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The health and well-being of caregivers raising children with and without Autism Spectrum Disorder in the South African context.

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Abstract

Background: Children require a nurturing environment to develop optimally and reach their full potential. A critical component of this environment is the health and well-being of caregivers so that they can provide responsive caregiving. It is believed that parents or caregivers of children with ASD will have poorer health and well-being than parents or caregivers of children without ASD. Therefore, caregivers of children with ASD may require more support to enable them to provide responsive caregiving to these children.

Methods: This study was a quantitative study that employed an analytical, comparative design. The purpose of this study is to determine if there is a significant difference in the health and well-being of caregivers of children with ASD and caregivers of children without ASD in the South African context. Two hundred and eight participants from two schools in Kwa-Zulu Natal completed a paper-based survey containing 3 questionnaires relating to health-related quality of life; stress, anxiety and depression and parental self-efficacy. Parenting constructs such as stress, anxiety and parental self-efficacy are measured and described, and the association between Health-related Quality of Life and constructs such as stress, anxiety and parental self-efficacy is explored. It took place at a special needs school in KZN and mainstream school in the same district.

Results: The results of this study demonstrated a poorer HRQOL in some of the areas of functioning in caregivers of a child with ASD compared to caregivers of a child without ASD. The results from this study demonstrate the importance for health practitioners to focus on the caregivers' health and well-being as part of the child's intervention.

Conclusion: Intervention is mainly child-focussed however it is important for practitioners to understand the caregiver's health and well-being as this will have a positive influence of the child and in turn, lead to successful intervention. It is therefore important to have a family-centred approach. The QOL of the parents or caregivers of children with ASD will improve through support and intervention which will positively impact on the child's development. If the caregiver is receiving the appropriate support, their QOL will improve and they will be able to provide nurturing care that the child needs.

Key words: autism, health related quality of life, low and middle income countries, parental self-efficacy, parenting stress.

Chapter 1

Introduction

1.1 Introduction

This chapter describes the problem statement and rationale for the study. It also defines the most prominent terminology used in this study and lists the most common abbreviations. The chapter concludes with an outline of the five chapters in this dissertation.

1.2 Problem statement and rationale

Autism Spectrum Disorder (ASD) is a life-long, neurodevelopmental disorder characterised by difficulties in the following areas: verbal and non-verbal communication, social interaction as well as restricted and repetitive behaviours (American Psychiatric Association, 2013). Studies have reported that caring for children with ASD is emotionally, financially, socially and physically challenging and therefore negatively impacts the parents quality of Life (QOL); (Al-Farsi, Al-Farsi, Al-Sharbati, & Al-Adawi, 2016; Alhazmi, Petersen, & Donald, 2018; Eapen, Črnčec, Walter, & Tay, 2014). QOL is defined as an individual's "perception of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns" (Eapen et al., 2014). QOL evaluates the non-health-related aspects of life while health-related quality of life (HRQOL) is used for specific aspects of health (Gurková, 2011).

Health-related quality of life is a term that applies to health care (Ferrans, Zerwic, Wilbur, & Larson, 2005). Whilst parents and caregivers of children with other disabilities have been reported to have increased stress and psychological problems (Parkes, Caravale, Marcelli, Franco, & Colver, 2011; Raina et al., 2005), research reports that parents and caregivers of children with ASD may have even higher levels of stress and poorer health and QOL than parents of typically developing children or children with other disabilities (Alhazmi et al., 2018; Benjak, Vuletić Mavrinac, & Pavić Šimetin, 2009; Hayes & Watson, 2013). The evidence in the literature suggests that caregivers of children with ASD have a lower HRQOL due to the challenges of raising a child with ASD.

It is known that a parent or caregiver forms a critical part of the child's life, no matter what developmental stage and it is important that their health, well-being and QOL is addressed so that they can provide the child with nurturing care (Fewster, Uys, & Govender, 2020; World Health Organisation, 2018). According to the World Health Organization (WHO) there are five components that are essential for optimal child development, these include: adequate nutrition, good health, security and safety, responsive caregiving and opportunities for early learning (World Health

Organisation, 2018). Nurturing care is dependent on opportunities and resources available to them and these are dependent on their caregiver's health and well-being. For caregivers to provide responsive caregiving, they need to be well and healthy themselves.

There are factors, such as stress and depression, that negatively influence the caregiver's health and well-being and impacts the caregivers' QOL (Abbeduto et al., 2004). Studies have reported that raising a child with ASD leads to higher levels of stress and depression (Cutress & Muncer, 2014; Dabrowska & Pisula, 2010). Stress has a negative impact on caregivers' mental health and significantly affects their HRQOL (Johnson, Frenn, Feetham, & Simpson, 2011). Research has been conducted on the correlation between parenting stress and parental HRQOL and behaviour characteristics of a child with ASD (Hsiao, 2016). Caregivers' of an ASD child therefore are expected to have higher levels of stress due to the child's behaviours which will in turn affect their HRQOL (Peters-Scheffer, Didden, & Korzilius, 2012). Furthermore, these caregivers' have been found to have poor HRQOL across all domains, namely: physical, psychological, social and environmental health (Alhazmi et al., 2018).

There is relatively little known about ASD in Africa when compared to high income countries (HICs) and the prevalence rate is not known as no studies have been conducted in order to discover the prevalence rate in Africa (Ametepee & Chitiyo, 2009). Most of the research is conducted in HICs such as those in Europe, with very little research being conducted in low to middle income countries (LMIC), specifically in Sub-Saharan Africa (Ametepee & Chitiyo, 2009; Bakare & Munir, 2011; de Vries, 2016). Limited published research is available which reports on the quality of life of caregivers and/or parents of children with ASD in South Africa. A study by Schlebusch et al., (2016) examined *family* QOL and found that families with more established family routines reported a better family quality of life. Alhazmi et al., (2018) conducted a study on the QOL among parents of South African children with autism spectrum disorder. The results from this study demonstrated a significant reduction in QOL across all QOL domains, namely: physical, psychological, social and environmental health (Alhazmi et al., 2018). There is a need for data from Sub-Saharan Africa as research has indicated that the majority of children in 2016 living with developmental disabilities such as ASD live in LMIC (94.9%) compared to those living in HIC (5.1%)(Olusanya et al., 2018).

As noted above there is limited published research with regards to the HRQOL of caregivers raising children with ASD in South Africa and this is something that requires investigation. This is especially important since many of the children with ASD do not have easy and regular access to appropriate services such as health care, education and support services, these resources are also limited in LMIC

(Fewster et al., 2020; Reddy, Fewster, & Gurayah, 2019; Schlebusch et al., 2016) is limited as well as access to other resources such as education and support services (Reddy et al., 2019). With the increase in the prevalence rate of ASD worldwide, it is important to understand the burden and challenges on caregivers so that we can tailor support to assist parents (Alhazmi et al., 2018; Samadi & Samadi, 2020). If one has a better understanding of what is affecting the stress felt by the parents, intervention may take a more targeted approach to supporting caregivers which would have a positive impact the intervention outcomes for the child (Hayes & Watson, 2013). Knowledge about a caregiver's quality of life will help practitioners' partner with caregiver to ensure able to participate in their child's intervention in a meaningful way for them. Professionals may also use this information to suggest caregivers access additional support if necessary. It is important for practitioners to assess caregivers HRQOL as research indicates that if practitioners improve caregivers HRQOL this may ultimately increase the effectiveness of interventions designed to enhance child development (Fewster et al., 2020; Giallo, Wood, Jellett, & Porter, 2013; Hoefman et al., 2014). Current interventions focus mainly on the child and therefore do not assist with the needs of the primary caregiver or parents and therefore the parents HRQOL is not improved which may impact the ability of the caregivers to provide nurturing care for the child.

The aim of this study is therefore to determine if there is a significant difference in the health and well-being of caregivers of children with ASD and caregivers of children without ASD in the South African context. In addition, the association between HRQOL and parenting constructs such as stress, anxiety and parental self-efficacy is explored.

1.3 Terminology

Table 1 contains a list of words used in the dissertation. The key terms are followed by their definitions.

Table 1. The terminology used in this dissertation.

Key term	Terminology
Autism Spectrum Disorder (ASD)	Autism Spectrum Disorder is a lifelong neurodevelopmental disorder characterised by impairments in social interaction, verbal and nonverbal communication and a restricted repertoire of activities and interests (American Psychiatric Association, 2013).
ASD specific school (Term specific to South Africa)	This refers to a school that caters specifically for children on the Autism Spectrum. A school such as this will include 'high levels of specialised support' (Pillay, Duncan, & de Vries, 2020, p. 3).
Caregiver	In this study, the term 'caregiver' refers to someone that is looking after the child, who may be their legal guardian but is not necessarily their biological parent. Parent and caregiver are used interchangeable in this study to refer to the child's legal guardian.
Children with Autism Spectrum Disorder (ASD)	In this study, the term 'children with ASD' refers to children diagnosed with ASD. A Paediatrician, Psychiatrist or Clinical Psychologist can diagnose a child with ASD in South Africa.
Children without ASD	In this study, the term 'children without ASD' refers to 'general population', specifically neurotypically developing children.
Health-related quality of life (HRQOL)	"Health-related quality of life refers to how well a person functions in their life and his or her perceived well-being in physical, mental and social domains of health" (Hays & Reeve, 2016, p. 5)
Mainstream school (Term specific to South Africa)	A school that has 'low level support for learners' (Pillay et al., 2020).
Parent	For this study, the term 'parent' referred to an individual that was over the age of 18 and a biological parent or caregiver of the child partaking in the study. Parent and caregiver are

	used interchangeable in this study to refer to the child’s legal guardian.
Parenting stress	“Parenting stress can be defined as the aversive psychological reaction to the demands of being a parent.” (Deater-Deckard, 1998, p.2)
Parental self-efficacy	“Parental self-efficacy is a potentially important cognitive construct, related to child and family functioning, that can be broadly defined as the expectation caregivers hold about their ability to parent successfully. (Jones & Prinz, 2005, p.2).
Parental well-being	“Concerns individual care in a healthy way and covers aspects such as awareness of the physical condition, stress reduction and self-responsibility in care” (Pinto, Fumincelli, Mazzo, Caldeira, & Martins, 2017, p.2).
Quality of life (QOL)	“An individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (Harper et al., 1998, p.551).
Nurturing care	“A stable environment that is sensitive to children’s health and nutritional needs, with protection from threats, opportunities for early learning and interactions that are responsive, emotionally supportive and developmentally stimulating.” (Britto et al., 2017, p.91).
High income country (HIC)	“The World Bank has used an income classification to group countries for analytical purposes.” (Fantom & Serajuddin, 2016, p.4). “It divides countries into four groups- low income, lower middle income, upper middle income, and **high income**- using gross national income (GNI) per capita valued annually in US dollars using a three-year average exchange rate (Fantom & Serajuddin, 2016, p4). The classification is published annually and can be viewed on http://data.worldbank.org.
Low and middle-income country (LMIC)	“The World Bank has used an income classification to group countries for analytical purposes.” (Fantom & Serajuddin, 2016, p.4). “It divides countries into four groups- low income,

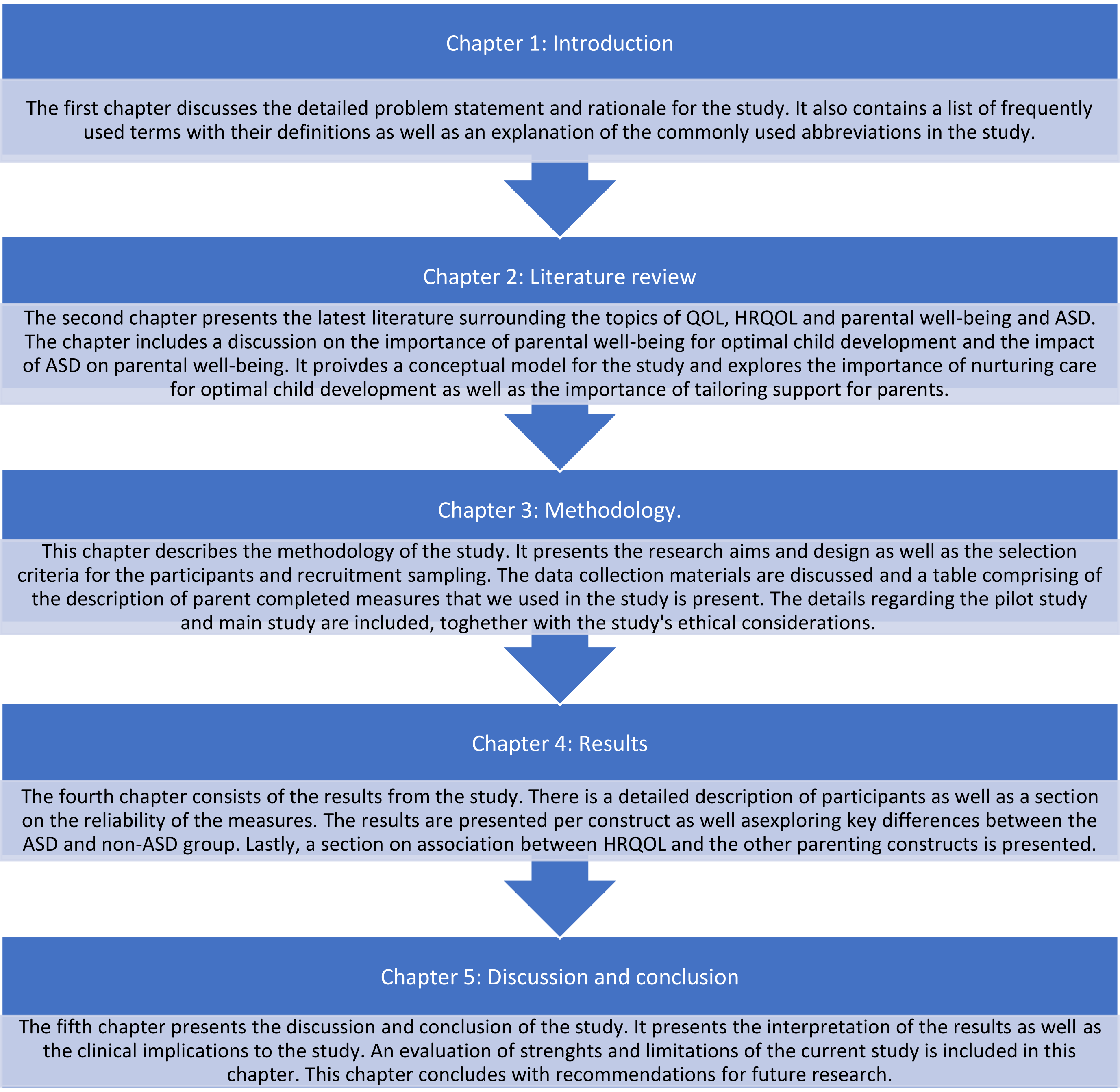
	lower middle income, upper middle income, and high income- using gross national income (GNI) per capita valued annually in US dollars using a three-year average exchange rate (Fantom & Serajuddin, 2016, p4). The classification is published annually and can be viewed on http://data.worldbank.org.

1.4 Abbreviations

ASD:	Autism Spectrum Disorder
DASS:	Depression, Anxiety and Stress scale.
HRQOL:	Health-related quality of life
P-SEMI:	Parenting Self Efficacy Measuring instrument.
QOL:	Quality of Life
WHO:	World Health Organization
WHO BREF:	An abbreviated version of the WHOQOL-100. WHO QOL Questionnaire-BREF.
LMIC:	Low and middle-income country
HIC:	High income country

1.5 Chapter outline of the dissertation

Figure 1 illustrates an outline of the five chapters presented this dissertation. A short description of the main discussion points for each chapter is provided.



Chapter 1: Introduction

The first chapter discusses the detailed problem statement and rationale for the study. It also contains a list of frequently used terms with their definitions as well as an explanation of the commonly used abbreviations in the study.

Chapter 2: Literature review

The second chapter presents the latest literature surrounding the topics of QOL, HRQOL and parental well-being and ASD. The chapter includes a discussion on the importance of parental well-being for optimal child development and the impact of ASD on parental well-being. It proivdes a conceptual model for the study and explores the importance of nurturing care for optimal child development as well as the importance of tailoring support for parents.

Chapter 3: Methodology.

This chapter describes the methodology of the study. It presents the research aims and design as well as the selection criteria for the participants and recruitment sampling. The data collection materials are discussed and a table comprising of the description of parent completed measures that we used in the study is present. The details regarding the pilot study and main study are included, toghether with the study's ethical considerations.

Chapter 4: Results

The fourth chapter consists of the results from the study. There is a detailed description of participants as well as a section on the reliability of the measures. The results are presented per construct as well asexploring key differences between the ASD and non-ASD group. Lastly, a section on association between HRQOL and the other parenting constructs is presented.

Chapter 5: Discussion and conclusion

The fifth chapter presents the discussion and conclusion of the study. It presents the interpretation of the results as well as the clinical implications to the study. An evaluation of strenghts and limitations of the current study is included in this chapter. This chapter concludes with recommendations for future research.

Figure 1. Outline of the dissertation chapters.

1.6 Summary

This chapter introduced the problem statement and rationale for this study. It highlights the reasons for why a scientific study is warranted to compare the HRQOL levels of caregivers raising a child with ASD, to those caregivers of a child without ASD, in South Africa. The terminology that is frequently used in the study is defined, and an explanation of the abbreviations used is provided. Finally, this chapter presents an overview of all the chapters that forms part of this dissertation.

Chapter 2

Literature review

2.1 Introduction

This chapter presents the literature on the importance of caregivers' health and well-being to create a responsive family environment which is essential for optimal early childhood development, by focussing on the Nurturing Care Framework and the Developmental Systems Model. The following sections investigate the impact of ASD on parental health and well-being; and introduce the concept of HRQOL, particularly the HRQOL of parents and caregivers of children with ASD. This section is followed by a description of the South African context. Lastly, the conceptual model of this study is presented.

2.2 The importance of parental health and well-being for optimal child development

The fields of early childhood development and early childhood intervention strongly emphasise the importance of parental health and well-being as a springboard to create a responsive family environment which is conducive for optimal child development. The following sections discuss two prominent frameworks that explores the associations between parent characteristics and child development.

2.2.1. Nurturing Care Framework

The World Health Organisation (WHO), UNICEF and the World Bank group developed the Nurturing Care Framework for early childhood development (World Health Organisation, 2018). The framework identifies five components that are essential for optimal child development. Figure 2 is based on the components of Nurturing Care Framework and illustrates all of the five areas required to produce nurturing care for a child and therefore enable them to develop optimally. These are (1) adequate nutrition, (2) good health, (3) security and safety, (4) responsive caregiving, and (5) opportunities for early learning. This framework is a roadmap for action and outlines the following: (a) the importance of promoting and improving health, well-being and human capital from the earliest years; (b) the identification of the major threats to childhood development; (c) the protection of children and promoting development; and (d) the importance of supporting parents or people taking care of children (i.e., caregivers) in order to provide nurturing care for their children.

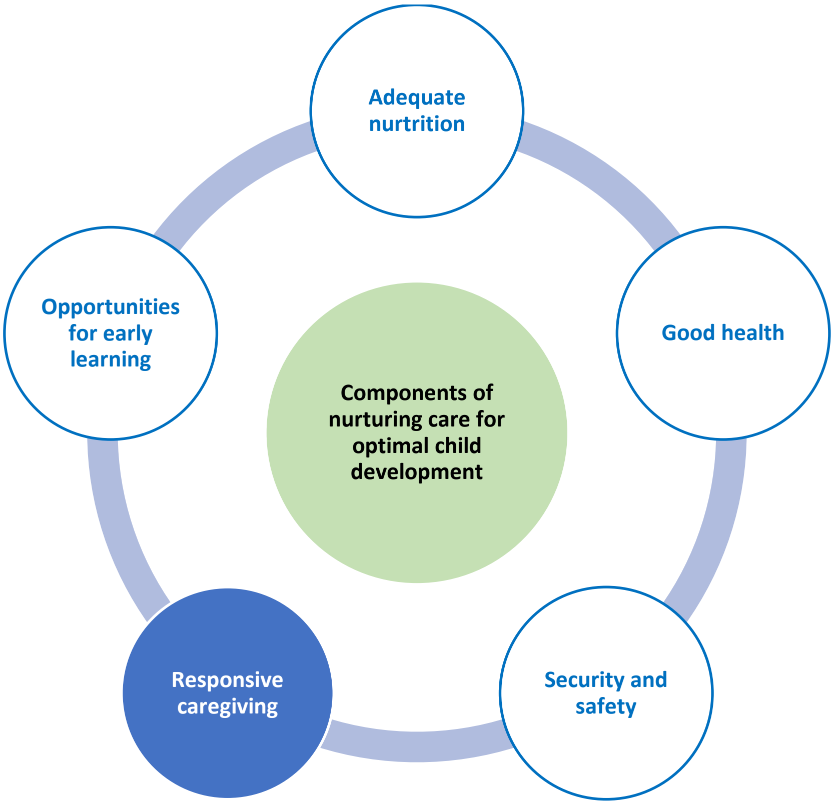


Figure 2. Components of Nurturing Care for optimal child development

Children require appropriate nurturing care to reach optimal child development, and this is dependent on the opportunities that children are exposed to and the resources that are available to them. These opportunities and resources may be dependent on their caregivers' health and well-being. If parents are not well and healthy, they might be unable to provide responsive caregiving. Responsive caregiving includes the ability to protect their child from injury and illness, as well as responding appropriately to their child to facilitate social engagement and learning (World Health Organisation, 2018).Therefore, the involvement and strengthening of the family is paramount for optimal child development. Having a better understanding and awareness of parental health and well-being can lead to the providing appropriate support to parents. The Nurturing Care Framework identifies three elements required for family strengthening: access to quality services, skills building, and caregiver or parental support (Britto et al., 2017). Supporting the health and well-being of parents (and in particular those parents who are struggling) can reduce the burden of risk for poor childhood development, as well as the costs of these risks to human development (Richter, 2018).

2.2.2 Developmental Systems Model

The Developmental Systems Model looks at the links between (a) family stressors (including child characteristics and family characteristics), (b) family patterns of interaction and (c) child developmental outcomes (Guralnick, 2005). In this model Guralnick (2001, 2005) proposes four factors which affect family patterns of interaction, namely: personal characteristics of parents; financial resources, social support, and child characteristics. The model suggests that child characteristics (such as having ASD) and family stressors (such as a caregiver health and well-being) can influence the family's patterns of interaction, which in turn influence optimal child development. The Developmental Systems Model highlights the importance of understanding caregiver health and well-being to support positive family interaction patterns (Guralnick, 2001, 2005). Figure 3 is an adaptation of the Developmental Systems Model and highlights the relationship between parental health and well-being, family patterns of interaction and child development (Guralnick, 2001).

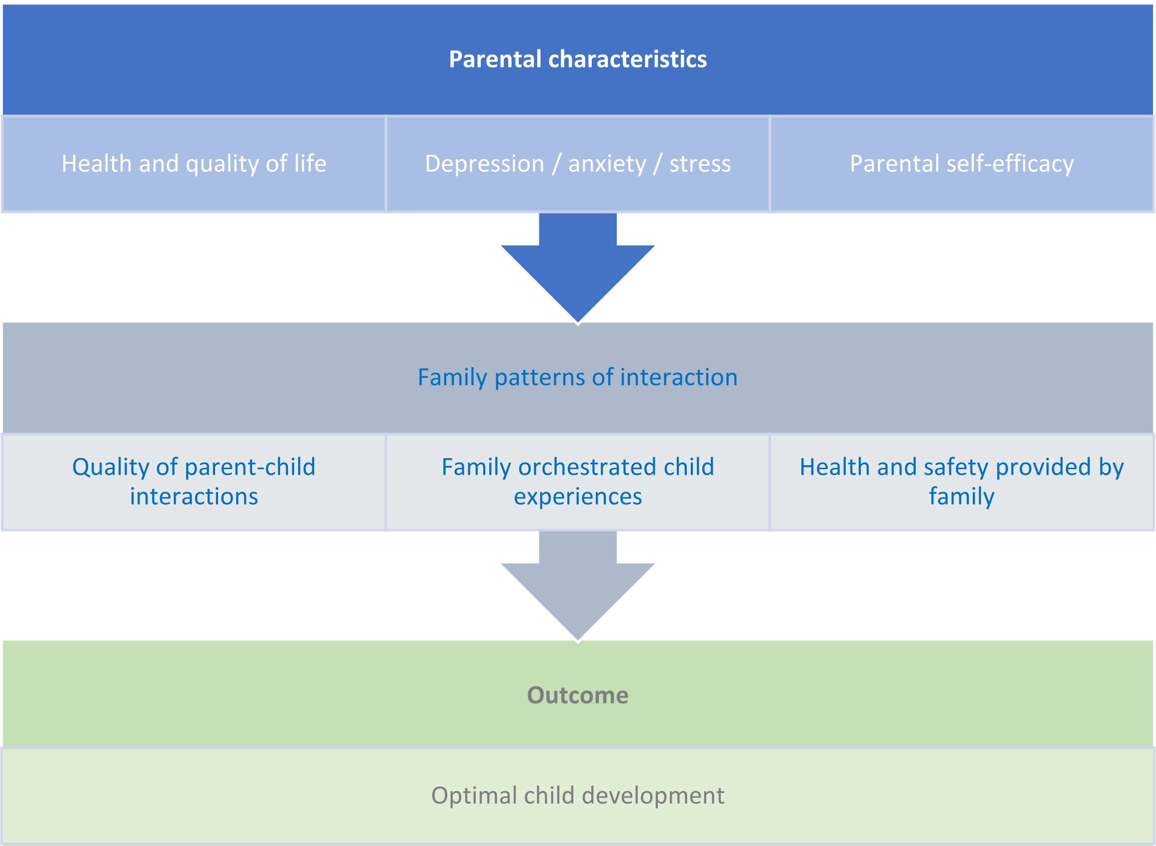


Figure 3. Relationship between parental characteristics, family patterns of interaction, and child development

2.3 Parental health and well-being

2.3.1 Defining health-related quality of life

In the 1970s, researchers from economics, health care and social sciences developed conceptualisations for the term “life quality” (Cummins & Lau, 2006). The WHO defines QOL as an individual’s “perception of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns” (Eapen et al., 2014). The general concept of quality of life measures all aspects of life on general well-being and was found to be too broad to be used for a health care context. While QOL evaluated non health-related aspects of life, HRQOL is used within specific aspects of health (Gurková, 2011).

The WHO define health as “a state of complete physical, mental and social wellbeing and not merely the absence of disease” (Gurková, 2011). The definition of HRQOL seems to vary (Hsiao, 2016), and while there is no universal definition of QOL, it is widely accepted as a multidimensional concept (Tavernor, Barron, Rodgers, & Mcconachie, 2013). There has been agreement that HRQOL is a multidimensional construct built up of three core domains, these include: physical well-being, emotional well-being and social well-being (Gurková, 2011; Lipscomb, Gotay, & Snyder, 2005). These three domains are in keeping with the WHO definition of health (Gurková, 2011).

When considering the difference between QOL and HRQOL, it is evident that QOL consists of all aspects of life beyond simply health care, these include: standard of living, education and public safety which gives it a broad meaning compared to HRQOL which refers to aspects of life that are health related (Gurková, 2011; Lipscomb et al., 2005). Therefore, HRQOL is considered a subset that relates to the health domain of QOL. HRQOL is the term used when focussing on health-related QOL and is a primary component of QOL (Ferrans et al., 2005).

2.3.2 Measuring health-related quality of life

In the last 15 years several questionnaires have been developed and used to measure HRQOL. These include, amongst others, the WHO QOL Questionnaire-BREF (WHOQOL-BREF); the 12 Item Short-Form Health survey; the EuroQOL Five- Dimensional Questionnaire (EQ5D), and the 36-Item Short Form Survey (SF-36). All these questionnaires are self-administered and the majority of them use Likert scale response formats, except for the EQ-5D, which uses a descriptive scoring system to determine health states, as well as a visual analogue scale which captures a person’s rating of their current health.

The majority of the questionnaires are divided into several sub-sections or subscales and total scale scores are obtained by summing the scores for each of the subscales. For example,

- The WHOQOL-BREF divides HRQOL into four dimensions namely: physical health, psychological health, social relations, and environment, and it is one of the more common measures of HRQOL (Latefa A. Dardas & Ahmad, 2014a).
- The 12 Item Short- Form Health survey has 12 items and measures both the physical and the mental dimensions of HRQOL (Allik, Larsson, & Smedje, 2006).
- The EQ-5D consists of five items measuring 5 dimensions of HRQOL namely: mobility, self-care, usual activities, pain/discomfort and anxiety/depression (Hoefman et al., 2014; Konerding, 2013).
- The SF-36 has 36 items and measures the impact of participant's physical and emotional health on quality of life (Johnson et al., 2011a).

There are two questionnaires that have been developed specifically to be filled out by caregivers of children with ASD. They are:

- Care-related quality of life instrument (Carer QOL) that is based on the EuroQOL, and is an ASD specific tool used to measure the impact of caregiving for children with ASD (Hoefman et al., 2014).
- Quality of Life in Autism (QOLA). The QOLA consists of two parts and measures the parents' perception of their quality of life as well as their perception of how problematic their child's ASD related difficulties are for them (Eapen et al., 2014).

The WHOQOL-BREF (although not a questionnaire specifically developed for caregivers) has often been used to capture the self-reported HRQOL of parents of children with ASD or other disabilities. In these instances, the questionnaire captures how caring for an individual with a health condition (for example, caring for a child with ASD) affects a caregiver's perception of their HRQOL. The WHOQOL was also used in the only study up to date that measured the HRQOL of caregivers of children with ASD in South Africa (Alhazmi et al., 2018). The next section describes a more detailed description of recent studies reporting the HRQOL in caregivers of children with ASD.

2.3.3 HRQOL of parents raising children with ASD

As mentioned in the previous section, traditionally, the HRQOL of an individual is captured using self-report tools from the perspective of the individual with the health concern or condition. While parents or caregivers of children with ASD do not have the disability themselves, they are at risk of having less optimal health and well-being (Hsiao, 2016). This will be explored in more detail in the next section). It is becoming increasingly important to understand and monitor the health and well-being of caregivers who are raising children with ASD (Ali Dardas, 2014; Fewster et al., 2020). Key findings from some of the recent studies reporting the HRQOL in caregivers of children with ASD are provided in Table 2.

Table 2. Selected studies reporting on the health-related quality of life for parents and caregivers of children with Autism Spectrum Disorder

No	Author, Year and Country	Participants	Design	Results
WHO Quality of life- BREF (WHOQOL- BREF)				
1.	(Alhazmi et al., 2018) South Africa	52 parents. Mean parental age 33.4 years.	Comparative study	Parents of children with ASD had lower mean QOL scores for all domains compared to parents of typically developing children. Significant differences were found in four QOL domains: physical, environmental, psychological, and social.
2.	(Pisula & Porębowicz-Dörsmann, 2017) Poland	202 parents. Mean age of mothers (ASD- 39.56 years, control- 39.94 years) and mean age of fathers (ASD- 41.87 years, control- 41.62 years).	Comparative study	Parents of children with ASD scored lower than parents of children with typically developing children in the following domains: physical, psychological, and social relationships. There was no difference in the environmental domain.
3.	(Latefa A. Dardas & Ahmad, 2014a) Jordan	184 parents of children with ASD. Mean age of 37 years.	Descriptive study	Parents showed acceptable physical and social health; however, their environmental health was relatively poor. Fathers and mothers of children with ASD showed no significant differences in their QOL levels. The QOL of the parents was related to their stress levels, coping abilities and some key demographic and cultural factors.
12 Item short form (SF-12)				
4.	(Johnson et al., 2011) USA	64 female and male partners that were biological parents of one or more children between the ages of 2-18 years with a diagnosis of ASD.	Descriptive study	The stress of caregiving was associated with female physical health but not mental health. For males, only the stress personal family life subscale was associated with the mental and physical health. Higher discrepancy scores for family functioning were related to lower mental health for both males and females. The discrepancy score mediated the effect of personal and family life stress on male mental health but not physical health.
5.	(Benjak et al., 2009) Croatia	178 parents of children with ASD and 172 parents of non-disabled children matched by age, education and place of living.	Comparative study	Parents of children with ASD had poorer health than the control group in all areas except for physical health.
6.	(Allik et al., 2006) Sweden	31 mothers and 30 fathers of 32 children with Asperger's syndrome or High functioning Autism and 30 mothers and 29 fathers of 32 age and gender matched children with typical development.	Comparative study	The mothers of children with High Functioning Autism or Asperger's syndrome had poorer physical health compared to the controls as well as to the father's. In the group of children with High Functioning Autism or Asperger's, maternal health was related to behaviour problems.
Euro-QOL five-dimensional Questionnaire (EQ5D)				
7.	(Khanna, Jariwala, & Bentley, 2013a) USA	Primary caregivers (age 18-44) of children with ASD 18 years or younger.	Comparative study	Caregivers had a lower health utility score than their counterparts in the general adult US population.
8.	(Khanna, Jariwala, & Bentley, 2013b) USA	316 Primary caregivers of children with ASD.	A cross-sectional design	More than 60% of the participants reported 'anxiety/depression'.
CarerQOL				

No	Author, Year and Country	Participants	Design	Results
WHO Quality of life- BREF (WHOQOL- BREF)				
9.	(Hoefman et al., 2014) USA	224 families of children with ASD. The children were on average 8.4 years.	Descriptive study	Caregivers of children with ASD reported mental health problems (58%), physical health problems (52%) and financial problems (56%).
Quality of life in Autism (QOLA)				
10.	(Eapen et al., 2014) Australia	A clinical group, consisting of parents of children with ASD (23 mothers) and a control group, consisting of parents (13 mothers and 3 fathers) of children without ASD. The ASD children had a mean age of 46.8 months. The children without ASD had a mean age of 43.2 months.	Instrument development study	The measure has good internal consistency. It has good convergent validity with other measures of QOL and ASD symptom severity. It is a valuable assessment tool and warrants further psychometric evaluation.

It is evident from Table 2 that these studies have taken place in many countries, namely: Sweden, the United States of America, Poland, Croatia, Australia, and South Africa. Taken together the study findings indicate that parents of children with ASD often reported a lesser optimal level of health and well-being when compared to their peers in the general population who are raising children with typical development. However, it is important to note that when assessing QOL or HRQOL, one is assessing subjective perceptions of health and well-being. The measures capture a snapshot in time and therefore warrants cautious interpretation.

Parents and caregivers of children with ASD report a lower HRQOL compared to other parents and caregivers. As seen in the table above, the studies conducted in South Africa, Poland and Jordan showed that parents of children with ASD had lower QOL scores compared to parents of children without ASD (Alhazmi et al., 2018; Latefa A. Dardas & Ahmad, 2014b; Pisula & Porębowicz-Dörsmann, 2017). A study that investigated the HRQOL of parents in South Africa raising children with ASD. It was found that parents raising children with ASD had a poorer health-related life quality compared to parents raising children without ASD in the same community (Alhazmi et al., 2018). This study found parents to have poor HRQOL across all domains, namely: physical, psychological, social and environmental health (Alhazmi et al., 2018).

In another study, parents raising a child with a developmental disability report poor QOL, physical health, mental health and increased stress (Bonis, 2016; Scherer, Verhey, & Kuper, 2019; Vasilopoulou & Nisbet, 2016). However, Mugno, Ruta, D'Arrigo, and Mazzone (2007) report that caregivers of children with Pervasive Developmental Disorders (PDD) display higher levels of stress compared to caregivers of children with cerebral palsy and other intellectual disabilities. When comparing mothers of children with ASD and mothers of children with other disabilities, mothers of children with ASD have been found to have higher stress and psychological problems (Rivers & Stoneman, 2003). There are a number of studies that have similar findings, stating that parents of children with ASD have a poorer HRQOL (Benjak et al., 2009; Yamada et al., 2012). It is therefore well documented that parents raising a child with ASD leads to higher levels of stress and a poorer HRQOL than parents raising children with other disabilities or without disabilities (Hayes & Watson, 2013; Kim, Kim, Voight, & Ji, 2018; Rivers & Stoneman, 2003).

Risk and resistance models are now being investigated to assess what variables will increase families' resilience. A study conducted by Lee, Bain, Curtiss, Volker, Lopata, Thomeer, Rodgers and Toomey

(2018) found that there are no risk or resistance variables that would significantly affect a caregivers' physical health. It was however found that a child's risk variables such as functional impairments and social functioning as well as caregiver's ecological variables such as resources impacted the caregivers' mental health related QOL (G. K. Lee et al., 2018).While it is documented that children with ASD put strain on the caregivers or parents, there is a lack of data available which documents QOL in ASD research (Eapen et al., 2014). Research which documents QOL has become a useful indicator of the impact of individuals with ASD on parental and family well-being (Eapen et al., 2014). However documenting QOL outcomes, specifically in the field of autism, is still relatively new, and research relating to parents HRQOL is limited. The QOL of a child with ASD is dependent on the QOL of the parent which stresses the importance of understanding and ultimately improving the parent's QOL where necessary (Burgess & Gutstein, 2007).

2.4 The broader impact of ASD on parental health and well-being

While the previous section focused specifically on HRQOL of parents and caregivers of children with ASD, this section provides a broader look at the well-documented negative impacts of ASD on caregiver functioning including depression, stress, anxiety, and lower parental self-efficacy. While discussing these negative aspects it is, however, important to acknowledge that many positive impacts of ASD on the family, have also been documented (see 2.6).

2.4.1 The negative impact of ASD

Depression, Stress and Anxiety

Raising a child with ASD is understood to be a challenging task (Hoefman et al., 2014). Many studies have been conducted on psychological distress of parents and caregivers of children with ASD and the majority of these studies all report that parents and caregivers of children with ASD have increased stress. The high demands of looking after and raising children with ASD can often have a negative effect on the caregivers and may result in depression, anxiety, psychological distress as well as other mental or physical problems related to their health (Hoefman et al., 2014; Hsiao, 2016; Johnson et al., 2011). A study conducted on Jordanian parents of children with ASD, found that raising a child with ASD affected the parents psychological functioning and was a source of stress for the parents (Ali Dardas, 2014). Similarly, parents living in Oman and raising children with ASD were found to experience stress, anxiety and depression as a result of caring for a child with ASD (Al-Farsi et al., 2016). Many children with ASD have behaviour that is unpredictable and caregivers report that this increases their stress and decreases their coping abilities (Larson, 1998, 2006). There is evidence to support that long-term caregiving for a child with disabilities may result in poor emotional and physical health in caregivers (Murphy, Christian, Caplin, & Young, 2007). Several studies have reported that parenting a child with ASD results in high levels of stress and depression (Abbeduto et al., 2004; Cutress & Muncer, 2014; Estes et al., 2009). In fact, Mugno, Ruta, D'Arrigo, & Mazzone, (2007) conclude that caregivers of children with Pervasive Developmental Disorders (PDD) display higher levels of stress compared to caregivers of children with cerebral palsy and other intellectual disabilities.

Studies have also stressed the importance of medical and social support that these parents of children with ASD require to alleviate the financial burden and general stressors they face when it comes to raising a child with ASD (Bitsika, Sharpley, & Mailli, 2015). Parents of children with ASD, have more medical challenges for their child, needing therapy, counselling, treatment and physician visits and therefore would benefit from increased medical support (Gurney, McPheeters, & Davis, 2006). The personal characteristics of parents, financial resources, social support and child characteristics would affect a family's pattern of interaction and would be particularly affected in a family with a child with ASD (Murphy et al., 2007).

When it comes to raising a child with a disability, there is a substantial emotional and financial strain on families (Ali Dardas, 2014; Latefa Ali Dardas & Ahmad, 2014; World Health Organisation, 2018). Research reports that raising a child with a disability results in high expenses, loss of employment or lost career development opportunities (Leonard, Johnson, & Brust, 1993). Children with disabilities and developmental difficulties require as much or even more nurturing care than any other child (World Health Organisation, 2018). It has been reported that 250 million children (under the age of 5), in 141 LMIC's live in conditions of extreme poverty (Richter, 2018). According to Buescher, Cidav, Knapp, and Mandell, (2014), the cost of supporting an individual with an Autism Spectrum Disorder (ASD) and intellectual disability during their lifespan was $2.4 million in the United States and £1.5 million in the United Kingdom. The largest cost components of this figure (for children with ASD) were access to special education and intervention services and parental productivity loss. Financial strain, as well as maternal depression, are risk factors and have been found to occur at a higher rate in LMICs compared to HICs. The financial burden and psychological stress related to caring for a child with ASD has been well documented (Buescher et al., 2014; Chan et al., 2012; Hoefman et al., 2014).

2.4.2 The links between health-related quality of life and other parental well-being constructs

The impact of raising a child with ASD on the health and well-being of parents was already described in detail in Section 2.3. This section provides an overview of the studies that explored the links, or relationships, between parental constructs such as depression, anxiety, stress and QOL or HRQOL.

Several studies have reported that parenting a child with ASD resulted in higher levels of stress and depression and this had a negative impact on the caregivers' QOL (Abbeduto et al., 2004; Cutress & Muncer, 2014; Dabrowska & Pisula, 2010; Estes et al., 2009). Similarly, stress had a negative effect on the parents' mental health and was found to be a significant predictor of mental HRQOL (Al-Farsi et al., 2016; Hsiao, 2016; Johnson et al., 2011). Hsiao, (2016) considered the correlation between parenting stress, parental HRQOL, and behaviour characteristics of a child with ASD. They reported that parental stress has a direct effect on parental HRQOL and the performance of a child with ASD has a direct effect on parental stress and parental HRQOL. It has been found that ASD-related problem behaviour as well as comorbidities affect the parents stress and in turn affect the parents mental HRQOL (Peters-Scheffer et al., 2012; Reed & Osborne, 2012). Peters-Scheffer et al. (2012) stated that parents that are exposed to chronic stress involved with caring for a child with a disability are affected in several domains in their lives, such as poor health and mental health statues which would then be seen to affect their HRQOL. It appears that behaviour problems are the most challenging for parents to cope with (Reddy et al., 2019). Some research has reported a number of positive experiences from parenting a child with ASD, such as spiritual growth, emotional growth and personal gain, however this does not necessarily result in improved HRQOL and these parents stress the importance of receiving support in order to improve the life of their child (Reddy et al., 2019).

2.5 The South African context

This section provides a background to the South Africa context, which is particularly important as many families are living in extreme poverty. The statistics of people living in extreme poverty in South Africa increased from 11 million in 2011 to 13.8 million in 2015 (Walker, 2017).

Most of the studies conducted are conducted in the more affluent Western countries despite the fact that approximately 90% of individuals with ASD live in low to middle income countries (LMIC) (de Vries, 2016; Samadi & Samadi, 2020). According to the Centres for Disease Control and Prevention (CDC), the overall prevalence of ASD in 2010 was found to be 1 in every 68 children aged 8 years (Baio, 2014). National organisations for children and families with Autism exist in more than 80 countries, indicating an increase in awareness of the diagnosis of Autism globally (Samadi & Samadi, 2020). There has been an increase in studies and interest on the impact on parents' caring for a child with ASD however there has not been as many studies conducted in the less affluent countries (Samadi & Samadi, 2020). A substantial base of empirical evidence exists in high income countries which documents the impact of the behaviours of a child with ASD on families, specifically the impact on parents and/or caregivers, there is, however, very little evidence in countries such as South Africa.

There is very limited research on ASD in Sub-Saharan Africa (Bakare & Munir, 2011; Malcolm-Smith, Hoogenhout, Ing, Thomas, & De Vries, 2013; Schlebusch et al., 2016). There is little known about ASD in Africa, the prevalence rate for Autism in Africa is not known (Ametepee & Chitiyo, 2009). The focus on research in Sub-Saharan Africa has been on communicable diseases, such as malaria, with little focus on neurodevelopmental disorders such as ASD (Franz, Chambers, von Isenburg, & de Vries, 2017). In order to investigate the limited research on ASD in Sub-Saharan Africa, a comparison was done on the number of publications from each continent by Franz et al (2017). A total of 24, 467 publications were identified, with only 120 of those from Sub-Saharan Africa (Franz et al, 2017). A study conducted by Olusanya et al., (2018) released figures, stating that there were 1 099306 cases of children younger than 5 years with ASD in 2016 in Sub-Saharan Africa. Although there is little published data on the incidence and prevalence of ASD in South Africa, there is no reason to believe that there is a difference in the incidence and prevalence rates in Sub-Saharan Africa.

There is a need for further research to be conducted in LMIC where most children with ASD live. As previously mentioned, most studies are conducted in HIC (Samadi & Samadi, 2020). These studies would therefore release data which would result in very different consequences (Samadi & Samadi, 2020). It is important for future research to be conducted with different cultural groups in order to have a better understanding of caregiving in different contexts therefore leading to better and more appropriate support and packages (Samadi & Samadi, 2020).

It must also be noted that South Africa has limited resources for education, health care and support services (Reddy et al., 2019). In a study conducted in the Western Cape, 940 children with ASD were identified as attending school, this indicates a rate of 0.08% demonstrating that the Western Cape is unable to meet the needs of the community (Pillay et al., 2020). There has been a significant increase (by 71.3% in the last 26 years) in the number of children under the age of 5, in sub-Saharan Africa with epilepsy, intellectual disability, sensory impairments, ASD and attention-deficit hyperactivity disorder (ADHD) (Olusanya et al., 2018). There is a poor outcome for these children due to unfavourable cultural beliefs, discrimination, risk of neglect, maltreatment and violence (Olusanya, de Vries, et al., 2018). These children are therefore possibly not reaching their full potential. Children need nurturing care to reach their full potential. The Sustainable Development Goals (SDG's) now include disability with the hope to decrease the current rate of children with disabilities in sub-Saharan Africa (Olusanya, de Vries, et al., 2018). The prospects for this global vision in sub-Saharan Africa is uncertain, however sub-Saharan Africa is critical for achieving significant improvement with regards to the burden of developmental disabilities worldwide (Olusanya et al., 2018). Some of the SDGs include: poverty reduction, food security, improved nutrition, ensuring healthy lives and wellbeing and inclusive and equitable quality education (Olusanya et al., 2018). Nurturing care refers to situations and environments that promote health, nutrition, security, safety, responsive caregiving and opportunities for early learning (World Health Organisation, 2018). If children are not provided with nurturing care in their early years, they are more likely to have learning difficulties in school, at a later stage, which may impact their earnings and well-being later on in life (World Health Organisation, 2018). There is an increase in research investigating the link between poverty, disability and health however there is already a link reported between these three (Groce et al., 2019).

It is documented that children are not reaching their full potential if they are exposed to poor health, nutrition, exposure to stress and limited opportunities for early learning (World Health Organisation, 2018). Researchers are well aware of what is required in order to improve services in low middle income country (LMIC) for families and young children (Richter, 2018). Parent groups as well as home visits for the most vulnerable families in HIC and LMIC have been found to improve young children's growth and development (Yousafzai, Rasheed, Rizvi, Armstrong, & Bhutta, 2014). There are a few examples in LMIC whereby the services to all children at risk have scaled up. India's Integrated Child Development which was started in 1975, now supports more than 46 million mothers of children between the period of birth and 3 years of age while the early childhood programme in Chile (Chile grows with you) reaches almost 80% of all poor children (Richter, 2018).

From studies conducted in South Africa, it is evident that caregivers of children with ASD had difficulty coping, especially with resource limitations, financial burdens, limited skills and the stigma that comes to caring for a child with ASD (Reddy et al., 2019). These families have also reported the need to improve their emotional well-being (Schlebusch, Dada, & Samuels, 2017). Studies have also highlighted the poor guidance from health care professionals as well reduced awareness of ASD and stigma for families with children with ASD (Reddy et al., 2019). The challenges faced by caregivers of children with ASD in South Africa highlights the need for further research to be conducted in Sub-Saharan Africa but more specifically, in South Africa.

2.6 An important caveat

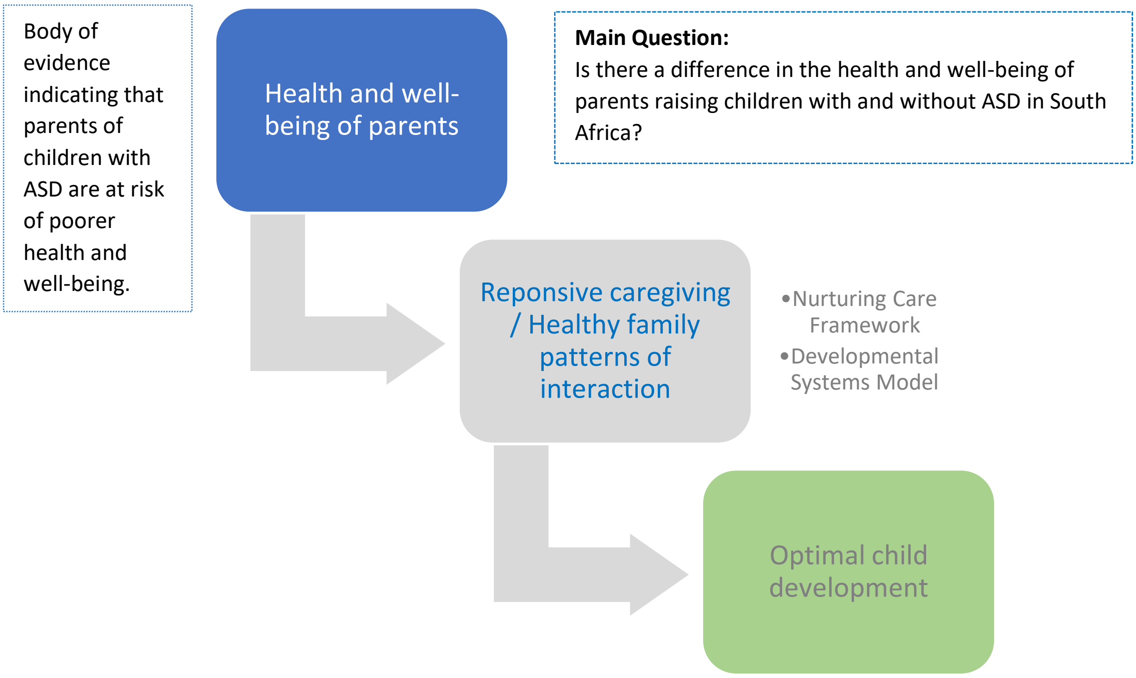
It must be noted that some studies have reported a positive outlook on raising a child with ASD. Bayat, (2007) found that 62% of the families that participated in the study, reported that their family was closer as a result of having a child with a disability (Bayat, 2007). The same study revealed that having a child with ASD, brought the siblings closer, illustrating the positive aspects of raising a child with a disability (Bayat, 2007). Gray, 1993a investigated the perceived stigma of parents of children with ASD. One would assume most parents of ASD children feel stigmatised due to their child's condition. This particular study however reported that although the majority of the parents did feel stigmatised, a large portion did not feel stigmatised due to their child's condition (Gray, 1993). Schlebusch and Dada (2018) reported the positive and negative cognitive appraisal of the impact of children with ASD on the family. The study found that families saw the impact that the child with ASD had on the family as both positive and negative (Schlebusch & Dada, 2018). Although the cost of raising a child with ASD is a negative factor, the families found the positive side of raising a child with ASD made them more aware of other people's needs and struggles (Schlebusch & Dada, 2018).

It is therefore important to note that the negative impacts of raising child with ASD are not the only impacts, and that many parents also report on the positive impacts of having a child with a disability. Even though parenting a child with ASD can be a huge burden on the family, some parents have however reported a positive meaning to caring for a child with ASD (Reddy et al., 2019). Parents discovered the challenges involved with raising a child with ASD included limited resources, financial burdens, decreased awareness of ASD and poor guidance from health care professionals (Reddy et al., 2019). These parents developed coping strategies to enable them to deal with these challenges (Reddy et al., 2019). The positive outcomes from raising a child with ASD included positive personality traits such as resilience and perseverance as well as improved spiritual faith and appreciation for life (Reddy et al., 2019).

2.7 Conceptual model of this study

It is well documented that children need a nurturing care environment to develop optimally (World Health Organisation, 2018). An important component of this environment is to have healthy and well caregivers to provide responsive caregiving in order for a child to develop optimally (World Health Organisation, 2018). There is a risk however that the health and well-being of parents raising children with ASD is impaired (Hsiao, 2016). It is therefore important to measure parents' health and well-being as well as how the parenting constructs relate to one another because we need healthy and well parents to do responsive caregiving (NCF) and a health family patterns of interaction (Developmental Systems Model) to promote optimal child development for children with ASD.

This study aims to see if there is a significant difference in the health and well-being of parents raising children with ASD compared to parents raising children without ASD. The results from this study will determine if there is an association between HRQOL and parenting constructs such as stress, anxiety and parental self-efficacy. Figure 4 illustrates the outline of this study and indicates the link between health and well-being of parents and the responsive caregiving and supportive interaction patterns described in the two conceptual models presented earlier in the chapter.



Body of evidence indicating that parents of children with ASD are at risk of poorer health and well-being.

Main Question:
Is there a difference in the health and well-being of parents raising children with and without ASD in South Africa?

Figure 4. Conceptual model of this study

Knowing the health and well-being of parents of children with ASD in South Africa by comparing their HRQOL, depression, anxiety and stress, and parental self-efficacy with their peers without children with ASD and having a better understanding of how these constructs relate to one another, will help us to create better parent support services that can build and support caregivers and their capacity to provide nurturing care to their children.

2.8 Summary

This chapter presented the literature on the importance of parental health and well-being and the need to create a responsive family environment to ensure children develop optimally. It focusses on both the Nurturing Care Framework as well as the Developmental Systems Model. The effect that ASD has on parental health and well-being is discussed. The term, HRQOL is explained, specifically the HRQOL of caregivers raising children with ASD. There is a description of the South African context and in conclusion, the conceptual model of this study is presented.

Chapter 3

Methodology

3.1 Introduction

This chapter focusses on the methodology for the study. It states the research aims and design, as well as the participant selection and recruitment procedures. The study measures are described; followed by a presentation of the pilot study. Thereafter, the main study is described with regards to the ethical considerations and data collection procedures.

3.2 Research aims

The study has the following primary research aim: To determine if there a difference in the health and well-being of caregivers of children with ASD and caregivers of children without ASD in the South African context. To address the main research aim, the following sub-aims were investigated:

I. To measure and describe the **HRQOL** of caregivers who have children with and without ASD.
II. To measure and describe other parenting constructs such as **depression, anxiety and stress** and **parental self-efficacy** for both caregiver groups.
III. To determine the potential differences between the two parent groups on HRQOL and other parenting constructs.
IV. To explore associations between the HRQOL and other parenting constructs such as, depression, anxiety and stress, and parental self-efficacy.

3.3 Research design

This study is a quantitative study and employed an analytical, comparative design (Cantrell 2011). The study involves the comparison between two groups, namely caregivers of children with ASD and caregivers of children without ASD. A comparative research design is common in special education research with regards to comparing those with a disability and those without a disability (Mertens & McLaughlin, 2013). One concern that needs to be addressed when using a comparative study is differential selection. If the two groups are not comparable on key characteristics, then these characteristics may affect the results, rather than the independent variable being contrasted, which in this case is the presence or absence of ASD. Figure 5 illustrates the two groups and the three study constructs under investigation.

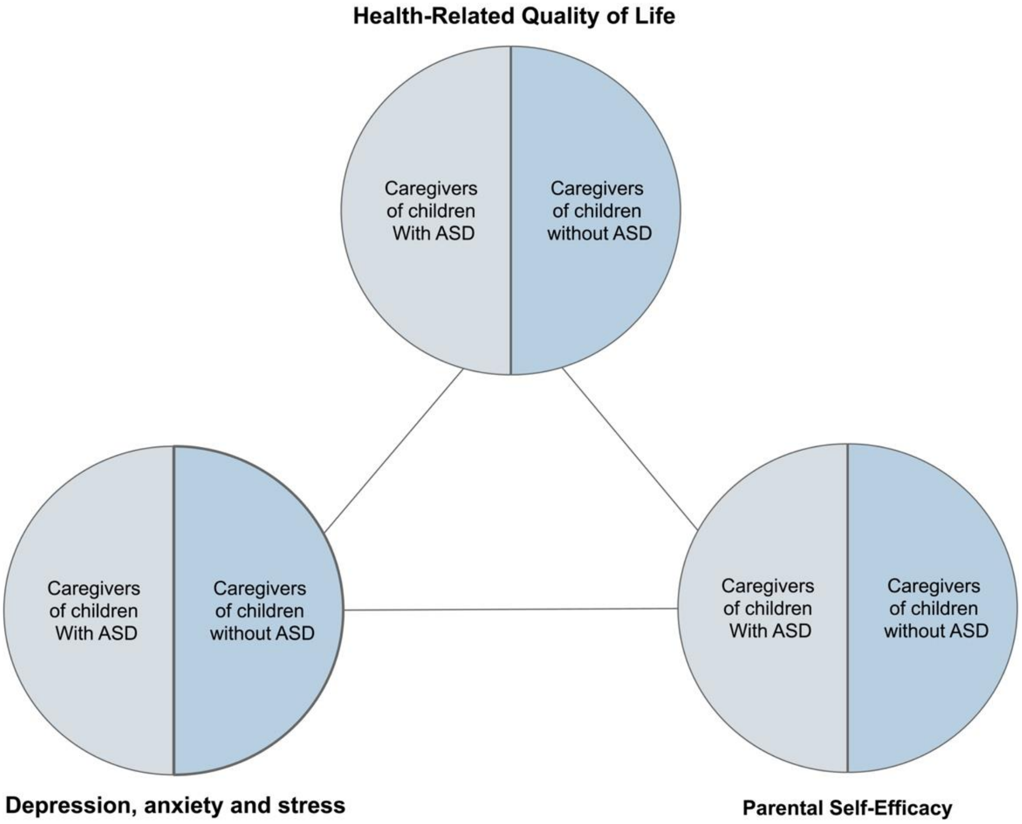


Figure 5. Overview of the two caregiver groups and three study constructs

3.4 Participants

3.4.1 Selection criteria

Two caregiver groups participated in this study. The first group were caregivers of children with ASD. The second group were caregivers of children without ASD. The following inclusion and exclusion criteria were determined for each parent group:

Criteria for the caregiver of a child with ASD

- The child must be enrolled at an ASD-specific LSEN (learners with special educational needs) school in the eThekwini district in Kwa-Zulu Natal province of South Africa.
- The caregiver must have a long-term caring responsibility for the child and the child must live with the caregiver.
- Caregivers should be willing and able to complete the questionnaire in English.
- Only one caregiver per family is required.
- The child must be between the ages of 5 and 13 years of age.
- Parents (or caregivers) must be over the age of 18.

Several co-morbidities often co-exist with a diagnosis of ASD. For this reason, children who attended the school would have a primary diagnosis of ASD and were not excluded from the study based on additional co-morbidities such as ADHD etc.

Criteria for the caregiver of a child without ASD

The following inclusion criteria were selected for the study:

- The child must be enrolled at a mainstream school in the same district as the ASD specific school mentioned above.
- The caregiver must have a long-term caring responsibility for the child and the child must live with the caregiver.
- Caregivers should be willing and able to complete the measures in English.
- Only one caregiver per family is required.
- The child must be between the ages of 5 and 13 years of age.
- Parents (or caregivers) must be over the age of 18.

3.4.2 Research sites and sampling

One of the largest schools that caters for learners with special educational needs (including learners with ASD, Grade R to Grade 7) is located in eThekwini district in Kwa-Zulu Natal province of South Africa. Children are admitted based on a series of pre-admissions assessments during which the teacher and therapists assess the child to see if they are suitable for the school. One of the documents required during this phase is a psychologists or other suitably qualified medical professional report specifying a diagnosis of ASD and recommending the child to the school. This school was identified as a recruitment site to invite caregivers of children with ASD to participate in the study. The school principal was contacted, and a meeting set up to discuss the study. Thereafter, the deputy principal was appointed to assist the researcher with the study. The study's aims and objectives were explained, as well as the data collection process and what was required from the school. Once the inclusion and exclusion criteria were outlined, the deputy principal identified children that would meet the selection criteria for the study.

A mainstream school (also Grade R to Grade 7) was identified in the eThekwini district, which is the same district as the ASD school. The schools were matched on their quintile levels. Again, the school principal was contacted, and a meeting was set up. The deputy principal was appointed to assist the researcher with the study. The same process was followed with regards to informing the deputy principal about the study. She randomly selected classes throughout the school and issued the questionnaire to caregivers that met the selection criteria.

Convenience and purposive sampling was used for this study, with the two schools forming the sampling frame (Etikan, 2016) that resulted in a naturally occurring boundary for the sampling group. The sample size for this current study was calculated according to the following formula suggested by Charan & Biswas (2013) for cross-sectional quantitative studies:

Sample size = $r+1/r$ x $[(SD^2) \times (Z_\beta + Z_{\alpha/2})^2]/(d)^2$

Where r = ratio of control cases; SD = standard deviation (taken from previous studies); Z_β = standard variate for power for 80% power the value is 0.84; $Z_{\alpha/2}$= standard normal variate for significance (for this study the value is (1.96); d^2= expected mean difference between cases and controls (based on previous studies). The standard deviation in previous research in parents of children with ASD for the SF-36 is 25.2 (Yamada et al., 2012), and the expected mean difference between parents of children with ASD for the SF-36 is 7.94. Therefore, in this study the sample size for the current study is [*1*+1/*1* x $[(25.2^2) \times (0.84 + 1.96)^2]/(7.94)^2]$ = 158. A minimum of 160 participants had to be recruited, and preferably at least 80 participants per parent group.

3.5 Study measures

In addressing the research aims for this study, the following measures were used:

1) Demographics questionnaire - to capture demographic information.
2) WHOQOL-BREF – to measure HRQOL.*
3) Depression Anxiety Stress Scales (DASS-21) - to measure parental feelings of depression, stress and anxiety.
4) The Parenting Self-efficacy Measuring instrument (P-SEMI) - to measure self-efficacy in the different domains of parenting.

*The QOLA and CarerQOL are measures that have been specifically developed for caregivers of children with ASD (Eapen et al., 2014; Hoefman et al., 2014). However, it was decided to not use these tools for this study as the development of these tools is still in infancy. The study done using the QOLA had a small sample size and therefore the results had to be considered as preliminary (Eapen et al., 2014). The study was also conducted on preschool children and only responses with mother's, therefore further research needs to be done using the tool with older children and with father's responses (Eapen et al., 2014). The study conducted using the CarerQOL had some limitations with regards to the study sample and data collection. The study was conducted with a high ratio of boys and included mainly highly educated working mother's which would not fit the participant selection for this study (Hoefman et al., 2014). The results from the study were also noted to possibly be affected as there was a discrepancy in the two sites used, in terms of wealth and cultural differences (Hoefman et al., 2014). The WHOQOL-BREF has been used in comparative studies with parents of children with ASD (see table 2) and therefore, the WHOQOL-BREF was selected as the most appropriate measure to measure the HRQOL of the study participants. The selected measures are described in detail in Table 3. A description of the reliability of the measures when used with caregivers of children with ASD is provided, as well as the subscales and anchors and a few examples of the items.

Table 3. Description of the study measures

<table>
<tr><th>Name of measure and Author</th><th>Aim</th><th>Reliability for use with parents of children with ASD</th><th>Subscales</th><th>Anchors and sample items</th></tr>
<tr><td rowspan="5">World Health Organization Quality of Life – Abbreviated (WHOQOL-BREF)
(WHO, 1997)</td><td rowspan="5">Measures the impact of physical and psychological health, social relationship and the environment on quality of life.</td><td rowspan="5">The internal consistency ranged from .70 to .77 for the four domains, in a group of mothers with children with ASD (Latefa A. Dardas & Ahmad, 2014b; Shu & Lung, 2005)</td><td>The questionnaire consists of 26 items (rated on a 5-point Likert scale) which covers four broad areas:</td><td><table><tr><td><i>Not at all/ very dissatisfied</i></td><td><i>A little amount/ dissatisfied</i></td><td><i>A moderate amount/ neither satisfied nor dissatisfied</i></td><td><i>Very much/Satisfied</i></td><td><i>An extreme amount/Very satisfied</i></td></tr><tr><td><i>1</i></td><td><i>2</i></td><td><i>3</i></td><td><i>4</i></td><td><i>5</i></td></tr></table></td></tr>
<tr><td>Physical health</td><td>To what extent do you feel that physical pain prevents you from doing what you need to do?</td></tr>
<tr><td>Psychological health</td><td>How much do you enjoy life?</td></tr>
<tr><td>Social relationships</td><td>How satisfied are you with your personal relationships?</td></tr>
<tr><td>Environment</td><td>How satisfied are you with your access to health services?</td></tr>
<tr><td rowspan="4">Depression Anxiety Stress Scales (DASS-21)
(Lovibond & Lovibond, 2005)</td><td rowspan="4">Measures the frequency of parental behaviours and/or intensity of parental feelings of depression, stress and anxiety.</td><td rowspan="4">The internal consistency ranged from .83 to .94 in a group of parents of children with ASD (Lai, Goh, Oei, & Sung, 2015)</td><td>The questionnaire consists of 21 items (rated on a 4-point Likert scale). A DASS total score is computed from the three subscale scores:</td><td><table><tr><td><i>Did not apply to me at all</i></td><td><i>Applied to me to some degree, or some of the time</i></td><td><i>Applied to me to a considerable degree or a good part of time</i></td><td><i>Applied to me very much or most of the time</i></td></tr><tr><td><i>0</i></td><td><i>1</i></td><td><i>2</i></td><td><i>3</i></td></tr></table></td></tr>
<tr><td>Anxiety</td><td>I was aware of dryness of my mouth.</td></tr>
<tr><td>Depression</td><td>I couldn’t seem to experience any positive feeling at all.</td></tr>
<tr><td>Stress</td><td>I found it hard to wind down.</td></tr>
<tr><td rowspan="7">The Parenting Self Efficacy Measuring Instrument (P-SEMI)
(Harty, 2009)</td><td rowspan="7">Measures self-efficacy in six domains of parenting.</td><td rowspan="7">Cronbach’s alpha values for the scale ranged from 0.8 to 0.9 (Harty, 2009).</td><td>The questionnaire consists of 43 items (rated on related a 6-point Likert-scale). A P-SEMI total scores is computed from the six subscale scores:</td><td><table><tr><td><i>Always</i></td><td><i>Almost always</i></td><td><i>Often</i></td><td><i>Sometimes</i></td><td><i>Seldom</i></td><td><i>Never</i></td></tr><tr><td><i>1</i></td><td><i>2</i></td><td><i>3</i></td><td><i>4</i></td><td><i>5</i></td><td><i>6</i></td></tr></table></td></tr>
<tr><td>Showing affection</td><td>I can make time to tell my child I love him/her no matter how I am feeling.</td></tr>
<tr><td>Engaging in play</td><td>I can get my child to participate in play activities even when s/he doesn’t want to.</td></tr>
<tr><td>Facilitating routines</td><td>I can maintain the established routine when my child protests.</td></tr>
<tr><td>Establishing discipline strategies</td><td>I can set realistic limits and boundaries for my child.</td></tr>
<tr><td>Providing appropriate learning activities</td><td>I can teach my child the necessary things s/he needs to know to become successful and independent one day.</td></tr>
<tr><td>Promoting communication</td><td>I can create daily opportunities for conversation with my child.</td></tr>
</table>

Demographic Questionnaire	Captures all the demographic information of the participants in the study.	The questionnaire was developed by researchers at The Centre of Autism Research in Africa (CARA) for use across CARA research studies.	The questionnaire consists of 24 items and is divided into 2 sections:	
			About you and family	What is your relation to the child in your family?
			About your child (tailored to whether the child has autism or not)	At what age did you first become concerned?

3.6 Pilot study

A pilot study was conducted at a mainstream school and a centre for ASD learners in KwaZulu-Natal (different research sites than those identified for the main study). The pilot study was conducted to gain information regarding the questionnaire clarity and the data collection process. The caregivers were asked to comment on the following aspects on the questionnaire: the time it took to complete the questionnaire, the clarity of the questions, the ease of completion as well as any additional information that would enable the researchers to determine if the test tools and layout were adequate for the main study (Ploughman, Austin, Stefanelli, & Godwin, 2010).

A total of 16 completed questionnaires and feedback forms were returned. There was a poor response rate, specifically from the non-ASD group. With regards to the timing, caregivers reported a range of 10-45 minutes to complete the questionnaire. Caregivers who returned the questionnaires reported that the instructions were easy to understand and had no negative comments with the layout of the questionnaire. The results also included valuable comments and suggestions to improve the terminology and questions to make them clearer and more specific. These changes were complete before the final printing took place. Detailed feedback can be seen in Table 4.

Table 4. Feedback from the pilot study

Question	Response	Action done in response
1. How long did it take to complete the questionnaire?	15-45 minutes	This was what we predicted, and during the main data collection we did not stipulate the time it would take but stated how many pages there were.
2. Were there any words or terms you did not understand?	'Housewife/home executive' was seen as outdated terminology. 'Discipline'- parent did not like this concept/term.	Housewife/ home executive changed to full time mother/father. This was changed to 'manage my child's behaviour'.
3. On a scale 1-10, how easy or difficult were the instructions to understand? *1- easy to understand instructions* *10- way too difficult, instructions not clear*	9/10 people were happy with the majority voting 1/2. The person that voted 10, did not have any concrete recommendations for change.	There were no recommendations to change and therefore no changes were made.
4. On a scale of 1-10, how did you find the layout of the survey? *1- Way too complicated, not easy to read each question and complete the answer.* *10- Fantastic layout, easy to read each question and easy to complete the answer.*	The majority voted 9/10 with one person voting one. This person did not have any suggestions or recommendations.	No recommendations were made and therefore no changes were made.

5. Do you have any comments or recommendations to make this process a bit easier for the participant in the study?	"I was expecting questions that we would answer - a personal account can give a lot of insight into the reality of what we live like - so maybe more essay questions not only multiple choice. Maybe spend time interviewing parents in their homes".	This was not feasible and would go against the study design. This person is suggesting a qualitative, descriptive study and this study is a quantitative study. Consequently this was not incorporated into the final questionnaire for distribution.
	"Perhaps include spousal support questions, especially if despite a 2-parent family 1 parent shoulders all the responsibility for care, transport, teaching, and support of the ASD child. Also perhaps a quick check if there was a specific or non-specific reason for the participants responses in section F example: a stressful event or death in the family.	This was a helpful suggestion, the following comment was added at the bottom of section F: If anything significant happened over the past week to trigger these responses, please say so (eg. traumatic event/stressful situation). If yes, please tell us what in the space below.
	The first question read "what is your relation to the child with ASD in your family?	This created confusion to parents of children without ASD. The question was changed to "what is your relation to the child in your family?"

The 16 questionnaires from the pilot study were used to test out the codebook and data capture spreadsheet. A codebook was developed so that the researcher could input the data into a spreadsheet. This codebook was developed and finalised by the researcher, through discussions with the study supervisors and the statistician. All pilot data was entered into the codebook to evaluate its layout and coding used. This was done to assess if the codes and spreadsheet are accurate and easy to use. Some minor modifications were made to the codebook as a result of the feedback from the pilot participants, such as the inclusion of additional codes for some of the items and adjusting the code book numbering and column naming.

3.7 Main study

3.7.1. Ethical considerations

Before the study could commence, ethics approval was obtained by the UCT's Faculty of Health Science Human Research Ethics Committee (Appendix A). Following this, the Department of Education KZN was contacted to get approval to conduct the study in the schools (Appendix B). Once permission was granted, the two principals at the two schools were contacted. A meeting was organised whereby the outline of the study could be explained as well as what was required from the schools for this study. The principals were then asked for permission to conduct the study at their schools (Appendix C).

3.7.2. Data collection procedures

The school principals of the two research sites and selected staff members identified children that met the participant criteria (see Section 3.4). For the mainstream school, 170 families that met the study criteria were randomly selected by the school staff. For the ASD-specific school, all 180 children with ASD were identified and all families were invited to take part in the study.

The schools were issued the survey packs to be handed out by the teachers. All identified children received a survey pack to take home to their parent(s) or caregivers. One survey pack was issued to each household. For two-parent families, the family could self-select which caregiver answers the questionnaire.

The survey pack consisted of (a) an information letter, (b) informed consent form, (c) a combined survey, and (d) a return envelope. The information letter outlined the purpose of the study, allowing participants to have all the necessary information to make an informed decision whether to partake in the study or not. The information letter stated that participation in the study is completely voluntary and caregivers were informed that they could stop participating in the study at any point until the questionnaires had been handed in. They were also informed that their responses would be kept confidential.

The completed surveys were returned to school in a sealed envelope. The teachers then placed the envelopes in a sealed box. This box was emptied and re-sealed by the researcher at the end of each week. The teachers sent out reminder letters, which was the schools' method of communication at the end of week one and two. It was then decided to give an additional two weeks and collect the remaining questionnaires at the end of the school term. The data collection process is described in more detail in the next section and illustrated in the flow diagram (Figure 6).

Recruitment of caregivers of children without ASD. The deputy principal randomly selected 15 classes throughout the school and gave 10 survey packs per class for the teacher to hand out to children that met the selection criteria. Twenty more survey packs were sent out to improve the response rate. Reminders were sent out to everyone, on the same day and again in the following weeks. In total, 140 questionnaires were returned.

Recruitment of caregivers of children with ASD. A 150 survey packs were distributed to children with ASD. A further 30 survey packs were requested by the school to ensure that every family that met the selection criteria were invited to take part in the study. At the end of the study period, 83 questionnaires were returned.

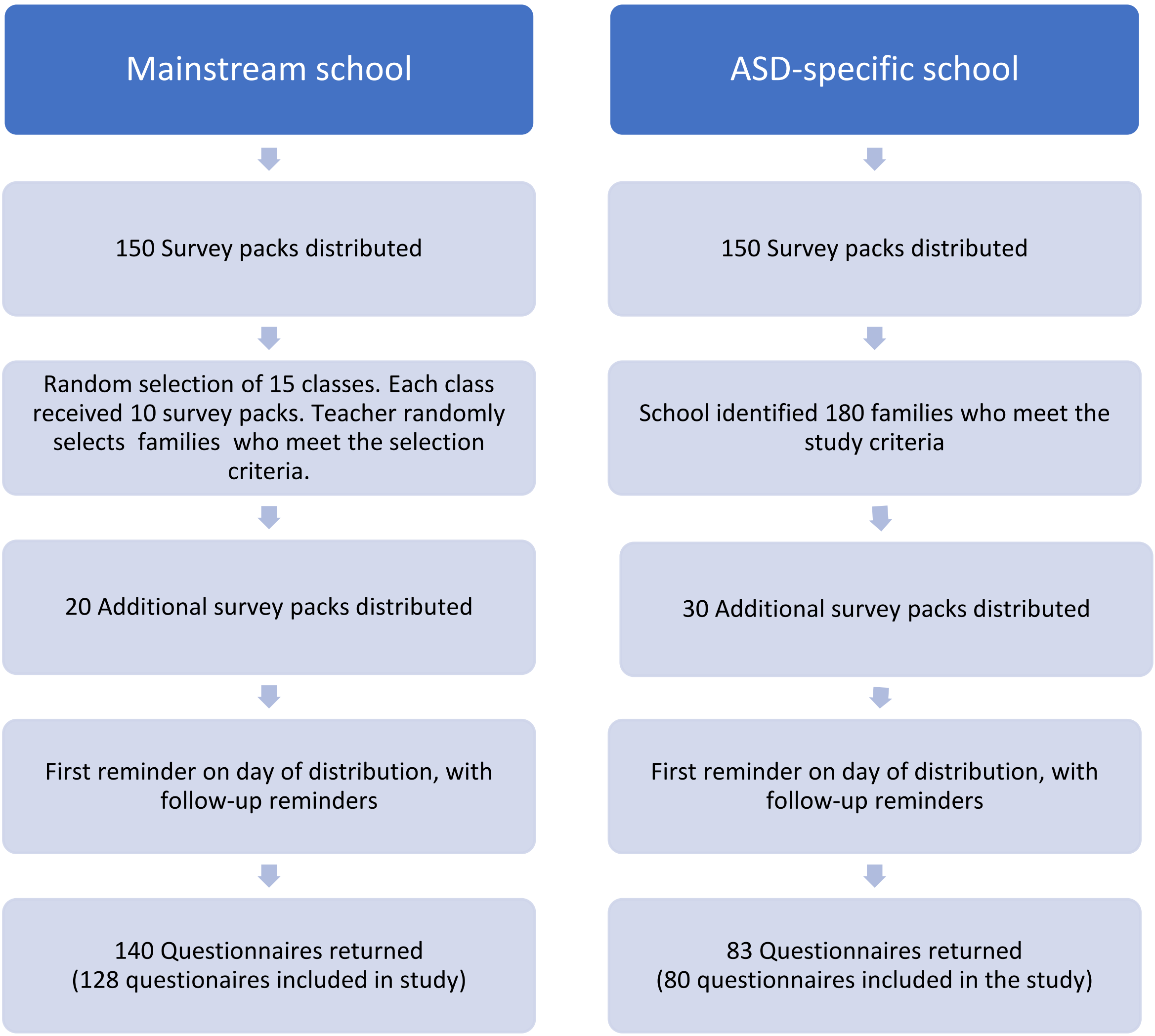


Figure 6. Data collection procedures

3.7.6. Data input

Once the surveys were returned, each complete questionnaire received a unique identification number. All raw data was captured on a Microsoft Excel spreadsheet, and analysed using Python. Once the initial data capture was completed a percentage of the entries were checked by an independent data capturer to ensure that data had been correctly captured on the Microsoft Excel spreadsheet.

All individual questionnaires that had more than 20% of their data as missing, were excluded from data analysis. Therefore 15 of the questionnaires received were not included in the final data set. All data analyses and results are reported in chapter 4.

3.8 Summary

This chapter described the methodology for this study. The research aims and design were outlined. The participants were described, looking at both the inclusion and exclusion criteria of the two caregiver groups. The data collection material used in the study were reported as well as the details of the survey pack. Following this, the details and feedback from the pilot study were discussed. Lastly, the main study was presented, in terms of ethical considerations and data procedures.

Chapter 4

Results

4.1 Introduction

This chapter presents the results from the study. Firstly, it explains the data analysis procedure, followed by the reliability of the instruments. Thirdly, the participants from the study are described. The participants performance across the different instruments is then presented. Finally, the correlation between study constructs is reported.

4.2 Data analysis procedure

Data were analysed using Python with significance set at p < 0.05. Descriptive statistics were used to present demographic data. The total scores for the subtests and the total for the WHOQOL, DASS and P-SEMI was calculated. Cronbach Alpha values were determined for the total WHOQOL, DASS and PSEMI scales. A Cronbach alpha value of 0.7 to 0.9 is considered to be adequate while a value greater than 0.9 is considered to be excellent (Eapen et al., 2014).

The two groups were compared to determine the differences in scores for the HRQOL and the other parenting constructs measured by the DASS and P-SEMI. Participants with missing data for each measure were excluded from the analysis of that measure, and therefore the total sample for each measure differs.

The data from the 3 measures was not normally distributed. However, with regards to the WHOQOL and the DASS, the two groups had equal variance and the sample size was over 200 participants, consequently, we conducted a two tailed independent sample t-tests to determine the difference between the two groups of participants. The PSEMI total and the majority of the subscales showed equal variance between the two groups; however learning and discipline did not have equal variance. However, we conducted a two tailed independent sample t-test because most of the sub scales and the total sub scale showed equal variance, and the sample size was over 200 participants.

Effect size (Cohen's d) was computed for all the mean scores, as a measure of the magnitude of the effect of the difference (Rice & Harris, 2005). A small effect size measured .1 while a medium effect size was .3 and a large effect size was .5 (Rice & Harris, 2005).

Finally, the correlation between the parenting constructs for each of the two groups was investigated to see if there was any significant correlation between any of the constructs under investigation. In this analysis, the strength of the correlation is viewed as low if the value is less than .35, while values of .36-.67 indicate a moderate correlation and values of .68-1 indicate a strong correlation (Taylor, 1990).

4.3 Description of participants

A total of 208 caregivers participated in this study, 80 caregivers of children with ASD and 128 caregivers of children without ASD. Table 5 provides a comprehensive overview of the demographics of the study participants per group. This includes mean age and standard deviation of the caregivers, relation to the child, how many children are in the household, the family type, the highest level of education and the ethnic background, and languages spoken in the home environment. It also gives details on the employment status, the total household income as well as caregivers thoughts about their income. With regards to the information about the children, it presents the mean age and standard deviation of the child, as well as the child's gender represented in the study. With regards to the children with ASD, it represents the mean age of diagnosis as well as the child's current level of language ability as reported by the caregivers.

Table 5. Overview of study participants (n=206)

Participant characteristics	**Children without ASD**	**Children with ASD**
Age of caregivers		
Father mean age in years (SD)	42.16 (8.12)	42.45 (7.17)
Mother mean age in years (SD)	38.28 (6.21)	38.27 (6.06)
Relation to child		
Mother	98	56
Father	21	17
Grandparent	6	3
Other (uncle / aunt / sibling)	2	3
No of children in household		
1 child	24	15
2 children	39	31
3 children	35	17
4 children	9	3
5 or more children	8	3
Family type		
Two-parent family	72	51
One-parent family	44	21
Blended or stepfamily	11	7
Highest level of education		

University	62	33
Post grade 12 Diploma/certificate	46	25
Grade 12	16	20
Grade 9-12	2	1
Grade 8 or less	1	1
No formal education	1	0
Ethnic background		
Black	98	47
Indian	10	16
White	10	7
Coloured	3	5
Asian	3	5
Don’t wish to say	4	0
Language		
Monolingual	120	65
Bilingual	6	13
Multilingual	2	2
Employment status		
Employed full-time	109	42
Not currently working, looking for work	3	9
Home executive/ housewife	4	5
Employed part-time	3	5
Do casual work	2	4
Not currently working, not looking for work	0	2
Other	3	12
Total household income		
No income	1	0
R1- R400 per month	2	0
R401-R800 per month	0	1
R1601-R3200 per month	2	5
R3201-R6400 per month	7	6
R6401- R12800 per month	14	16
R12801-R25600 per month	26	20
R25601- R51200 per month	38	8
R51201 or more per month	9	1
I don’t wish to say/ don’t know	29	17
Thoughts of total income		
Struggling	15	13
Just getting by	43	30
Doing ok	40	26
Managing well with some money left over each month	16	4
Well off	5	1
I don’t wish to say	9	6
Gender of child		
Boy	35	73
Girl	93	7
Child’s age		
Child’s mean age in years (SD)	9.65 (1.87)	9.92 (2.2)

Child’s mean age of diagnosis in years (SD)		4 (23.03)
Child’s language level		
No words yet or very few (less than 5)	-	7
Some single words (5-15 words)	-	4
Lots of single words (15-50)	-	15
Mostly phrases (2-3 word combinations)	-	5
Lots of phrases and sentences with lots of mistakes	-	17
Speaks in full sentences	-	22

The participants were asked to select which languages they speak. In the total group, one hundred and eighty-five participants (89%) selected one language, nineteen participants (9%) selected two languages and four participants (2%) selected three languages. In the group without ASD, one hundred and twenty participants (93%) selected one language, 6 participants (5%) selected two languages and 2 participants (2%) selected three languages. In the group with ASD, sixty-five participants (81%) selected one language, thirteen (16%) selected two languages and two selected (3%) three languages. The most common languages spoken include: IsiZulu, English and IsiXhosa. This is expected form the ethnic background presented from the participants. In the group without ASD, the majority of the participants are Black (n= 98; 77%) with the remaining participants 10 Indian (8%), 10 White (8%), 3 Coloured (2%) and 3 Asian. Four participants in the group without ASD ‘did not wish to say’. In the group with ASD, 47 participants are Black (59%), 16 are Indian (20%) and 7 are White (9%). Five participants are Coloured (6%) and 5 are Asian (5%).

When considering the employment status of the sample of the total group, the majority (73%) of the participants are employed full-time. This is consistent with the high percentage of participants having achieved a university degree (46%). Seven percent of the participants are employed part-time or do casual work. Twelve participants (6%) are either not currently working or looking for work while two (1%) are not currently working, not looking for work or are home executives (4%). Twelve participants selected ‘other’ as their answer which makes up 15% of the participants. In the group without ASD, one hundred and nine participants and employed full-time (88%). Three participants are not currently working but looking for work, four participants are a home executive or housewife. Three participants are employed part-time whilst two do casual work. In the group with ASD, forty-two participants are employed full-time (53%) and nine are not currently working but looking for work. Five participants are a home executive or housewife and five are employed part-time. Four do casual work and two are not working and not looking for work, while twelve participants selected ‘other’. In the group without ASD, one hundred and eight participants (84%) either have a University degree or post Grade 12 diploma or certificate. Fifty-eight participants (73%) in the group with ASD have a University degree or post grade 12 diploma or certificate. Sixteen participants (13%) in the group without ASD have a

Grade 12 compared to 20 (25%) in the ASD group. Two participants (2%) in the group without ASD have a Grade 9-12 education and two participants (2%) have a Grade 8 or less. One participant (1%) in the group with ASD has a Grade 9-12 and one participant (1%) has Grade 8 or less.

When investigating the participants perception of their income, in the total group, it was interesting to note that most of the participants reported that they were 'just getting by' (35%) or 'doing ok' (32%). Twenty-eight participants (13%) reported that they were 'struggling'. Only six participants (3%) considered themselves to be 'well off.' It is important to note that several families in this study report having more than one child in the household. When comparing the group of parents without ASD to the group of parents with ASD, it appears that the parents of children with ASD have a poorer perception of their finances and income compared to the parents of children without ASD. Only five percent of parents of children with ASD felt they were managing well with some money left over at the end of the month compared to 13% in the children without ASD group. Sixteen percent of parents of children with ASD felt as if they were struggling, compared to eleven percent of parents in the children without ASD group.

When focussing only on the children with ASD in the study, it was evident that most of the children received their ASD diagnosis between the ages of 4 and 6. The age of diagnosis is older in South Africa, than what has been reported in other countries. Finally, the caregiver report of language levels of the ASD children, were documented. The children's language levels varied but most of the children were found to be verbal. Only 7 children (10%) had 'no words yet or very few words (less than 5)'. Sixty-three percent (63%) reported to use short phrases and sentences to communicate and 27% to used words and word combinations. This can be expected from this sample of children as they are all at a ASD specific school and consequently most of them are receiving intervention of some kind.

With regards to the two groups and the gender of the children, there was a big difference in the number of boys in the group with ASD compared to girls in the group with ASD. There were seventy three (91.25%) boys and only seven (8.75%) girls in the group with ASD. The margins were closer in the group without ASD. There were thirty five (27.34%) boys and ninety three (72.65%) girls.

4.4 Reliability of measures

WHOQOL-BREF. The WHOQOL-BREF was used to evaluate the caregivers HRQOL for both groups of caregivers, with and without children with ASD. The WHOQOL-BREF has previously been used to determine caregivers of children with ASD. In a group of mothers with children with ASD (Dardas & Ahmad, 2014; Shu & Lung, 2005). The internal consistency of the WHOQOL-BREF ranged from .70 to

.77 for the four domains. For this study, the Cronbach alpha value for the total WHOQOL was .87, indicating good reliability and internal consistency.

DASS-21. The DASS-21 was used to measure the frequency of parental behaviours and/or intensity of parental feelings of depression, anxiety and stress. The DASS has been used with a similar sample before, i.e., a group of parents of children with ASD (Lai et al., 2015). The internal consistency of the DASS subscales ranged from .83 to .94 in this group of parents of children with ASD (Lai et al., 2015). For this study, the Cronbach alpha value was .91, indicating good reliability and internal consistency.

P-SEMI. In a previous study, the P-SEMI was used to measure parents self-efficacy in the different domains of parenting and found to be a reliable measure (Harty, 2009). In a South African sample of parents of children with ASD the Cronbach alpha value was .95 (Osman-Kagee, 2020). The Cronbach alpha value for this study was 0.9, indicating good reliability and internal consistency.

4.5 Participant performance across the study constructs

4.5.1 Health-related quality of life

The WHOQOL-BREF measuring HRQOL consisted of four domains, namely: physical health, psychological, social relationships and environment. Five participants had missing data and their results were excluded in the analyses for this measure. The results from the WHOQOL can be seen in the table below. Group 1 is parents of children without ASD (n = 126) and Group 2 is parents of children with ASD (n = 77).

Table 6. Health-related quality of life of the two parent groups (n=203)

WHOQOL-BREF measure	**Group 1- without ASD**	**95% CI- TD**	**Group 2- with ASD**	**95% CI- ASD**	**Difference score**	***t***	***p***	***d***
Physical health domain	3.23 (0.45)	3.15- 3.31	3.11 (0.56)	2.98- 3.24	0.12	1.64	0.10	0.23
Psychological domain	3.66 (0.48)	3.57- 3.74	3.42 (0.53)	3.30- 3.54	0.24	3.22	0.00*	**0.46**
Social relationships domain	3.78 (0.72)	3.65- 3.91	3.48 (0.91)	3.27- 3.68	0.3	2.60	0.00*	**0.37**
Environment domain	3.57 (0.64)	3.46- 3.68	3.24 (0.78)	3.07- 3.42	0.33	3.25	0.00*	**0.47**
HRQOL Total	14.25 (1.91)	13.91- 14.59	13.27 (2.41)	12.72- 13.82	0.98	3.20	0.00*	**0.46**

- *For the WHOQOL-BREF a higher score indicates a higher/ better quality of life.*
- *An asterisk indicates statistically significant difference (p < 0.05)*
- *A **bold d** value indicates a medium effect size (d=0.3-0.5)*

When comparing the total HRQOL score for two parent groups, there was a statistically significant difference of 0.98, t= 3.2, $p < .00$ and d= .46. There was no significant difference between the groups (*p*<0.05) in the physical health domain, however there was a statistically significant difference found in the other three domains (psychological, social relationships, environment). There was a medium effect size (*d*= .37-.47) in all the statistically significant domains.

4.5.2 Depression, anxiety and stress

The DASS measured depression, anxiety and stress. Table 7 reports the results of Group 1 (124 parents of children without ASD) and Group 2 (78 parents of children with ASD). There was no statistically significant difference between the two groups for the total DASS score, as indicated by the difference score of 0.39, *t*= -1.56, *p*= .11 and *d*= -.22. There was also no statistically significant difference found between the groups for any of the sub-domains.

Table 7. Depression, Anxiety and Stress of the two parent groups (n=202)

DASS-21	**Group 1- without ASD**	**95% CI- TD**	**Group 2- ASD**	**95% CI- ASD**	**Difference score**	***t***	***p***	***d***
Anxiety	0.41 (0.50)	0.32-0.50	0.51 (0.64)	0.37-0.66	0.1	-1.26	0.20	-0.18
Depression	0.45 (0.59)	0.34- 0.55	0.58 (0.64)	0.44- 0.73	0.13	-1.55	0.12	-0.22
Stress	0.62 (0.63)	0.51- 0.73	0.76 (0.70)	0.60- 0.92	0.14	-1.5	0.13	-0.21
DASS Total	1.48 (1.59)	1.20- 1.77	1.87 (1.85)	1.45- 2.29	0.39	-1.56	0.11	-0.22

- *For the DASS, a higher score is better.*
- *An asterisk value indicates statistically significant difference.*
- *A **bold d** value indicates a medium effect size.*

4.5.3 Parental self-efficacy

The P-SEMI consisted of six sub-domains, namely: affection, discipline, play, communication, routines and learning. This measure investigates the parent's belief or confidence or competence to successfully parent their child. Table 8 reports on Group 1 (126 parents of children without ASD) and Group 2 (79 parents of children with ASD).

Table 8. Parental self-efficacy of the two parent groups (n=205)

P-SEMI	**Group 1- without ASD**	**95% CI- TD**	**Group 2- with ASD**	**95% CI- ASD**	**Difference score**	***t***	***p***	***d***
Affection	1.56 (0.69)	1.44- 1.68	1.55 (0.68)	1.40- 1.70	0.01	0.08	0.93	0.01
Discipline	2.21 (0.75)	2.07-2.34	2.63 (1.05)	2.39- 2.87	0.42	-3.34	0.00*	**-0.48**
Play	2.28 (0.76)	2.14- 2.41	2.39 (0.80)	2.21- 2.57	0.11	-0.97	0.32	-0.14
Communication	1.87 (0.79)	0.07- 1.73	2.10 (0.86)	0.09- 1.91	0.23	-1.91	0.05	-0.27
Routines	2.10 (0.74)	1.97- 2.24	2.22 (0.86)	2.02- 2.41	0.12	-0.99	0.31	-0.14
Learning	1.93 (0.76)	1.79- 2.06	2.34 (1.01)	2.12- 2.57	0.41	-3.33	0.00*	**-0.47**

P-SEMI Total	11.97 (3.94)	11.28- 12.67	13.26 (4.68)	12.21- 14.31	1.29	-2.10	0.03*	-0.30

- *For the -PSEMI, a lower score is better.*
- *An asterisk value indicates statistically significant difference.*
- *A **bold d** value indicates a medium effect size.*

The results depicted a statistically significant difference between the two groups in the PSEMI total score and the discipline and learning domains. The P-SEMI total score demonstrated a statistically significant difference of 1.29, *t*= -2.1, *p*= .03 and *d*= -.30. However, there was no significant difference between the groups in the following domains: affection, play, communication and routines.

4.6 Associations between health-related quality of life and other constructs

The second study objective was to investigate the association between the HRQOL and other parenting constructs such as depression, stress and anxiety, and parental self-efficacy. The WHOQOL-BREF was therefore correlated with the P-SEMI and the DASS. The tables below show the strength of the correlations and if these are statistically significant for Group 1 (parents of children without ASD) and Group 2 (parents of children with ASD).

Table 9. Group 1 (parents of children without ASD) Data Pearson's Correlation and Significance

	HRQOL-physical health	HRQOL-psychological	HRQOL-social relationships_3	HRQOL-environment	WHOQOL_total	P_SEMI_Affection	P_SEMI_Discipline	P_SEMI_Play	P_SEMI_Communication	P_SEMI_Routines	P_SEMI_Learning	P_SEMIL_total	Anxiety_Score	Depression_Score	Stress_Score	DASS_21_total
HRQOL-physical health	1	0.6**	0.54**	0.66**	0.81**	-0.23*	-0.13	-0.27**	-0.16	-0.3**	-0.23**	-0.25**	-0.24**	-0.29**	-0.23**	-0.28**
HRQOL-psychological	0.6**	1	0.5**	0.63**	0.79**	-0.14	-0.04	-0.19*	-0.14	-0.23**	-0.13	-0.17	-0.09	-0.16	-0.08	-0.12
HRQOL-social relationships	0.54**	0.5**	1	0.61**	0.83**	-0.18	-0.07	-0.3**	-0.22*	-0.18*	-0.24**	-0.23*	-0.17	-0.35**	-0.27**	-0.29**
HRQOL-environment	0.66**	0.63**	0.61**	1	0.88**	-0.18*	-0.03	-0.28**	-0.2*	-0.24**	-0.18	-0.21*	-0.22*	-0.31**	-0.24**	-0.28**
HRQOL_total	0.81**	0.79**	0.83**	0.88**	1	-0.22*	-0.07	-0.32**	-0.22*	-0.28**	-0.24**	-0.26**	-0.21*	-0.34**	-0.26**	-0.3**
P_SEMI_Affection	-0.23*	-0.14	-0.18	-0.18*	-0.22*	1	0.54**	0.74**	0.82**	0.75**	0.86**	0.9**	-0.17	-0.09	-0.08	-0.12
P_SEMI_Discipline	-0.13	-0.04	-0.07	-0.03	-0.07	0.54**	1	0.53**	0.52**	0.67**	0.64**	0.75**	-0.03	-0.03	-0.08	-0.05
P_SEMI_Play	-0.27**	-0.19*	-0.3**	-0.28**	-0.32**	0.74**	0.53**	1	0.78**	0.73**	0.78**	0.87**	-0.08	-0.03	-0.03	-0.00
P_SEMI_Communication	-0.16	-0.14	-0.22*	-0.2*	-0.22*	0.82**	0.52**	0.78**	1	0.71**	0.84**	0.89**	0.08	0.13	0.16	0.14
P_SEMI_Routines	-0.3**	-0.23**	-0.18*	-0.24**	-0.28**	0.75**	0.67**	0.73**	0.71**	1	0.8**	0.89**	-0.07	-0.07	-0.02	-0.06
P_SEMI_Learning	-0.23**	-0.13	-0.24**	-0.18	-0.24**	0.86**	0.64**	0.78**	0.84**	0.8**	1	0.94**	-0.1	0.00	0.01	-0.03
P_SEMIL_total	-0.25**	-0.17	-0.23*	-0.21*	-0.26**	0.9**	0.75**	0.87**	0.89**	0.89**	0.94**	1	-0.07	-0.00	0.01	-0.02
Anxiety_Score	-0.24**	-0.09	-0.17	-0.22*	-0.21*	-0.17	-0.03	-0.08	0.08	-0.07	-0.1	-0.07	1	0.75**	0.75**	0.9**
Depression_Score	-0.29**	-0.16	-0.35**	-0.31**	-0.34**	-0.09	-0.03	0.03	0.13	-0.07	0.00	-0.00	0.75**	1	0.8**	0.93**
Stress_Score	-0.2**	-0.08	-0.27**	-0.24**	-0.26**	-0.08	-0.08	0.03	0.16	-0.03	0.01	0.01	0.75**	0.8**	1	0.93**
DASS_21_total	-0.28**	-0.12	-0.29**	-0.28**	-0.3**	-0.12	-0.05	-0.00	0.14	-0.06	-0.03	-0.02	0.9**	0.93**	0.93**	1

- *An * next to the correlation can indicate * p < .05. ** p < .01.*

When investigating the caregivers of children without ASD, the correlations between the measures were generally weak. HRQOL was weakly correlated to parenting self-efficacy, *r* (124) =-.26, p = .004 and depression, anxiety and stress, *r* (122) = -.30, *p* = .001. This indicates that there is a weak correlation between the WHOQOL and other parenting constructs in the caregivers of children without ASD group.

A stressor such as ASD could negatively affect a caregivers QOL and may therefore be expected to increase the correlation between QOL and stress, anxiety and depression. The table below shows the correlation and significance for the caregivers of children with ASD.

Table 10. Group 2 (parents of children with ASD) Data Pearson’s Correlation and Significance

	HRQOL-physical health	HRQOL-psychological	HRQOL-social relationships	HRQOL-environment	WHOQOL_total	P_SEMI_Affection	P_SEMI_Discipline	P_SEMI_Play	P_SEMI_Communication	P_SEMI_Routines	P_SEMI_Learning	P_SEMIL_total	Anxiety_Score	Depression_Score	Stress_Score	DASS_21_total
HRQOL-physical health	1	0.6**	0.66**	0.73**	0.85**	-0.09	-0.33**	-0.19	-0.1	-0.22	-0.22	-0.23*	-0.39**	-0.41**	-0.42**	-0.43**
HRQOL-psychological	0.6**	1	0.65**	0.57**	0.79**	-0.28*	-0.39**	-0.39**	-0.33**	-0.38**	-0.37**	-0.4**	-0.57**	-0.64**	-0.47**	-0.6**
HRQOL-social relationships	0.66**	0.65**	1	0.7**	0.9**	-0.25*	-0.31**	-0.26*	-0.34**	-0.31**	-0.31**	-0.34**	-0.45**	-0.59**	-0.45**	-0.53**
HRQOL-environment	0.73**	0.57**	0.7**	1	0.89**	-0.14	-0.33**	-0.18	-0.16	-0.18	-0.17	-0.23*	-0.43**	-0.53**	-0.42**	-0.49**
HRQOL_total	0.85**	0.79**	0.9**	0.89**	1	-0.22	-0.39**	-0.29*	-0.27*	-0.31**	-0.3**	-0.34**	-0.52**	-0.63**	-0.51**	-0.59**
P_SEMI_Affection	-0.09	-0.28*	-0.25*	-0.14	-0.22	1	0.53**	0.74**	0.81**	0.67**	0.72**	0.82**	0.22	0.2	0.21	0.23
P_SEMI_Discipline	-0.33**	-0.39**	-0.31**	-0.33**	-0.39**	0.53**	1	0.72**	0.59**	0.72**	0.68**	0.82**	0.24*	0.26*	0.3**	0.29*
P_SEMI_Play	-0.19	-0.39**	-0.26*	-0.18	-0.29*	0.74**	0.72**	1	0.82**	0.82**	0.85**	0.93**	0.16	0.28*	0.26*	0.25*
P_SEMI_Communication	-0.1	-0.33**	-0.34**	-0.16	-0.27*	0.81**	0.59**	0.82**	1	0.78**	0.84**	0.9**	0.21	0.25*	0.25*	0.25*
P_SEMI_Routines	-0.22	-0.38**	-0.31**	-0.18	-0.31**	0.67**	0.72**	0.82**	0.78**	1	0.81**	0.9**	0.26*	0.3**	0.31**	0.31**
P_SEMI_Learning	-0.22	-0.37**	-0.31**	-0.17	-0.3**	0.72**	0.68**	0.85**	0.84**	0.81**	1	0.93**	0.22	0.31**	0.27*	0.29*
P_SEMIL_total	-0.23*	-0.4**	-0.34**	-0.23*	-0.34**	0.82**	0.82**	0.93**	0.9**	0.9**	0.93**	1	0.25*	0.3**	0.3**	0.3**
Anxiety_Score	-0.39**	-0.57**	-0.45**	-0.43**	-0.52**	0.22	0.24*	0.16	0.21	0.26*	0.22	0.25*	1	0.76**	0.81**	0.92**
Depression_Score	-0.41**	-0.64**	-0.59**	-0.53**	-0.63**	0.2	0.26*	0.28*	0.25*	0.3**	0.31**	0.3**	0.76**	1	0.83**	0.92**
Stress_Score	-0.42**	-0.47**	-0.45**	-0.42**	-0.51**	0.21	0.3**	0.26*	0.25*	0.31**	0.27*	0.3**	0.81**	0.83**	1	0.95**
DASS_21_total	-0.43**	-0.6**	-0.53**	-0.49**	-0.59**	0.23	0.29*	0.25*	0.25*	0.31**	0.29*	0.3**	0.92**	0.92**	0.95**	1

- *An * next to the correlation can indicate * p < .05. ** p < .01.*

There was a statistically significant negative correlation between HRQOL and parenting self-efficacy for this group of caregivers *r*(77)= -.34, p= .002. The HRQOL and depression anxiety and stress in parents of children with ASD were significantly correlated *r*= (76)= -.59, *p* <.001. Significant strong correlations were noted in the several of the DASS and WHOQOL domains.

Significant strong correlations were reported in the following sub-domains: the DASS anxiety score and WHOQOL psychological subdomain (*r*= -.57, *p*= 0); the DASS anxiety score and WHOQOL total (*r*= -.*52* p= .00); the DASS depression score and WHOQOL psychological subdomain (*r*= -.64, *p*= *.00)*; the DASS depression score and WHOQOL social relationships sub-domain (*r*= -. 59, *p*= .00); the DASS depression score and WHOQOL environment sub-domain (*r*= -.53, *p*= .00); the DASS depression score and WHOQOL total (*r*= -.63, *p*= .00); the DASS total and WHOQOL psychological sub-domain (*r*= -.60, *p*= .00), the DASS total and WHOQOL social relationships sub-domain (*r*= -.53, *p*= .00) and DASS total and WHOQOL total (*r*= -.59, *p*= .00). Significant moderate correlations were noted in the following sub-domains: the DASS anxiety score and WHOQOL social relationships sub-domain (*r*= -.45, *p*= .00); the DASS anxiety score and WHOQOL environment sub-domain (*r*= -.43, *p*= .00); the DASS stress score and the WHOQOL psychological subdomain (*r*= -.47, *p*= .00); the DASS stress score and the WHOQOL social relationships sub-domain (*r*= -. 45, *p*= .00*)*; and the DASS total and WHOQOL environment sub-domain (*r*= -.49, *p*= .00). There was a statistical significance and a low, positive correlation between the DASS total and P-SEMI total.

4.7 Summary

This chapter presented the study results. The data analysis procedure was explained first, followed by the reliability of the measures used in this study. Thirdly, the description of the participants was presented. The participant performance across the different instruments is then investigated. This specifically looks at the differences between the two groups and focusses on the three instruments used in the study. The results are broken down, looking at the caregivers HRQOL using the WHOQOL, their mental health, using the DASS and finally parenting efficacy, using the P-SEMI. Lastly, the correlation between the different measures for the two groups is presented.

Chapter 5

Discussion and Conclusion

5.1 Introduction

In this chapter, the results from the study are discussed in relation to the main aim and objectives. The main aim of the study was to determine if there is a difference in the health and well-being of caregivers of children with ASD and caregivers of children without ASD in the South African context. The differences between the two groups will be discussed in terms of their HRQOL; stress, anxiety and depression; and parental self-efficacy. This will be followed by will be a discussion of the associations between these constructs. Following this, the implications for the study are mentioned as well as the limitations. Lastly, the summary and conclusion for the study are discussed.

5.2 Key findings

The results from the study are presented in the figure below and discussed in subsequent sections.

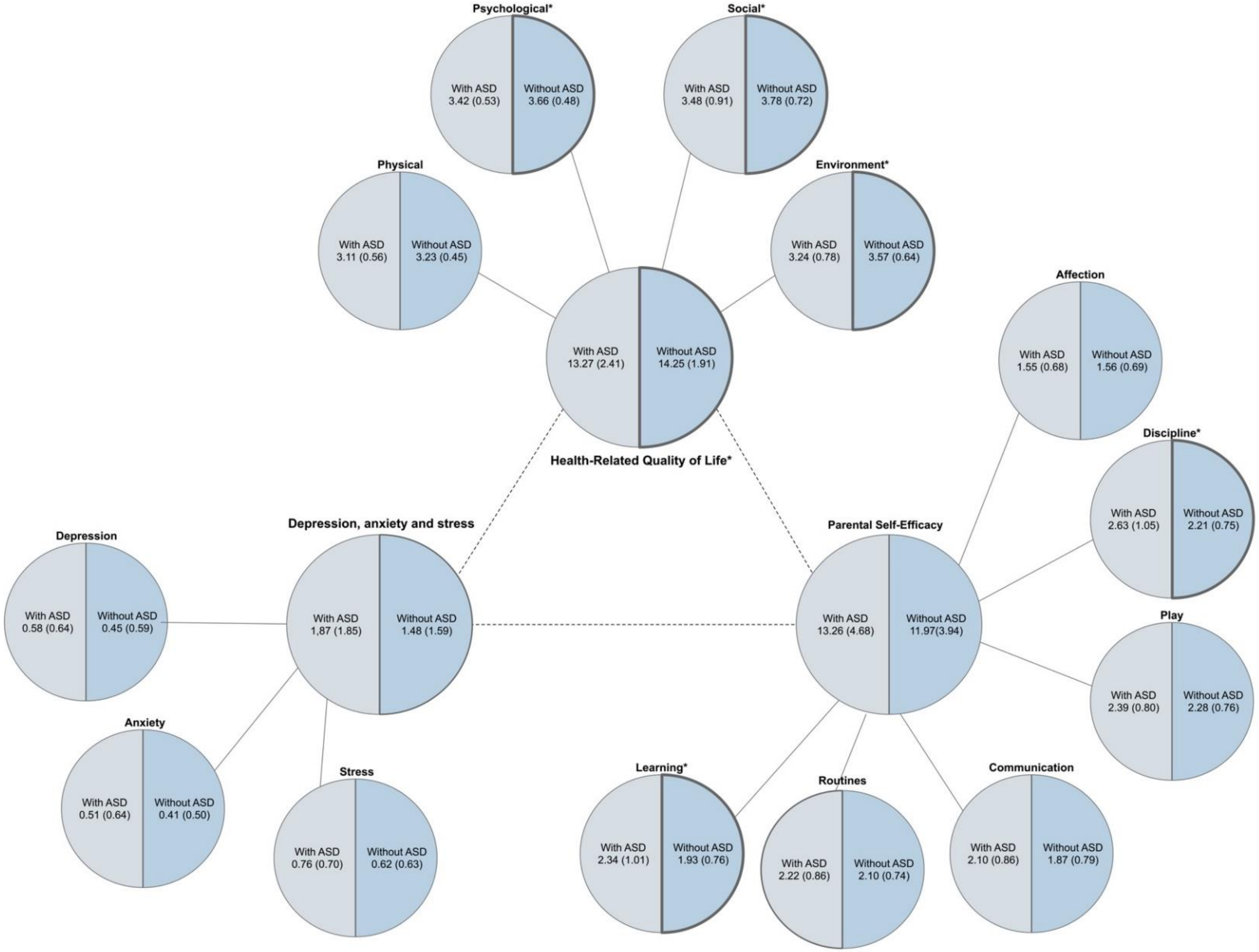


Figure 7. Overview of results reported in previous chapter.

An * next to the domain or sub-domain indicates a significant difference between the groups (p<0.05)

5.2.1 HRQOL between the two groups is significantly different

The results from this study indicated a statistically significant difference between the two groups in three HRQOL domains, namely: psychological, social relationships and environment. There was no statistically significant difference between the two groups for the physical health domain. This is consistent with the findings from another study conducted in South Africa, focussing on the QOL of parents of children with autism (Alhazmi et al., 2018). The only difference is that Alhazmi et al., (2018) found a significant difference in the parents QOL across all four domains (including physical) and not just the three found in this study. There are several reasons why this could be the case. The study conducted by Alhazmi et al., (2018) used much younger participants (mean age of child with ASD and without ASD was 5.4 years and 5 years respectively) compared to this study (mean age of child with ASD and without ASD 9.9 years and 9.6 respectively). The participants in the Alhazmi et al., (2018) study were not all based in school whereas all participants in this study were placed at a school. Considering the younger age group and the lack of school placement meant that the parents or caregivers are spending more time with the child and are providing more hands on, physical caregiving. These children may also require more assistance with activities of daily living. This would all impact the caregiver's physical aspect of their QOL and may have accounted for the difference in findings between this study and that of Alhazmi et al., 2018.

A significant difference between the two groups was found in the psychological domain in this study. Previous studies have found similar results amongst parents of children with ASD (Alhazmi et al., 2018; Ali Dardas, 2014). The areas that this domain measures, include: body image and appearance, negative feelings, positive feelings, self-esteem, spirituality, religion, thinking, learning, memory and concentration (Harper et al., 1998). There are many factors that affect a caregiver's psychological health. Research has found that caring for a child with ASD results in high levels of stress and depression and this has a negative impact on these caregivers' QOL which could be a possible explanation as to why the caregivers of children with ASD had a poorer HRQOL in the psychological domain (Abbeduto et al., 2004; Cutress & Muncer, 2014; Estes et al., 2009). The results from this study are therefore in keeping with previous studies.

The social relationships domain measures personal relationships, social support and sexual activity (Harper et al., 1998). There is huge importance of social support that these caregivers of children with ASD require to alleviate the financial burden and general stressors they face when it comes to raising a child with ASD (Bitsika et al., 2015). Often caregivers of children with ASD limit their social interactions with family and friends due to possible embarrassment and prefer to isolate themselves (Gray, 1993). This isolation will affect the amount of support that they receive or can access as caregivers which may be one explanation for the statistically significant difference in this domain between the two groups of caregivers.

This study reported a significant difference in the environment domain. This domain measures financial resources, freedom, physical safety and security, health and social care, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, physical environment and transport (Harper et al., 1998). This finding is consistent with studies conducted in South Africa as well as Jordan (Alhazmi et al., 2018; Ali Dardas, 2014). Both studies found that the lowest score for caregivers QOL was reported in the environment domain of HRQOL (Alhazmi et al., 2018; Ali Dardas, 2014). Some mothers of children with ASD may reduce their working hours or not work at all, therefore increasing financial stress experienced as individuals and as a family (Latefa Ali Dardas & Ahmad, 2014). This is one potential explanation for why caregivers of children with ASD would have poorer HRQOL when it comes to measures in the environmental domain.

It is evident that the results from this study support the findings from previous studies findings that indicate that caregivers of children with ASD have poorer elements of their HRQOL (Abbeduto et al., 2004; Alhazmi et al., 2018; Cutress & Muncer, 2014; Latefa Ali Dardas & Ahmad, 2014; Harper et al., 1998; Lai et al., 2015). This study extends what is known about HRQOL of caregivers of ASD in South Africa in in numerous ways. This study extends the age range of children to include participants from a school going age whereas Alhazmi et al., (2018) focussed primarily on preschool aged children. The majority of the participants in this study were from cultural and linguistic groups previously under-represented in research. Finally, the sample size from this study is also robust compared to other studies done in Sub-Saharan Africa.

5.2.2 Anxiety, depression and stress between the two groups is not significantly different

There was no statistically significant difference found between the two groups when comparing stress, anxiety and depression. Although the results between the groups were not significant the DASS scores in the ASD group were generally higher than those in the group of caregivers of children without ASD. This result is contradictory to findings from other studies as their results showed that raising a child with ASD leads to heightened stress and anxiety for the caregivers as well as increased levels of depression (Abbeduto et al., 2004; Cutress & Muncer, 2014; Estes et al., 2009). When comparing raising a child with ASD to raising a child with other difficulties, such as cerebral palsy and intellectual disabilities, the parents raising a child with ASD were reported that have higher levels of stress (Mugno et al., 2007). It was therefore expected that a statistically significant difference in stress, anxiety and depression would exist between the two groups, which was not the case with this study. However, this data does indicate a stronger correlation when measuring stress, anxiety and depression with QOL in the ASD group compared to the group of caregivers with children without ASD. In a study conducted in Oman, depression and stress were higher in caregivers of children with ASD compared to caregivers of children without ASD (depression: p= 0.04 and stress=0.04) (Al-Farsi et al., 2016). Anxiety scores from this study in Oman however were also not statistically significant (Al-Farsi et al., 2016).

There are several possible reasons for this finding. It must be noted that the DASS is a general tool for measuring stress, depression and anxiety. It is plausible that the use of a more specific parenting stress index would allow for a more specific representation of the differing levels of parental stress present in the two groups. Secondly, the DASS asks parents to focus on the levels of depression, anxiety and stress felt in the last 7 days, it is therefore not investigating the long-term stress felt by this group of parents. Furthermore, it is important to note that the data was collected at a time when extreme weather conditions were predicted throughout KZN and the schools were closed, which could have impacted the stress that both groups were experiencing. This study may have been conducted during a time when everyone’s stress levels were increased. Another possible explanation could be because the children with ASD used in this study have all been placed in an appropriate ASD specific school that caters for their needs. This is thought to possibly reduce the parents stress and anxiety as the children and themselves are receiving some level of structured intervention and support. Parents have reported that their lives are improved when their children are receiving appropriate education (Kuhlthau et al., 2014)These are all possible explanations as to why there was no significant difference noted in stress, anxiety and depression between the two groups.

5.2.3 Parental self-efficacy between the two groups: discipline and learning are significantly different

The results from the P-SEMI depicted a statistically significant difference between the groups in the discipline and learning subtests. There was no statistically significant difference noted in the other subtests (affection, play, communication and routines).

It is well documented that children with ASD exhibit some challenging behaviours such as self-injury, tantrums, non-compliance, oppositional behaviour and aggression (L. C. Lee, Harrington, Louie, & Newschaffer, 2008; Shawler & Sullivan, 2017). The results from this study are therefore in keeping with previous research which reports that these behaviours can be difficult to manage which is why one sees a difference in the discipline subtest with regards to parental self-efficacy when comparing disciplining a child with ASD to a child without ASD (L. C. Lee et al., 2008). Shawler et al., (2017) conducted a study to explore harsh or punitive parental discipline strategies. They hypothesised that parental discipline strategies mediate the association between parenting stress and child disruptive behaviours. The results found that 41% of their sample displayed disruptive behaviour and the high levels of stress felt by the parents impaired their ability to effectively discipline their children which in turn influences the child's disruptive behaviour (Shawler & Sullivan, 2017). We know that these parents of children with ASD can have high levels of stress and therefore are unable to effectively discipline their children. When comparing behaviours of children with ASD and children without ASD, it has been found that children with ASD show more noncompliant behaviour and have more difficulty resisting temptations (Ostfeld-Etzion, Feldman, Hirschler-Guttenberg, Laor, & Golan, 2016). This could be a possible reason as to why there is a significant difference between the two groups when it comes to discipline.

Parents and teachers have found that the challenging behaviours exhibited by a child with ASD are of great importance due to their effect on the child's ability to learn (Pearson et al., 2006). It may impact their educational intervention and therefore lead to poor long-term outcomes for the child (Shawler & Sullivan, 2017). This could be one possible explanation as to why the subtest learning in this study was found to have a significant difference for the parents of children with ASD compared to children without ASD. The questions asked in the learning section were specifically about the parents' ability to provide the child with learning opportunities and activities for their child to learn new skills. Research documents that children with ASD have challenging behaviours which would make it challenging for parents or caregivers of children with ASD to take their child on outings to places such as a park or museums and create learning opportunities that parents or caregivers of children without ASD can. Caregivers would find this part of parenting, challenging.

It must be noted that all these children used in this study are of school going age and will be receiving support at school and possibly receiving both Occupational therapy and Speech therapy. This intervention would support and improve difficulties in the areas listed above, such as sharing and turn-taking. Research has found that the support parents receive from school or school services and staff are one of the biggest reliefs for parents stress (Tehee, Honan, & Hevey, 2009).

It was a surprising result that there was no statistically significant difference found in the communication subtest as it is well- known that children with ASD have communication difficulties (American Psychiatric Association, 2013). Most of the children used in this study however were verbal and were able to communicate using short phrases and sentences and this, as well as the fact that these children are placed in a special needs school, could explain why there was no difference in the communication subtest. Thus, the results from this study seem to suggest that HRQOL in this sample of parents is more related to challenges in discipline and learning rather than in areas of communication.

This study therefore extends the current research as it provides data on children with ASD at a school going age as opposed to younger children that are not placed in a school environment. It allows one to realise the benefits to a parents QOL based on their child with ASD being placed in a school but also the difficulties that these parents continue to face eg. Learning and discipline.

5.2.4 HRQOL, and Depression, Anxiety and Stress, are moderately correlated within parents of children with ASD

The question with regards to the second objective of the study is to discuss if an association exists between the HRQOL and other parenting constructs such as stress and anxiety, and parental self-efficacy. To do this, the WHOQOL was correlated with the P-SEMI and the DASS. Some statistically significant correlations were found in the ASD group, which were not present in the group of caregivers of children without ASD. In the ASD group, the DASS total and WHOQOL total were statistically significant and were found to have a moderate, negative correlation. It was also found that the depression subscale of the DASS has a higher correlation with the WHOQOL psychological, WHOQOL social relationships and WHOQOL environment as well as WHOQOL total. The results from this study are consistent with other research findings which states that raising a child with ASD leads to more depressive symptoms in the parents compared to raising a child without ASD (Lai et al., 2015).

This is supported by research, indicating that raising a child with ASD can negatively affect the parents and may result in depression, anxiety, psychological distress as well as other mental or physical problems related to their health (Hoefman et al., 2014). The WHOQOL environment and depression score had a higher correlation (-0.53). It must be noted that this domain includes finances and it is known that financial burden and psychological stress related to caring for a child with ASD is well documented (Buescher et al., 2014; Chan et al., 2012; Hoefman et al., 2014). The results also showed a higher correlation between WHOQOL social relationships and depression score. This domain includes personal relationships, social support and sexual activity. It is known that parents of children with ASD have little social interaction and social support which could be one explanation for this result (Bitsika et al., 2015; Gray, 1993). The other domain in WHOQOL that had a higher correlation with the depression score was the WHOQOL total.

It was expected to find a correlation between the WHOQOL, measuring HRQOL and other parenting constructs in the ASD group. Although there was no statistically significant difference found with the DASS scores between the two groups, findings from this study indicate that there is a significant correlation between DASS and WHOQOL scores for caregivers of children with ASD. In LMIC countries, parents may have elevated stress compared to parents from HIC. Depression may be worth investigating in parents of children with disabilities as we found in this ASD group.

5.3 Clinical implications of the study findings

Intervention has traditionally focussed primarily on the child however, evidence shows that by understanding the health and well-being of the caregiver, the child will be influenced positively and intervention is more likely to be successful (Fewster et al., 2020). Evidence indicates that providing family-centred interventions rather than using a child-focussed approach will lead to more effective intervention which is why practitioner's need to focus on the caregivers and their health and well-being (Vivanti et al., 2018). Furthermore, it has been established that QOL of parents and caregivers of children with ASD can be improved through support and intervention which in turn will have a positive impact on child development (Fewster et al., 2020; Hayes & Watson, 2013). By caregiver's receiving the support they require, they will ultimately improve their QOL (Fewster et al., 2020), which will make it easier for them to provide the nurturing care that their child needs (World Health Organisation, 2018).

The clinical implications of this study relate to being aware of the potential impact of parental well-being and child characteristics on caregivers HRQOL. Data from this study suggest that the domains of HRQOL that differ between the two group of parents are the social and environmental domains. The most affected areas in HRQOL from this sample are environment and social domains. Therefore it is important for practitioners to ask caregivers about their access to informal support systems and structures and to facilitate caregivers to link in with exisitng social support opportunities such as parent support groups.

This study found a negative correlation between HRQOL and depression. It is important for the clinician to ascertain and document levels of stress and depression at the beginning of the caregiver professional partnership and to make the relevant referrals to other health care professionals if necessary. Furthermore, there appears to be an association between child characteristics and how that affects the caregivers HRQOL. In this study, caregivers reported learning and discpline subtests to be challenging aspects of parenting. Although not formally documented in this study, it is important for clinicians to determine the presence of behaviours that challenge and to ascertain the level of impact these behaviours have on caregivers well-being. Tools such as a child's behaviour checklist would be a helpful clinical tool to complete at the initial assessment to guide such a discussion with caregivers.

5.4 Strengths and limitations of the study

This study has several strengths including:

- Conducting a pilot study helped to refine the data collection procedures.
- This study focusses on participants from cultural groups previously underrepresented in research and is the first study investigating the caregiver's health and well-being in KwaZulu-Natal. The mean age of the children in this study without ASD and with ASD was 9.6 years and 9.9 years respectively. This study was therefore conducted on caregivers of children of a school going age which extends the current available empirical data from a preschool population into a school-aged population.
- There were 208 participants included in this study, 80 caregivers of children with ASD and 128 caregivers of children without ASD. This study therefore has a more robust sample size than many other studies conducted in Sub-Saharan Africa to date.

However, there were a few limitations that were experienced whilst conducting this study. They were:

- The choice of measure to report depression, anxiety and stress has several limitations. The DASS is a generic depression and anxiety measure which is not designed specifically to measure the stressors specifically due to parenting. The questions are therefore not specific to parenting stressors but rather stressors in general. It also only asks and reports how an individual feels over the last 7 days which is a short-term measure for depression, stress and anxiety. It would be beneficial to use a long-term measure. This limitation may have contributed to the fact that there was no statistically significant difference noted between the groups with regards to depression, anxiety and stress. Consequently, measures such as the parenting stress index (PSI; (Abidin, Flens, & Austin, 2013), which contain items specifically related to parenting, may give more helpful information regarding specific aspects of parenting stress.
- During the data collection period, schools were closed due to bad weather. This reason may have impacted the number of returned questionnaires and resulted in a poorer response rate and this contextual factor may also have impacted on the overall stress levels felt by both groups of caregivers.
- This study did not use a measure to investigate the behaviour of the child which would have been helpful to explore the correlation between behaviour, parenting self-efficacy and

HRQOL. It is well documented in literature that the severity of the child's Autism, and more specifically their behaviour, could impact the caregivers HRQOL (Hsiao, 2016; Peters-Scheffer et al., 2012; Reed & Osborne, 2012). However, as the focus of this study was on constructs relating to caregiver well-being, we did not document child characteristics. Parent report of the frequency and intensity of child behaviour could have been investigated using measures such as the child behaviour checklist (CBCL; (Nolan et al., 1996).

- The children from the ASD group were recruited from an ASD specific school and are therefore all receiving services of some kind. These services would have had an impact on their child's ability to communicate. The ability for children to access these services may positively impact their caregivers' HRQOL by increasing the child's overall communication skills and therefore the results from this study are not representative of all parents of children with ASD. Parents of children with ASD who are minimally verbal, or caregivers of children with ASD that are not placed in a special needs school, may display different levels of HRQOL.
- Similarly both groups of parents had high education and income levels and we acknowledge that this could have affect the amount and frequency of social support and other resources that they were able to mobilize, which could have acted as a buffer to feelings of stress, depression and anxiety.
- Although children with typical development were randomly selected by teachers from their classrooms, more specific instructions could have been issued to the teachers for distributing the questionnaire packs, to minimize any potential teacher biases.

5.5 Recommendations for future research

The results from this study have pointed towards the needs of future research to be done on caregivers raising children with ASD in South Africa. The recommendations for extending this work are as follows:

- This study was conducted on caregivers of children with ASD that have been placed in an appropriate ASD specific school. It is believed that if the study is conducted on a group of caregivers of children with ASD that are younger or not yet placed in a ASD specific school, their HRQOL may be even poorer. This is due to the caregivers having less support and possibly facing more challenges due to their child not being placed in a school environment.
- It is recommended that a measure be included to assess the child's severity of behaviour. It is documented that poor behaviour increases the caregivers' stress. It is believed therefore that

children with more severe behaviours would lead to parents having increased stress levels and therefore poorer HRQOL.

- This study used a generic measure (DASS) to measure the caregivers' depression, anxiety and stress. For future research, it is recommended that a specific parenting stress measure is used to gain more specific results of stress, depression and anxiety that are parenting specific. A long-term measure of depression, anxiety and stress may also be more appropriate rather than measuring the stress in the last 7 days.
- This study briefly mentions the positive impact of raising a child with ASD. There is a need to do more extensive research in caregiver well-being and collecting data about positive aspects of caring for children with ASD. Factors to consider for research would be resilience, effect on the family unit, perseverance, and appreciation for life.
- Regression analyses could be performed on the existing data to determine the contribution of each of the parenting constructs to caregivers HRQOL.

5.6 Conclusion

In this study, we investigated if there is a difference in the HRQOL of caregivers of children with ASD and caregivers of children without ASD in the South African context and to see if correlations existed between HRQOL and describe other parenting constructs such as stress and anxiety and parental self-efficacy for both caregiver groups.

The results of this study demonstrated that there is a statistically significant difference in the psychological, social relationships and environmental domains of health-related quality of life of caregivers of a child with ASD compared to caregivers of a child without ASD. There was no statistically significant difference in the depression, anxiety and stress between the two groups. However, depression scores for caregivers of children with ASD were moderately correlated with the WHOQOL social relationships and environment scores. With regards to parenting efficacy, there was only a statistically significant difference in the learning and discipline subtests. When comparing HRQOL and other parenting constructs, there was a low correlation in the ASD group with the P-SEMI however there was a stronger correlation between stress, anxiety and depression and HRQOL.

Most of the QOL studies to date have been conducted in Western and well-resourced countries. There is a need for more research to be conducted in Africa and more specifically in South Africa. There is a gap in research measuring the impact of raising children with ASD on caregivers in a resource-limited setting such as South Africa (de Vries, 2016). In addition, Sub-Saharan Africa is where the majority of children with disabilities are living and therefore there is an urgent need for research to be conducted in LMIC (Olusanya, Davis, et al., 2018).

There are many cultural, economic and educational factors that may influence a caregivers QOL living in South Africa (Alhazmi et al., 2018). These factors include poverty, low levels of education, poor access to jobs and services, mental and physical ill health, violence, human immune deficiency virus (HIV), alcohol and drug abuse (Sung-King, Lake, Sanders, & Hendricks, 2019). It is also evident that caregivers from low and middle class income families caring for children with ASD in developing countries have difficulties accessing professional support services that are required in order to provide an ASD child with appropriate services (de Vries, 2016). This, together with all the factors that have been mentioned, could lead to a low QOL for caregivers raising children with ASD in South Africa. It is therefore even more critical for professionals working with children with ASD and the caregivers of the children, to focus on the factors affecting caregivers and parents HRQOL to maximise the impact of intervention on the child's performance. The professionals need to ensure that plans are put in place to target the whole family system rather than focussing on the child alone (Latefa A. Dardas & Ahmad, 2014b).

5.7 Summary

This chapter presented the interpretation of the results from this study. The results were presented per study measure that was used. It focussed firstly on the HRQOL between the two groups, followed by measures of anxiety, depression and stress between the two groups. Parental self-efficacy between the two groups is then explained and lastly, the association between HRQOL and other parenting constructs. Following the interpretation of the results from this study, the implications are discussed as well as the limitations to the study. The summary and conclusions are presented and lastly, recommendations for future research are presented.

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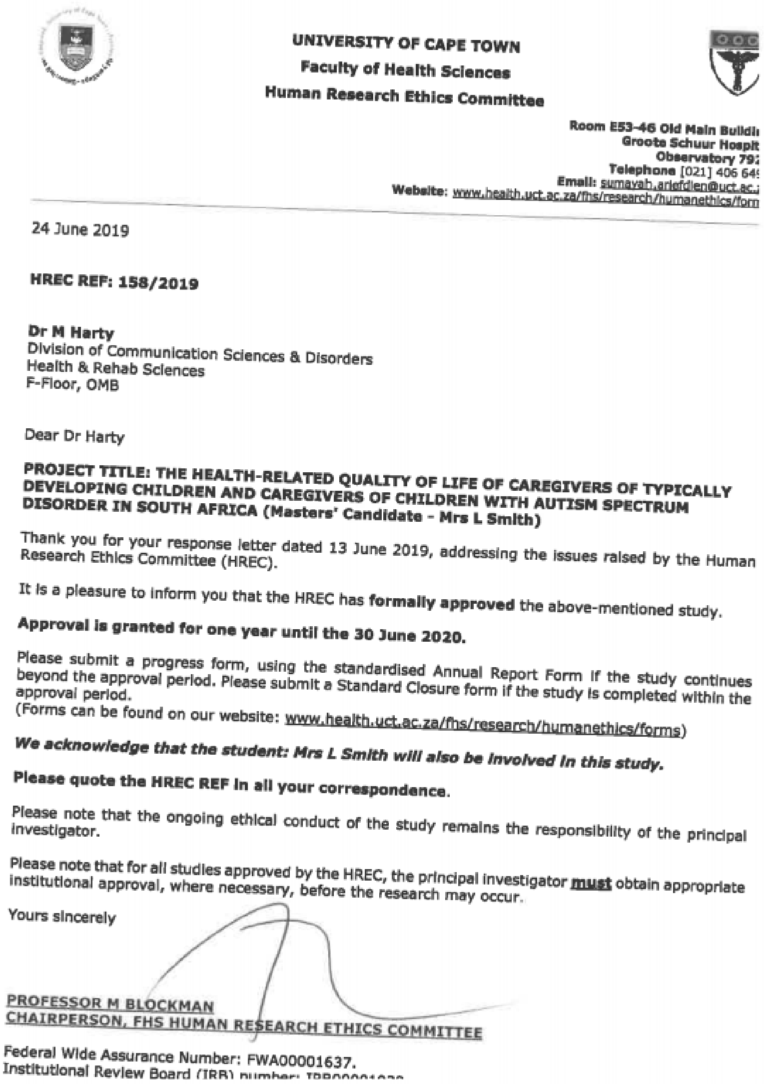
Appendices

Appendix A- Ethics approval from the University of Cape Town's Faculty of Health Sciences Human Research Ethics Committee



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Buildi
Groote Schuur Hospit
Observatory 79
Telephone [021] 406 64
Email: sumayah.ariefdien@uct.ac.
Website: www.health.uct.ac.za/fhs/research/humanethics/form

24 June 2019

HREC REF: 158/2019

Dr M Harty
Division of Communication Sciences & Disorders
Health & Rehab Sciences
F-Floor, OMB

Dear Dr Harty

PROJECT TITLE: THE HEALTH-RELATED QUALITY OF LIFE OF CAREGIVERS OF TYPICALLY DEVELOPING CHILDREN AND CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN SOUTH AFRICA (Masters' Candidate - Mrs L Smith)

Thank you for your response letter dated 13 June 2019, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 June 2020.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: Mrs L Smith will also be involved in this study.

Please quote the HREC REF in all your correspondence.

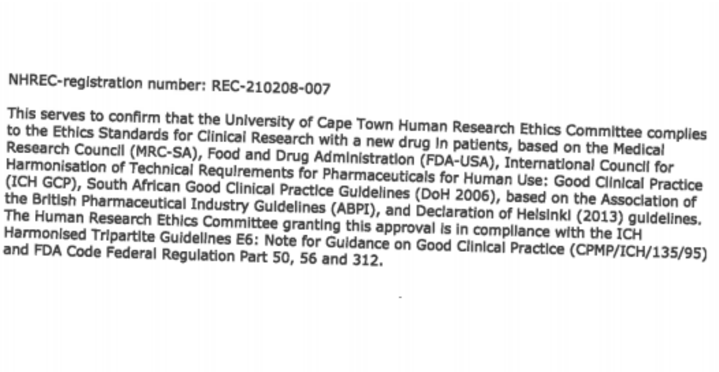
Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

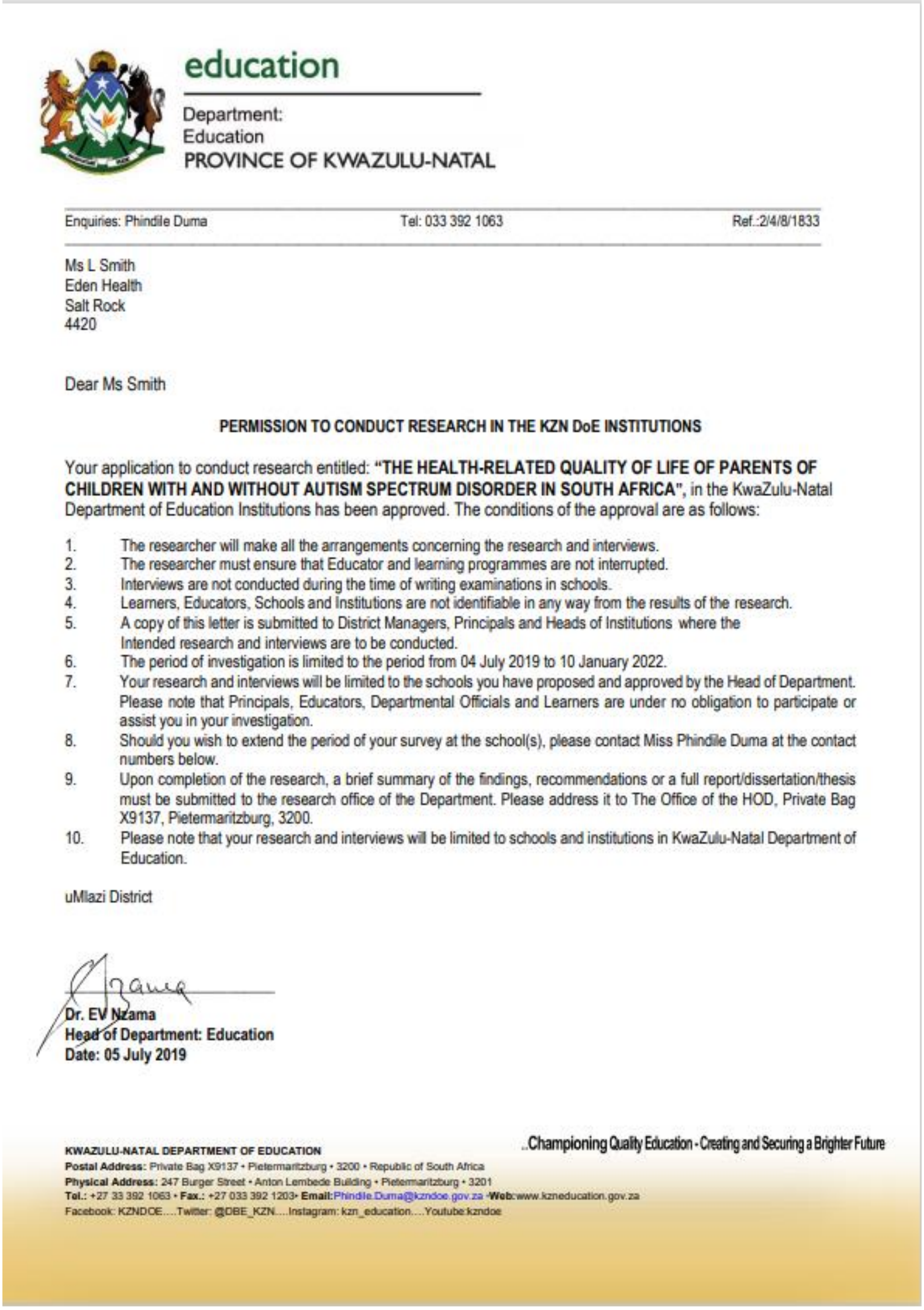
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number:



NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Appendix B- Approval to conduct research at schools from the Department of Education



education

Department:
Education
PROVINCE OF KWAZULU-NATAL

Enquiries: Phindile Duma Tel: 033 392 1063 Ref.:2/4/8/1833

Ms L Smith
Eden Health
Salt Rock
4420

Dear Ms Smith

PERMISSION TO CONDUCT RESEARCH IN THE KZN DoE INSTITUTIONS

Your application to conduct research entitled: **"THE HEALTH-RELATED QUALITY OF LIFE OF PARENTS OF CHILDREN WITH AND WITHOUT AUTISM SPECTRUM DISORDER IN SOUTH AFRICA"**, in the KwaZulu-Natal Department of Education Institutions has been approved. The conditions of the approval are as follows:

1. The researcher will make all the arrangements concerning the research and interviews.
2. The researcher must ensure that Educator and learning programmes are not interrupted.
3. Interviews are not conducted during the time of writing examinations in schools.
4. Learners, Educators, Schools and Institutions are not identifiable in any way from the results of the research.
5. A copy of this letter is submitted to District Managers, Principals and Heads of Institutions where the Intended research and interviews are to be conducted.
6. The period of investigation is limited to the period from 04 July 2019 to 10 January 2022.
7. Your research and interviews will be limited to the schools you have proposed and approved by the Head of Department. Please note that Principals, Educators, Departmental Officials and Learners are under no obligation to participate or assist you in your investigation.
8. Should you wish to extend the period of your survey at the school(s), please contact Miss Phindile Duma at the contact numbers below.
9. Upon completion of the research, a brief summary of the findings, recommendations or a full report/dissertation/thesis must be submitted to the research office of the Department. Please address it to The Office of the HOD, Private Bag X9137, Pietermaritzburg, 3200.
10. Please note that your research and interviews will be limited to schools and institutions in KwaZulu-Natal Department of Education.

uMlazi District

Dr. EV Nzama
Head of Department: Education
Date: 05 July 2019

..Championing Quality Education - Creating and Securing a Brighter Future

KWAZULU-NATAL DEPARTMENT OF EDUCATION
Postal Address: Private Bag X9137 • Pietermaritzburg • 3200 • Republic of South Africa
Physical Address: 247 Burger Street • Anton Lembede Building • Pietermaritzburg • 3201
Tel.: +27 33 392 1063 • **Fax.:** +27 033 392 1203• **Email:** Phindile.Duma@kzndoe.gov.za •**Web:** www.kzneducation.gov.za
Facebook: KZNDOE....Twitter: @DBE_KZN....Instagram: kzn_education....Youtube:kzndoe

Appendix C- Letter to the schools to request permission to conduct study at the schools

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD
HEALTH SCIENCES

DHRS
Department of Health and Rehabilitation Sciences
FACULTY OF HEALTH SCIENCES

Divisions of Communication Sciences & Disorders • Disability Studies •
Nursing & Midwifery • Occupational Therapy • Physiotherapy

F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

To whom it may concern

My name is Louise Smith, I am a Speech-Language Pathologist and am undertaking the research project for a master's degree. I am currently conducting research on a project entitled: **"*The health-related quality of life of parents of children with and without Autism Spectrum Disorder in South Africa* ".** Ethics approval from the University of Cape Town's Faculty of Health Sciences Human Research Ethics committee has been obtained (HREC REF 158/2019).

I would like your permission to conduct this research project at your school. The procedure will be as follows:

- I will briefly meet with the teachers in order to make them aware and discuss the inclusion/ exclusion criteria for the study.
- The teachers will be asked to identify participants in their class that meet the selection criteria for this study. If they wish to discuss or confirm this further with me or my Supervisor (Dr. Michal Harty), we will be available telephonically or via e-mail (see contact details below).
- The teachers will be asked to send forms home with these participants. The parents will receive all the necessary information for the study. They will be asked to return the consent forms and the completed questionnaires to the class teacher. The parents will return all the questionnaires in a self-adhesive envelope which will be provided.
- The teachers will be asked to collect the envelopes once they are returned (each day) and place them in a sealed box that will be provided in the classroom. The sealed box will be emptied once a week and re-sealed. The process will take place over a two-week period.
- The teacher will be asked to send out reminders (provided) at the end of the second week, to return all consent forms and completed questionnaires.

This initial process of discussing the inclusion and exclusion criteria and identifying children in the class that meet the selection criteria will take no longer than an hour. Results of the study will be shared with you. We will also publish the results of the study in an academic journal and may present findings to colleagues at a relevant academic conference. The schools name will not be disclosed during any presentation of the results of the study. After reading the information above:

1. I understand what is expected of the school during this project.
2. I understand that there are no risks or benefits to the school if I agree for this project to be conducted at our school.

I ……………………………………………………………………………… (full name and surname)

Give my consent ………………….

Do not give my consent …………………..

___________________________________ ______________________________

Principal/Director's signature Date (day, month, year)

If you have any questions or concerns about the research, you may contact the researcher or the supervisor or the chair of the UCT FHS HREC:

Researcher	**Supervisor**	**Chair of the FHS:HREC**
Mrs. Louise Smith	Dr. Michal Harty	Prof. Marc Blockman
Email: lousmith_9@hotmail.com	E-mail: michal.harty@uct.ac.za	E-mail: marc.blockman@uct.ac.za
Phone number: 083 400 4383	Phone number: 021 406 6313	Phone number: 021 406 6492

Thank you for your time and cooperation.

Louise Smith: Student Dr M. Harty: Project supervisor

Appendix D- Project Information Sheet

UNIVERSITY OF CAPE TOWN
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HEALTH SCIENCES

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F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

Dear Participant

You are being invited to participate in a research project entitled: “***The health-related quality of life of parents of children with and without Autism Spectrum Disorder in South Africa*"**.

My name is Louise Smith, I am a Speech-Language Pathologist and am undertaking a research project for a master’s degree. Ethics approval from the University of Cape Town’s Faculty of Health Sciences Human Research Ethics committee has been obtained (HREC REF 158/2019).

You have been asked to participate in a survey for parents of children with Autism Spectrum Disorder (ASD) and parents of children without ASD. The survey consists of one questionnaire, including: one demographics questionnaire, one parenting measure, one quality of life questionnaire and one mental health questionnaire. It is crucial that you complete all the questions on all 12 pages.

There are no direct risks or benefits to you while participating. If you participate you will provide the researcher with information that will help them to better understand the stress and burden on parents with children on the Autism Spectrum and how this impacts their health-related quality of life (HRQOL). It will benefit all allied health professionals working with children on the Autism Spectrum, as the more we understand about the HRQOL, the better we can support parents and tailor make future intervention.

On completion of the consent forms you will be added into a lucky draw and given the chance to win a Checkers voucher to the value of R200. You stand a 1 in 150 chance of winning the lucky draw.
Participation in this study is completely voluntary and you are able to stop participating in the study at any point up until your forms have been handed in. Some of the information you provide may be shared with other professionals who are interested in the difference between the health-related quality of life of parents with children with ASD and parents of children without ASD. However, your identity will be kept completely confidential as your name will not be linked to your answers and will not be captured in the data analysis. You have the right to ask questions about this study throughout its duration and to have them answered before, during or after you have handed in your forms.

If you have any difficulty understanding what is being asked in the questionnaires or have any questions regarding this project, please feel free to phone, message or e-mail myself (Mrs. Louise Smith) or my supervisor (Dr. Michal Harty). If you find yourself feeling anxious after completing the questionnaire and wish to speak with a counsellor, you can contact SADAG or lifeline on the numbers provided below (available 24 hours a day):

- South African Depression and Anxiety Group: 0800 456 789
- LifeLine South Africa: 0861 322 322

If you have any questions about the project, you can call the primary investigator (Dr. Michal Harty) or Prof. Marc Blockman, Chair of the Human Research Ethics Committee if you have any questions regarding your rights or well-being as participants in the study (see contact details below)

If you have any questions or concerns about the research, you may contact the researcher or the supervisor or the chair of the UCT FHS: HREC: **Researcher**	**Supervisor**	**Chair of the FHS: HREC**
Full name: Louise Smith	Full name: Dr. Michal Harty	Full name: Prof. Marc Blockman
Email: lousmith_9@hotmail.com	E-mail: michal.harty@uct.ac.za	E-mail: marc.blockman@uct.ac.za;
Phone number: 083 400 4383	Phone number: 021 406 6313	Phone number: 021 406 6492

Please return this full pack in the A5 envelope provided.

(this includes the consent form & 12 page questionnaire)

Thank you for your time and cooperation.

Louise Smith: Student

Dr M. Harty: Project supervisor

Appendix E- Informed Consent Form

UNIVERSITY OF CAPE TOWN
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Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

INFORMED CONSENT FORM:

Title of the project: "*The health-related quality of life of parents of children with and without Autism Spectrum Disorder in South Africa*." (HREC REF 158/2019).

After reading the information sheet provided, I can declare that:

(Place an X next to the correct option)

Declaration	**Yes**	**No**
I have read through the information sheet and understand what is expected of me		
I understand that my consent is required		
I understand that there are no risks or benefits for me if I choose to participate in the study		
I understand that participation is voluntary, and I can withhold my consent without any consequences to myself or my child		
I understand that I can withdraw from the study at any time		
I understand that I nor my child will be personally identified should this research study be published		

I ………………………………………………………………………………… (full name and surname)

Give my consent: ………………….

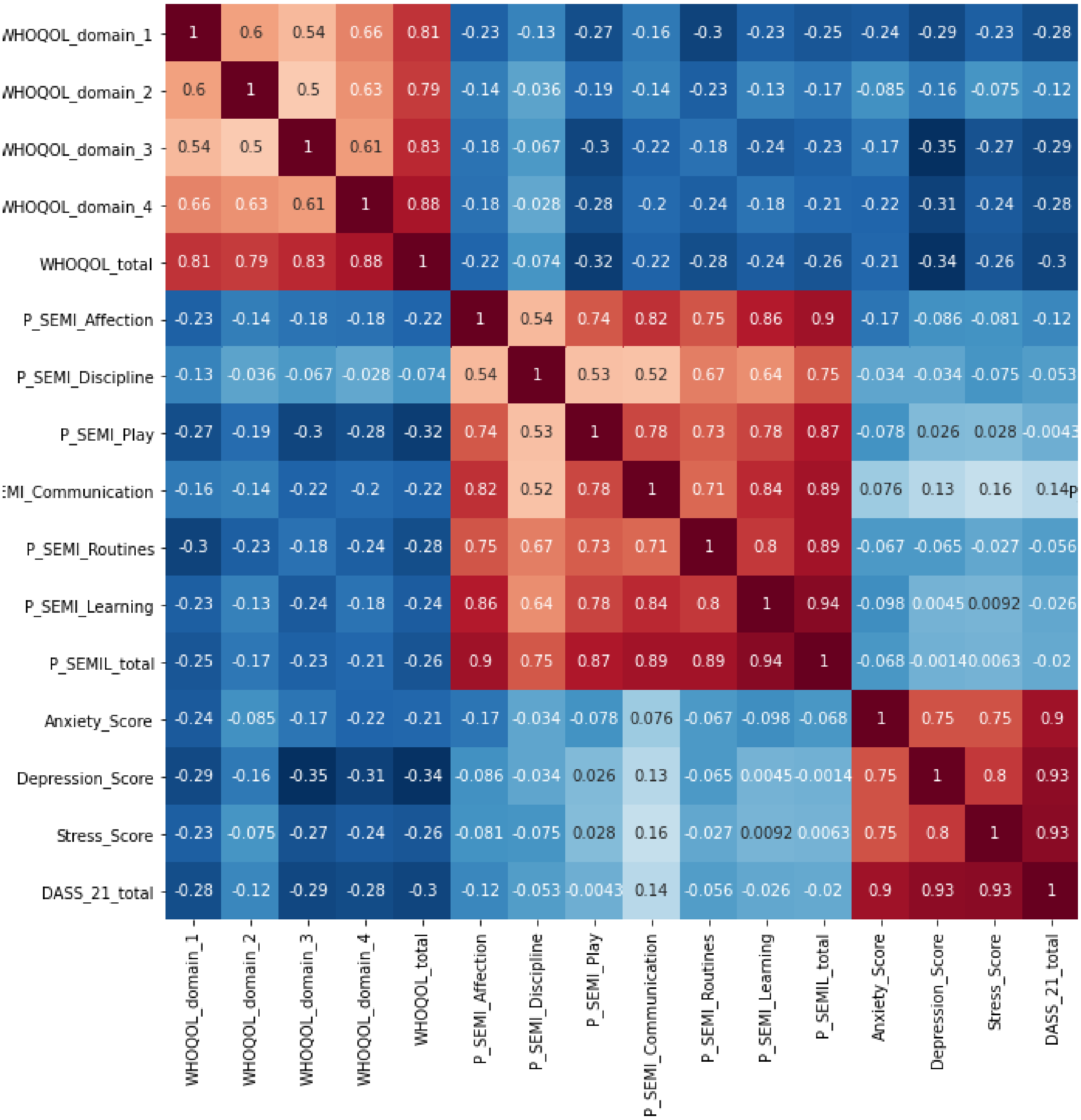
Do not give my consent: …………………..

(Place an X next to the correct option)

________________________________ ________________________________

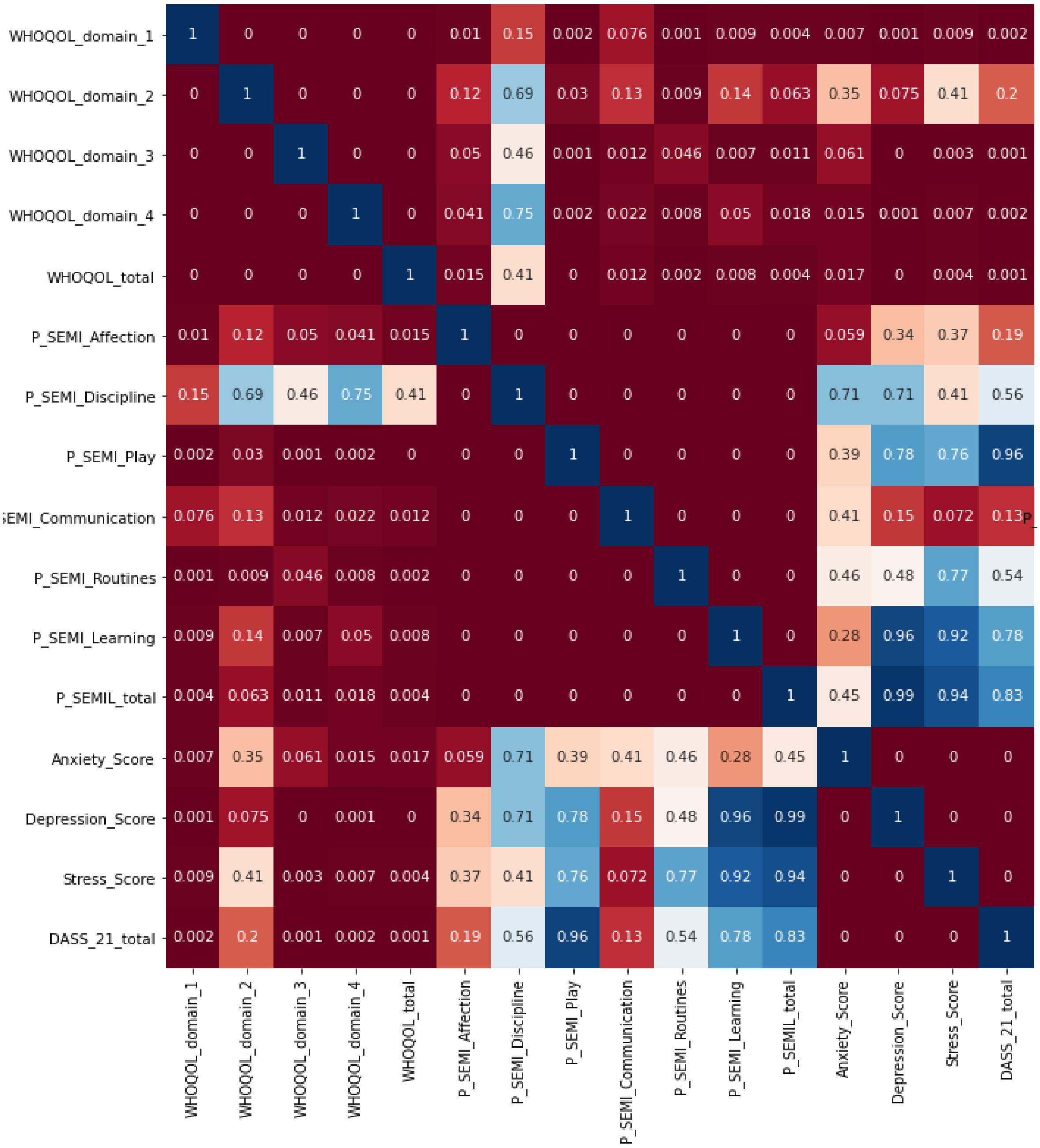
Participant's signature Date (day, month, year)

Appendix F- Group 1 (parents of children without ASD) Data Pearson’s Correlation



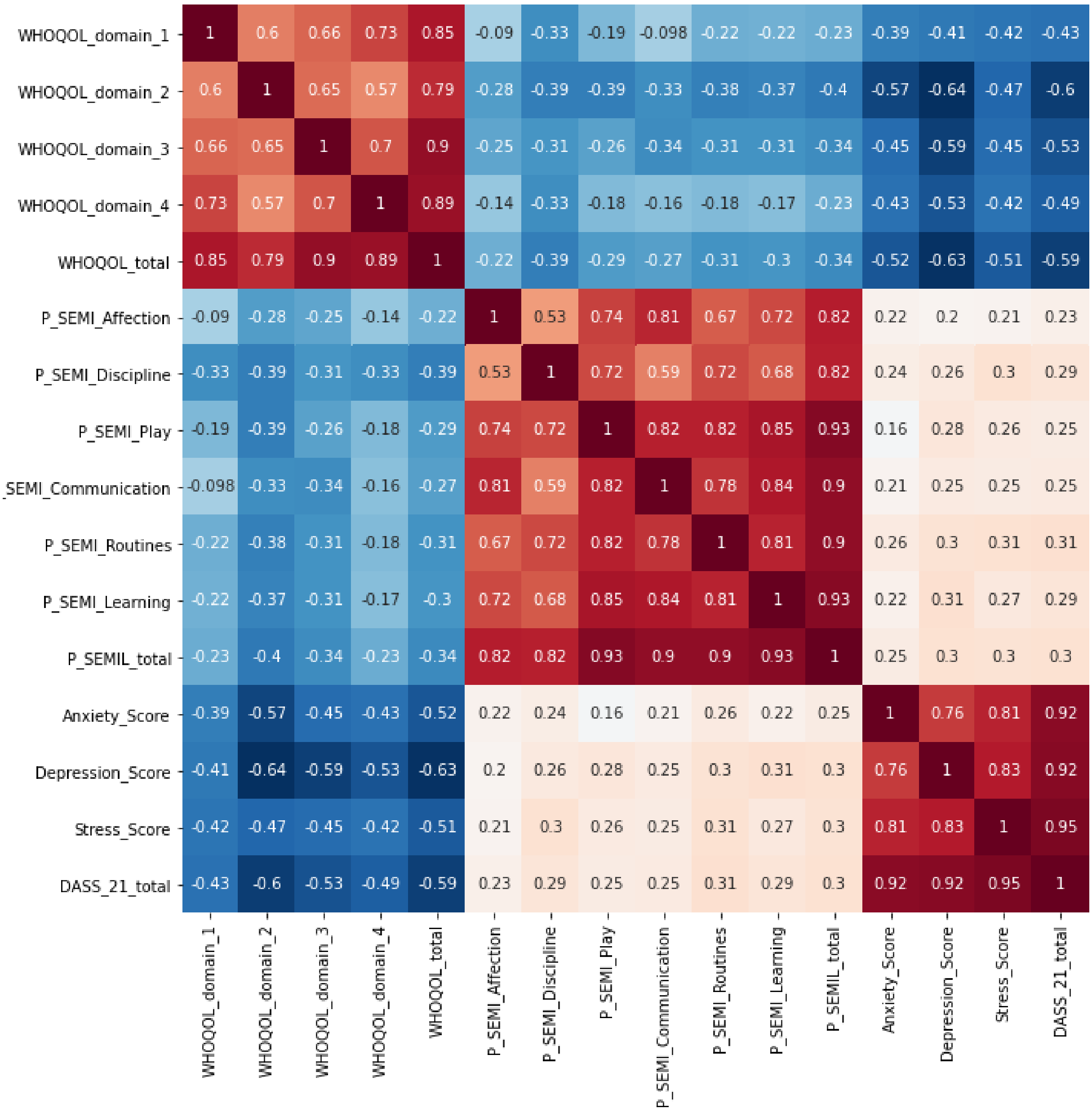
	WHOQOL_domain_1	WHOQOL_domain_2	WHOQOL_domain_3	WHOQOL_domain_4	WHOQOL_total	P_SEMI_Affection	P_SEMI_Discipline	P_SEMI_Play	P_SEMI_Communication	P_SEMI_Routines	P_SEMI_Learning	P_SEMIL_total	Anxiety_Score	Depression_Score	Stress_Score	DASS_21_total
WHOQOL_domain_1	1	0.6	0.54	0.66	0.81	-0.23	-0.13	-0.27	-0.16	-0.3	-0.23	-0.25	-0.24	-0.29	-0.23	-0.28
WHOQOL_domain_2	0.6	1	0.5	0.63	0.79	-0.14	-0.036	-0.19	-0.14	-0.23	-0.13	-0.17	-0.085	-0.16	-0.075	-0.12
WHOQOL_domain_3	0.54	0.5	1	0.61	0.83	-0.18	-0.067	-0.3	-0.22	-0.18	-0.24	-0.23	-0.17	-0.35	-0.27	-0.29
WHOQOL_domain_4	0.66	0.63	0.61	1	0.88	-0.18	-0.028	-0.28	-0.2	-0.24	-0.18	-0.21	-0.22	-0.31	-0.24	-0.28
WHOQOL_total	0.81	0.79	0.83	0.88	1	-0.22	-0.074	-0.32	-0.22	-0.28	-0.24	-0.26	-0.21	-0.34	-0.26	-0.3
P_SEMI_Affection	-0.23	-0.14	-0.18	-0.18	-0.22	1	0.54	0.74	0.82	0.75	0.86	0.9	-0.17	-0.086	-0.081	-0.12
P_SEMI_Discipline	-0.13	-0.036	-0.067	-0.028	-0.074	0.54	1	0.53	0.52	0.67	0.64	0.75	-0.034	-0.034	-0.075	-0.053
P_SEMI_Play	-0.27	-0.19	-0.3	-0.28	-0.32	0.74	0.53	1	0.78	0.73	0.78	0.87	-0.078	0.026	0.028	-0.0043
EMI_Communication	-0.16	-0.14	-0.22	-0.2	-0.22	0.82	0.52	0.78	1	0.71	0.84	0.89	0.076	0.13	0.16	0.14
P_SEMI_Routines	-0.3	-0.23	-0.18	-0.24	-0.28	0.75	0.67	0.73	0.71	1	0.8	0.89	-0.067	-0.065	-0.027	-0.056
P_SEMI_Learning	-0.23	-0.13	-0.24	-0.18	-0.24	0.86	0.64	0.78	0.84	0.8	1	0.94	-0.098	0.0045	0.0092	-0.026
P_SEMIL_total	-0.25	-0.17	-0.23	-0.21	-0.26	0.9	0.75	0.87	0.89	0.89	0.94	1	-0.068	-0.0014	0.0063	-0.02
Anxiety_Score	-0.24	-0.085	-0.17	-0.22	-0.21	-0.17	-0.034	-0.078	0.076	-0.067	-0.098	-0.068	1	0.75	0.75	0.9
Depression_Score	-0.29	-0.16	-0.35	-0.31	-0.34	-0.086	-0.034	0.026	0.13	-0.065	0.0045	-0.0014	0.75	1	0.8	0.93
Stress_Score	-0.23	-0.075	-0.27	-0.24	-0.26	-0.081	-0.075	0.028	0.16	-0.027	0.0092	0.0063	0.75	0.8	1	0.93
DASS_21_total	-0.28	-0.12	-0.29	-0.28	-0.3	-0.12	-0.053	-0.0043	0.14	-0.056	-0.026	-0.02	0.9	0.93	0.93	1

Appendix G- Group 1 (parents of children without ASD) Data Pearson’s R Significance



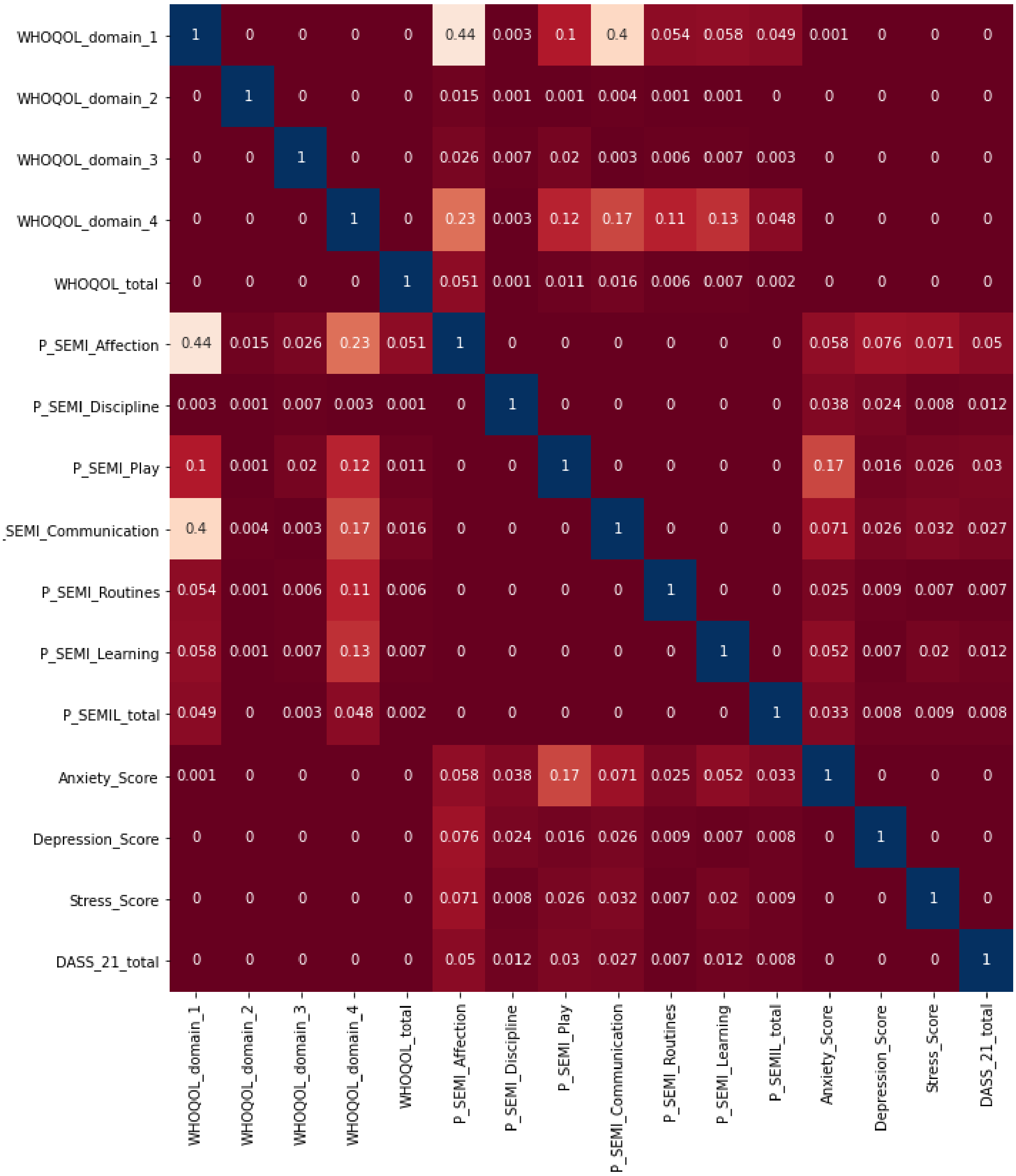
	WHOQOL_domain_1	WHOQOL_domain_2	WHOQOL_domain_3	WHOQOL_domain_4	WHOQOL_total	P_SEMI_Affection	P_SEMI_Discipline	P_SEMI_Play	P_SEMI_Communication	P_SEMI_Routines	P_SEMI_Learning	P_SEMIL_total	Anxiety_Score	Depression_Score	Stress_Score	DASS_21_total
WHOQOL_domain_1	1	0	0	0	0	0.01	0.15	0.002	0.076	0.001	0.009	0.004	0.007	0.001	0.009	0.002
WHOQOL_domain_2	0	1	0	0	0	0.12	0.69	0.03	0.13	0.009	0.14	0.063	0.35	0.075	0.41	0.2
WHOQOL_domain_3	0	0	1	0	0	0.05	0.46	0.001	0.012	0.046	0.007	0.011	0.061	0	0.003	0.001
WHOQOL_domain_4	0	0	0	1	0	0.041	0.75	0.002	0.022	0.008	0.05	0.018	0.015	0.001	0.007	0.002
WHOQOL_total	0	0	0	0	1	0.015	0.41	0	0.012	0.002	0.008	0.004	0.017	0	0.004	0.001
P_SEMI_Affection	0.01	0.12	0.05	0.041	0.015	1	0	0	0	0	0	0	0.059	0.34	0.37	0.19
P_SEMI_Discipline	0.15	0.69	0.46	0.75	0.41	0	1	0	0	0	0	0	0.71	0.71	0.41	0.56
P_SEMI_Play	0.002	0.03	0.001	0.002	0	0	0	1	0	0	0	0	0.39	0.78	0.76	0.96
EMI_Communication	0.076	0.13	0.012	0.022	0.012	0	0	0	1	0	0	0	0.41	0.15	0.072	0.13
P_SEMI_Routines	0.001	0.009	0.046	0.008	0.002	0	0	0	0	1	0	0	0.46	0.48	0.77	0.54
P_SEMI_Learning	0.009	0.14	0.007	0.05	0.008	0	0	0	0	0	1	0	0.28	0.96	0.92	0.78
P_SEMIL_total	0.004	0.063	0.011	0.018	0.004	0	0	0	0	0	0	1	0.45	0.99	0.94	0.83
Anxiety_Score	0.007	0.35	0.061	0.015	0.017	0.059	0.71	0.39	0.41	0.46	0.28	0.45	1	0	0	0
Depression_Score	0.001	0.075	0	0.001	0	0.34	0.71	0.78	0.15	0.48	0.96	0.99	0	1	0	0
Stress_Score	0.009	0.41	0.003	0.007	0.004	0.37	0.41	0.76	0.072	0.77	0.92	0.94	0	0	1	0
DASS_21_total	0.002	0.2	0.001	0.002	0.001	0.19	0.56	0.96	0.13	0.54	0.78	0.83	0	0	0	1

Appendix H- Group 2 (parents of children with ASD) Data Pearson's Correlations



	WHOQOL_domain_1	WHOQOL_domain_2	WHOQOL_domain_3	WHOQOL_domain_4	WHOQOL_total	P_SEMI_Affection	P_SEMI_Discipline	P_SEMI_Play	P_SEMI_Communication	P_SEMI_Routines	P_SEMI_Learning	P_SEMIL_total	Anxiety_Score	Depression_Score	Stress_Score	DASS_21_total
WHOQOL_domain_1	1	0.6	0.66	0.73	0.85	-0.09	-0.33	-0.19	-0.098	-0.22	-0.22	-0.23	-0.39	-0.41	-0.42	-0.43
WHOQOL_domain_2	0.6	1	0.65	0.57	0.79	-0.28	-0.39	-0.39	-0.33	-0.38	-0.37	-0.4	-0.57	-0.64	-0.47	-0.6
WHOQOL_domain_3	0.66	0.65	1	0.7	0.9	-0.25	-0.31	-0.26	-0.34	-0.31	-0.31	-0.34	-0.45	-0.59	-0.45	-0.53
WHOQOL_domain_4	0.73	0.57	0.7	1	0.89	-0.14	-0.33	-0.18	-0.16	-0.18	-0.17	-0.23	-0.43	-0.53	-0.42	-0.49
WHOQOL_total	0.85	0.79	0.9	0.89	1	-0.22	-0.39	-0.29	-0.27	-0.31	-0.3	-0.34	-0.52	-0.63	-0.51	-0.59
P_SEMI_Affection	-0.09	-0.28	-0.25	-0.14	-0.22	1	0.53	0.74	0.81	0.67	0.72	0.82	0.22	0.2	0.21	0.23
P_SEMI_Discipline	-0.33	-0.39	-0.31	-0.33	-0.39	0.53	1	0.72	0.59	0.72	0.68	0.82	0.24	0.26	0.3	0.29
P_SEMI_Play	-0.19	-0.39	-0.26	-0.18	-0.29	0.74	0.72	1	0.82	0.82	0.85	0.93	0.16	0.28	0.26	0.25
_SEMI_Communication	-0.098	-0.33	-0.34	-0.16	-0.27	0.81	0.59	0.82	1	0.78	0.84	0.9	0.21	0.25	0.25	0.25
P_SEMI_Routines	-0.22	-0.38	-0.31	-0.18	-0.31	0.67	0.72	0.82	0.78	1	0.81	0.9	0.26	0.3	0.31	0.31
P_SEMI_Learning	-0.22	-0.37	-0.31	-0.17	-0.3	0.72	0.68	0.85	0.84	0.81	1	0.93	0.22	0.31	0.27	0.29
P_SEMIL_total	-0.23	-0.4	-0.34	-0.23	-0.34	0.82	0.82	0.93	0.9	0.9	0.93	1	0.25	0.3	0.3	0.3
Anxiety_Score	-0.39	-0.57	-0.45	-0.43	-0.52	0.22	0.24	0.16	0.21	0.26	0.22	0.25	1	0.76	0.81	0.92
Depression_Score	-0.41	-0.64	-0.59	-0.53	-0.63	0.2	0.26	0.28	0.25	0.3	0.31	0.3	0.76	1	0.83	0.92
Stress_Score	-0.42	-0.47	-0.45	-0.42	-0.51	0.21	0.3	0.26	0.25	0.31	0.27	0.3	0.81	0.83	1	0.95
DASS_21_total	-0.43	-0.6	-0.53	-0.49	-0.59	0.23	0.29	0.25	0.25	0.31	0.29	0.3	0.92	0.92	0.95	1

Appendix I- Group 2 (parents of children with ASD) Data Pearson’s R Significance



	WHOQOL_domain_1	WHOQOL_domain_2	WHOQOL_domain_3	WHOQOL_domain_4	WHOQOL_total	P_SEMI_Affection	P_SEMI_Discipline	P_SEMI_Play	P_SEMI_Communication	P_SEMI_Routines	P_SEMI_Learning	P_SEMIL_total	Anxiety_Score	Depression_Score	Stress_Score	DASS_21_total
WHOQOL_domain_1	1	0	0	0	0	0.44	0.003	0.1	0.4	0.054	0.058	0.049	0.001	0	0	0
WHOQOL_domain_2	0	1	0	0	0	0.015	0.001	0.001	0.004	0.001	0.001	0	0	0	0	0
WHOQOL_domain_3	0	0	1	0	0	0.026	0.007	0.02	0.003	0.006	0.007	0.003	0	0	0	0
WHOQOL_domain_4	0	0	0	1	0	0.23	0.003	0.12	0.17	0.11	0.13	0.048	0	0	0	0
WHOQOL_total	0	0	0	0	1	0.051	0.001	0.011	0.016	0.006	0.007	0.002	0	0	0	0
P_SEMI_Affection	0.44	0.015	0.026	0.23	0.051	1	0	0	0	0	0	0	0.058	0.076	0.071	0.05
P_SEMI_Discipline	0.003	0.001	0.007	0.003	0.001	0	1	0	0	0	0	0	0.038	0.024	0.008	0.012
P_SEMI_Play	0.1	0.001	0.02	0.12	0.011	0	0	1	0	0	0	0	0.17	0.016	0.026	0.03
_SEMI_Communication	0.4	0.004	0.003	0.17	0.016	0	0	0	1	0	0	0	0.071	0.026	0.032	0.027
P_SEMI_Routines	0.054	0.001	0.006	0.11	0.006	0	0	0	0	1	0	0	0.025	0.009	0.007	0.007
P_SEMI_Learning	0.058	0.001	0.007	0.13	0.007	0	0	0	0	0	1	0	0.052	0.007	0.02	0.012
P_SEMIL_total	0.049	0	0.003	0.048	0.002	0	0	0	0	0	0	1	0.033	0.008	0.009	0.008
Anxiety_Score	0.001	0	0	0	0	0.058	0.038	0.17	0.071	0.025	0.052	0.033	1	0	0	0
Depression_Score	0	0	0	0	0	0.076	0.024	0.016	0.026	0.009	0.007	0.008	0	1	0	0
Stress_Score	0	0	0	0	0	0.071	0.008	0.026	0.032	0.007	0.02	0.009	0	0	1	0
DASS_21_total	0	0	0	0	0	0.05	0.012	0.03	0.027	0.007	0.012	0.008	0	0	0	1