were notable limitations in this study. More efforts have been injected in creating awareness of ASD globally thus more studies are conducted year on year to improve the body of knowledge of the disorder. Based on this, parents are faced with a number of requests from researchers to complete survey questionnaires. This then impacts on the responses received from participating parents. Thus the sample size of this study was small. Previous studies have reported higher non-response rates from parents of ASD children (Emmen et al., 2013; Greef & Van der Walt, 2010). Participants in this study were single parents and coupled parents, using the Hollingshead Two factor Index which focuses on the family not the individual was also another notable limitation in the study. The questionnaires were developed in English only and South Africa has eleven official languages thus language barriers may have been another limiting factor in the study. However the language was simplified in order to bridge the language barrier that may have risen and also the researcher is fluent in more than three South African languages which bridged some of the language barriers. South Africa has nine provinces and only two

provinces were sampled for this study i.e. Gauteng and KwaZulu Natal. Three South African major cities were chosen for sampling i.e. Johannesburg, Pretoria and Durban. These cities were chosen because they are well developed in terms of schooling and the availability of practitioners when compared to other smaller provinces. Thus the study may not be generalized in the entire South African populace as the sample did not represent all nine provinces.

5.3 Implications

Previous studies have reported an association between parent's hassles and raising a child with ASD. This particular study was also in line with these findings. More psychological therapy is to be channeled towards the well-being of parents. Mental health practitioners as well as psychiatrists should exercise caution when reporting the diagnosis of ASD as confronting the reality of a child with ASD has been found to have adverse emotional consequences for parents which may later lead to less optimal parenting behaviors (Emmen et al., 2013). Other factors such as the parents SES background also play a fundamental role in the ability of the parent to raise a child with ASD. Thus, based on these results socio economic status plays a fundamental part in the parenting of children with SES. Parents from disadvantaged background may benefit from social welfare programs as well as subsidized government health care system.

5.2. Recommendations

This study applied a quantitative research approach. Most parents during the process of data collection were more expressive. A qualitative research approach may discover more understanding in the topic of understanding resilience and socio SES in the parenting of children with ASD as participants preferred to expressed their experiences. Professionals and practitioners should care when caring for children who present symptoms of ASD and take the parents' emotional state into account as the discovery of the diagnosis may be devastating to some parents.

5.3 Conclusion

The main objective of this study was to understand the role of resilience and SES in the parenting of children with ASD in South Africa. Previous studies have mentioned that parents of children with ASD are faced with more than usual parental stress. Mothers of children with ASD show more levels of daily stresses when compared with fathers. Fathers tend to cope better than mothers because they are perhaps less involved in the child's daily activities when compared with fathers. Daily parenting challenges are not the only challenges parents' face. Other parental challenges include excessive costs, attached in parenting a child with ASD. An example of these costs includes therapy costs, child minding costs and schooling costs. Some of the challenges mentioned earlier in the literature are the difficulties in finding a diagnosis for the child. In South Africa this problem could be even higher. The country faces a scarcity of psychiatric professionals. Such scarcity creates a problem for parents, as they have to wait in unendurable lines and navigate through the maze of public health facilities in order to receive service from practitioners. Mash and Johnston (1990) outlined a model of parental stress that suggests an interactional relationship between the child, the parent and the environment. The model emphasizes that parental stresses may have an impact in the child. The model further states that unconducive environments may also have negative impacts in the child as well as the parent. Studies have found an association between the characteristics of a child with ASD and the levels of stress in parents. Parents of children with ASD who present externalizing problems such as tantrums and anger reported high levels of stress (Hastings, 2003; Boonen et al., 2014). Other studies found that mothers reported higher stress levels as compared to fathers (Higgins et al., 2005).The current study found differences in parental daily hassles between mother and father, replicating previous studies. Resilient families are better able to cope with crisis situations. A sub scale of family resilience associated with family spirituality had a negative correlation with parental daily hassles. This suggests that families who engage in religious activities showed less parentally daily hassles (intensity).More studies ought to be conducted in South Africa which will research parental hassles in raising a child with ASD.

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Appendices

Appendices

A- Ethics Approval letter

University of the Witwatersrand, Johannesburg
Faculty of Humanities – Postgraduate Office
Private Bag 3, Wits 2050, South Africa • **Tel:** +27 11 717 4002• **Fax:** +27 11 717 4037• **Email:** Sarah.Mfupa@wits.ac.za

Student Number: 856243

Mrs Ayanda Purity Simelane
5 Ferrerira Road
Ashley
Pinetown
Durban 3610
KwaZulu-Natal South Africa

18 June 2014

Dear Mrs Simelane

APPROVAL OF PROPOSAL FOR THE DEGREE OF MASTER OF ARTS BY COURSEWORK AND RESEARCH REPORT IN PSYCHOLOGY

I am pleased to be able to advise you that the readers of the Graduate Studies Committee have approved your proposal entitled "*The role of resilience and socio-economic status in the parenting of children with autism spectrum disorder in South Africa*". I confirm that Ms Renate Gericke and Mr Joseph Seabi have been appointed as your supervisor in the School of Human and Community Development.

The research report is normally submitted to the Faculty Office by 15 February, if you have started the beginning of the year, and for mid-year the deadline is 31 July. All students are required to RE-REGISTER at the beginning of each year.

You are required to submit 2 bound copies and one unbound copy plus 1 CD in pdf (Adobe) format of your research report to the Faculty Office. The 2 bound copies go to the examiners and are retained by them and the unbound copy is retained by the Faculty Office as back up.

Please note that should you miss the deadline of 15 February or 31 July you will be required to submit an application for extension of time and register for the research report extension. Any candidate who misses the deadline of 15 February will be charged fees for the research report extension.

Kindly keep us informed of any changes of address during the year.

Note: All MA and PhD candidates who intend graduating shortly must meet your ETD requirements at least 6 weeks after your supervisor has received the examiners reports. **A student must remain registered at the Faculty Office until graduation.**

Yours Sincerely

SD Mfupa

Sarah Mfupa
Postgraduate Division
Faculty of Humanities
Private Bag X 3
Wits, 2050

B- Medical Clearance Ethics Approval

R14/49 Ms Ayanda Simelane

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140415

NAME: (Principal Investigator)	Ms Ayanda Simelane
DEPARTMENT:	School of Human and Community Development Chris Hani Baragwanath Academic Hospital Johannesburg Hospital School, Browns School, Unica School and The Key School
PROJECT TITLE:	The Role of Resilience and Socio-Economic Status in the Parenting of Children with Autism Spectrum Disorder in South Africa (Additional study sites 18/09/2014)
DATE CONSIDERED:	25/04/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Joseph Seabi and Renate Gericke
APPROVED BY:	Professor A Woodiwiss, Co-Chairperson, HREC (Medical)
DATE OF APPROVAL:	08/08/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

C- Gauteng Department of Education Approval Letter

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 22 August 2014

TITLE OF PROJECT: The role of resilience and socio-economic status in the parenting of children with autism spectrum disorder in South Africa

UNIVERSITY: Witwatersrand

Principal Investigator: A Simelane

Department: Psychology

Supervisor (If relevant):

Permission Head Department (where research conducted): Not yet but verbally agreed

Date of start of proposed study: Aug 2014
Date of completion of data collection: Dec 2016

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.
- Permission is obtained from the Head of Department at Chris Hani Baragwanath Hospital where to research is to be conducted
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

.....
Recommended
(On behalf of the MAC)
Date: 22 August 2014

.....
Approved/Not Approved
Hospital Management
Date: 25/08/14

D- Gauteng Province letter of Approval

GAUTENG PROVINCE
EDUCATION
REPUBLIC OF SOUTH AFRICA

Enq: Gugu Khumalo
Tel: 011666 9066

TO : **Mrs. R. Van Biljon**
Johannesburg Hospital School

FROM : **Mr. Raymond Martin**
District Director

DATE : **22 August 2014**

PURPOSE : **Research Permission**

Dear Colleague,

Kindly be informed that Ms. Ayanda Simelane who is currently registered with the University of Witwatersrand, will be conducting research in your school and the topic is: The role of resilience and socio-economic status in the parenting of children with Autism Spectrum Disorder in South Africa.

Her findings in this study will assist professionals and organisations to implement better support programs for parents with autistic children.

Participants will be informed that being part of the study is voluntary and that they would have the right to withdraw from this study, without penalty, at any stage of the research.

Hope for a positive outcome at the end of the research.

Thanking you for your cooperation.

Yours in Education

Mr Raymond Martin
Johannesburg East District Director

DISTRICT: JOHANNESBURG EAST
Tel: (011) 666 9002, Cell: 082 464 8225, Fax: 086 266 7734 | Email: Raymond.Martin@gauteng.gov.za
142/144 Fourth Street, Benmore, Sandton, Private Bag X9910, Sandton, 2146
www.education.gpg.gov.za | Call Centre: 0800 005 175

E- Gauteng Department of Education Research Approval Letter

GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

For administrative use:
Reference no: D2015 / 271

GDE RESEARCH APPROVAL LETTER

Date:	19 August 2014
Validity of Research Approval:	19 August 2014 to 3 October 2014
Name of Researcher:	Simelane A.P.
Address of Researcher:	5 Fleischer Road
	Carersham Glen
	Pinetown
	3610
Telephone Number:	078 347 0566
Email address:	ayanda.simelane@students.wits.ac.za
Research Topic:	The role of resilence and socio-economic status in the parenting of children with Autism Spectrum Disorder
Number and type of schools:	ONE LSEN school
District/s/HO	Johannesburg East

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

The following conditions apply to GDE research. The researcher may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

2014/08/20

Office of the Director: Knowledge Management and Research
9th Floor, 111 Commissioner Street, Johannesburg, 2001
P.O. Box 7710, Johannesburg, 2000 Tel: (011) 355 0506
Email: David.Makhado@gauteng.gov.za
Website: www.education.gpg.gov.za

F-

Psychology Department
School of Human and Community Development
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011)717 4500 Fax: (011) 717 4559

June 2014

INFORMATION SHEET

Study Title

The role of resilience and socio-economic status in the parenting of children with Autism Spectrum Disorder in South Africa

Who I am

My name is Ayanda Simelane; I am a Masters Research student in Psychology at the University of the Witwatersrand.

What I am doing

I am conducting research to understand the role of resilience and socioeconomic status in parenting autistic children in a sample of South African students. The findings in this study will assist professionals and organization to implement better support programs for parents with autistic children.

Your participation

I am asking you to participate in research that will be conducted in English or in your preferred language and will take approximately 20 minutes.

Please understand that **participation in this study is entirely voluntary**. If you agree to participate, you will complete the packet of questionnaires provided by the researcher. Please note that you may terminate your participation in the research at any point in time you feel the need to. If you decide to terminate your participation there will be no penalties and you will not be prejudiced in any way.

G- Information Sheet (continued)

Confidentiality

All participation records identifying your information will be kept in a locked file cabinet at the psychology department and will not be available to others. The researcher will refer to you by a fictitious number or pseudonym (another name) in any publication to protect your identity.

Risks/discomforts

At the present time, we do not see any major risks in your participation. You may experience some discomfort given the personal nature of the information you will be providing. Please take note that support will be offered to you after the interview if you feel the need for it. Please speak to the researcher for counselling assistance options and available counselling organisations near you.

Benefits

Your participation in this study will not yield any immediate benefits to you. However, it will be instrumental and helpful in the completion of my Masters research project. This study may provide important data and contribute to the existing body of knowledge from the specific local context that can be used to inform the body of literature that exists on the subject being researched.

Once the study is completed the research report will be made available to the general public.

Who to contact if you have been harmed or have any concerns

Approval to conduct this study has been granted by the University's Human Research Ethics Committee. If you have any questions or complaints about ethical aspects of the research or feel that you have been harmed in any way by participating in this study, please contact:

Renate Gericke	Dr Joseph Seabi
Lecturer/ Clinical psychologist	Senior Lecturer/Educational Psychologist
Project Supervisor	Project Supervisor
011-717 45555	011-7178331
Renate.gericke@wits.ac.za	Joseph.seabi@wits.ac.za
Department of Psychology	Department of Psychology

Regards
Ayanda Simelane (Researcher)
Student-MA Research in Psychology
(The University of the Witwatersrand---Johannesburg)

H- Consent Form

Psychology Department
School of Human and Community Development
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011)717 4500 Fax: (011) 717 4559

June 2014

Study Title

The role of resilience and socio-economic status in the parenting of children with Autism Spectrum Disorder in South Africa

CONSENT

I hereby agree to participate in research on "understanding the role of resilience and socio-economic status in the parenting children with Autism Spectrum Disorder in South African". I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop participating at any point should I not want to continue and that this decision will not in any way affect me negatively.

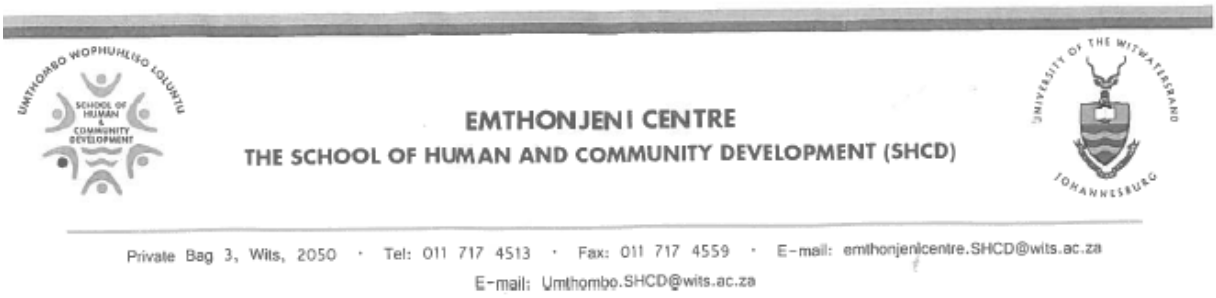
I understand that this is a research project whose purpose is not necessarily to benefit me personally in the immediate or short term.

I understand that my participation will remain confidential.

……..

Signature of participant **Date**:……..

I- Emthonjeni Centre (Referral Letter)



EMTHONJENI CENTRE
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 · Tel: 011 717 4513 · Fax: 011 717 4559 · E-mail: emthonjenicentre.SHCD@wits.ac.za
E-mail: Umthombo.SHCD@wits.ac.za

05 December 2014

To whom it may concern

Ms. Ayanda Simelane has been given permission to refer her research participants to the Emthonjeni Centre for therapy.

Please contact the centre for further confirmation.

Yours sincerely

Nthabiseng Modikoane
Emthonjeni Centre
School of Human & Community Development
University of the Witwatersrand
Tel: 011 717-4513
Fax: 011 717-8324

Emthonjeni Centre
School of Human & Community Development
University of the Witwatersrand
Private Bag X3, Wits 2050
Tel: 011 717 4513
Fax: 011 717 8324

J- Participant Background Information Sheet

Background Questionnaire

Hollingshead Two Factor Index

Participant #:_____ Date: _____ / _____ / _____

Parents Age: _____ Childs Age:_____

Occupation:

_____

Education:

_____ Under 7 years of school _____ 7-9 Years of School _____ 10-11 Years of School

_____ High School Graduate _____ 1 – 3 Years of College (includes technical degree)

_____ Four Year College Graduate _____ Professional (MA, MS, PhD, MD)

Your ethnicity: _____ Home language: _____

Your zip code: _____ How long at this residence: _____

Your Marital Status: _____

Length of time since Childs Diagnosis: _____

Your current living arrangements: ___ Husband ___ Wife____ Significant Other ___ Friend(s)

K- Participant Background Information

Hollingshead Score: _____

If you live with your spouse or significant other, please answer the questions below regarding that person

Is this person the biological parent of one of your children? ____ Yes _____ No

What is his or her Age: _____ Occupation: _____

Education:

____ Under 7 years of school _____ 7-9 Years of School _____ 10-11 Years of School

____ High School Graduate _____ 1 – 3 Years of College (includes technical degree)

____ Four Year College Graduate ____ Professional (MA, MS, PhD, MD)

His / her ethnicity: _____ His / her Home language: _____

Hollingshead Score: _____

Total Hollingshead Score: _____

Thank you for your participation

L- Family Resilience Assessment Scale

FAMILY RESILIENCE ASSESSMENT SCALE

Please read each statement carefully. Decide how well you believe it describes your family now from your viewpoint. Your family may include any individuals you wish.

1. Every family has problems	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
2 Everything we go through as a family happens for a reason	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
3 Our family structure is flexible to deal with the unexpected	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
4 Our friends are part of everyday activities	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
5 Our friends value us and who we are	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
6 The rules in our family are not set in stone	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
7 The rules in our family change according to family needs	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
8 The things we do for each other make us feel a part of the family	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
9 We accept stressful events as part of life	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree

M- Family Resilience Assessment Scale (Continued)

10 We accept that problems occur unexpectedly	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
11 We all have input into major family decisions	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
12 We are able to work through pain and come to an understanding	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
13 We are adaptable to demands placed on us as a family	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
14 We are careful how much we do for friends	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
15 We are careful what we say to each other	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
16 We are open to new ways of doing things in our family	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
17 We are understood by other family members	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
18 We ask neighbours for help and assistance	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
19 We attend church / synagogue / mosque services	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

N- Family Resilience Assessment Scale (Continued)

20 We believe friends can take advantage of us	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
21 We believe we can handle our problems	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
22 WE can ask for clarification if we do not understand each other	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
23 We can be honest and direct with each other in our family	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
24 We can blow off steam without upsetting someone	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
25 We can compromise when problems come up	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
26 We can deal with family differences in accepting a loss	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
27 We can depend on people in this community	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
28 We can question the meaning behind messages in in our family	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
29 We can solve major problems	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree

O- Family Resilience Assessment Scale (Continued)

30 We can survive if another problem comes up	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
31 We can talk about the way we communicate in our family	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
32 We can work through difficulties as a family	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
33 We consult with each other about decisions	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
34 We define problems positively to solve them	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
35 We discuss problems and feel good about the solutions	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
36 We discuss things until we reach a resolution	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
37 We do volunteer work in the community	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
38 We feel free to express our opinions	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
39 We feel good giving time and energy to our family	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree

P- Family Resilience Assessment Scale (Continued)

40 We feel people in this community are willing to help in an emergency	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
41 We feel secure living in this community	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
42 We feel taken for granted by family members	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
43 We feel we are strong in facing big problems	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
44 We get upset if someone complains in our family	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
45 We have close friends we really care for	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

Q- Family Resilience Assessment Scale (Continued)

46 We have faith in a supreme being	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
47 We have the strength to solve our problems	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
48 We keep our feelings to ourselves	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
49 We know there is community help if there is trouble	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree

R- Family Resilience Assessment Scale (Continued)

50 We know we are important to our friends	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
51 We learn from each other's mistakes	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
52 We mean what we say to each other in our family	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
53 We participate in activities specifically for our situation	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
54 We participate in church activities	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
55 We receive gifts and favours from neighbours	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
56 We seek advice from religious advisors	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
57 We seldom listen to family members concerns or problems	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree

S- Family Resilience Assessment Scale (Continued)

58 We share responsibility in the family	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree
59 We show love and affection for family members	☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

T- Family Resilience Assessment Scale (Continued)

60 We tell each other how much we care for one another	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
61 We think this is a good community to raise children	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
62 We think we should not get too involved with people in the community	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
63 We trust things will work out even in difficult times	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
64 We try new ways of working with others	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
65 We understand communication from other family members	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree
66 We work to make sure family members are not emotionally or physically hurt	☐	Strongly agree
	☐	Agree
	☐	Disagree
	☐	Strongly disagree

U- Parental Daily Hassle Scale



Parenting Daily Hassles

SCALE

The statements below describe a lot of events that routinely occur in families with young children. These events sometimes make life difficult. Please read each item and circle how often it happens to you (rarely, sometimes, a lot, or constantly) and then circle how much of a 'hassle' you feel that it has been for you FOR THE PAST 6 MONTHS. If you have more than one child, these events can include any or all of your children.

EVENT	How often it happens				Hassle (low to high)				
1. Continually cleaning up messes of toys or food	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
2. Being nagged, whined at, complained to	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
3. Meal-time difficulties with picky eaters, complaining etc.	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
4. The kids won't listen or do what they are asked without being nagged	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
5. Baby-sitters are hard to find	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
6. The kids schedules (like pre-school or other activities) interfere with meeting your own household needs	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
7. Sibling arguments or fights require a 'referee'	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
8. The kids demand that you entertain them or play with them	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
9. The kids resist or struggle with you over bed-time	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
10. The kids are constantly underfoot, interfering with other chores	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
11. The need to keep a constant eye on where the kids are and what they are doing	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
12. The kids interrupt adult conversations or interactions	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
13. Having to change your plans because of unprecedented child needs	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
14. The kids get dirty several times a day requiring changes of clothing	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
15. Difficulties in getting privacy (eg. in the bathroom)	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
16. The kids are hard to manage in public (grocery store, shopping centre, restaurant)	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
17. Difficulties in getting kids ready for outings and leaving on time	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
18. Difficulties in leaving kids for a night out or at school or day care	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
19. The kids have difficulties with friends (eg. fighting, trouble, getting along, or no friends available)	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5
20. Having to run extra errands to meet the kids needs	Rarely	Sometimes	A lot	Constantly	1	2	3	4	5

Questionnaire completed by *mother/father/adoptive parent/foster carer* (please specify)

V- Principal's Approval Letter (Browns School)

THE BROWNS' SCHOOL

Private Bag X04, Ashwood, 3605
28 Mariannridge Drive, Pinetown, 3610

TEL : (031) 700 353
FAX : (031) 700 311
E-mail : browns@brownsschool.co.z
Website : www.brownsschool.co.z

26 August 2014

Email: Ayanda.Simelane@students.wits.ac.za

To whom it may concern

Approval for Research at The Browns' School

We hereby confirm that approval has been granted to Ms Ayanda Simelane to conduct research at The Browns' School in accordance with the proposal titled "The role of resilience and socio-economic status in the parenting of children with Autism spectrum disorder in South Africa".

Yours sincerely,

Mr D J Smyth
PRINCIPAL

/rs

THE BROWNS' SCHOOL
PRIVATE BAG X04
ASHWOOD, 3605

W- Principal's Approval Letter (Unica School)

UNICA SCHOOL FOR CHILDREN WITH AUTISM

P.O. BOX 35182, MENLO PARK, 0102
CECILIA ROAD, NEW HOPE CAMPUS, ASHLEY GARDENS
TEL: 012 460 6539 / 012 346 1103
FAX: 012 460 6324
HOSTEL: 012 329 0647

REG NO: GDE 211177 TS D4

PRINCIPAL: DR J.C. LOMBARD

DEPUTY: J. PERUMAL

3 September 2014

Re: RESEARCH AT UNICA SCHOOL

Topic*: Role of resilience and socioeconomic status in the parenting of children with Autism Spectrum Disorder in South Africa*

We herewith give permission to Ayanda Simelane to conduct the proposed research at our school.

Thank you for your interest in our school. We kindly request that a bound copy of the research project as well as any articles be made available to Unica School upon completion.

Sincerely

Dr J.C. Lombard
Principal

X- Principal's Approval Letter (Johannesburg Hospital School)

JOHANNESBURG HOSPITAL SCHOOL

Nurture our Youth with Knowledge

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aqua@iburst.co.za
Ground Floor and 1st Floor
Gate 13
Joubert str ext
Braamfontein

1 September 2014

This letter serves to confirm that we give A Simelane (student number : 856243) permission to use our school to conduct research for her studies on " The Role of Resilience and Socio-Economic Status in the Parenting of Children with Autism Spectrum Disorder in South Africa".

We also provide permission for her to spend time in the context to gain an understanding of the school environment and all the services it provides. We will be happy to answer any questions in this regard. We would like to confirm that we are in full support of her research and are interested in the outcome of the study.

P C van Biljon

P C van Biljon
Principal

W-Principal's Approval Letter (The Key School)



Physical address: 7 Rhodes Avenue
Parktown, 2193
Postal address: P O Box 84611
Greenside, 2034
Johannesburg
South Africa
Phone: 27 11 726 2445/1061
Fax: 27 11 726 7901
Aftercare: 082 555 6412
Email: head@thekeyschool.co.za
Website: www.thekeyschool.org

4 September 2014

This is to confirm that Mrs Ayanda Simelane, a masters student at Wits, has permission to conduct her research entitled "The role of resilience and socio-economic status in the parenting of children with Autism Spectrum Disorder in South Africa" at The Key School.

We would be appreciate that the results of the study be submitted to the school on completion of the research.

Yours faithfully

Dr Jenni Gous
Principal

X- Action In Autism Approval Letter

ACTION in AUTISM

www.actioninautism.org.za

A Non-Profit Organisation (NPO)

Registration No. 047-002-NPO

Tel: 031-2074858 Fax: 0865568973

E-mail Address: actioninautism@gmail.com

74 Keal Road, Sydenham, Durban 4091

24 October 2014

To whom it may concern

Re: The Role of Resilience and socio-economic status in the parenting of Autism spectrum disorder in South Africa – Ayanda Simelane

This is to confirm that the above topic and the collection of data for the purposes of Ayanda Simelane's Masters research was approved by the Chairperson of Action in Autism, Liza Aziz.

Ayanda adhered to and submitted all the requirements of the organisation for research, and we were happy for her to distribute her questionnaire to the parents of the children at Action in Autism, as well as parents attending our AGM and Parent Support Group meeting.

We wish Ayanda well with her research.

Yours sincerely,

KIRSTEN MILLER
Manager
Action in Autism Early Learning Centre