Families raising a child with Autism Spectrum Disorder: Determining the relationship between family routines and family quality of life

by

Liezl Schlebusch

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SUPERVISOR: Dr. Alecia E. Samuels

CO-SUPERVISOR: Dr. Shakila Dada

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"In normal life we hardly realize how much more we receive than we give, and life cannot be rich without such gratitude. It is so easy to overestimate the importance of our own achievements compared with what we owe to the help of others."

— Dietrich Bonhoeffer

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Abstract

Using a family quality of life approach in early childhood intervention recognises that the impact of disability spreads beyond the child and that it places demands on various domains of family life. It is recommended that service providers recognise the responsibility to serve the family as a whole and that an enhanced family quality of life can be an appropriate outcome for services to families of young children with disabilities. To be able to enhance family quality of life, it is important to understand how family dynamics and family beliefs influence family quality of life. The purpose of this study was to determine the relationship between regular family routines and family quality of life in families raising a child with Autism Spectrum Disorder (ASD); and secondly, to investigate whether this relationship is mediated by the cognitive appraisal of the impact of ASD on the family. A sample of 180 families of young children with ASD who are receiving disability-related services in one South African province completed a survey of three family measures. Structural equation modeling examined the mediating effect of cognitive appraisal on the relationship between the regularity of family routines and family quality of life. The results suggest that: (a) there is a positive relationship between the regularity of family routines and family quality of life, and (b) that the cognitive appraisal of the impact of ASD on the family acts as a partial mediator on this relationship. The findings support the importance of creating and maintaining regular family routines in relation to families' quality of life, and highlight the role of the how families' appraise the impact of ASD on the family.

Keywords: autism spectrum disorder, cognitive appraisal, early childhood, family routines, family quality of life, impact on the family, negative appraisal, positive appraisal, structural equation modeling.

Opsomming

Die familie lewenskwaliteit perspektief in vroeë kinderintervensie bepaal dat ‘n kind met ‘n gestremdheid ‘n impak op verskeie areas van die familie se lewe het. Om die familie se lewenskwaliteit te kan verhoog is dit belangrik om te verstaan hoe familie dinamika en die familie se sienswyses hulle lewenskwaliteit beïnvloed. Die doel van hierdie studie was dus om die verband tussen die reëlmatigheid van familie roetines en hul tevredenheid met hulle lewenskwaliteit te ondersoek. Die familie se beoordeling van die impak van Outisme Spektrum Versteurings (OSV), en hoe dit die verhouding tussen familie roetines en hul lewenskwaliteit beïnvloed, is ook ondersoek. Een honderd en tagtig families met ‘n kind met OSV, wat gestremdheid-verwante hulp ontvang in een van Suid-Afrika se provinsies het aan die studie deelgeneem. Ouers het ‘n vraelys met drie familie instrumente voltooi. Die verbanskap tussen die reëlmatigheid van familie roetines en hul lewenskwaliteit en die invloed van die beoordeling van die impak van OSV is met behulp van strukturele vergelykingsmodelle getoets. Die resultate toon dat (a) daar ‘n positiewe verband tussen die reëlmatigheid van ‘n familie se roetines en hul tevredenheid met hul lewenskwaliteit is, en (b) dat die beoordeling van die impak van OSV op die familie ‘n gedeeltelike invloed op hierdie verbandskap het. Die bevindinge beklemtoon die belangrikheid van die skep en instandhouding van familie roetines en die invloed van die beoordeling van die impak van OSV op die familie.

Sleutelwoorde: impak op die familie, familie lewenskwaliteit, familie roetines, kognitiewe beoordeling, negatiewe beoordeling, outisme spektrum versteuring, positiewe beoordeling, strukturele vergelykingsmodelle, vroeë kinderjare.

CHAPTER 1
PROBLEM STATEMENT AND RATIONALE

1.1. Introduction

This chapter presents the problem statement and the purpose of the research. Furthermore, frequently used terms are defined and abbreviations explained. The chapter concludes with an outline of each of the six chapters of the thesis.

1.2. Problem statement and rationale

The mission of early childhood intervention is to provide services to help young children with a disability and their families to thrive in life (Meisels & Shonkoff, 2000). However, to focus on and include the family was not always the case. The child with a disability, or the child and mother, was the central focus of early disability research and practice (Brown, MacAdam–Crisp, Wang, & Iarocci, 2006; Seligman & Darling, 2007). This child-centred focus is particularly evident in research on families with a child with autism spectrum disorder (ASD), which is dominated by a negative portrayal of the challenges associated with the child and the associated stress and depression of mothers (Gardiner & Iarocci, 2012; Karst & Van Hecke, 2012). However, the impact of having a child with ASD extends beyond the main caregiver to the entire family system (Gabovitch & Curtin, 2009; Smith & Elder, 2010).

Viewing families from a systems perspective broadens the traditional child-centred focus. A family systems perspective views the family as a complex and interactive social system, where each family member is linked to each other and to their environment (Minuchin, 1985). Thus, what impacts one member of the family (e.g. childhood disability) impacts the entire family system, suggesting a need for family-focused research (Seligman & Darling, 2007).

Although family-focused ASD research has become more common, it remains underdeveloped. Many of the current studies tend to focus on the challenges families experience when raising a child with ASD and the negative impact of ASD on family functioning (Cridland, Jones, Magee, & Caputi, 2013). This highlights the need for research efforts to investigate various aspects of family life that can facilitate positive coping and adaptation for these families.

Family quality of life is a multidimensional construct that explores multiple aspects of family life when raising a child with a disability (Samuel, Rillotta, & Brown, 2012). The family quality of life framework moves away from a child-centred focus to that of the whole family, exploring the full range of positive and negative family experiences when raising a child with a disability (Brown et al., 2006). Family quality of life is defined as the conditions where the family's needs are met, where family members enjoy their life together, and where they have the chance to do things which are important to them (Park et al., 2003). It focuses on different aspects of family life, such as the family's emotional well-being, physical or material well-being, parenting aspects, family interaction, and disability-related support and services (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). Enhancing the family quality of life has been proposed as an appropriate outcome for services to families of young children with disabilities (Summers et al., 2005). Families who have resources and skills may provide a nourishing home environment that meets the needs of all family members and supports their child's development (Dunst, 2002).

Researchers are encouraged to investigate dynamic concepts (i.e. concepts amenable to change as opposed to static or difficult to change concepts) that may influence a family's quality of life (Zuna et al., 2010). There is also a specific call for family-focused ASD research to focus *within* families to be able to develop and create support services for those families who are not functioning well (Cridland et al., 2013). Family routines are a dynamic family concept embedded in the cultural and ecological context of families' lives and offers a way to focus on processes within the family (Denham, 2002). The regularity, or rhythm, of family routines is identified as a protective factor in resilient families, meaning that the regularity of family routines can influence the outcome of a potentially stressful situation (Fiese et al., 2002). However, research that investigated the impact of ASD on family routines reported that the unpredictability associated with ASD interfered with the frequency and regularity of family routines (Crespo et al., 2013). This warrants further investigation – to determine how the regularity of family routines in families raising a child with ASD relates to their family quality of life.

Given the frequently reported negative impact of a child with ASD on families (Cridland et al., 2013; Karst & Van Hecke, 2012), it is important to consider how the meaning a family ascribe to the impact of ASD influence their family quality of life. In trying to better understand the stress and coping process, researchers established that the way people define the impact of a stressor (e.g. how they cognitively appraise or interpret a stressful situation) plays an intervening role in the outcome of the situation (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). In the context of childhood disability, cognitive appraisal has two distinct dimensions, i.e. positive appraisal and negative appraisal (Trute, Hiebert-Murphy, & Levine, 2007). This means that families can appraise the impact of childhood disability on the family as a positive event (e.g. making life more meaningful for the family), and simultaneously as a negative event (e.g. leading to limitations in social contacts outside the family home). Potentially these two dimensions of cognitive appraisal could therefore influence the outcome of a stressful situation. Thus, how families appraise a situation (e.g. how they perceive the impact of ASD on the family) could potentially mediate the relationship between a stressor (e.g., the disruption of regular family routines due to the difficulties associated with ASD) and the outcome of stress (e.g., feeling less satisfied with their family quality of life).

Having a better understanding of how everyday family routines relate to a family's satisfaction with their quality of life, and to understand the intervening effect of the meaning a family ascribe to the impact of ASD, will lead to a better understanding of how these families function and how to best support the multiple aspects of their family life. Given the high prevalence rates of ASD and the associated pervasive challenges reported, family-focused ASD research is critical (Cridland et al., 2013). The purpose of this study is therefore to determine the relationship between the regularity of family routines and family quality of life, and to determine the contribution of the cognitive appraisal of the impact of ASD on this relationship, in families raising a young child with ASD.

1.3. Terminology

The following terms are used frequently in this study and are therefore defined.

Cognitive appraisal

Cognitive appraisal is the meaning that people make of stressful events in their life (Folkman et al., 1986; Trute & Hiebert-Murphy, 2002). This study focuses on parents' cognitive appraisal (i.e. their interpretation or the meaning they ascribe) to the impact of ASD on the family. In the context of childhood disability, such as ASD, both positive appraisal and negative appraisal of the impact of disability on the family can coexist (Trute et al., 2007). For example, a positive appraisal of the impact of ASD is that the experience makes the family more aware of other people's needs and struggles which are based on a disability. An example of a negative appraisal of the impact of ASD is that there may be increased time demands created in looking after the needs of the child with ASD.

Family

This study uses the definition of family developed by Rillotta, Kirby, Shearer, and Nettelbeck (2011) where families are defined as the people who are closely involved in the day-to-day affairs of the household, who support each other on a regular basis, and are related by blood ties or by marriage or by a close personal relationship.

Family routines

Different researchers define family routines somewhat different (Denham, 2003). This study adopts the definition developed by Boyce, Jensen, James, and Peacock (1983) where family routines are defined as "observable, repetitive behaviours which involve several family members and which occur with predictable regularity in the ongoing life of families" (p. 198).

Family quality of life

Family quality of life is defined as "conditions where the family's needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them" (Park et al., 2003, p. 368). The five domains of family quality of life in this study are Emotional Well-Being, Parenting, Family Interaction, Physical/Material Well-Being, and Disability-related Support (Hoffman et al., 2006).

Regularity of family routines

The regularity of family routines, also sometimes referred to as family routinisation in the literature, is defined as the predictable family routines which characterises day-to-day, week-to-week existence within a given family unit (Boyce et al., 1983).

1.4. Abbreviations

AIC	:	Akaike information criterion
ASD	:	Autism spectrum disorder
CFA	:	Confirmatory factor analysis
CFI	:	Comparative fit index
CI	:	Confidence interval
FICD Scale	:	Family Impact of Childhood Disability Scale
FQOL	:	Family quality of life
RFR	:	Regularity of family routines
RMSEA	:	Root mean square error of approximation
SEM	:	Structural equation modeling

1.5. Outline of chapters

The six chapters of the thesis are schematically presented in Figure 1.1. This is followed by a brief description of each chapter.

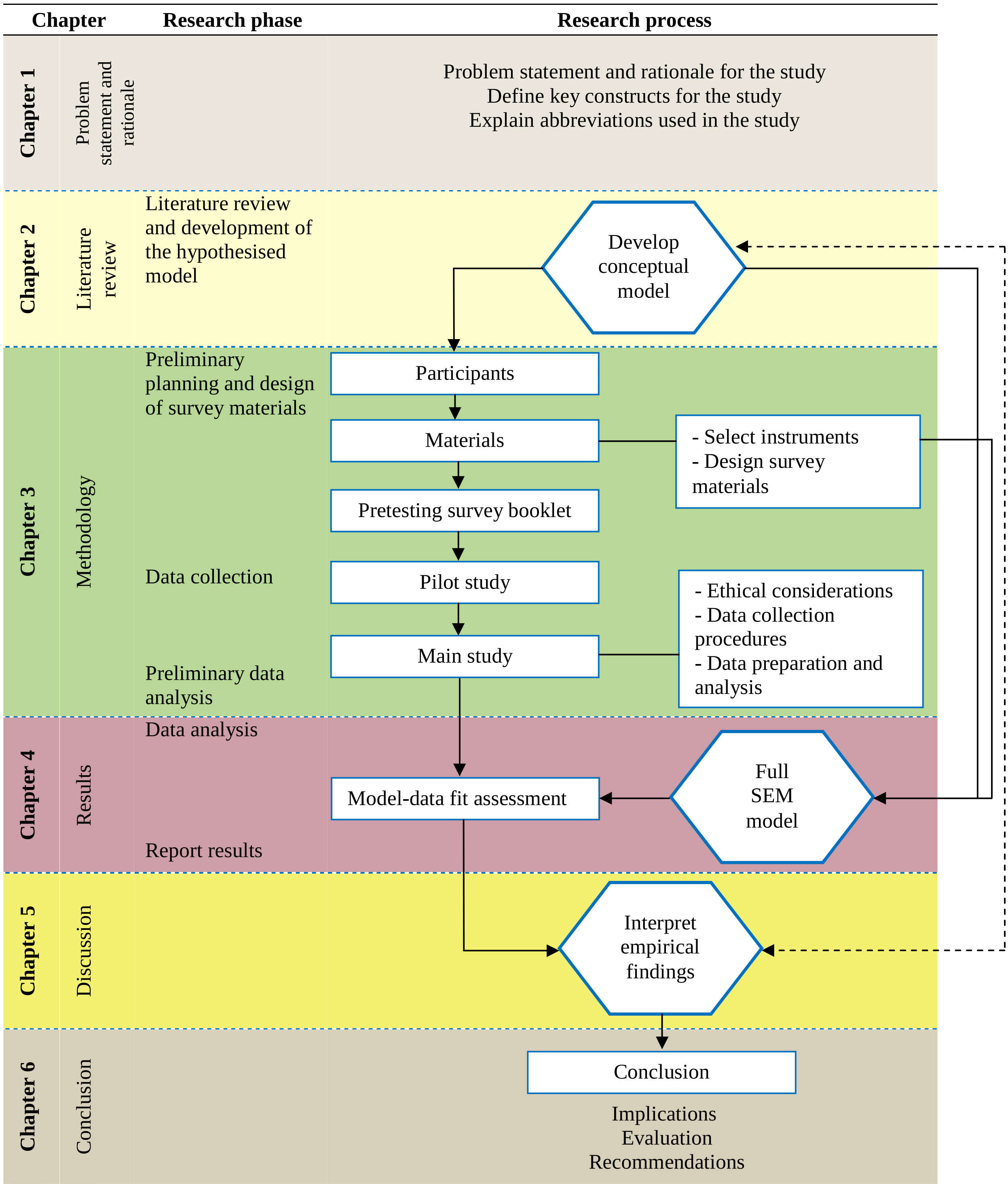


Figure 1.1 Schematic overview of the thesis.

As illustrated in Figure 1.1, the problem statement and rationale for the study is presented in Chapter 1. The chapter also includes the definition of frequently used terms and an explanation of abbreviations used.

Chapter 2 presents a literature review of the theoretical underpinnings and research findings that relate to family quality of life, family routines and parents' cognitive appraisal of the impact of ASD on the family. A conceptual model of the hypothesised relationships between these constructs is presented at the end of the chapter.

Chapter 3 describes the methodology of the study. The research aims and the design are specified, followed by information of the participants. The materials used in the study are described, with a focus on the instrument selection. The design and pretesting of the survey materials and the pilot study is described. Thereafter, the main study is described in terms of the ethical considerations, data collection procedures and the data preparation and analysis.

Chapter 4 contains the specified SEM model (including the measurement model and the structural model) and a description of the results of the study. The results of the study are reported in two phases, namely (a) the results of the measurement model, and (b) the results of the structural model. Descriptive results of each instrument, as well as the results of the influences of individual family member demographics and family unit characteristics on the family quality of life are also reported.

In Chapter 5, the results are interpreted and discussed in relation to the research aims of the study. Similarities and differences to previous findings are highlighted and significant contributions and implications are reported.

Finally, Chapter 6 presents the most important conclusions regarding the study's findings. The implications of the results are discussed and the study is evaluated in terms of its strengths and limitations. Recommendations for further research are also provided.

1.6. Summary

This chapter presented the problem statement and purpose for the study by highlighting the implications of having a broader perspective about childhood disability – to not only focus on the child with ASD, but to also include the family by investigating family level constructs that might influence the family's quality of life. Definitions of frequently used terms were provided and abbreviations explained. The chapter concluded with an outline of the six chapters contained in the thesis.

CHAPTER 2
LITERATURE REVIEW

2.1. Introduction

This chapter offers a critical review of the literature on family life when raising a child with ASD. The chapter begins with an overview of using a family systems perspective and addresses the complexities of defining "family" and "ASD". Secondly, the concept of family quality a life is proposed as a framework for understanding and supporting families raising a child with a disability. Subsequently, the role of family routines and the meaning (or cognitive appraisal) of the impact of a childhood disability such as ASD on a family's quality of life are explored. The chapter concludes with the conceptual model of the study, which is derived from the diverse empirical and theoretical work reviewed in the chapter.

2.2. Family systems perspective in families raising a child with ASD

Researchers have advocated the use of a family systems perspective when studying families and children with disabilities (Minuchin, 1985; Seligman & Darling, 2007). A family systems perspective views the family as a complex and interactive social system, what affects one member of the family impacts the entire family system (Minuchin, 1985). A family systems perspective rejects the view that linear relationships characterise family life, or that the only important relationship is between mother and her child. Instead, a family systems perspective considers families as unique, interactive and reactive units, with their own basic social system of rules, values and goals (Cridland et al., 2013). Viewing families from a systems perspective have broadened the traditional unitary, child-centred perspectives, and now seek to understand, from multiple levels of analysis, how child, family and service characteristics, as well as surrounding socio-cultural contexts, interact and overlap in their contributions to family functioning (Gardiner & Iarocci, 2012). In order to better understand and serve families with a child with a disability, it is important to move beyond individual family members and address the family as a unit of focus. However, defining a family tend to be particularly difficult in today's world (Newman & Grauerholz, 2002).

2.2.1. *Defining families*

"The family" is often defined as a group of individuals, related by blood ties, marriage or adoption, who form a socio-economic unit, and where the adult members are responsible for the upbringing of children (Giddens & Sutton, 2014). This dominant operational definition of the family has become a matter of considerable controversy because it fails to take account the realities of diverse family lives that do not fit this implicit model (McCarthy & Edwards, 2011). This is even more relevant in a multicultural, multiracial and modernising society like South Africa. Although no single definition of family can be comprehensive enough to cover the different types of families in South Africa, it is important to define it broadly enough to avoid elevating the nuclear family to the position of norm against which all other family types are measured (Ziehl, 2001).

The different types of families in South Africa are the products of various cultures and social contexts (Smit, 2001). The most common family type is the nuclear family (which consists of parents with their biological or adoptive children only). However, the proportion of nuclear families is declining, while the proportion of extended families is increasing – with Black African families having the highest proportion of three-generation families (Department of Social Development, 2012). More than 40 percent of all households in South Africa are headed by a single parent, and the majority of these families are headed by women. In addition, other important types of families existent in the country include skip-generation households and child-headed households, as well as same-sex partnerships, polygynous partnerships, and migrant families.

The definition developed by Rillotta, Kirby, Shearer, and Nettelbeck (2011) who views the family as the people who are closely involved in the day-to-day affairs of the household, who support each other on a regular basis, and are related by blood ties or by marriage or by close personal relationship captures the diversity of South African families. This definition allowed the researcher to focus on the interactions of family members and how they define and experience their family life (Shaw, 2007).

2.2.2. *Defining autism spectrum disorder*

Viewing a childhood disability such as ASD from a systems perspective acknowledge that disability is not only clinically defined, but also defined by the experiences of families within their socio-cultural context. ASD is currently conceptualised in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2013) as “a behaviourally defined neurodevelopmental disorder associated with the presence of social-communication deficits and restricted and repetitive behaviours” (Ousley & Cermak, 2013, p. 20). Although substantial gains have been achieved in the knowledge of understanding the clinical symptoms of ASD, and advances made in research on genetics and environmental aspects, there are still major uncertainties remaining (Rutter, 2011).

Ferguson (2002) proposed that a family's interpretation of the meaning of disability cannot help but reflect to some degree the larger context of social attitudes and historical realities within which that interpretation emerges. The way a disability is defined and labelled, how families respond and adapt to a disability, and the barriers and opportunities created by a disability, are all part of a process that evolves over time, at multiple levels, within particular historical and political contexts (Skinner & Weisner, 2007). Research on families with a child with ASD suggests that parents hold a wide variety of beliefs about the cause, the course, and the outcome of their child's ASD (Hebert & Koulougliotі, 2010); and that families construct a meaning of ASD based on their cultural values, personal experiences, upbringing, family attitudes, friends and community (Hebert & Koulougliotі, 2010).

2.2.3. *Family-focused ASD research*

Most of the studies that looked at families with children with ASD is dominated by a negative portrayal of the impact of disability that elicits an elaborate representation of problems and risks (Gardiner & Iarocci, 2012; Karst & Van Hecke, 2012; Sivberg, 2002). Hayes and Watson (2013) conducted a meta-analysis of studies comparing the experience of parenting stress in parents of children with and without ASD. They reported that parenting a child with ASD was associated with greater parenting stress when compared to families with children who are typically developing, or those with other disabilities (e.g., Down syndrome, cerebral palsy, intellectual disability). It is recognised that having a child with ASD poses a range of distinct challenges on families. These challenges include, but are not limited to, accommodation of inflexible daily routines, management of unique intolerances, lack of spontaneity, and required assistance with self-care, mobility, communication and cognitive or emotional tasks on a daily basis (Cridland et al., 2013). On the other hand, very limited studies exist that investigates the effect of the family system on the child with ASD (Kelly, Garnett, Attwood, & Peterson, 2008).

However, the experience of parenting stress is not the sole experience for parents of children diagnosed with ASD (Hayes & Watson, 2013). In an exploratory study, Little and Clark (2006) found that apart from pressing worries (mostly about adulthood and the future of their child), parents also experience prevalent joys (e.g., observing their child being happy, watching them grow, mature and succeed). Bayat (2007) examined family resilience in families of children with ASD and presented evidence that many families displayed resilience and have become stronger as a result of disability in the family. Another study by Phelps, McCammon, Wuensch, and Golden (2009) found that although stress is a major concern for caregivers of children with ASD, enrichment of their lives and personal growth may also occur in varying degrees. These positive findings underscore the importance of using a balanced view when assessing the family life of families raising a child with a disability (Turnbull, Summers, Lee, & Kyzar, 2007).

2.3. Family quality of life

Family quality of life is a multidimensional construct that explore multiple aspects of family life when raising a child with a disability (Samuel et al., 2012). Since the time of Aristotle, researchers were fascinated with *eudaimonia*, or human flourishing. They asked questions about how to measure well-being and how to enhance a person's state of 'doing well and living well'. Numerous disciplines (e.g. health, economics, urban planning, business, and employment) have expanded on this idea and have started to examine well-being and quality of life in greater depth (Zuna, Turnbull, & Summers, 2009). However, research efforts to examine the quality of life for vulnerable populations (i.e. individuals with disabilities) only began in the early 1980s (Schalock, 2000, 2004), and only started to include the family of a person with a disability in the beginning 2000s (Brown et al., 2006; Wang & Brown, 2009).

Although family quality of life is a relatively new field, it is a natural evolution of quality of life research from the perspective of the individual with a disability to the perspective of families (Samuel et al., 2012). Family quality of life is most often defined as the goodness of family life, or the conditions where the family's needs are met, where family members enjoy their life together as a family, and that they have the chance to do things which are important to them (Park et al., 2003). The family quality of life framework provides a way to seek positive approaches that can improve the quality of life of families raising a child with a disability. The outcome of this approach is families that are functioning optimally within their home and community (Brown, Schalock, & Brown, 2009; Turnbull, Summers, Lee, & Kyzar, 2007; Wang & Brown, 2009). Families that function well support the development of their children and the functioning and ongoing stability of societies

(Isaacs et al., 2007; Samuel et al., 2012). Supporting the family quality of life in the early childhood years will potentially enhance their capabilities and skills to deal with adversities and challenges across their full lifespan.

Family well-being and family quality of life can both be considered family-level outcomes and are often used in conjunction or synonymously in the literature. The term family well-being is defined differently across different studies and lacks an explicit definition (Turnbull et al., 2007). On the other hand, studies that investigated family quality of life tend to focus on family support and the development of instruments to measure different domains of family life (Turnbull et al., 2007). The measurement of family quality of life therefore enables researchers to gain a better understanding of family well-being (Hu, Summers, Turnbull, & Zuna, 2011). The most current definition of family quality of life captures this intricate association of well-being and quality of life, defining family quality of life as "a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact" (Zuna, Summers, Turnbull, Hu, & Xu, 2010, p. 262). The present study uses the term family quality of life and the way it is conceptualised in the field, however, the term family well-being will be used when reporting on findings of previous studies that specifically used that terminology.

To address the complexity of family quality of life, and to make it easier to understand and assess, researchers conceptualised family quality of life in terms of different dimensions that can be measured by indicators that are common to all families, with a focus on emphasis on examining the perceptions and dynamics of the family unit as a whole (Samuel, Rillotta, & Brown, 2012; Zuna, Summers, Turnbull, Hu, & Xu, 2010). The current two leading initiatives in family quality of life research are the International Family Quality of Life Project and the Family Quality of Life Initiative of the Beach Center on Disability at the University of Kansas. The work of these two groups concentrated on four areas, namely the establishing of conceptual and theoretical grounds, instrument development, exploratory research, and examining the impact of predictor variables of child, family, and support characteristics on family quality of life (Gardiner & Iarocci, 2012). The way that these two endeavours conceptualise the dimensions of family quality contains both similarities and differences, but importantly, both of them use underlying theoretical frameworks that recognises the family environment of the person with a disability (Samuel et al., 2012). The

Family Quality of Life Scale (Brown et al., 2006) developed by the International Family Quality of Life Project is more extensive and focuses on a lifespan approach, while the Beach Center focus primarily on families of children with disabilities. Therefore, this study aligns with the Beach Center's conceptualisation of family quality of life as having five dimensions, namely (a) Family Interaction, (b) Parenting, (c) Physical/Material Well-Being, (d) Emotional Well-Being, and (e) Disability-related Support (Hu et al., 2011; Samuel et al., 2012).

2.3.1. *The unified family quality of life theory*

In an attempt to synthesise family quality of life research, Zuna et al. (2010) proposed a unified family quality of life theory that seeks to explain what causes family quality of life to vary among families of children with intellectual and other disabilities. The development of this theory is based on existing theory, empirical studies, and the researchers own logic. The unified family quality of life theory proposes a model with four major explanatory concepts, i.e. (a) systemic concepts (e.g., healthcare systems, policies), (b) performance concepts (e.g., formal support programmes and services), (c) individual family member concepts (i.e. characteristics, demographics and beliefs), and (d) family unit concepts (i.e. family dynamics and family characteristics). The theory proposes that these four concepts interact with each other. Singly or combined, these concepts predicts a family quality of life outcome, which then produces new family strengths, needs, and priorities that re-enter the model as new input resulting in a continuous feedback loop throughout the life cycle of the family.

The unified theory of family quality of life is complex because families are complex (Zuna et al., 2010). However, the authors recognise that no single study could test the broad scope of the theory and recommend using the overarching family quality of life theory as a framework for middle-range theories that can be translated into testable variables. Researchers are encouraged to validate the proposed relationships of the family quality of life theory and to investigate family quality of life concepts that are amenable to change (Zuna et al., 2010).

Two of the propositions of the theory are that individual family member concepts (i.e. demographics, characteristics and beliefs) and family unit concepts (e.g. family dynamics and characteristics) serve as direct predictors of family quality of life. Individual family member concepts refer to the demographics of the individual (i.e. basic traits such as age, gender), the characteristics of the individual (i.e. multidimensional traits such as child behaviour, parent depression) and beliefs of the individual (e.g. the meaning of a child's disability for the family). Family unit concepts refer to family characteristics (i.e. traits or descriptors of the family as a whole, such as family income, family size and family form) and family dynamics (i.e. aspects of interactions and ongoing relationships between two or more family members).

When investigating how dynamic family unit concepts influence family quality of life, family routines may be considered as a way to focus on processes within the family (Fiese et al., 2002). Furthermore, family routines are also considered to be amenable to change (Spagnola & Fiese, 2007). Understanding how family routines relate to family quality of life will add to the understanding of how family dynamics influence family quality of life. Additionally, understanding the role of the more static concepts (such as the individual family member demographics and family unit characteristics) and how that influence family quality of life will help guide to practitioners to support a diverse range of families.

2.4. Family routines

Family routines is a dynamic family concept that represent a way to focus on whole-family processes which are embedded in the cultural and ecological context of families' lives (Denham, 2002). Different types of family routines are distinguished by the concrete goals they serve, such as preparing and eating a meal, or getting a child ready for bed (Howe, 2002). Family routines involve family interaction that are more closely descriptive of the work of daily living and are defined as the observable, recurring behaviours which involve several family members and which occur with predictable regularity in the ongoing life of families (Boyce et al., 1983; Howe, 2002). Therefore, family routines can be considered episodic (i.e. having a clear beginning and an end), have temporal regularity with a cyclic reoccurrence (i.e. daily or weekly reoccurrence), and have internal regularity (i.e. following the same or similar pattern whenever the routine is enacted).Daily routines are one important way in which families retain some stability in their family life and to provide a sense of identity, thus who they are (Fiese et al., 2002). The manner in which families behave together (the consistent healthy patterns of family unit interaction) is important to the functioning of the family as a whole and to the development of individual family members (Black & Lobo, 2008; Dickstein, 2002).

2.4.1. *Ecocultural theory*

Ecocultural theory focuses on families and their routines to explain the meanings and variations in the development and well-being of children and their families (Weisner, 1984). Ecocultural theory suggests that all families actively construct family routines that are compatible with their children's characteristics and consistent with their family goals and values, and that all families try to sustain these routines (Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Weisner, 1984; Weisner, 2009). Skinner and Weisner (2007) compared sustaining daily routines to the "cloak of competence" that permits everyday social interaction and functioning of families. Four processes are involved in sustaining family routines, namely (a) fitting the routine to the family's resources, (b) balancing varied family interests and conflicts, (c) the meaningfulness of family activities with respect to goals and values, and (d) providing stability and predictability of the daily routine (Weisner, Matheson, Coots, & Bernheimer, 2005; Weisner, 2002b). Ecocultural theory suggests that family routines that have better resource fit, less conflict, more meaningfulness, and enough predictability are better for families, and provide greater well-being for the family (Weisner, 2009).

The predictability, or regularity of family routines which is required for sustaining family routines, reflect a general characteristic of family organisation (Howe, 2002). Predictable routines are associated with parental competence, child health, parent-child harmony, and academic achievement (Fiese et al.,2002). Furthermore, predictable family routines guides behaviour and an emotional climate that supports child development (Spagnola & Fiese, 2007). Families with family routines that offer a high level of predictability and that is important for the entire family, indicated a more positive overall well-being (McCubbin & McCubbin, 1988). This aligns with what Boyce et al. (1983) proposed – that some degree of behavioural regularity is an almost universal characteristic of families and that the phenomenon of family routines may have a biological, developmental foundation in an intrinsic human predisposition toward rhythmic activity.

However, frequent unexpected or uncontrollable change places a strain on family routines and are likely to disrupt the routines (Weisner et al., 2005; Weisner, 2002a; Worthman, 2010). Changes in the family routines of families with children with developmental disabilities are often required once there is the realisation that the child will require additional resources (Spagnola & Fiese, 2007). Some families with strong sources of support and adequate information about their child's condition will most likely be able to smoothly establish and maintain their family routines, while other families might be challenged by the competing demands on family time and personal strains associated with parenting a child with special needs (Spagnola & Fiese, 2007). The effects of disability on family routines are potentially twofold, on the one hand disability challenges existing routines and, on the other hand, disability invoked a higher need for routine in daily life (Zisberg, Young, Schepp, & Zysberg, 2007).

2.4.2. *Family routines of families raising a with a child with ASD*

To understand the effect of ASD on family routines, the researcher examined a recent systematic review of the family routines in the context of chronic conditions (Crespo et al., 2013). Seven of the 39 empirical studies included in the systematic review pertained specifically to families of children with ASD. The details of these seven studies are presented in Table 2.1. To provide an overview of the research done on the family routines of families with a child with ASD, the studies are summarised according to their aims, participants, study design, and most important findings.

Table 2.1

Studies Assessing the Family Routines in Families Raising a Child with ASD

	Author, year and country of study	Aim of the study	Study participants	Study design	Most important findings
1	Gray (1997) Brisbane, Australia	To examine the social construction of normal family life among parents of children with ASD.	Parents of children with ASD (high functioning or Aspergers) (N = 53; 32 mothers and 21 fathers).	A descriptive qualitative research design with semi-structured interviews.	The families' understanding of 'normal' family life was linked to factors such as their ability to socialise (e.g. going shopping, dining in a restaurant, visiting friends), the emotional quality of their interactions among family members, and the routines and rituals that comprised their perceptions of what normal families do.
2	Werner DeGrace (2004) Oklahoma, USA	To understand a family's experiences negotiating the family's daily life and the meanings the family ascribe to these routines.	The family unit of children with severe ASD (N = 5 families).	A qualitative phenomenological design using in-depth semi-structured interviews.	Families with children with severe ASD experienced difficulty engaging in daily activities that hold positive meaning. The families rely on stringent patterns of routines that revolve around the child with ASD.
3	Weiskop, Richdale, and Matthews (2005) Melbourne, Australia	To evaluate a parent-training programme using behavioural principles to reduce sleep problems in children with ASD or fragile X syndrome.	Five children with ASD, seven children with fragile X syndrome, and their parents.	A multiple baseline across-participants design.	Sleep problems of children with ASD and fragile X syndrome were reduced after behavioural intervention, which included bedtime routines.
4	Larson (2006) USA	To determine how the propensity for routinisation of children with ASD influence participation in family activities.	Mothers of a child with ASD (N = 9).	A qualitative interpretive interactionist approach using in-depth semi-structured interviews.	Family routines are essential building blocks for these families and a regularity that supported the family's emotional environment. The order and structure of daily routines assisted to integrate the child with ASD into family activities. Mothers did experience challenges in developing workable family routines when the systems of ASD became prominent. Furthermore, developing routines required considerable skill and focus on orderliness and the emotions of those family members participating. Successful routines took time to develop and needed to be responsive to the child's emotional and developmental needs and create a liveable family life for other family members.

	Author, year and country of study	Aim of the study	Study participants	Study design	Most important findings
5	Schaaf, Toth-Cohen, Johnson, Outten, and Benevides (2011) Philadelphia, USA	To explore the lived experiences of how sensory-related behaviours of children with ASD affected family routines.	Parents of children with ASD (N = 4, 3 mothers, 1 father).	A qualitative phenomenological design using in-depth semi-structured interviews.	The child's sensory behaviours are one of the factors that limited family participation in work, family and leisure activities. Furthermore, parents employed specific strategies to manage family routines in light of the child's sensory-related behaviours.
6	Rodger and Umaibalan (2011) Queensland, Australia	To determine how the routines of families of children with ASD compare to the routines of families with typically developing children.	Mothers of children with ASD (n = 12) and mothers of typically developing children (n = 10; N = 22).	A quantitative study using the Family Routines Inventory and the Family Ritual Questionnaire.	The findings revealed higher means scores for all variables for the families of typically developing children. However, the only statistically significant difference was that families of children with ASD participated in fewer vacations.
7	Marquenie, Rodger, Mangohig, and Cronin (2011) Queensland, Australia	To describe the experiences of dinnertime and bedtime routines and rituals in Australian families with a young child with ASD.	Mothers of children with ASD (N = 14).	A descriptive qualitative research design with semi-structured interviews.	Two overarching themes emerged, i.e. 'centred on ASD' and 'ASD alters meaning'. Mothers experienced dinnertime routines as unstructured and chaotic, whereas bedtime routines contained some positive meaningful interactions and rituals.

As reported in Table 2.1, only two of the seven studies conducted were not qualitative studies using semi-structured interviews. One quantitative study was an intervention study that contained elements of bedtime routines (Weiskop et al., 2005), while the other was a study that compared the family routines of families of children with ASD to families of children with typical development (Rodger & Umaibalan, 2011).

The findings highlights that families of children with ASD face unique challenges in enacting family routines (Larson, 2006; Marquenie et al., 2011; Schaaf et al., 2011; Werner DeGrace, 2004). Children with ASD might be overly dependent on routines, and highly sensitive to changes in their environment. However, like families of typically developing children, the families desire and work towards the positive mutual engagement with their children in their everyday routines (Downs, 2008; Gray, 1997; Larson, 2006; Rodger & Umaibalan, 2011). These findings are consistent with ecocultural theory, which posits that the central task of everyday family life is the accommodations (i.e., intentional adjustments) that families make to sustain their family routines. These accommodations can be unremarkable and mundane to those doing them, yet promotive of the family's well-being (Weisner, 2009). When, and if, these families are successful in the process of introducing necessary changes to family routines, the predictability and meaningfulness of these routines provide a sense of mastery over the difficulties via achievement of positive adaptations (Boyd, McCarty, & Sethi, 2014; Crespo et al., 2013). Moreover, the ordinary, everyday experiences of the family influenced parents' appraisal of the normality, or abnormality, of their families (Gray, 1997). This indicates that family routines can potentially influence the meaning a family ascribe to the impact of ASD, which is discussed in the next section.

2.5. Cognitive appraisal

Since the 1980s, researchers focussed on how families adapt to the potentially stressful situation of having a child with a disability. Instead of blaming parents for most childhood disabilities, or determining the detrimental and damaging effects of a child with a disability born into a family, researchers investigated how families adapt to the potentially stressful situation of having a child with a disability (Ferguson, 2002). Within this context of stress, coping, and adaptation, researchers have relied heavily on the work of Rueben Hill (1949, 1958) who developed a theoretical model of stress that is still cited in the family literature (Lavee, Mccubbin, & Patterson, 1985; Malia, 2006; Patterson, 2002a, 2002b). Hill's classic ABCX model, describes a family crisis (X) as an interactive outcome of three factors: A, an initial stressor event, combined with B, a family's resources for dealing with crises, and C, the family's definition of the stressor (i.e. appraisal of the situation). This conceptualisation allowed researchers to recognise and interpret the successful coping strategies and positive adaptations that families report (Ferguson, 2002).

2.5.1. *Stress, appraisal, and coping*

The process model of stress and coping (Folkman et al., 1986) is based in part on Hill's stress and coping theory, where importance is assigned to the appraisal of a stressor, which mediates the detrimental effects of stressors. Cognitive appraisal is a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her wellbeing (Folkman et al., 1986). Thus, coping is influenced by the appraised characteristics of the stressful context, including its controllability. This model of stress and coping has been useful in identifying concepts that are relevant in understanding families with children with disabilities (Trute et al., 2007). The importance of cognitive appraisal is particularly relevant for these families, because unlike controllable situations where the source of stress can be reduced or eliminated, low-control situations (i.e. the diagnosis of ASD cannot be change) often requires strategies where a person changes the self to fit the situation.

In the context of childhood disability, positive appraisal and negative appraisal of the disability can coexist (Trute et al., 2007). Family members can simultaneously define ASD as having a positive impact or a negative impact on the family. The way families interpret, define, and understand caring for their child with ASD play an important role in family functioning. Trute, Hiebert-Murphy, and Levine (2007) found that a negative appraisal of the impact of childhood disability by fathers and mothers to be a significant predictor of their longer-term family well-being, while similar findings suggest that a greater endorsement of negative appraisals is associated with higher levels of psychological distress in the family system (Stuart & McGrew, 2009). Conversely, a review done by Neely-Barnes and Dia (2008) highlighted the importance of positive parental cognitive appraisal of the impact of disability, and found that families who could re-frame disability in a positive way had better family adjustment. This internal tension between positive and negative appraisals is what Larson (1998) called the paradox of disability. For example, on the one hand loving the child as he or she is, and on the other hand wanting to erase the disability, or dealing with the incurability of the disability while pursuing solutions. Larson concluded that by embracing this paradox of disability, mothers could create a positive bias and regain a sense of control, which in turn renewed their optimism in maternal work.

One way to lessen the detrimental effects of negative appraisals is to positively reappraise a stressful situation. Positive reappraisal refers to cognitive strategies for reframing a situation to see it in a positive light (Folkman & Moskowitz, 2000). Reframing a situation in which people focus on the value of their efforts and appraise them positively, may be especially important in helping people sustain efforts, such as those caring for a person with a disability, over long periods of time. An associated outcome of positive reappraisal is *positive affect* (Folkman & Moskowitz, 2000). While negative affect goes hand in hand with chronic stress, increasing empirical evidence shows that positive affect (experiences of positive moods such as happiness and joy) also occurs during chronic stress. Positive affect promotes creativity and flexibility in thinking and problem solving; facilitates the processing of important information even if that information is negative and may potentially damage self-esteem; may serve as a buffer against adverse physiological consequences of stress; and in the context of chronic stress may also help prevent clinical depression (Folkman & Moskowitz, 2000). These findings about positive affect stress the important role of cognitive appraisal (positive and negative appraisal), especially in the context of families with a child with a disability.

2.5.2. *Parents' cognitive appraisal of the impact of ASD*

To have a better understanding of the role that cognitive appraisal plays in families raising a child with ASD, a systematic search and review process were carried out. The search was conducted using Academic Search Complete, CINAHL, E-Journals, Family and Society Studies Worldwide, Health Source: Nursing/Academic Edition, Humanities Source, MasterFILE Premier, MEDLINE, PsycINFO, and TOC Premier. The following search terms were used: cognitive appraisal and autis*. (The inclusion criteria and exclusion criteria of the study-selection process are provided in Appendix A.) An illustration of the study-selection process for reviewing the literature on cognitive appraisal of families raising a child with ASD is displayed in Figure 2.1.

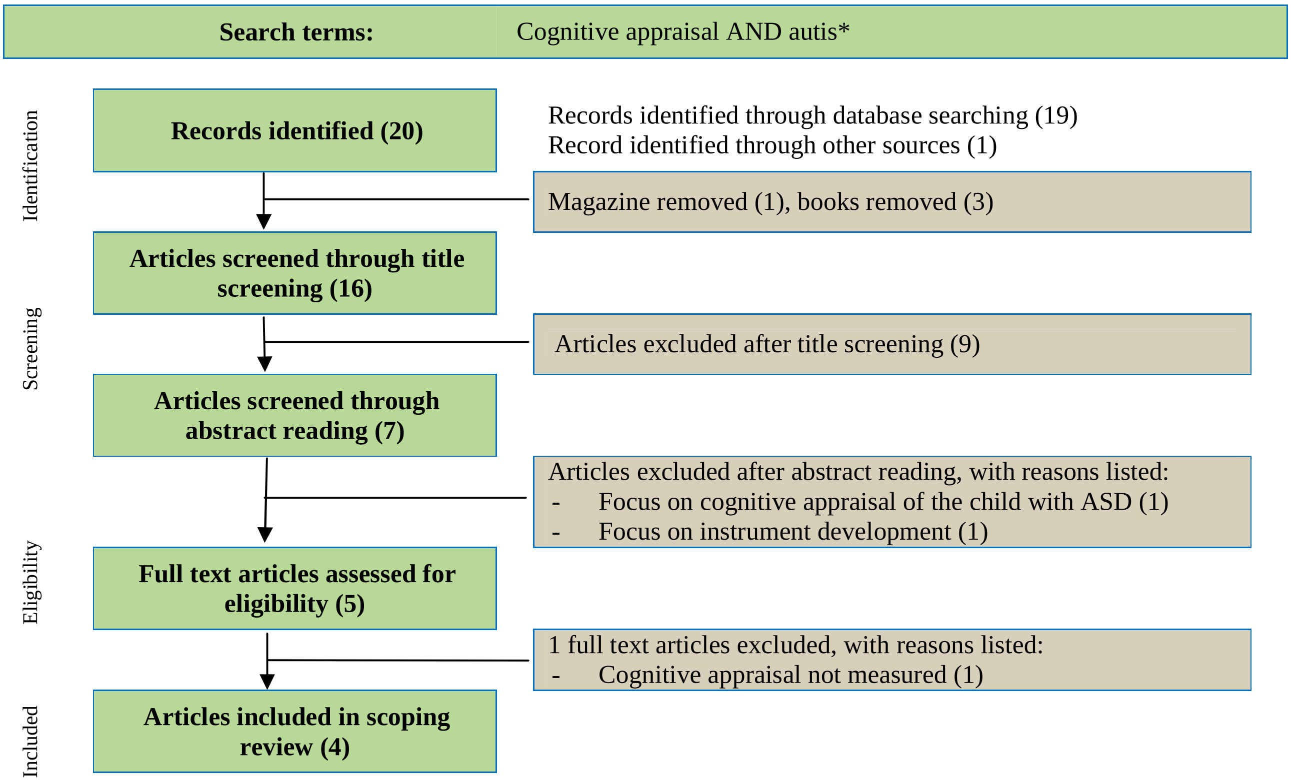


Figure 2.1 Flow diagram of the study-selection process for reviewing the literature on the cognitive appraisal of families raising a child with ASD.

As showed in Figure 2.1, 19 records were identified through the electronic search and one record through a hand search. Four records were excluded because they did not fit the publication type criteria. The remaining 16 journal articles were all included in the screening process. During the title screening process, eight articles were excluded because they did not focus on either cognitive appraisal or families of children with ASD, and one duplicate was removed. The abstract screening process resulted excluding of a further two articles, one focussed on the cognitive appraisal of the child with ASD, and not the family members, and the other reported the development of an instrument to measure cognitive appraisal. The remaining five full text studies were assessed to decide if they were eligible to include in the review. One study was excluded in this process because it did not fit the selection criteria (i.e. did not measure cognitive appraisal). The remaining four studies included in the scoping review are presented in Table 2.2. The four studies were critically reviewed using elements of the Critical Review Form for Quantitative Studies developed by the McMaster University (Law et al., 1998). Comments of the critical review of these studies are included in Table 2.2.

Table 2.2

Studies Assessing the Cognitive Appraisal of ASD

Author, year and country of study	**Aim of the study**	**Study population, N**	**Design and measurement of cognitive appraisal**	**The role of cognitive appraisal**
1. Fong (1991) New Jersey, USA	To examine cognitive appraisals, and trying to explain differences in maternal adaptation to the presence of a child with ASD in the home.	Mothers of adolescents with ASD (N = 16).	Mixed method design. Measured cognitive appraisal of mothers by categorising their response as irrelevant (e.g. he is just doing a task), benign (e.g. he looks happy), or threatening (e.g. she's going to have a tantrum) after watching a videotape of adolescents with ASD engaged in a variety of everyday activities.	High-stress mothers made more threatening appraisals and had a greater negative emotional reaction to experimental stimuli, as compared to low-stress mothers. Low-stress mothers also made threatening appraisals, but were then more likely to reappraise the situation in a more benign fashion. This supported that emotional responses may relate more directly to the types of cognitive appraisals people make than to the objective characteristics of the stressors.
	√ Purpose of the study was clearly stated and background information provided.	√Sample was described in detail. × Small sample size limits generalisability of results.	√ Description of the study design provided. Design is appropriate for addressing the study question. √ Reliability and validity of measurement and procedures reported.	√ Results were reported in terms of statistical significance. √ Clinical importance was reported. √ Conclusions were appropriate given the studies methods and results. Limitations were acknowledged.
2. Tunali and Power (2002) USA	How mothers cope with the stresses of raising a child with ASD compared to mothers of typically developing children.	Mothers of children with ASD (29) and mothers of children without ASD (29), (N = 58).	Mixed method design using semi-structured interviews and standardised questionnaires.	The results indicated that mother's respond to the uncontrollable stress of raising a child with ASD by redefining what constitutes the fulfilment of various human needs and/or find alternative ways to fulfil them.
	√ Purpose of the study was clearly stated and background information provided.	√Sample was described in detail.	√ Description of the study design provided. Design is appropriate for addressing the study question. √ Reliability and validity of measurement reported.	√ Results were reported in terms of statistical significance. √ Clinical importance was reported. √ Conclusions were appropriate given the studies methods and results. The limitation of using self-reports was acknowledged.

Author, year and country of study	Aim of the study	Study population, N	Design and measurement of cognitive appraisal	The role of cognitive appraisal
3. Plant and Sanders (2007) South-East Queensland, Australia	To examine the predictors, mediators and moderators of parent stress in families of preschool-aged children with developmental disability.	Families of children with developmental disabilities. Of these, 23.8% of the children was diagnosed with ASD (N = 105, all mothers).	Quantitative survey design. Measured the cognitive appraisal of caregiving responsibilities using an adapted version of Ways of Coping Checklist.	Parents' cognitive appraisal of care-giving responsibilities had a mediating effect on the relationship between the child's level of disability and parent stress.
	√ Purpose of the study was clearly stated and background information provided.	√Sample was described in detail. × Small sample size restricted the use of SEM analysis that could determine plausibility of the hypothesised model.	√ Description of the study design provided. Design is appropriate for addressing the study question.	√ Results were reported in terms of statistical significance. √ Clinical importance was reported. √ Conclusions were appropriate given the studies methods and results. The limitation of using self-reports was acknowledged.
4. Paynter, Riley, Beamish, Davies, and Milford (2013) Queensland, Australia	To understand the factors underlying family outcomes when children with ASD attend early intervention, using the ABCX model of Family Adaptation.	Parents of children aged 2.5 to 6 years with ASD who were attending an autism-specific intervention service (N = 43; 18 fathers, 25 mothers).	Quantitative survey design. Measured the appraisal of ASD with the Family Impact of Childhood Disability Scale.	The way families appraised caring for a child with ASD also affected their outcomes. Having more positive appraisals of caring for a child with ASD was linked to better relationship quality, while negative appraisals were correlated with higher parenting stress and negative impact on the family. This suggests that the impact of stressors (e.g., level of severity of ASD) is mediated by the way the stressor is perceived by families.
	√ Purpose of the study was clearly stated and background information provided.	√Sample was described in detail. × Small sample size restricted the use of path analysis that could determine plausibility of the ABCX model.	√ Description of the study design provided. √ Reliability and validity of measurement and procedures reported. Poor internal consistency of two of the instruments was acknowledged.	√ Results were reported in terms of statistical significance. √ Clinical importance was reported. √ Conclusions were appropriate given the studies methods and results. Limitations were acknowledged.

As summarised in Table 2.2., the critical review of the studies revealed that the participants were predominantly mothers, that the relatively small sample sizes restricted to use of more advanced statistical analysis such as SEM, and that the use of self-reports might be susceptible to social desirability biases. These limitations should be kept in mind when interpreting the findings. However, the findings did support the positive outcome of reappraising a stressful situation (Fong, 1991) or redefining a stressful situation (Tunali & Power, 2002). The findings support the mediating role of cognitive appraisal in the stress and coping process (Paynter et al., 2013; Plant & Sanders, 2007). Moreover, the findings support the theory that positive appraisal relate to more positive outcomes (e.g. better relationship quality) and that greater negative appraisal relate to greater negative outcomes (e.g. higher parenting stress).

2.6. Conceptual model of the study

The theoretical and empirical literature reviewed in this chapter provided an overview of the study constructs (i.e. family quality of life, family routines, and cognitive appraisal of a childhood disability). It explained the plausibility of the relationships between these constructs. The propositions of the unified family quality of life theory, the theoretical underpinnings of ecocultural theory, and supportive empirical findings offered the theoretical link between the regularity of family routines and family well-being or family quality of life. The process model of stress and coping, and the supportive findings of empirical studies indicate the mediating role of cognitive appraisal. Based on these theoretical frameworks and supporting empirical findings, the following conceptual model is proposed, as illustrated in Figure 2.2.

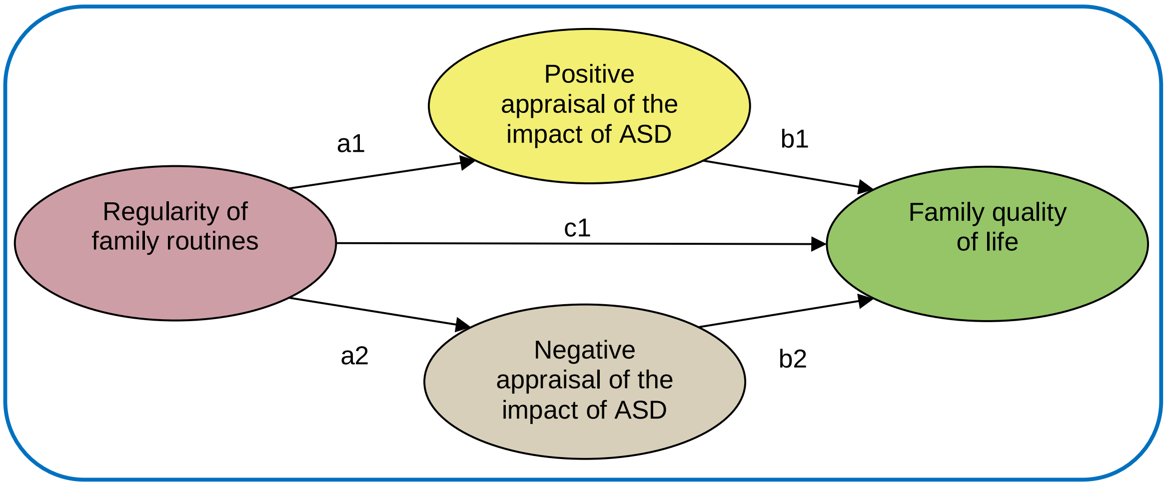


Figure 2.2 The conceptual model of the study.

As illustrated in Figure 2.2, it is proposed that there is a direct, positive relationship between the regularity of a family's routines and their perceived family quality of life (path c1). This relationship is mediated by the parents' cognitive appraisal of the impact of ASD on the family. Positive appraisal of the impact of ASD will have a partially, positive mediating effect (path a1, b1), while negative appraisal of ASD will have a partially, negative mediating effect (path a2, b2) on the direct relationship between the regularity of family routines and family quality of life. It is hypothesised that the positive appraisal and negative appraisal of the impact of ASD will be separate constructs that can co-occur simultaneously. And lastly, it is assumed that these hypothetical constructs can be measured quantitatively in a reliable and valid manner. The aim of this study is therefore to determine the relationship between the regularity of family routines and family quality of life, as well as the potential mediating effect of positive and negative appraisal of ASD on this relationship, in families raising a child with ASD.

2.7. Summary

This chapter offered a critical review of the literature on family quality of life, family routines, and the role of the meaning ascribe to a potentially stressful situation in families raising a child with a disability, and particularly those with a child with ASD. An overview of each construct that underpins the study was provided. The theoretical and empirical literature was reviewed to determine possible relationships between the constructs. The chapter concluded with the synthesised conceptualisation of a model that illustrates the hypothesised relationships between the regularity of family routines and family quality of life, and the mediating effect of positive and negative appraisal.

CHAPTER 3
METHODOLOGY

3.1. Introduction

This chapter provides an overview of the methodology used in the study. The aims of the study are presented, followed by the research design. The selection criteria, recruitment and sampling, and description of the participants are then presented. Materials used in the study are described, focusing specifically on the selection process of existing instruments. Thereafter, the pretesting of the survey booklet and the pilot study is described. Lastly, the main study is described in terms of the ethical considerations, data collection, and data preparation and analysis.

3.2. Research aims

The main research aim was to determine the relationship between the regularity of family routines and family quality of life, including the mediating effect of parents' cognitive appraisal of the impact of ASD on this relationship, in families raising a child with ASD. To fully explore the main research aim, the following sub-aims were addressed:

i. To develop a conceptual model, based on theory and empirical studies, of the relationships between the regularity of family routines, cognitive appraisal of the impact of ASD on the family, and family quality of life. (This will be the structural model.)
ii. To identify and select existing, quantitative instruments with reported psychometric properties, that measures the constructs identified in the conceptual model.
iii. To specify the measurement model for each selected measuring instrument.
iv. To specify a full structural equation modeling (SEM) model for the study by combining the structural model of sub-aim (i) and the measurement model of sub-aim (iii).
v. To measure and describe the regularity of family routines, the cognitive appraisal of the impact of ASD on the family, and the family quality of life in the study population.
vi. To assess the influences of individual family member demographics of the parent(s) and child with ASD, and family unit characteristics on the family quality of life.
vii. To determine whether the hypothesised SEM model is plausible when fitted to the data collected. (The measurement model assessing the validity of the instruments will be

assessed first, and the structural model assessing the relationships between the constructs will be assessed subsequently.)

3.3. Research design

This study used a quantitative survey design. Survey approaches are often used to assess aspects of family functioning (Sabatelli & Bartle, 1995) and is specifically suitable to confirm the validity of instruments and to test the hypothesised linkages between constructs (Forza, 2002). The survey consisted of a hand-delivered, self-administered, paper-based survey.

First, a hand-delivered survey was preferred to mail surveys because not all potential participants have access to postal delivery, and the high cost involved in this method of distribution. Secondly, a self-administered survey was preferred to interview type surveys because of the large sample size required and the wide geographical area covered. Additionally, a self-administered survey was deemed more suitable to reach participants which would otherwise be difficult to reach. Participants could complete the questionnaire at their convenience, in their homes and at their own pace. Thirdly, a paper-based survey was preferred to an internet survey. The justification was two-fold, (a) 64.8% of households in South Africa do not have access to the internet (Statistics South Africa, 2012) , and (b) the length of the survey would have been problematic given the recommended briefness of internet surveys.

The disadvantage of using a survey design was the potential low response rates from people with low literacy levels, those who dislike writing or those who have difficulty reading, and that the queries of the participant cannot be clarified (Blair, Czaja, & Blair, 2014). The major advantages were the larger number of families that could be reached with this design and that the design was particularly suitable to measure the unobservable constructs of this study. Purposive sampling was used to include families whose children are receiving disability-related schooling and intervention in Gauteng, a province in South Africa. The reason to include only one province of South Africa (Gauteng) is because of the diversity and unequal access to early intervention services and schooling for children with ASD found across the country’s nine provinces (Statistics South Africa, 2014). Gauteng is the smallest province in South Africa, accounting for only 1.5% of the land area, but highly urbanised, containing the country's largest city, Johannesburg, and its administrative capital, Pretoria. As of 2011, it has a population of nearly 12.3 million, making it the most populous province in South Africa (Statistics South Africa, 2012). The province is divided into five municipalities - three metropolitan municipalities (i.e. City of Johannesburg, City of Tshwane, and Ekurhuleni), and two district municipalities (i.e. Sedibeng and West Rand).

3.4. Participants

3.4.1. *Selection criteria*

The selection criteria for participants were (a) a parent or caregiver of (b) a child diagnosed with ASD, (c) the child had to be younger than nine years old, and (d) the child had to attend disability-related schooling or intervention services in Gauteng, and lastly (e) the parent or caregiver had to be English literate to complete the self-administered survey. The following sections discuss the justification and measurement of the selection criterion.

First, a parent or primary caregiver was the selected respondent, but were asked to think about their family when completing the questions. “The family” was defined as people who think of themselves as part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis (Poston et al., 2003). Respondents were reminded in various sections of the survey to think about their family when answering the questions. Thus, although only one family member was the respondent, the data are directed particularly to issues and concerns of the family unit (Brown et al., 2006).

Secondly, the diagnosis of the child with ASD was based on parental report. This method was preferred because of the difficulties for some families to get an official diagnosis of ASD for their child, although their child is already attending a school or organisation for children with ASD. To help disadvantaged families that are unable to afford a private assessment, some organisations such as Autism South Africa offer an ASD diagnostic assessment clinic one Saturday morning each month. To control for potential sampling error, various structures was put in place, namely (a) organisations that specifically offer services for children with ASD was contacted to assist with the recruitment of participants and (b) these organisations identified the children with ASD attending their school and only delivered a survey packet to the identified families.

Thirdly, children with ASD had to be 8;11 (years; months) or younger. The study followed the age criteria set by UNESCO that defines early childhood as the period from birth to eight years old. The study specifically focused on families raising a young child. This is to control for potential differences in the family routines, the appraisal of the impact of ASD on the family, and family quality of life in families with older children.

Finally, the required attendance of disability-related schooling or intervention services was based on the previous findings of Eskow et al. (2011) who examined the differences in the family quality of life of families of children with ASD who were receiving disability-related services and those on a waiting list. The family quality of life of those receiving services was reportedly higher than those families not yet receiving services. To control for the effect of services received only those families who are receiving disability-related services were included in this study.

3.4.2. *Recruitment of participants and sampling*

This study used non-probability, purposive sampling methods to recruit participants. There are currently no accurate statistics available as to the total number of children with disabilities in South Africa (Proudlock, 2014; Statistics South Africa, 2014). Similarly, there is no reliable information on the total number of organisations who provide services for children with ASD in Gauteng. Therefore, to access the study population, experienced fieldworkers of Autism South Africa and the Association for Autism helped the researcher to identify organisations in Gauteng that provides intervention and/or schooling for children with ASD, under the age of nine. Forty seven organisations were identified as possible access points to recruit potential participants. Additionally, a snowball sampling technique was used to identify additional organisations not identified by the two fieldworkers, resulting in a further eight organisations. The total number of 55 organisations was contacted telephonically to inform them about the nature and scope of the study. After this initial conversation, a request for permission to conduct research was sent electronically. Eighteen of the 55 organisations did not have learners with ASD, or their learners with ASD were older than nine years old, and two organisations did not reply. That resulted in 35 organisations, located in all five municipal districts of Gauteng that assisted in this study. The organisations taking part included both public and private schools or centres. Between the 35 organisations, 380 families were identified as potential participants. Each of the 380 families received a survey packet, of which 180 families completed and returned the survey, resulting in a return rate of 47.37% (no families who did not consent to participate in the study returned a survey).

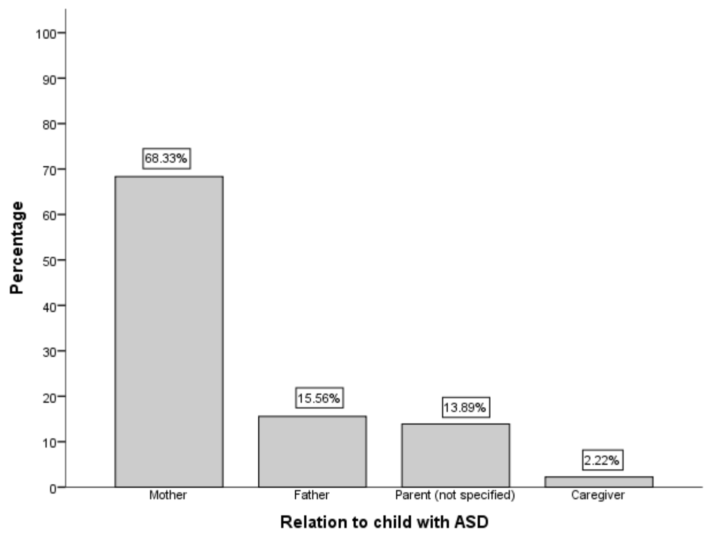
3.4.3. *Description of participants*

A description of the 180 participating families is provided by describing the individual family member demographics (i.e. demographic information of the parent or caregiver who completed the survey and demographic information of the child with ASD) and family unit characteristics (i.e. the family structure and form, and the family income).

Table 3.1 describes the demographics of the parent or primary caregiver in terms of their relation to the child with ASD, ethnic background, educational background, and employment status.

Table 3.1

Descriptive Demographics of the Parent or Primary Caregiver

Description	Results
Relation to the child with ASD (N=180) Of the respondents, 68.33%(123) were mothers, 15.56%(28) were fathers, 13.89%(25) only stated that they are the parent (not specifying their role as father or mother), and 2.22% (4) were other biological caregivers (aunts or grandmothers).	

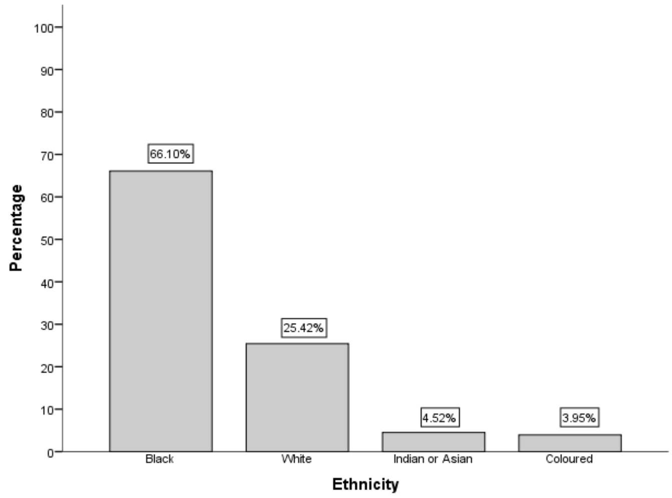
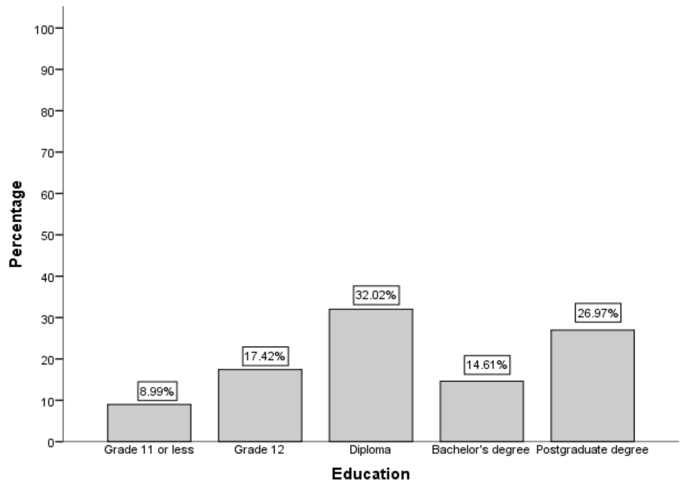
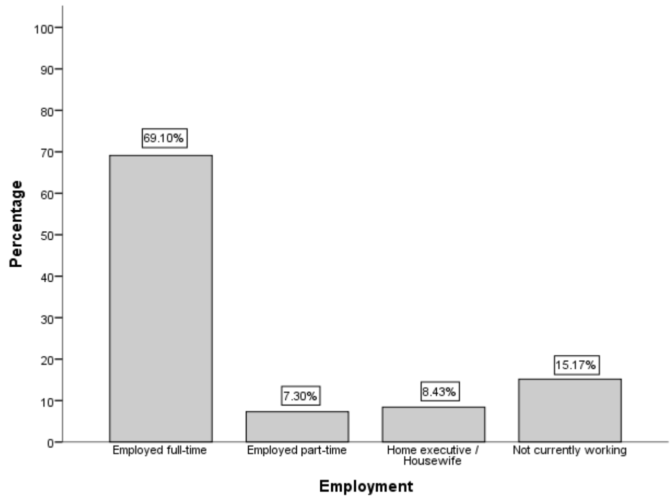
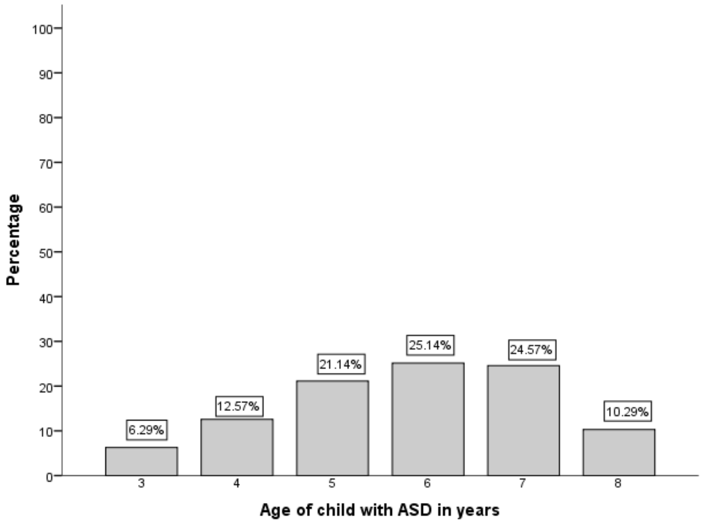
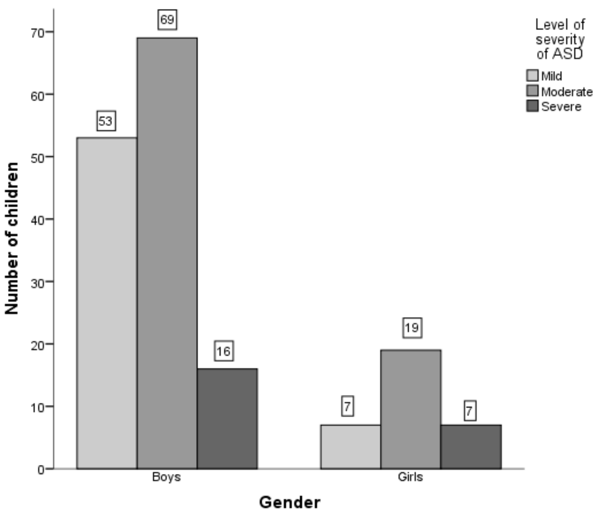
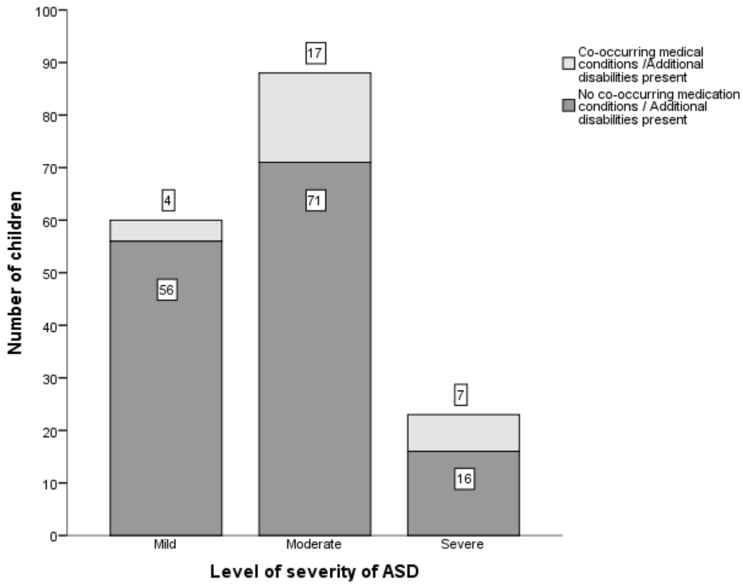
Description	Results
Ethnic background (n=177) In terms of ethnicity, 66.10%(117) of the respondents were Black/African, 25.42%(45) were White, 4.52%(8) were Indian/Asian, and 3.95%(7) were Coloured. These categories were selected according to the categories used in the national South African census (Statistics South Africa, 2012).	
Educational background (n=178) As can be seen from the adjacent graph, 8.99%(16) of respondents indicated that they completed Grade 11 or less, 17.42%(31) completed Grade 12, 32.02%(57) had a professional or vocational diploma, 14.61%(26) had a bachelor’s degree, and 26.97%(48) had a postgraduate degree.	
Employment Status (n=178) In terms of employment status, the majority, 69.10%(124) of the respondents were working full-time. There were 7.30%(13) that worked part-time, while 8.43%(15) reported that they were housewives. The respondents that were not currently working amount to 15.17%(26).	

Table 3.1 illustrates that the majority of the respondents were mothers, with a black ethnical background, had a tertiary education, and were employed full-time. The next table, Table 3.2 describes the demographics of the child with ASD. The child's age, level of severity of ASD, and any co-occurring medical conditions or additional disabilities present (based on parental report) are described.

Table 3.2

Descriptive Characteristics of the Child with ASD

Description	Results
Age of the child with ASD The age of the children with ASD ranged from 3 to 8 years old, with an average age of 5.80 years (*SD* = 1.38). Of the total number of children with ASD, 6.29%(11) were 3-year olds, 12.57%(22) were 4-year olds, 21.14%(37) were 5- year olds, 25.14%(44) were 6 -year olds, 24.57%(43) were 7- year olds, and 10.29%(18) were 8 year olds.	
Level of severity of ASD (based on parental report) grouped by child's gender From the total number of children with ASD involved in this study, 80.90%(144) were boys and 19.10%(34) were girls. In terms of severity of ASD: 38.41%(53) boys had a mild level of ASD, 50%(69) boys had a moderate level of ASD, and 11.59%(16) boys had a severe level of ASD. Of the girls, 57.57%(19) had a moderate level of ASD, with an equal 21.21%(7) described as having a mild or severe level of ASD respectively.	

Description	Results
Co-occurring medical conditions and/or additional disabilities present (n = 171) Of the 60 children described as having a mild level of ASD, 6.67%(4) had co-occurring medical conditions or additional disabilities, while 93.33%(56) did not. Of the 88 children described as having a moderate level of ASD, 19.32%(17) had co-occurring medical conditions or additional disabilities, while 80.68%(71) did not. Of the 23 children described as having a severe level of ASD, 30.43%(7) had co-occurring medical conditions or additional disabilities, while 69.57%(16) did not.	

As displayed in Table 3.2, the average age of the children with ASD were 5.8 years (*SD* = 1.38) There were almost four times more boys than girls. According to parental report, just more than half of the children (51%) were described as having a moderate level of ASD, with 35% described as having a mild level of ASD, and 14% described as having a severe level of ASD. The next section describes the characteristics of the family unit, as reported in Table 3.3.

Table 3.3

Descriptive Characteristics of the Family Unit

Description	Results
FAMILY STRUCTURE **Other family members living in the household (N=180)** The adjacent table indicates the type of other family members living with the different family types. Grandparents were present in 17.7%(32) of the participating families. Other family members (e.g., uncle, niece, nephew) were present in 22.22%(40) of the families, and 12.78%(23) of families indicated a paid helper as part of the family household.	**Other Family Members Living in the Household (Grouped by family type, N=180)**

Family members	Two-parent family	One-parent family	Blended or stepfamily	Total
Grandparents	12.78% (n=23)	3.88% (n=7)	1.11% (n=2)	17.7% (n=32)
Other family members	12.22% (n=22)	7.78% (n=14)	2.22% (n=4)	22.22% (n=40)
Paid helper as part of the family	9.44% (n=17)	2.77% (n=5)	0.56% (n=1)	12.78% (n=23)

<table>
<tr><th>Description</th><th>Results</th></tr>
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The mean age of family members

Ages of fathers ranged from 29 to 59, with a mean of 39.78 (*SD* = 6.37). Ages of mothers ranged from 23 to 59, with a mean of 36.70 (*SD* = 6.27). Ages of the oldest child ranged from 3 to 31, with a mean of 9.60 (*SD* = 6.03), and ages of the youngest child ranged from newborn to 8, with a mean of 4.40 (*SD* = 2.31). The ages of the children with ASD ranged from 3 to 8 years old, with a mean age of 5.80 (*SD* = 1.38).

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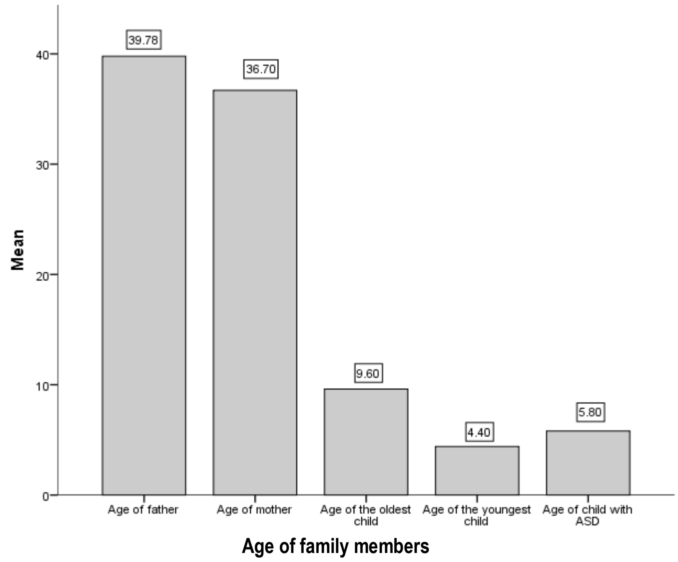

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Number of children in the household

Most families, 42,13%(75) had two children in the household, followed by 28.65%(51) of families who only had one child, and 19.10%(34) who had three children. The remaining 10.12%(18) had four of more children living in the household.

The majority of families, 95.5%(171) had only one child with ASD living in the household, while 4.5%(8) had two children with ASD in the household. There were no families reporting more than two children with ASD living in the household.

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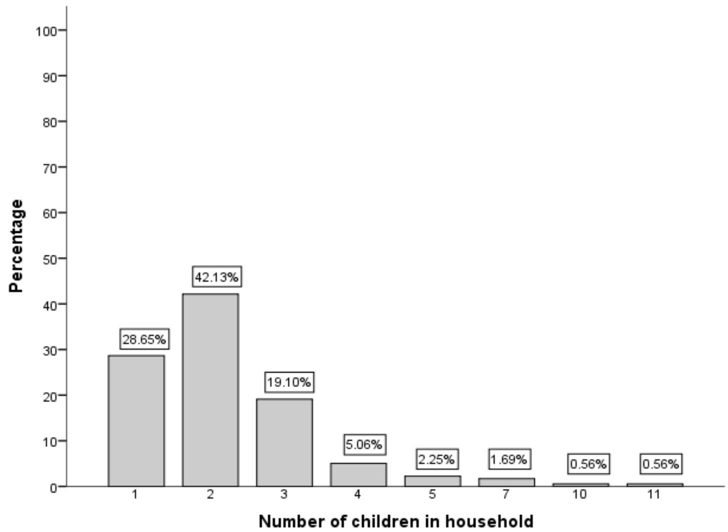

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Family type (N=180)

Of the total number of participating families, 75%(135) were two-parent families, 20%(36) were one-parent families, and 5%(9) were blended or stepfamilies (two separate families that merged into a new family unit).

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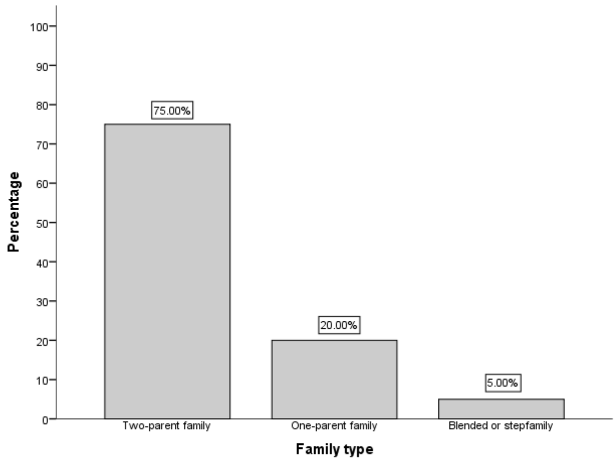

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Table 3.3 illustrates the diversity of the participating families – that families takes many shapes and forms, ranging from two-person bonds to large complex systems. It also describes the people who are closely involved in the day-to-day affairs of the household and identify those who support and care for each other often, whether they are related by blood, marriage, or close personal relationship.

Families were asked to report their total monthly household income according to five income categories, and to consider what they think about this income, rating their appraisal from (1) *struggling* to (5) *well off*. Figure 3.1 illustrates both the families' monthly household income according to the specified categories, and the families' appraisal of their monthly income.

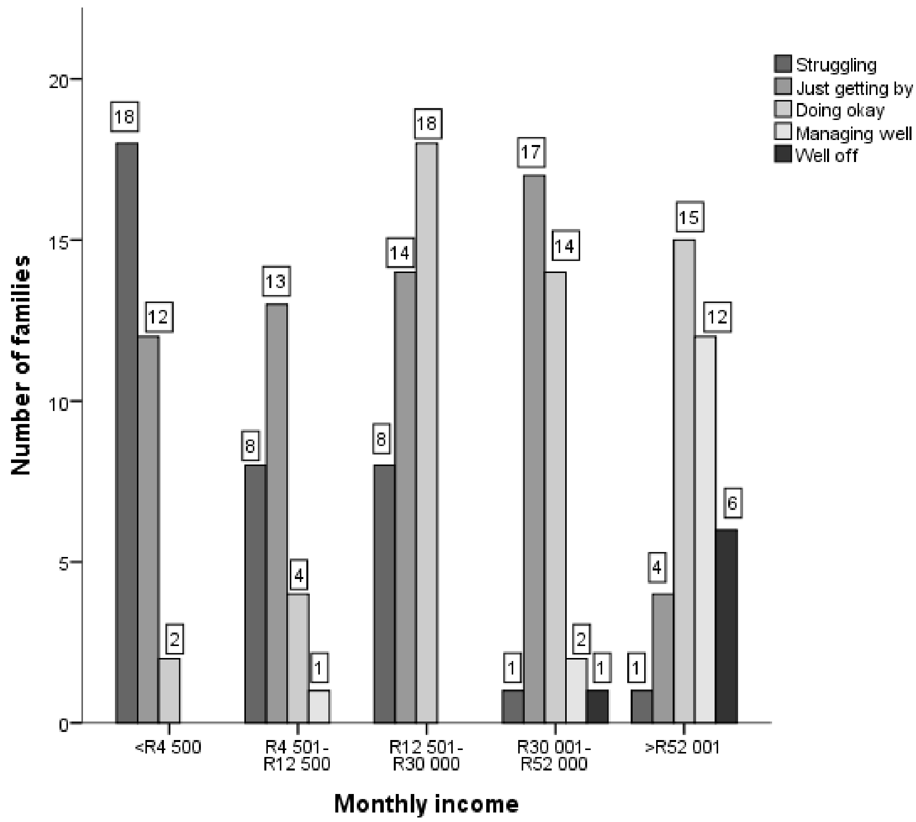


Figure 3.1 Monthly household income and the families' appraisal of this income.

Figure 3.1 highlights the discrepancies between the actual household income and the way families feel about their income. For each income category, families indicated a diverse range of answers about how they feel about this income. Families earning less than R4500 per month in South Africa are considered poor families (Masemola, Van Aardt, & Coetzee, 2011).

3.5. Materials

In addressing the research aims of this study, it was necessary to use valid and reliable instruments that could measure the three constructs included in the conceptual model (i.e. the regularity of family routines, cognitive appraisal of the impact of ASD on the family, and family quality of life). It was important to consider how each construct differed from other closely related constructs and to ensure that the selected instruments measure the constructs as defined and conceptualised in this study. The measuring instruments are discussed in the following section in terms of the selection process, followed by a brief description and reported validity and reliability results.

3.5.1. *Measuring the regularity of family routines*

A review of the literature on family routines and rituals identified eight instruments that measure different aspects of family routines and rituals (Denham, 2003). Two of the eight instruments focussed particularly on measuring the regularity of family routines, or routine frequency – (a) the Family Routine Inventory (Boyce et al., 1983; Jensen, James, Boyce, & Hartnett, 1983) and (b) the Family Times and Routines Index (McCubbin & Tompson, 1991). The Family Times and Routines Index is based on the Family Routines Inventory, and examines the extent to which a routine is true for a family, as well as the degree the family views the routine as important. This instrument was originally selected and used in the pilot study, but due to the complexity of having two scales for each question (i.e. the degree in which the routine is true for the family and the importance of the routine) the Family Routines Inventory was the preferred instrument (see Section 3.6 for a discussion of the pilot study outcomes).

The Family Routines Inventory measures 28 positive, strength-promoting family routines. The 28 routines are divided into 10 routine categories, namely Workday Routines, Weekend and Leisure Time, Children's Routines, Parent(s)' Routines, Bedtime, Meals, Extended Family/Friends, Leaving and Homecoming, Disciplinary Routines, and Chores. There are four rating options for each routine, 1 (*never/almost never*), 2 (*sometimes/1-2 times a week*), 3 (*mostly/3-5 times a week*), and 4 (*always/almost every day*). From this information a frequency score is calculated by weighing each endorsed routine by the frequency of its performance by the family. *Always* is assigned a weight of 3, *mostly* is assigned a weight of 2, *sometimes* is assigned a weight of 1, and *almost never* is assigned a weight of 0 (taken to mean that a family does take part in this particular routine). This weighing of endorsed routines by frequency of performance results in a frequency score, which is reported to be the method of choice, based on both face validity and temporal stability of the measure (Jensen et al., 1983). The reliability of the Family Routines Inventory focussed on temporal stability, with a reported reliability correlation coefficient of the frequency score of .79 (Jensen et al., 1983).

3.5.2. *Measuring the positive and negative appraisal of the impact of ASD on the family*

A systematic search was followed to identify instruments that measure parental cognitive appraisal of the impact of disability on the family. The search was conducted using Academic Search Complete, CINAHL, E-Journals, Family and Society Studies Worldwide, Health Source: Nursing/Academic Edition, Humanities Source, MasterFILE Premier, MEDLINE, PsycINFO, and TOC Premier. The following search terms were used: cognitive appraisal, impact, disab*, measure*. Six articles resulted from this systematic search, with only one article referring to an instrument. The Family Impact of Childhood Disability Scale (FICD Scale) was the only identified measure in the systematic search that assesses the subjective interpretation of parents regarding the positive and negative impact of childhood disability on the family (Trute et al., 2007; Trute & Hiebert-Murphy, 2002).

The FICD Scale includes 10 positive and 10 negative questions. There are four rating options for each question 1 (*not at all*), 2 (*to a mild degree*), 3 (*to a moderate degree*), and 4 (*to a substantial degree*). Cronbach alpha's of .89 for the negative subscale and .81 for the positive subscale are reported (Trute et al., 2007). Results are reported as a positive sub-score and a negative sub-score. The FICD Scale is reported to be conceptually and empirically different from a measure of overall family functioning and the two dimensions of positive appraisal and negative appraisal appear to be independent factors (Trute & Hiebert-Murphy, 2002). Findings by Trute and Hiebert-Murphy (2002) indicated that there were no differences found between mothers and fathers in the appraisals of the impact of their child's developmental disability on the family.

3.5.3. *Measuring family quality of life*

A review of all the quantitative instruments that measure family quality of life, family well-being, and family satisfaction in the disability field, healthcare field, and general family field identified 16 instruments (Hu et al., 2011). The researcher used the findings from this review, and evaluated the 16 identified instruments against a set of selection criteria to select the most appropriate measure for measuring family quality of life in this study. The specified inclusion criteria were (a) the instrument should have a specific purpose to measure family satisfaction of multiple domains identified as family quality of life in the literature, (b) the instrument should focus on families of children with disabilities, and (c) the instrument should have reported validity and reliability results. Figure 3.2 represents the schematic representation of this selection process in identifying the final instrument used in this study.

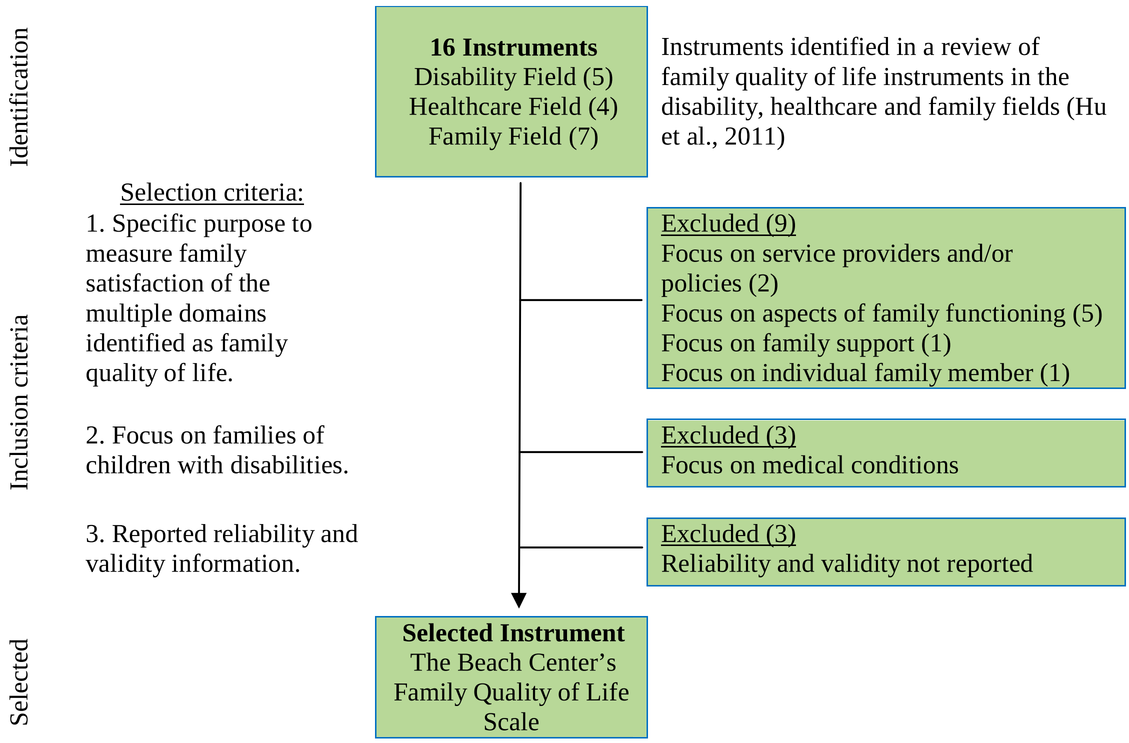


Figure 3.2 Flow diagram of the Family Quality of Life instrument selection process.

As illustrated in Figure 3.2, 16 instruments were identified as measuring perspectives of family quality of life, family well-being and family satisfaction. Nine instruments were excluded because they did not focus on different domains identified as family quality of life. A further four instruments were excluded since they did not focus on families of children with disabilities. Three instruments were excluded because they did not have reported validity and reliability results. The remaining instrument that best fit the purpose of this study was *The Beach Center's Family Quality of Life Scale* (FQOL Scale).

The selected FQOL Scale was developed by researchers at the Beach Center on Disability at the University of Kansas in the United States of America (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Park et al., 2003; Poston et al., 2003; Verdugo, Córdoba, & Gómez, 2005; Zuna, Selig, Summers, & Turnbull, 2009). The FQOL Scale was primarily developed for young families of children with disabilities living in the United States of America. The instrument is increasingly being adapted to use in other countries such as Spain (Balcells-Balcells, Giné, Guàrdia-Olmos, & Summers, 2011; Verdugo et al., 2005), in other contexts - such as with families of typically developing children (Zuna, Selig, Summers, & Turnbull, 2009), and for families of children with specific disabilities, for example children with a hearing impairment (Jackson, Wegner, & Turnbull, 2010), and children with ASD (Eskow et al., 2011).

The FQOL Scale consists of 25 questions. There are five rating options for each item, 1 (*very dissatisfied*), 2 (*dissatisfied*), 3 (*neutral*), 4 (*satisfied*), and 5 (*very satisfied*). Psychometric analysis provided support for a five-factor solution for the 25 questions, namely Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and Disability-Related Support (Hoffman et al., 2006). The internal consistency of the overall FQOL Scale was reported as a Cronbach coefficent alpha of .88. The alphas for the subscales ranged from .74 to .90 (Hoffman et al., 2006). The FQOL Scale has demonstrated concurrent validity with specified subscales to other existing instruments (Hoffman et al., 2006) and confirmatory factor analysis that indicated adequate fit of data obtained from families of young children without disabilities to the theoretical model of family quality of life (Zuna et al., 2009). The scores of the five subscales are added to obtain a total score, which is then averaged into a single mean score. Permission obtained to use the FQOL Scale is reported in Appendix B.

3.5.4. *Measuring family member demographics and family unit characteristics*

Demographics of the parent and the child with ASD and characteristics of the family unit were included in the demographic section of the survey booklet. The complete demographic section including all the questions can be viewed in Appendix C.

3.5.5. *Survey materials*

After selection of the instruments, the survey materials were designed. The survey materials included permission letters to the organisations, the final survey packet (cover letter and survey booklet in an envelope), and a postcard.

3.5.5.1. Permission letters

A permission letter was sent to organisations to inform them about the nature of the study, the selection criteria of the participants, what is expected from them if they are willing to assist, and that they will have access to the results of the study (see Appendix D). Organisations that wanted to assist with the study had to fill in and sign a permission to recruit participants form (see Appendix E).

3.5.5.2. Survey packet

Using a self-administered questionnaire to collect data required that the survey questionnaire had to be totally self-explanatory. Participants could look over the survey before deciding whether or not to complete it, therefore it had to be easy to understand and straightforward to complete (Blair et al., 2014; Dillman, 2007). The specific survey design attempted to achieve two main objectives. First, to increase the response rate (respondent-friendly questionnaire design can improve response rates to modest degrees) and secondly, to reduce or avoid measurement error (the best opportunity for achieving clear responses to questions is to keep both the wording and the visual appearance of questions simple). The design of the survey was based on specific design concepts (Blair et al., 2014; Dillman, 2007). This included the following: The survey booklet was printed vertically in an A4 booklet format; related questions were grouped together to increase the logical order of questions; instructions were included specifically where it applies; answer categories were vertically listed; and the cover page of the booklet used a simple and neutral graphical design to create a positive first impression.

The survey packet consisted of an envelope that included an information letter and the survey booklet. The cover letter informed the participants about the nature of the study, giving them sufficient information to make a reasonable, informed judgement about whether they wish to take part or not. The letter explained that their participation is voluntary, that their responses will be kept confidential, that they (or their family) will not be identified in any results, publication or presentation arising from the study, and that they can withdraw with no negative consequences. See Appendix F for an example of the cover letter.

3.5.5.3. Thank you and reminder postcard

Additional materials included a thank you and reminder postcard – thanking those families who participated in the study, and reminding those who would still like to participate, but have not yet. An example of the reminder postcard can be viewed in Appendix G.

3.6. Pretesting the survey booklet

To discover potential response problems the survey booklet was pretested (Blair et al., 2014). The main aim was to identify all potential sources of response error. After all questions have been written and ordered, the booklet was reviewed and critiqued by three different rounds of expert reviews. Table 3.4 reports on the three review rounds, the specific aims, participants and procedures, recommendations and suggested adaptations.

Table 3.4

Pretesting the Survey Booklet: Aims, Participants and Procedures, Recommendations, and Adaptations

Aim	Participants and Procedures	Recommendations	Adaptations
<u>Round 1:</u> To determine the face value of the survey. To obtain an expert opinion about the format and order of the questions. To identify potential problems with data coding and analysis.	Consultation with a statistician.	More structured categories should be used to determine the family structure. Include numbers for all subsections of questions. Provide categories for the monthly household income.	Formulate categories to determine the family structure. Allocate a number for each question. Create categories for the monthly household income.
<u>Round 2:</u> To determine if the survey instructions are meaningful and easy to follow. To determine if there are any problems with the terminology used in the questions. To determine if there are sufficient response categories for each question.	A week long online discussion with a panel of eight experts from the 2014 Ph.D. group at the Centre for Augmentative and Alternative Communication. The survey booklet was send to the experts before hand, asking them to critically appraise the survey during a weeklong online discussion. Guiding questions were provided to ensure that all elements of the survey were critically evaluated (see Appendix H).	Feedback obtained from this review included the identification of grammar errors, identification of questions that were difficult to understand, comments about outdated terminology used, instructions that were not clear and overall feedback regarding the look and feel of the questionnaire. The length of the survey and the complexity of having two rating scales on the Family Times and Routines Index measure were identified as potentially problematic issues.	The terminology referring to the traditional definition of parents and disability were changed to reflect a more current understanding of family and disability. For example, "*Having a disabled child has led to an improved relationship with spouse*" was changed to "*My child with ASD has led to an improved relationship with my partner*". Furthermore, the terminology referring to parents in the traditional manner (i.e. a nuclear family with one working parent and one stay-at-home parent) were changed to reflect a more current understanding of family. For example "*family*" was changed to "*my family*", "*children*" was replaced with "*my children*" and "*working parent*" was changed to "*working family member(s)*".
<u>Round 3:</u> To determine any errors or incorrect terminology.	Parent expert reviewed the survey booklet to determine errors.	Spelling and formatting errors were identified.	Errors were corrected.

As reported in Table 3.4, round one of the pretesting consisted of a meeting with a statistician, round two included a discussion with an expert panel of eight people, and the last round was done by a parent of a child with ASD. Recommendations were incorporated before printing the survey booklet for the pilot study.

3.7. Pilot study

A pilot study with a clear list of aims and objectives can encourage methodological rigour (Lancaster, Dodd, & Williamson, 2004), therefore, permission was requested and obtained to conduct a pilot study at a school similar to the organisations used in the main study. Seven families were identified that fit the participant selection criteria. The survey packet and an additional letter to explain the nature of the pilot study, was handed out to each family. Respondents were asked to complete the questionnaire and additionally, to circle or indicate any questions that they found difficult to answer. Four of the seven questionnaires were completed and returned (resulting in a return rate of 57%). The specific aims and procedures for the pilot study, as well as the results and recommendations obtained, are described in detail in Table 3.5.

Table 3.5

Pilot Study: Aims, Procedures, Results and Recommendations

Aim	Procedures	Results	Recommendations
To determine the clarity of the survey questions.	Participants were asked to circle questions that they found difficult to understand.	Of the four questionnaires returned, only one respondent circled five questions (Q20.9, 20.10, 20.22 and Q.21.14, 21.17). No other respondents indicated difficulty in understanding the questions.	Other respondents did not indicate any difficulty in understanding these particular questions. Q20.9 and 20.10 are included in the Family Times and Routines Index, but not in the final Family Routines Inventory used in the main study. No changes were made to the other questions.
To identify potential nonresponse questions.	All nonresponse questions were identified in the returned questionnaires. These questions were evaluated to identify missing data and to determine if there was a possible pattern indicating a problem with the question.	The five questions identified as difficult by the one participant (see above) had missing data. Only one other question had missing data for one other participant (Q.20.24).	None.
To identify wrong answers (i.e. questions that were interpreted incorrectly).	The returned questionnaires were evaluated for wrong or inconsistent information given.	Q2 was identified as potentially problematic since each of the respondents had a different response in terms of providing the date of birth.	Changed in the layout of Q2 and include dd/mm/yyyy symbols in the answer block.
		Q12. At what age was your child diagnosed with ASD? Some respondents answered in months, others in years.	Changed in the question to how long ago was your child diagnosed with ASD, include yy/mm symbols in the answer block.
To evaluate the data collection procedures.	The principal was asked for any procedural feedback that might improve the return rate of the questionnaires.	Feedback received included the possibility of including 2 more contact points with families. Thanking families and reminding those who have not participated to do so resulted in one more questionnaire returned.	A follow-up postcard (thanking those who participated and also reminding those who have not completed the questionnaire to do so) was included in the data collection procedures. Additionally, a reminder to be sent out a few weeks later via the organisation's existing communication channel was also included. These two additional points of contacts are supported in survey methodology (Dillman, 2007).

Aim	Procedures	Results	Recommendations
To identify if there are sufficient response categories for all the questions.	Evaluate question responses to determine if response options are sufficient for each question, i.e. if there is enough diversity in the participants' responses.	Q7. Total household income was identified as not having enough response categories because all the participants answered similarly.	The response options for the total household income were increased to allow for 6 different income categories. This is similar to a study done by Wang et al. (2004) where they determined that family income is a significant predictor of family quality of life by using different income categories. The 6 categories were based on an 2011 household income and expenditure patterns report of South Africa (Masemola et al., 2011).
To evaluate the length of the questionnaire.	Identify all redundant questions and evaluate ways to shorten the time it takes to complete the questionnaire.	Redundant questions identified: Q1.2 Gender of the children. Q8. How many people are supported on this income? The complexity of the two scales of the FTRI should be re-evaluated because it extends the time it takes to complete the questionnaire.	The Family Times and Routines Index was replaced with the Family Routines Inventory, which has fewer questions (28 compared to 32) and its frequency scale is reported to be the preferred scoring option. This change will result in 4 less questions, and also reduced the cognitive load of respondents having to report on both the frequency and the importance of each routine. Each routine thus have only one scoring option, not two.
To determine the appropriateness of the selection criteria in terms of the child's age.	Discuss age range of children with ASD accessing services with principal.	It was determined that children younger than 9 years old will increase the sample size and still fit in with the aim of this study.	Changed the participant selection criteria to increase age range of children with ASD to 8;11 (years;months).

In summary, the results of the pilot study included valuable recommendations that increased the quality of the main data collection, i.e. taking less time to complete the questionnaire, increasing the contact points with potential participants, and extending the age range of the child with ASD in the selection criteria to increase the sample size and still fit with the aim of this study. These recommendations and changes were incorporated before the final printing of the survey materials. The data collection procedures were revised and finalised before the main data collection commended.

3.8. Main study

The main study is discussed in terms of the ethical considerations, data collection procedures, and the data preparation and analysis procedures.

3.8.1. *Ethical considerations*

Before proceeding with the study, ethics approval was obtained from the Research Committee of the University of Pretoria's Faculty of Humanities (see Appendix I, Appendix J) and the Gauteng Department of Education (see Appendix K). Ethical considerations such as the protection from harm, obtaining informed consent, protecting the privacy and confidentiality of the participants, and minimising the potential misinterpretation and misuses of results were addressed in the study. See Section 3.5.5 on survey materials for a description of the letters to organisations and participants.

3.8.2. *Data collection procedures*

The first step was to identify organisations that cater for children with ASD (see the Section 3.4.2 for a description of the recruitment process). Each organisation was contacted telephonically to inform them about the study and to explain what will be required from them. An e-mail referring to the telephonic conversation, together with information letter (see Appendix D) and a template for a permission letter (see Appendix E) were then sent out. Upon approval from the identified organisations, the research surveys were hand delivered to each organisation. The principal or director then distributed a survey packet to each family who fit the participant selection criteria (see Section 3.4.1 for a description of the participant criteria). Each family received an envelope that contained a cover letter (see Appendix F) and the survey booklet. After the respondents completed the survey at a time and place convenient to them, they returned it in a sealed envelope to the organisation. To increase the points of contact with the families, a postcard (see Appendix G) was sent out to families after the first week, thanking those who already participated and reminding those who had not responded. A second reminder was then sent out through the organisations' existing news channels (newsletters, notes or e-mails) to remind those who still wanted to participate. After about three week's time since the initial hand-out, the researcher collected the completed questionnaires at each organisation and thanked the organisations for their support and participation. Only one survey was completed per family.

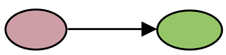
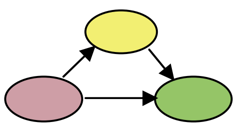
3.8.3. *Data preparation and data analysis procedures*

Data were analysed using IBM SPSS Statistics Version 22 and AMOS version 22. First, a codebook was developed for entering the data into SPSS (see Appendix L). Each completed survey received a unique identification number. After all the data was entered into SPSS, steps were taken to clean the data of errors. SPSS Descriptives were used to run an initial check on the data. Minimum and maximum values for each variable were obtained and questions that have data entered out of range were identified and corrected. Mean imputation was used to deal with missing data.

SEM techniques using the AMOS computer software system were used to assess the fit between the hypothesised SEM model and the data collected. SEM does not indicate a single statistical technique, but instead it refers to a family of related procedures. It was introduced by Jöreskog in the 1960s and is one of the most general multivariate methods, combining the best of factor analysis and multiple regression into a single framework or set of procedures (Kline, 2011). The study constructs identified in the conceptual model (i.e. regularity of family routines, positive appraisal, negative appraisal, and family quality of life) cannot be measured directly. Rather, these constructs are all variables (or latent constructs), presumed to reflect a continuum that is not directly observable. One of the most central features of SEM is this idea of latent factors that represent the core of what researchers want to measure (Hoyle & Smith, 1994). Furthermore, SEM recognises prediction error in a dependent variable that is not perfectly explained by a set of predictors, and measurement error in a variable that is not completely reliable. Using SEM allow the formulation of multiple hypotheses that can be tested in conjunction. In SEM, models are hypothesised that can be articulated verbally, visually depicted and quantitatively assessed (Iacobucci, Saldanha, & Deng, 2007; Iacobucci, 2009). Since SEM uses specific terminology and notations, a preliminary explanation of the terms and notations will allow for a more clear explanation of the process. The most frequent terminology and notations that will be used in the next chapter is displayed in Table 3.6.

Table 3.6

SEM Terminology and Notations

Terminology	Symbol	Definition
Full SEM model		The full SEM model includes the measurement model and the structural model.
Measurement model		This is a part of SEM model that includes all relations between the observed variables and the unobserved variables (or latent constructs). Confirmatory factor analysis establishes the patterns by which each observed variable loads on an unobserved variable.
Structural model		This is a part of SEM model which includes the relations between latent constructs. A particular latent construct can directly or indirectly influence changes in the values of certain other latent constructs in the model.
Observed variable or measured variable or	V	A measured variable is a variable that is directly measured or observed, e.g., “Our family solves problems together” scored on a 5-point Likert scale ranging from (1) *very dissatisfied* to (5) *very satisfied*.
Unobserved variable or latent construct	F	A latent construct can be defined as whatever its multiple indicators have in common with each other, e.g., family quality of life is considered a latent construct because it cannot be measured directly. Instead it is measured by multiple observed variables.
Error term	e	Measurement error associated with an observed variable.
Disturbance	d	Residual error (or disturbance) in the prediction of an unobserved factor.
Direct relationship/ Direct effect		Direct effect is a directional relation between two variables, e.g. the relationship between Regularity of Family Routines and Family Quality of Life.
Indirect relationship / Indirect effect		Indirect effect is the effect of an independent variable on a dependent variable through one or more intervening or mediating variables (Baron & Kenny, 1986). For example, the mediating or indirect effect of positive and negative appraisal on the relationship between the regularity of family routines and family quality of life.

In terms of SEM data analyses procedures, it is suggested to use several fit statistics (or fit indices) to assess the fit between the hypothesised model and the actual data collected

(Schreiber, Nora, Stage, Barlow, & King, 2006). The three fit indices used in this study are (a) the ratio of the chi-square (χ^2) to its degrees of freedom (*df*) and *p*-value, (b) the comparative fit index (CFI) and (c) the root mean square error of approximation (RMSEA). These indices, with their acronyms and general rules for acceptable fit is explained in Table 3.7.

Table 3.7

Summary of SEM Fit Indices

Explanation	Acronym	General rule for acceptable fit / Notes
Absolute indexes:		
Chi-square	χ^2 or CMIN	The smaller, the better.
Probability of χ^2	*p*	Ideally, for a model that fits the data, the χ^2 would not be significant ($p > 0.05$). However, by itself this does not determine whether to reject the model or retain it. Therefore, although a statistically significant model test statistic ($p <. 05$) does provide preliminary evidence against the model, other information about model-data correspondence must be considered (Kline, 2011). As sample size increases, χ^2 increases and its corresponding *p*-value declines (Iacobucci, 2010). Therefore χ^2 will almost always be significant (indicating a poor fit) even with almost modest sample sizes. As a result, the ratio of χ^2 to its degrees of freedom is used (see below).
Degrees of freedom	df	The larger, the better. Range $[0; \infty]$
Ratio of χ^2 to degrees of freedom	χ^2 /df	The model chi-square statistic (χ^2) divided by the degrees of freedom is often used and demonstrates reasonable fit if the statistic adjusted by its degrees of freedom does not exceed 3.0 (Kline, 2011).
Akaike information criterion	AIC	This evaluation of AIC values is used when two models with the exact observed variables are compared, with smaller values indicating better fit (Harlow, 2014).
Comparative fit index:		
Comparative fit index	CFI	CFI $\geq$ .95: excellent fit CFI = .90 - .95: acceptable fit
Other indexes:		
Root mean square error of approximation (with confidence interval)	RMSEA [LO90; HI90]	RMSEA = 0: exact / good fit RMSEA < .05: close fit RMSEA < .06 to .08: fair fit RMSEA < .10: acceptable fit RMSEA > .10: poor fit, unacceptable (Harlow, 2014)

As noted in Table 3.7, one of the intricacies with SEM analysis is the sample size. It is difficult to figure out the sufficient sample size ahead of time by using exact equations because there is no information beforehand about the strength of the relationships among the variables. However, as noted by Iacobucci (2010) the rule of thumb to have a sample size of 200 or more

(Kline, 2011) might be overly ambitious and that even with small sample sizes (e.g., 50 to 100) SEM models can perform well if the variables are reliable, the effects are strong, and the model not overly complex. This is also true for simple mediation SEM models that behaved statistically regularly for small sample sizes (Iacobucci et al., 2007). This study's medium sample size of 180 participants was therefore considered sufficient for doing SEM analysis.

Prior to testing the hypothesised model with SEM, preliminary data analysis was performed to make sure that the data met the assumptions for using SEM (Harlow, 2014). The assumption of independence was met because a single family member completed the research questionnaire only once. The assumption of normality was then tested. The observed data was assessed for univariate normality which can be an indicator of multivariate normality. The preliminary analyses suggested that the assumption of normality did not appear to be violated, except for one question on the Family Routine Inventory – "*My children go to school on the same days each week*" which had a reported skewness of 4.93 and kurtosis of 28.97. This could be explained due to the selection criteria that required only families of children attending a school on a regular basis to be included in the study. This question item was therefore excluded from further analyses. Since the assumption of normality was not violated, the study used maximum likelihood estimation which is not dependent on the instruments and does not demand an overly large sample size.

3.9. Summary

This chapter described the methodology used in the study. The research aims and design was stipulated. The participants were discussed in terms of the selection criteria, the recruitment and sampling methods, and a rich description of the characteristics of the participating families were provided. The study materials were reported, with a specific focus on the selection process of the instruments. The pretesting of the survey booklet and the pilot study with recommendations for the main study were discussed. Lastly, the main study was described in terms of the ethical considerations and data collection procedures, followed by the procedures used for the data preparation and analyses.

CHAPTER 4

RESULTS

4.1. Introduction

This chapter reports the results of the study. As schematically presented in Figure 4.1, the chapter commence with the specification of the SEM model. Following recommended SEM guidelines, the model-data fit assessment was done in two phases (the measurement model and the structural model), and the results are reported accordingly. The descriptive statistics of the measuring instruments and influences of the demographic variables on family quality of life are reported amid the two phases.

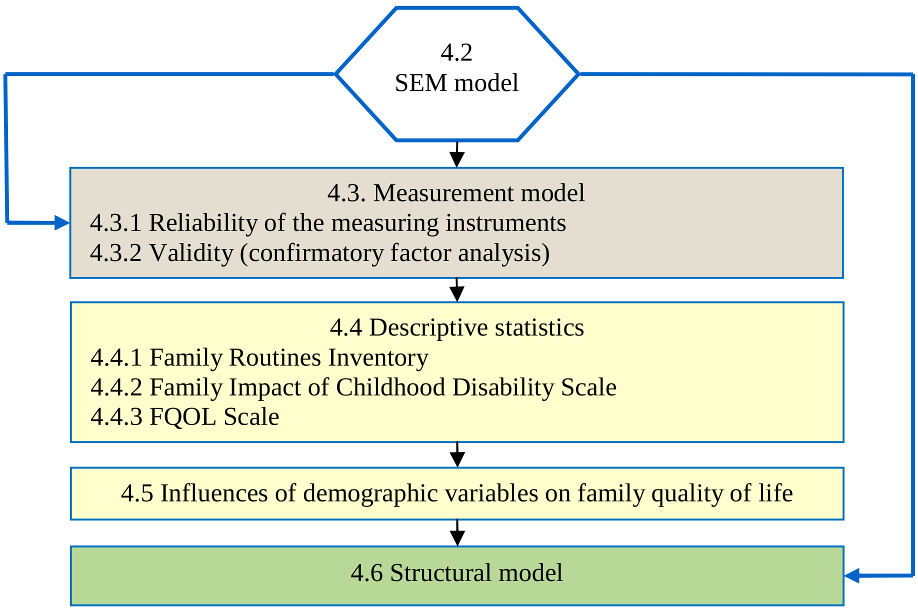


Figure 4.1 Schematic overview of the results chapter.

4.2. The full SEM model

The culmination of the conceptual model developed (see Chapter 2, Figure 2.2) and the measurement instruments selected (see Chapter 3, Section 3.5) resulted in the full SEM model of the study, which is specified in Figure 4.2. (For an explanation of the SEM notation used in the SEM model and subsequent SEM terminology see Section 3.8.3.)

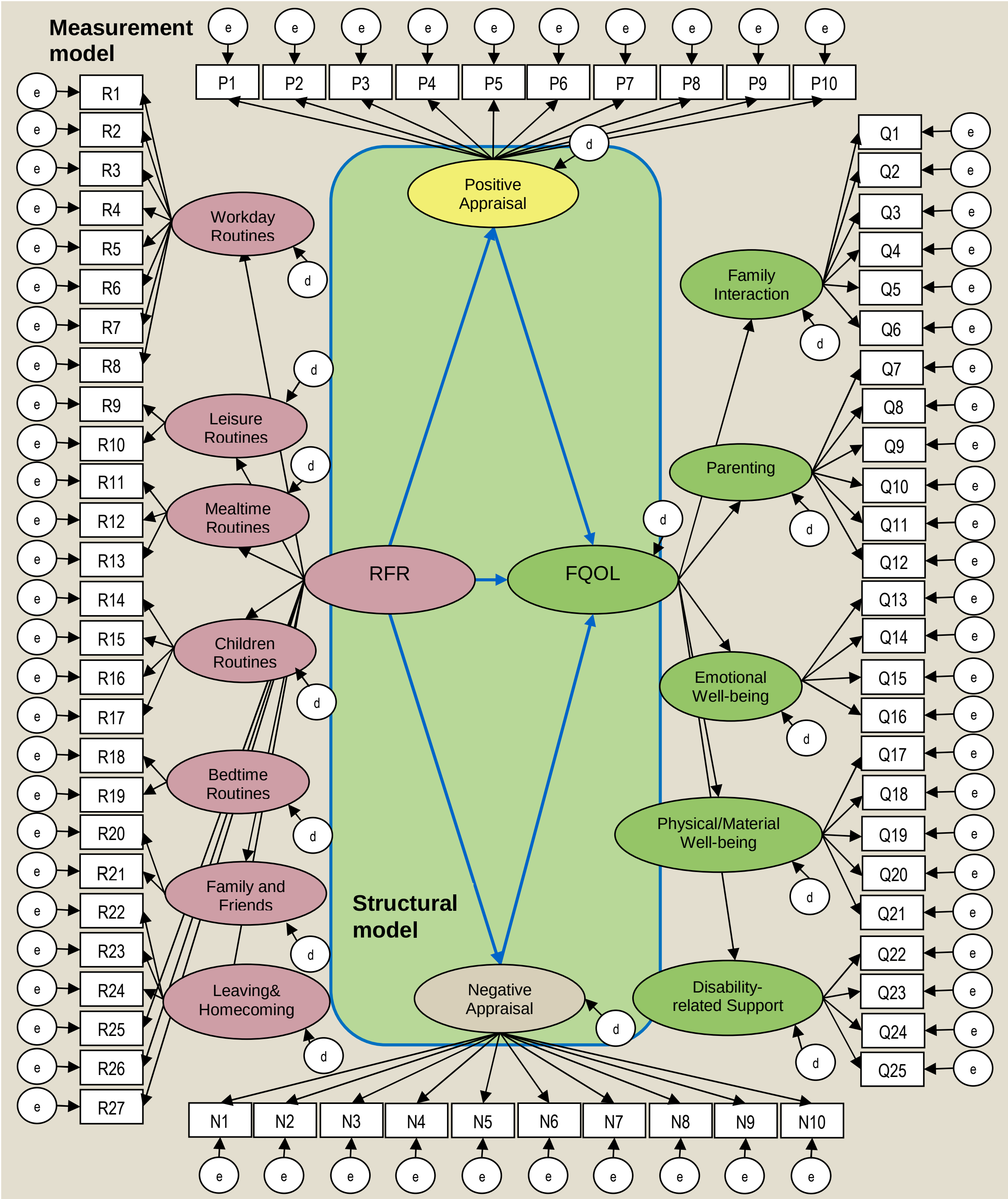


Figure 4.2 The full SEM model, including the measurement model and the structural model.
Note. RFR = Regularity of family routines, FQOL = Family quality of life. R, P, N, Q rectangles = responses to questions on survey. e = error in measured variable. d = disturbance in latent variable.

As illustrated in Figure 4.2, a distinction is made between the measurement model and the structural model of the SEM model. The measurement model concerns the relations between the unobserved latent constructs and their measured variables. For example, Positive Appraisal is measured by P1 to P10 (the10 questions on the FICD Scale that relates to the positive impact of ASD on the family), while Negative Appraisal is measured by N1 to N10 (the 10 questions on the FICD Scale that relates to the negative impact of ASD on the family). Similarly, Family Quality of Life is measured by Q1 to Q25 (the 25 questions on the FQOL Scale). Figure 4.2 also shows that Family Quality of Life is conceptualised as a second-order latent construct. A second-order latent construct is a construct whose indicators themselves are latent constructs. The first-order latent constructs of Family Quality of Life are (a) Family Interaction, (b) Parenting, (c) Emotional Well-Being, (d) Physical/Material Well-Being, and (e) Disability-related Support. Regularity of Family Routines is also conceptualised as a second-order latent construct, with (a) Workday Routines, (b) Leisure Routines, (c) Mealtime Routines, (d) Children Routines, (e) Bedtime Routines, (f) Family and Friends Routines, and (g) Leaving and Homecoming Routines as the first-order latent constructs. Thus, the four main latent constructs (Regularity of Family Routines, Positive Appraisal, Negative Appraisal, and Family Quality of Life) and how they are measured represents the measurement model. The structural model concerns the relations among these four main constructs – the direct relationship between Regularity of Family Routines and Family Quality of Life, and the mediating relationships of Positive Appraisal and Negative Appraisal.

It is recommended to do SEM analysis in two phases by separating the measurement portion and the structural portion of the model. If misspecifications are present in the measurement model it can be realised and addressed first, before assessing the structure among the latent constructs (Kline, 2011; Mueller & Hancock, 2008). Therefore, the model-data fit assessment was done in two phases, and the results reported are done accordingly.

4.3. The measurement model

First, the reliability of the instruments was determined. Thereafter the validity of each latent construct was assessed by using confirmatory factor analysis (CFA) techniques.

4.3.1. *Reliability*

To determine the reliability of the measuring instruments, the internal consistency was assessed by calculating Cronbach's alpha. This is the most common form of reliability because it requires an assessment at a single point in time on a single form, and it can be determine as long as multiple items exists (Harlow, 2014). The coefficient α should preferable be greater than or equal to .70 - .80 (Field, 2013). As reported in Table 4.1, the Cronbach's alpha for the overall scales indicated good to excellent internal reliability (.80 – 92). It is also recommended to determine the internal consistency for each of the sub-scales of an instrument (Field, 2013).

Table 4.1

Reliability of Measuring Instruments

Instrument and Subscales	Number of questions	α	Interpretation/ Comment
Overall Family Routines Inventory	27	.798	Good
Overall FICD Scale	20	.799	Good
Overall FQOL Scale	25	.924	Excellent
<u>Family Routines Inventory Subscales:</u>			
Workday Routines	8	.624	Acceptable
Leisure Routines	2	.555	Acceptable
Mealtime Routines	3	.592	Acceptable
Children Routines	4	.398[a]	Combine Children and Bedtime Routines to increase reliability[a]
Bedtime Routines	2	.436[a]	
[a]Child Routines (combined)	6	.520	Acceptable
[o]Family and Friends Routines	2	.469[o]	Keep as two separate variables[o]
Leaving and Homecoming Routines	3	.526	Acceptable
<u>FICD Subscales:</u>			
Positive Appraisal	10	.786	Good
Negative Appraisal	10	.862	Good
<u>FQOL Subscales:</u>			
Family Interaction	6	.861	Good
Parenting	6	.796	Good
Emotional Well-Being	4	.739	Good
Physical/Material Well-Being	5	.824	Good
Disability-related Support	4	.765	Good

[a] Children Routines and Bedtime Routines combined into one domain of Child Routines.
[o] Family and Friend Routines were distinguished as two separate variables (i.e. Communicating with Family Routines and Visiting Family and Friends Routines).

As reported in Table 4.1, the alphas for the two individual subscales of the FICD Scale were good (.79 for the Positive Appraisal subscale and .86 for the Negative Appraisal subscale).

The alphas for the five individual subscales of Family Quality of Life were also good (.74 to .86). However, the five subscales of the Family Routines Inventory were less optimal. Specifically, the Children Routines (.40), Bedtime Routines (.44) and Family and Friends routines (.47) showed a suboptimal internal consistency. After analysing these routines qualitatively, it was determined to combine the Children Routines and Bedtime Routines (since the bedtime routines questions were explicitly related to children) into one domain of Child Routines. This resulted in a more acceptable reliability coefficient of .52. The two Family and Friends Routines were also analysed and distinguished as two separate measured variables (i.e. Communicating with Family Routines and Visiting Family and Friends Routines). After these modifications, the individual subscales of the Family Routines Inventory ranged from .52 to .62, which is acceptable, given the unobservable nature of the latent construct and the small number of items (Field, 2013). Based on the reliability results, the measurement model for the Regularity of Family Routines was modified and treated accordingly in all further analyses.

4.3.2. *Validity*

Validity is the degree to which an instrument accurately measures what is supposed to measure. Ensuring validity starts with a thorough understanding of what is to be measured. CFA analysis is a confirmatory technique which analyse the dimensional structure of a measuring instrument – testing the structure proposed by the researcher (as illustrated in the measurement model of Figure 4.2) to verify whether the data obtained in the present study fitted the original model. The CFA model-data fit values of each instrument are reported, including model-fit indices (assessing the goodness-of-fit), and the factor loadings (assessing the parameter estimates). The factor loadings are examined for significance and effect size. The loadings can be seen as correlational effect sizes in CFA and is interpreted as small, medium, or large for values of .1, .3, and .5 or more, respectively (Harlow, 2014).

4.3.2.1. Measurement modeling of the Regularity of Family Routines

To confirm the validity of the construct of Regularity of Family Routines two factor structures were examined. Model 1 (a baseline unidimensional model with all 27 measured variables loading onto a single factor of Regularity of Family Routines) was compared to Model 2 (a second-order latent construct model of Regularity of Family Routines with five first-order latent variables and five measured variables). The results of the model fit assessment for both Model 1 and Model 2 are summarised in Table 4.2.

Table 4.2

Summary of the Fit Statistics of the Two Models of Regularity of Family Routines

Model	*p*	χ^2	*df*	χ^2/df	CFI	AIC	RMSEA 90%CI
1. One factor model	<.001	665.891	324	2.055	.515	827.891	.063 [.056;.070]
2. Second-order five factor model and five measured indicators	<.001	574.841	320	1.796	.638	744.841	.055 [.048;.062]

Note. *p* = *p*-value. χ^2 = chi-square. χ^2/df is the ratio of chi-square divided by the degrees of freedom. CFI = Comparative fit index. AIC = Akaike information criteria. RMSEA = Root mean square error of approximation. CI = confidence interval.

As shown in Table 4.2, the Akaike information criteria (AIC) index for Model 2 was smaller than the AIC index for Model 1. This index is used when comparing different models that have the same measured variables (such as these two models). The smaller value indicates a better fit, therefore Model 2 was the best fitting model for the Regularity of Family Routines. Although the χ^2 was relatively large and had a significant *p*-value, as is often the case with moderate to large samples, the χ^2/df indicated a reasonable fit, the CFI of .64 indicated a suboptimal fit, while the RMSEA of .055 along with its 90% CI [.048, .062] revealed a close fit. This indicated the model-data fit is not optimal, but plausible.

Figure 4.3 illustrates the factor loadings (standardised regression weights) of the measurement of the Regularity of Family Routines as conceptualise in Model 2. As observed in Figure 4.3, the factor loadings of the five latent constructs loading onto the Regularity of Family Routines ranged from .49 for Workday Routines to .88 for Leaving and Homecoming Routines. The five measured variables loading onto the Regularity of Family Routines ranged from .32 for Disciplinary Routines to .46 for Visiting Family and Friends Routines.

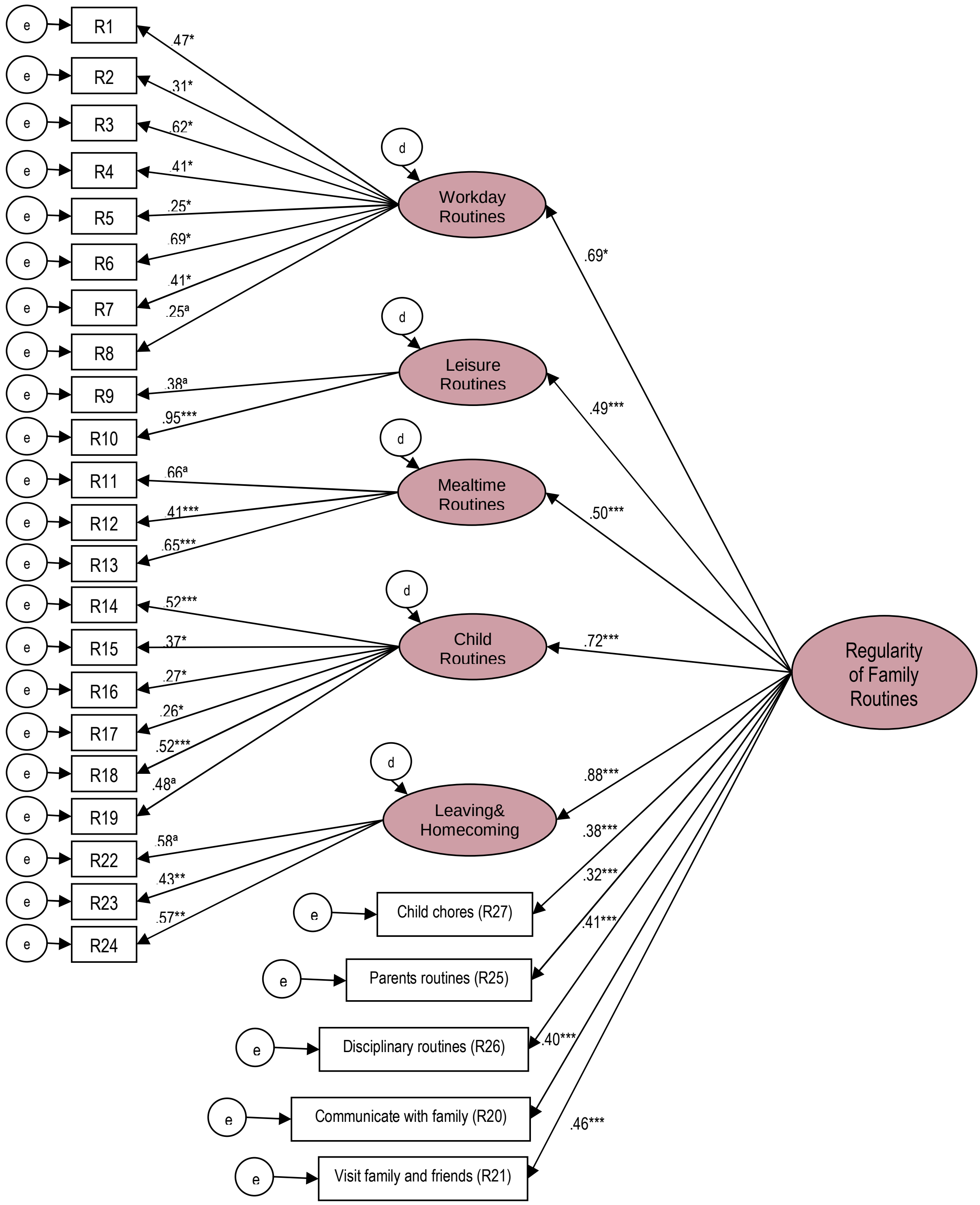


Figure 4.3 Factor loadings (standardised regression weights) of the Regularity of Family Routines.

Note. e = measurement error. d = disturbance.

[a] Standard error was not estimated.

* p < .05. *** p < .001.

As illustrated in Figure 4.3, the CFA of the Regularity of Family Routines model showed that all the hypothesised factor loadings were statistically significant and sufficiently large. This provided evidence of the construct of Regularity of Family Routines being measured in a valid manner.

4.3.2.2. Measurement modeling of the Cognitive Appraisal of the Impact of ASD

To confirm the validity of the latent constructs Positive Appraisal and Negative Appraisal, only model was considered because the relation between the two subscales was expected to be a zero, or low correlation – thus a one factor model was not considered. The Positive-Negative model consisted of the 10 measured variables loading onto Positive Appraisal, and the 10 measured variables loading onto Negative Appraisal. The fit statistics for the Cognitive Appraisal of the Impact of ASD model is reported in Table 4.3.

Table 4.3

Summary of the Fit Statistics of the Cognitive Appraisal Model

Model	***P***	**χ^2**	***df***	**χ^2/df**	**CFI**	**RMSEA** (90% CI)
Positive – Negative model	<.001	372.530	169	2.204	.806	.068 [.058-.077]

Note. p = p-value. χ^2 = chi-square. χ^2/df is the ratio of chi-square divided by the degrees of freedom. CFI = Comparative fit index. RMSEA = Root mean square error of approximation. CI = confidence interval.

As displayed in Table 4.3, the overall fit indices of the CFA analyses revealed the hypothesised model for Cognitive Appraisal offered a plausible fit to the data. Although the χ^2 was relatively large and had a significant p-value, the χ^2/df indicated a reasonable fit, the CFI of .80 indicated a suboptimal fit, while the RMSEA of .068 along with its 90% CI [.058, .077] revealed a fair fit. This indicated the model-data fit is not optimal, but plausible.

As anticipated from the literature (Larson, 1998; Trute & Hiebert-Murphy, 2002), there was a not a statistically significant correlation between Positive Appraisal and Negative Appraisal; Pearson's $r(180) = .07$, $p = .428$). A low or no correlation indicates good discriminant validity between the two subscales and as a result, they are treated as separate variables in the structural model. Figure 4.4 illustrates the factor loadings (standardised regression weights) of Positive Appraisal and Negative Appraisal.

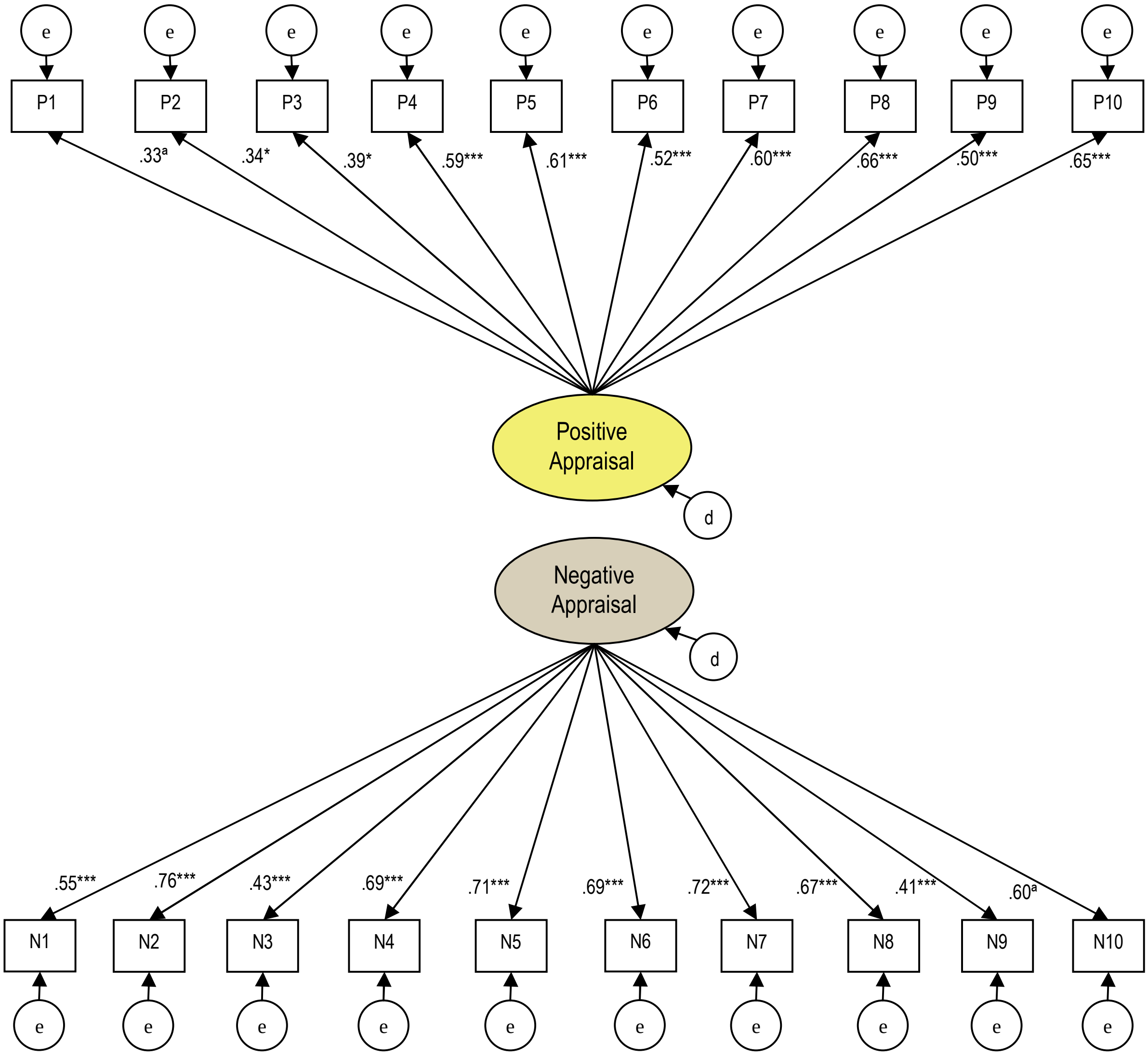


Figure 4.4 Factor loadings (standardised regression weights) of Positive Appraisal and Negative Appraisal.
Note. e = measurement error. d = disturbance.
[a] Standard error was not estimated.
* p < .05. ***p < .001.

As illustrated in Figure 4.4, the measured variables loading onto Positive Appraisal (P1 to P10) ranged from .33 to .66. The measured variables specified to measure Negative Appraisal (N1 to N10) ranged from .41 to .76. All the hypothesised factor loadings were statistically significant and sufficiently large. This provided evidence that the constructs of Positive Appraisal and Negative Appraisal was measured in a valid manner.

4.3.2.3. Measurement modeling of Family Quality of Life

To confirm the validity of the Family Quality of Life construct, a second-order five factor model was considered (Balcells-Balcells et al., 2011; Hoffman et al., 2006; Zuna et al., 2009). The fit statistics for the Family Quality of Life model are displayed in Table 4.4.

Table 4.4

Summary of the Fit Statistics of the Family Quality of Life Model

Model	***P***	**χ^2**	***df***	***χ^2 /df***	**CFI**	**RMSEA** (90% CI)
Second-order FQOL model	<.001	558.660	270	2.069	.852	.064 [.056-.071]

Note. p = p-value. χ^2 = chi-square. χ^2/df is the ration of chi-square divided by the degrees of freedom. CFI = Comparative fit index. RMSEA = Root mean square error of approximation. CI = confidence interval.

As reported in Table 4.4., the overall fit indices of the CFA analysis revealed that the hypothesised second-order Family Quality of Life model offered a plausible fit to the data. Although the χ^2 was relatively large and had a significant p-value, as is often the case with moderate to large samples, the χ^2/df indicated a reasonable fit, the CFI of .85 indicated a suboptimal fit, while the RMSEA of .064 along with its 90% CI [.064, .071] revealed a fair fit. The factor loadings (standardised regression weights) of Family Quality of Life as a second-order latent construct model are illustrated in Figure 4.5.

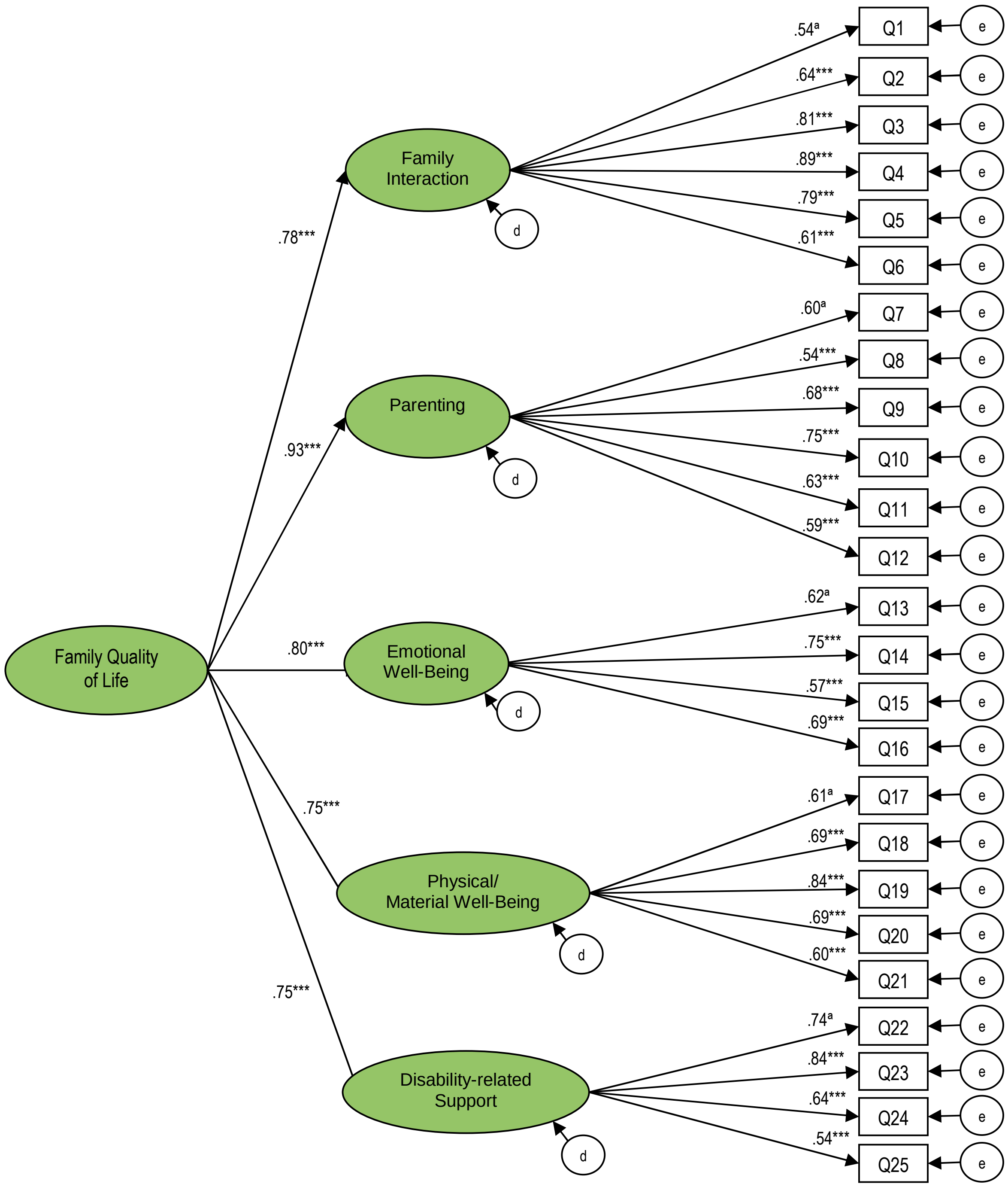


Figure 4.5 Factor loadings (standardised regression weights) of Family Quality of Life.
Note. e = measurement error. d = distortion.
[a] Standard error was not estimated.
***p < .001.

Figure 4.5 illustrates that the second-order Family Quality of Life model resulted in strong factor loadings of the measured variables (.54 -.89). The standardized regression weights of the regression of the five latent constructs onto the second-order Family Quality of Life construct were for Family Interaction (.78), Parenting (.93), Emotional Well-Being (.80), Physical/Material Well-Being (.75) and Disability-related Support (.75). All the hypothesised factor loadings were significant and sufficiently large, and similar to previous results (Hoffman et al., 2006). This provided evidence that the construct of Family Quality of Life was measured in a valid manner. This concluded the assessment of the measurement model.

4.4. Descriptive statistics

4.4.1. *Family Routines Inventory*

The descriptive statistics (*M*, *SD*) are reported for each measured variable, the five subdomains, and the overall score of the Family Routines Inventory, as displayed in Table 4.5. The frequency scores ranged from 0 (meaning that a family does not participate in this particular routine) to 3 (meaning that a family participated always or almost every day in this particular routine).

Table 4.5

Frequency of Family Routines on the Family Routines Inventory (in order from highest to lowest mean scores)

Key	Description	Mean	*SD*
	Measured variables:		
R5	My children do the same things each morning as soon as they wake up.	2.40	0.847
R1	Parent(s) have some time each day for just talking with the children.	2.37	0.813
R15	My children have some time each day for playing alone.	2.32	0.817
R11	My family eats dinner at about the same time each night.	2.27	0.847
R2	Parent(s) have certain things they do every morning while getting ready to start the day.	2.26	1.010
R23	We check in and out with each other when someone leaves or comes home.	2.23	0.994
R13	My family eats at least one meal together almost every day.	2.16	0.998
R26	Parent(s) have certain things we do each time our children get out of line.	2.14	0.872
R4	Working family member(s) take care of the children sometime almost every day.	2.12	1.012
R19	My children go to bed at the same time almost every night.	2.11	0.980
R18	My children have special things they do or ask for at bedtime (e.g. story, good-night kisses, a drink of water).	2.08	1.100
R6	Parent(s) and children play together sometime each day.	2.03	0.825

Key	Description	Mean	*SD*
R3	Working family member(s) have a regular play time with the children after coming home from work.	1.91	0.848
R25	My family has certain things we almost always do to greet the working family member(s) at the end of the day.	1.89	1.131
R16	My child with ASD attends regular therapy appointments.	1.84	1.056
R21	Parent(s) talk to their own parent(s) regularly.	1.77	0.986
R17	Parent(s) do therapy activities with their child with ASD as suggested by teachers, therapists, or other professionals.	1.75	0.957
R25	Working family member(s) come home from work at the same time each day.	1.72	1.046
R27	My children do regular household chores (e.g. caring for pets, picking up their toys).	1.50	1.051
R10	My family has a certain ‘family time’ each week when we do things together at home.	1.38	0.914
R12	At least some of my family members eat breakfast together almost every morning.	1.31	1.047
R14	Parent(s) read or tell stories to our children almost every day.	1.29	0.922
R7	My family does something together outside the home almost every day (e.g. shopping, walking, etc.)	1.26	0.796
R8	My family has a ‘quiet time’ each evening when everyone talks or plays quietly.	1.21	0.984
R22	My family visits with our relatives or friends regularly.	1.02	0.744
R20	Parent(s) have a certain hobby or sport they do regularly.	0.95	0.938
R9	My family goes some place special together each week.	0.82	0.829
	Subdomains:		
	Child Routines	2.21	0.625
	Workday Routines	1.95	0.468
	Leaving and Homecoming Routines	1.95	0.776
	Mealtime Routines	1.92	0.712
	Leisure Routines	1.10	0.732
	Overall Regularity of Family Routines	1.84	0.398

Note. Regularity of routines was scored on a scale of 0 (*almost never*) to 3 (*almost every day*).

From the results reported in Table 4.5 it was determined that the most frequent routine reported was the children’s morning routine as soon as they wake up. The two least frequent routines that scored less than 1 were parents’ having a regular hobby or sport, and the weekly visit of a special place together as a family. The subdomain with the highest frequency was Child Routines, while Leisure Routines scored the lowest.

4.4.2. *Family Impact of Childhood Disability Scale*

Table 4.6 displays the descriptive statistics (*M*, *SD*) of each measured variable and the two subdomains of the FICD Scale. The scores ranged from 1 (*not at all*) to 4 (*to a substantial degree*). Ten questions (P1 to P10) measured the appraisal of the positive impact of ASD, and 10 questions (N1 to N10) measured the appraisal of the negative impact of ASD on the family.

Table 4.6

Degree of Impact Ratings on the FICD Scale (in order from highest to lowest mean scores)

Key	Description	Mean	*SD*
	Measured variables:		
N3	It has led to additional financial costs.	3.53	0.808
P5	This experience has helped my family to appreciate how every child has a unique personality and special talents.	3.51	0.787
P8	The experience has made my family more aware of other people's needs and struggles which are based on a disability.	3.42	0.785
P7	My child's ASD has led to positive personal growth, or more strength in me as a person and/or my family members.	3.37	0.857
P9	The experience has taught my family that there are many special pleasures from my child with ASD.	3.28	0.830
N1	There have been increased time demands created in looking after the needs of my child with ASD.	3.23	0.901
P6	My family has become more tolerant of differences in other people and generally more accepting of physical or intellectual differences between people.	3.17	0.935
P4	The experience has made my family come to terms with what should be valued in life.	3.11	0.920
P10	Raising my child with ASD has made life more meaningful for my family.	3.06	0.993
N4	It has led to limitations in social contacts outside the home.	2.89	1.083
N7	It has led to a reduction in time I/we could spend with my/our friends.	2.74	1.119
P1	The experience has made my family more spiritual.	2.73	1.098
P2	My family members do more for each other than they do for themselves.	2.67	0.955
N10	Because of the circumstances of my child's ASD, there has been a postponement of major purchases.	2.57	1.192
N2	There has been an unwelcome disruption to "normal" family routines.	2.43	1.075
N8	My family experienced chronic stress.	2.36	1.117
P3	It has led to an improvement in my relationship with my partner.	2.25	1.111
N5	We had to postpone or cancel major holidays.	2.15	1.243
N9	The situation has led to tension with my partner.	2.02	1.084
N6	Because of the situation, I/we have hesitated to phone friends and acquaintances.	1.90	1.001
	Subdomains:		
	Positive Appraisal	3.06	0.540
	Negative Appraisal	2.58	0.719

Note. Positive Appraisal and Negative Appraisal of the impact of ASD on the family was scored on a scale of 1 (*not at all*) to 4 (*to a substantial degree*).

Table 4.6 illustrates that families' reported the implication of additional financial costs as the most substantial impact on the family. Second to this was that family members appreciate every child as having a unique personality and special talents because of having a child with ASD in the family. The least substantial impact was that families felt hesitant to phone friends and acquaintances. Positive Appraisal reported a higher mean score than Negative Appraisal.

4.4.3. *Family Quality of Life Scale*

Table 4.7 displays the descriptive features of the individual measured variables and the subdomains of the FQOL Scale. The scores ranged from 1 (*very dissatisfied*) to 5 (*very satisfied*).

Table 4.7

Satisfaction Ratings on the FQOL Scale (in order from highest to lowest mean scores)

Key	Description	Mean	*SD*
	Measured variables:		
Q5	My family members show that they love and care for each other.	4.27	0.897
Q25	My family has good relationships with the people who provide services and support to my child with ASD.	4.25	0.816
Q22	My child with ASD has support to accomplish goals at school.	4.21	0.887
Q18	My family gets medical care when needed.	4.18	1.058
Q1	My family enjoys spending time together.	4.16	0.842
Q23	My child with ASD has support to accomplish goals at home.	4.14	0.849
Q2	My family members talk openly with each other.	4.08	0.916
Q9	My family members teach the children how to get along with others.	4.07	0.864
Q17	My family feels safe at home, work, school and in our neighbourhood.	4.01	0.941
Q4	My family members support each other to accomplish goals.	3.95	1.088
Q18	My family members have transportation to get to the places they need to be.	3.89	1.276
Q7	My family members help the children learn to be independent.	3.89	0.836
Q10	Adults in my family teach the children to make good decisions.	3.86	0.929
Q8	My family members help the children with schoolwork and activities.	3.86	0.972
Q6	My family is able to handle life’s ups and downs.	3.85	0.921
Q12	Adults in my family have time to take care of the individual needs of every child.	3.82	1.034
Q11	Adults in my family know other people in the children’s lives (friends, teachers).	3.81	0.963
Q20	My family gets dental care when needed.	3.79	1.130
Q3	Our family solves problems together.	3.77	1.039
Q19	My family has a way to take care of our expenses.	3.64	1.196
Q24	My child with ASD has support to make friends.	3.49	1.126
Q15	My family members have some time to pursue our own interests.	3.28	1.167
Q13	My family has the support we need to relieve stress.	3.28	1.134
Q14	My family members have friends or others who provide support.	3.21	1.187
Q16	My family has outside help available that we use to take care of the special needs of all family members.	3.10	1.300
	Subdomains:		
	Disability-related Support	4.03	0.715
	Family Interaction	4.01	0.723
	Physical/Material Well-Being	3.90	0.852
	Parenting	3.89	0.657
	Emotional Well-Being	3.22	0.906
	Overall Family Quality of Life	3.83	0.610

Note. Family Quality of Life was scored on a scale of 1 (*very dissatisfied*) to 5 (*very satisfied*).

Table 4.7 shows that families felt most satisfied that family members show that they love and care for each other. Families also felt very satisfied with the relationship that they have with the people who provide service and support for their child with ASD. Families felt the least satisfied with friends or others who provide support, and the outside help available to take care of the special needs of all family members. The subdomain of Disability-related Support scored the highest satisfaction rating, while the subdomain of Emotional Well-Being scored the lowest.

In terms of the overall Family Quality of Life Score (the summative score of the subdomains), only one participant (0.56%) scored between 0.00 and 1.00 (*very dissatisfied*). The overall family quality of life satisfaction rating for the remaining participants were as follows: 16 participants (8.94%) scored between 2.00 (*moderately dissatisfied*) and 3.00 (*neither satisfied nor dissatisfied*), 86 participants (48.04%) scored between 3.0 (*neither satisfied nor dissatisfied*) and 4.00 (*moderately satisfied*), and 76 participants (42.46%) scored between 4.0 (*moderately satisfied*) and 5.0 (*very satisfied*). As reported in Table 4.7 the mean score for the Overall Family Quality of Life score was 3.83 (SD = 0.61).

4.5. Associations between demographic variables and Family Quality of Life

Demographic variables were not included in the a priori SEM model but additional analysis was conducted to investigate the potential effects of the demographic variables on Family Quality of Life. Due to the nature of the demographic variables different statistical tests were done to assess potential effects. Independent *t*-tests were used to compare the difference of the Family Quality of Life of two groups (e.g., comparing the difference of the Family Quality of Life between boys and girls with ASD. Secondly, one-way ANOVA analysis was conducted to determine the differences between the Family Quality of Life of several groups (this was only for the four different employment groups). Lastly, Spearman correlations were used to determine the associations between continuous demographic variables (e.g. the number of children in the household) and Family Quality of Life.

The independent *t*-test compares the means of two different groups. The difference between the two means tell you how the groups differ. If the *p*-value is less than .05 it means that the groups are significantly different. The effect size of the difference is calculated to discover whether the effect is important in practical terms. This is the Cohen's *d* value. Suggestions about what constitutes a large or small effect is: *d* = 0.2 (small), 0.5 (medium) and 0.8 (large) (Field, 2013). The results of the independent *t*-tests that assessed the difference of the Overall Family Quality of Life between groups are reported in Table 4.8.

Table 4.8

Independent t-tests to Compare the Differences of the Overall Family Quality of Life between Two Groups

Groups	*p*	Overall FQOL *(M)*	*SD*	*M-M*	*df*	*t*	*d*
Individual demographics:							
1. Boy with ASD	.823	3.83	0.625	0.02	175	0.223	0.04
2. Girl with ASD		3.81	0.555				
1. Additional disability or medical condition present	.297	3.72	0.620	-0.13	174	-1.045	0.21
2. No additional disability or medical condition present		3.85	0.611				
Family unit characteristics:							
1. Father living with the family	**.009**	3.89	0.592	0.28	177	2.63	**0.46**
2. Father not living with the family		3.61	0.630				
1. Grandparent(s) living with the family	.661	3.79	0.683	-0.05	177	-0.44	0.08
2. Grandparent(s) not living with the family		3.84	0.595				
1. Other family member(s) living with the family	.163	3.71	0.641	-0.16	177	-1.40	0.24
2. Other family member(s) not living with the family		3.87	0.600				
1. Paid helper living with the family	.913	3.82	0.449	-0.01	177	-0.109	0.02
2. Paid helper not living with the family		3.83	0.631				
1. Father working	**.017**	3.94	0.556	0.36	137	2.414	**0.55**
2. Father not working		3.58	0.663				
1. Mother working	.495	3.85	0.614	1.76	171	0.684	0.11
2. Mother not working		3.78	0.624				
1. Two-parent family	**.002**	3.91	0.576	0.36	168	3.218	**0.55**
2. One-parent family		3.55	0.661				

Note. *p* = *p*-value, *M* = mean. *M-M* = Difference in means between the two groups. *t* = *t*-test statistic. *df* = degrees of freedom. *d* = Cohen's *d* (effect size). Statistically significant differences (p < .05) and medium effect sizes in bold.

The results reported in Table 4.8 indicate that families who had a father living with them had a higher overall Family Quality of Life (M = 3.89, SD = 0.592) compared to those families who did not have a father present (M = 3.61, SD = 0.630). This difference can be considered to have a medium effect size (d = 0.46). Families who had a working father had a higher overall Family Quality of Life (M = 3.94, SD = 0.556) compared to families who did not have a working father (M = 3.58, SD = 0.663). This difference also indicates a medium effect (d = 0.55). Lastly, two-parent families had a higher overall Family Quality of Life (M = 3.91, SD = 0.567) compared to one-parent families (M = 3.55, SD = 0.661). Again this is considered a medium effect (d = 0.55). All these differences were statistically significant ($p < .05$), whereas the differences between other groups reported were not statistically significant ($p > .05$).

For the one-way ANOVA analyses, the only demographic variable assessed was the parent's employment status. The four different types of employment groups were compared to determine if they indicated different overall Family Quality of Life scores. The groups were (a) parents who work full-time, (b) parents who work part-time, (c) parents who are not currently working, and (d) housewives. The analysis of variance showed that there was no significant differences (p = .107) between these groups, $F(3,172) = 2.01$.

The third statistical test was to determine the correlations between continuous demographic variables and Family Quality of Life. The correlation coefficient is commonly used as a measure of the size of an effect, and indicates the direction of the effect. A positive correlation coefficient indicates a positive relationship, while a negative correlation coefficient indicates a negative relationship. Values of around .10 indicates a small effect, values around .30 indicates a medium effect, and values around .50 indicates a large effect (Field, 2013).

Table 4.9 report the correlations between individual family member demographics and Family Quality of Life – the parent demographics (age of father, age of mother, and educational background) and demographics of the child with ASD (age and level of severity of ASD) with Family Quality of Life. Additionally, the correlations between the family unit characteristics and Family Quality of Life were assessed (the family income, and the family structure – the age of the oldest child, the age of the youngest child, and the number of children in the household).

Table 4.9

Spearman Correlations between Individual Family Member Demographics and Family Unit Characteristics, and Family Quality of Life

	Family Interaction	Parenting	Emotional Well-Being	Physical/ Material Well-Being	Disability-related Support	Overall FQOL
Individual demographics:						
Parent						
Age of father	.052	.193*	.028	.140	-.025	.111
Age of mother	.030	.167*	-.061	.090	-.066	.026
Educational background	.069	.204**	.130	**.402****	.128	.256**
Child with ASD						
Age	.076	.109	.083	-.034	.003	.072
Level of severity of ASD	-.243**	-.134	-.271**	-.142	-.198**	-.236**
Family unit characteristics:						
Family income						
Monthly family income	.039	.122	.120	**.515****	.181*	.266**
Appraisal of this income	.198**	.287**	**.327****	**.589****	**.319****	**.445****
Family structure						
Age of oldest child	-.031	.077	-.034	-.168*	-.102	-.054
Age of youngest child	-.085	-.040	-.018	-.164	-.114	-.111
Number of children	-.013	.089	.022	-.091	-.098	-.029

Note. FQOL = Family Quality of Life. Correlations in bold indicate a medium effect (>.30) or large effect (>.50).
* $p < .05$. ** $p < .01$.

As reported in Table 4.9, only the appraisal of the family income showed a statistically significant, medium effect with Overall Family Quality of Life. Parent's educational background, family income, and appraisal of the monthly income showed significant medium to large effects with the Physical/Material Well-Being domain. Appraisal of the monthly household income also showed significant medium effects with the domains of Emotional Well-Being and Disability-related Support. (For an overview of the correlations between the demographic variables and the Regularity of Family Routines, Positive Appraisal and Negative Appraisal see Appendix L.)

4.6. The structural model

It was important to determine the correlations between the four latent constructs prior to assessing the structural model. It is recommended that relationships between latent constructs in the structural model should preferably be less than about |.70| to be able to justify that there are distinct constructs that are not multicollinear. If correlations are > .90 multicollinearity is most likely present. Table 4.10 shows the correlations between the Regularity of Family Routines, Positive Appraisal, Negative Appraisal and the domains of Family Quality of Life.

Table 4.10

Correlations between Regularity of Family Routines, Positive Appraisal, Negative Appraisal, and Family Quality of Life Domains

	Regularity of Family Routines	Positive Appraisal	Negative Appraisal	Overall FQOL	Family Interaction	Parenting	Emotional Well-Being	Physical/ Material Well-Being	Disability-related Support
Regularity of Family Routines	-	.199*	-.146	**.439*****	**.392****	**.449****	**.363****	.250**	.299**
Positive Appraisal		-	.081	.254***	**.312****	.295**	.113	.059	.234**
Negative Appraisal			-	**-.336*****	-.296**	-.218**	**-.475****	-.156*	-.269**

Note. FQOL = Family Quality of Life. Correlations in bold indicates a medium effect (>.30) to large effect (>.50).
* $p < .05$. ** p < .01. *** p < .001.

As indicated in Table 4.10, no problems related to multicollinearity were found, and each significant correlation between the variables was in the expected direction. (Appendix M reports the correlations between all the latent constructs.) The next step was to assess the structural model.

The structural model of this study can be described as a multiple mediation model because it includes not only one, but two mediators (i.e. Positive Appraisal and Negative Appraisal). As recommended by Preacher and Hayes (2008), the multiple mediators were tested in a single-step multiple mediation model, instead of two separate single mediator models. The weak correlation between Positive Appraisal and Negative Appraisal (Pearson's $r(180) = .07$, $p = .428$) further motivated testing the multiple mediation model in one step (Preacher & Hayes, 2008). First, the multiple mediation model was assessed in terms of how well the collected data fitted with the hypothesised model. The results of this analysis are reported in Table 4.11.

Table 4.11

Summary of Fit Statistics for the Multiple Mediation Model

Model 3	***P***	**χ^2**	***df***	**χ^2 /*df***	**CFI**	**RMSEA** (90% CI)
Multiple mediation model	<.001	1149.284	589	1.951	.726	.060 [.055; .065]

Note. *p* = *p*-value. χ^2 = chi-square. χ^2/df is the ration of chi-square divided by the degrees of freedom. CFI = Comparative fit index. RMSEA = Root mean square error of approximation. CI = confidence interval.

As displayed in Table 4.11, the overall fit indices of the SEM analyses revealed that the hypothesised model offered a suboptimal, but plausible fit to the data. Although the χ^2 was relatively large and had a significant *p*-value, the χ^2/df indicated a reasonable fit, the CFI of .73 indicated a suboptimal fit, while the RMSEA of .060 along with its 90% CI [.055, .065] revealed a fair fit.

Secondly, a mediation analysis was performed using the Baron and Kenny (1986) causal steps approach to determine whether mediation occurs. Using this approach, the researcher first asks whether the paths defining a specific indirect effect are significant. If either of the paths for a hypothesised indirect effect through the mediating variable is not statistically significant, the mediating variable is deemed not to be a mediator. Figure 4.6 illustrates the calculated path coefficients of the indirect effect (path a1&b1 and path a2&b2), and the direct effect (path c1). All the paths were found to be statistically significant ($p > .05$). Both the unstandardised and standardised path coefficients are reported in Figure 4.6.

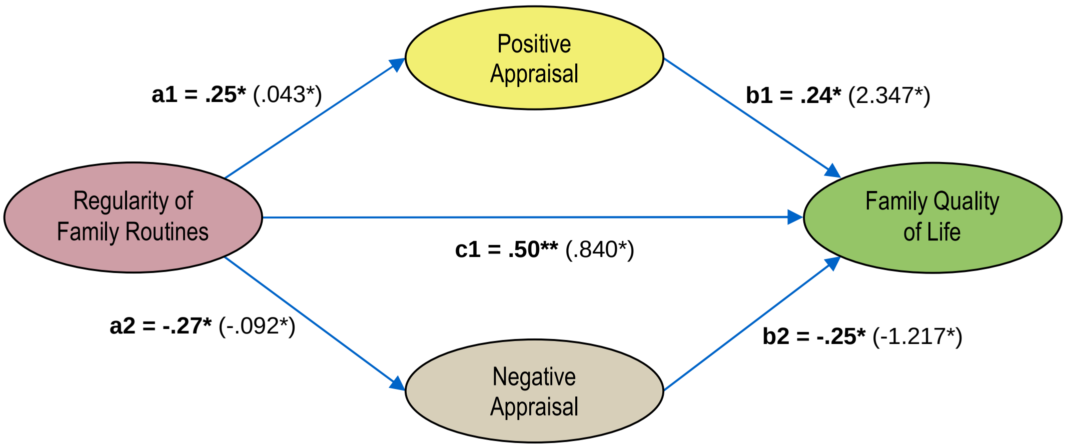


Figure 4.6 The direct effect (path c1) and indirect effect (path a1.b1) + (path a2.b2) of the multiple mediation model.
Note. Standardised regression weights in bold. Unstandardised regression weights in brackets.
* *p* < .05. ** *p* < .01.

As illustrated in Figure 4.6, the direct effect of Regularity of Family Routines in the mediation model was significantly associated with Family Quality of Life, $c = .84$, $p < .001$. This means that each increase in the frequency of Family Routines predicted approximately an increase of somewhat less than 1 point in Family Quality of Life. The standardised regression weight ($c = .50$, $p < .001$) indicates that this is a large effect.

The path between the Regularity of Family Routines and Positive Appraisal was significant, $c = 0.043$, $p < .05$. Although this relationship is significant, the standardised coefficient indicates a relatively small effect ($c = .25$, $p < .05$). This means that more frequent Family Routines is associated with a somewhat higher Positive Appraisal. The relationship between Positive Appraisal and Family Quality of Life was also significant, $c = 2.347$, $p < .05$. This means that an increase of Positive Appraisal had a corresponding increase of approximately 2 points in Family Quality of Life. The standardised regression weight ($c = .24$, $p < .05$) indicated a significant, but small effect.

Similarly, but in an opposite direction, the Regularity of Family Routines was significantly associated with Negative Appraisal, $c = .092$, $p < .05$. This relation had a negative direction, meaning that each increase in the frequency of Family Routines resulted in a lower Negative Appraisal of approximately 1 point. Although this prediction is significant ($p < .05$), the standardised regression weight indicates that this is a small effect. Furthermore, the relationship between Negative Appraisal and Family Quality of Life was significant in a negative direction, $c = -1.217$, $p < .05$. This means that for each increase in Negative Appraisal, the Family Quality of Life lowers with approximately 1 point. The standardised regression weight ($c = -.25$, $p > .05$) indicated a significant, but small effect.

The second step in the evaluation of mediation was to determine whether the direct effect (path c^1 in Figure 4.6) is smaller than the total effect (path c in Figure 4.7). The total effect of the Regularity of Family Routines on Family Quality of Life is the sum of the direct effect and all the indirect effects. The total effect of the Regularity of Family Routines on Family Quality of Life was significant, $c = 1.05$, $p < .001$. Using the unstandardised regression weight of 1.05, it means that each increase in the frequency of Family Routines predicted approximately a 1 point increase in Family Quality of Life. The standardised regression weight (c = .63, p < .001) indicates that this is a large effect. Figure 4.7 illustrates the path diagram of the total effect between the Regularity of Family Routines and Family Quality of Life (path c).

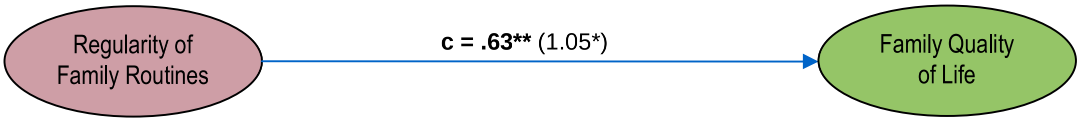


Figure 4.7 The total effect (path c) of the multiple mediation model.
Note. Standardised regression weights in bold. Unstandardised regression weights in brackets.
* p<.05. ** p<.01.

Therefore, because the direct effect was less than the total effect when there are no mediators (path c > path c1) the findings of the study indicates that a pattern consistent with the proposed mediation model has been obtained. Furthermore, the findings indicated that the direct effect (path c1) declined, but remained significant and clearly non-zero. This means that the mediators (Positive Appraisal and Negative Appraisal) partially accounted for the relation between the Regularity of Family Routines and Family Quality of Life.

4.7. Summary

This chapter reported the study results. The specified SEM model was assessed in two phases, and the results of the measurement portion and the structural portion was reported accordingly. Results of the measurement portion related to the reliability and validity of the measuring instruments. Descriptive results of each measuring instrument were reported, as well as the influences of demographic variables on Family Quality of Life. Finally, the results of the structural portion of the model described the relationship between the Regularity of Family Routines and Family Quality of Life, and the partial mediation effect of Positive and Negative Appraisal on this relationship.

CHAPTER 5
DISCUSSION

5.1. Introduction

In this chapter the results of the study are discussed in relation to the study aims. The main aim of the study was to determine the relationship between the regularity of family routines and family quality of life, and to determine the mediating effect of cognitive appraisal on this relationship. As illustrated in Figure 5.1, the findings of the measurement of each construct are first discussed individually. Thereafter, the influences of individual family member demographics and family unit characteristics on the quality of a family's life are interpreted. Finally, the implications of the relationship between the regularity of family routines and family quality of life, and the mediating effect of the appraisal of the impact of ASD on this relationship is discussed. In each section, the findings of this study are compared to previous research that support or contradict the findings, and important contributions and implications of the findings are described.

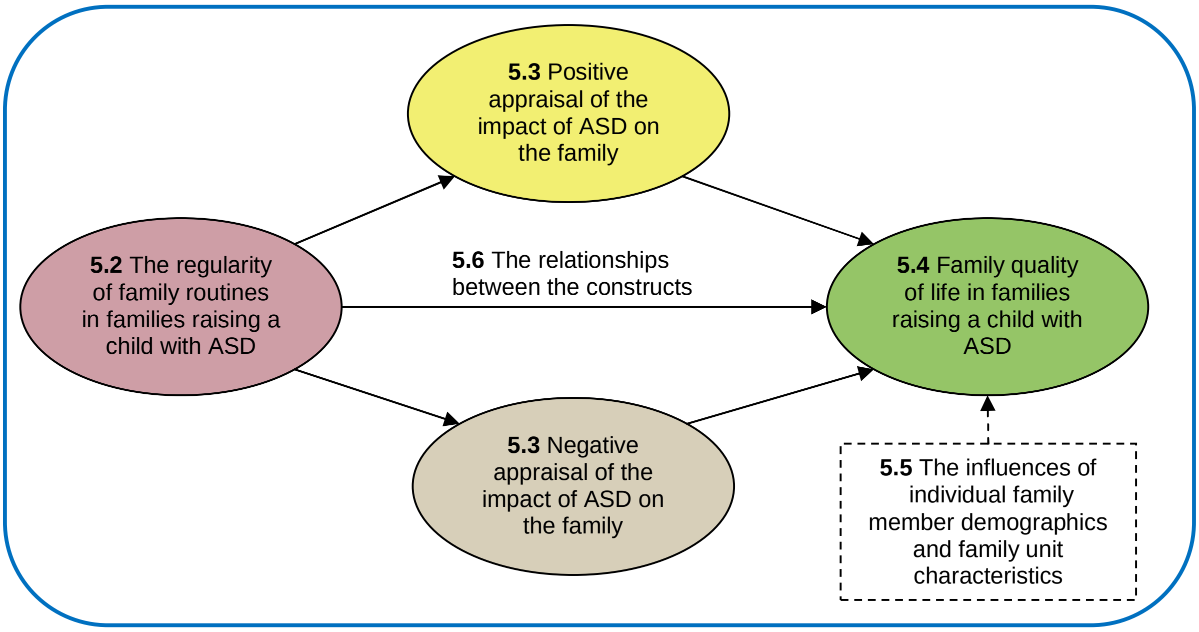


Figure 5.1 Schematic overview of the discussion chapter.

5.2. The regularity of family routines in families raising a child with ASD

The Family Routines Inventory measured 27 positive, strength-promoting family routines. The instrument was found to be reliable (α = .80) and CFA analysis indicated that the instrument was valid (see Section 4.3.2.1 for the CFA results). Families had to score the frequency of each particular routine according to four categories. A weight was then assigned to each category, which resulted in a frequency score with mean values ranging from 0 to 3 (see Section 4.4.1 for the results of the Family Routines Inventory).

From the data gathered in this study, the Child Routines were the most frequent family routines. This finding is similar to qualitative reports from families raising a child with ASD, who felt that the family routines revolve around the child with ASD (Marquenie et al., 2011; Werner DeGrace, 2004). However, a previous study that compared the family routines of families of children with ASD to families of children with typical development found that there was no statistical significant differences in the frequency of Child Routines between the families (Marquenie et al., 2011). What is important to note is that child routines can serve as building blocks to integrate the child with ASD into family activities. Family routines have the potential to be excellent learning opportunities for children with ASD, where learning and development can take place in a natural environment (Dunst, Hamby, Trivette, Raab, & Bruder, 2000). The family's routines can thus be considered an important feature for any planned intervention for children with ASD and their families, where children's capabilities can be strengthened and new competencies can be promoted (Bruder, 2010; Fiese, Foley, & Spagnola, 2006; Kashinath, Woods, & Goldstein, 2006; Wilcox & Woods, 2011; Woods & Goldstein, 2003; Woods & Lindeman, 2008). As reported by Larson (2006), it takes time to create successful routines, that the routines need to be responsive to the child's emotional and developmental needs, and that once the routines are in place, they smooth the way for participation of children with ASD in their family life.

A closer look at the data on family routines indicates that the least frequent family routines were those routines that were outside the family home (e.g. going shopping, visiting friends, going someplace special together, parent doing a hobby or sport), and the routines that can potentially create opportunities for positive meaning and bonding (e.g. read or tell stories to the children, quiet time in the evening, family time together at home). This indicates a potential concern, since previous qualitative reports from families raising a child with ASD reflect that by sharing leisure routines, opportunities of happiness, moments of normalcy and moments of control over one's life were created (Downs, 2008). Evidence from Gray (1997) also suggest that ordinary, everyday activities such as going shopping and visiting friends made the family feel "normal".

The findings on the family routines in this study underscore the importance of getting to know families and what they do and a daily basis (Bernheimer & Weisner, 2007). Some families might be able to adapt positively by making accommodations to sustain their family routines successfully, even with the potential challenges associated with ASD. Other families might struggle to create and maintain meaningful family routines. It is therefore important to further investigate the participation of the child with ASD in the family routines and to explore the accommodations and adaptations families make to create and sustain meaningful routines in their homes and communities.

5.3. Positive and negative appraisal of the impact of ASD on the family

The cognitive appraisal of parents was measured by the FICD Scale. This instrument was found to be both reliable ($\alpha = .80$) and valid (see Section 4.3.2.2). Ten questions measured the positive appraisal and 10 questions measured the negative appraisal of the impact of ASD on the family (see Section 4.4.2 for results of the FICD Scale).

Similar to reported findings by Trute et al. (2007) and Trute and Hiebert-Murphy (2002), there was a non-significant correlation between Positive Appraisal and Negative Appraisal. This indicated that these two constructs were indeed measuring different elements of cognitive appraisal of the impact of ASD. This result support Larson's (1998) term 'the paradox of disability', where positive and negative appraisals about disability can co-exist in families of children with disabilities.

The data gathered on the impact of ASD on the family indicates that parents rated the degree of the positive family impact of ASD higher than the degree of the negative family impact. This means that families reported that the positive impacts of ASD had a more substantial impact on the family than the negative impact of ASD on the family. This finding provides further evidence that the experience of parenting stress is not the sole experience for parents of children diagnosed with ASD (Hayes & Watson, 2013) and that families can simultaneously experience and appreciate the positive effects of ASD. When examining the data, it is interesting to note that seven of the 10 highest ranking items in terms of the degree of impact were positive appraisals. This indicates a somewhat different perspective to what is frequently reported in the literature about the negative impact of ASD on the family (Hayes & Watson, 2013; Karst & Van Hecke, 2012). The findings about the positive impacts of ASD therefore adds to the small, but existing body of positive outcomes for families raising a child with ASD (Bayat, 2007; Little & Clark, 2006; Phelps, McCammon, Wuensch, & Golden, 2009). This emphasises the need for researchers to not only focus on the negative implications of ASD on the family system, but to keep a balanced approach when doing research on families with a child with a ASD.

As mentioned before in the literature review, ASD is not exclusively clinically defined, but also defined by the experiences of families within their socio-cultural context (Skinner & Weisner, 2007). The meaning a family ascribe to a disability reflect to some degree the larger context of social attitudes and historical realities within which that interpretation emerges (Ferguson, 2002). Currently, controversies exist regarding the causes of ASD, appropriate treatment strategies and the desirability of aggressive treatment as opposed to social policies focused on accommodation and acceptance (Karst & Van Hecke, 2012; Silverman, 2008). There is a tension in the field between thinking about ASD as a devastating neurological condition, or a disorder that emerges only within the context of a medical and social system that makes people with ASD appear deviant (Silverman, 2008). These societal attitudes in terms of “fixing” or “acceptance” influence the way families define ASD. Therefore it is important for researchers and practitioners to reflect on their own interpretation of disability and ASD to positively support families in constructing their own meaning of ASD.

5.4. The family quality of life in families raising a child with ASD

The FQOL Scale measured family perceptions about their satisfaction with five different domains of family quality of life, i.e. Family Interaction, Parenting, Physical/Material Well-Being, Emotional Well-Being and Disability-related Support. The results of the analysis of the instrument's reliability ($\alpha = .92$) indicated excellent internal consistency. The CFA results indicated that the instrument is valid, but, as with all methods, the CFA results can only be generalised to the extent that they analysed this study's sample. However, both the reliability and validity findings provide further evidence about the universal property of the family quality of life construct (Balcells-Balcells et al., 2011; Verdugo et al., 2005) and, preliminary evidence about the suitability of the FQOL Scale in the South African context.

The data obtained about the families' quality of life indicated that they were most satisfied that their family members show that they love and care for each other, and least satisfied with the outside help available to take care of the needs of all family members (see Section 4.4.3 for the results of the FQOL Scale). In terms of the subdomains, families were most satisfied with the disability-related support, and least satisfied about their emotional well-being.

A closer look at the findings of disability-related support indicated that families felt mostly satisfied about their relationship with the service providers who support their child with ASD and the support that their child with ASD receives at school. However, families were less satisfied with the support for their child to accomplish goals at home and to make friends. This indicates a discrepancy between the support available at school and the support available at home and in the community. This reveal that the current focus of intervention services is on the child with ASD in the school environment, and emphasise the need for family-centred intervention services that will result in supportive environments that facilitate participation in all areas of the child's life. It is well established that participation plays a significant role in child development (Axelsson, Granlund, & Wilder, 2013; Dunst et al., 2001).

The low satisfaction of families' emotional well-being in this study is particularly concerning. This finding is similar to other studies that also used the FQOL Scale. A study done in Maryland, U.S. with 228 families with a young child with ASD who were receiving disability-related services reported a similar trend with emotional well-being scoring the lowest of the domains (Eskow et al., 2011). Similarly, a study of 180 families with a young child with a disability (including ASD) who were also receiving early intervention in a one Midwestern U.S. State (Summers et al., 2007) noted the same findings. Thirdly, a study of 107 families of a child with a disability (including ASD) who were receiving disability-related services reported the emotional well-being as the domain with the lowest satisfaction for *both* mothers and fathers (Wang et al., 2006). What is particularly concerning is that the Maryland study compared families of children with ASD who were receiving disability services to families who were awaiting services, and found the satisfaction of the emotional well-being of the families who were not receiving services to be even lower than those receiving services. This indicates a key area to focus on, both for practitioners and researchers. Services targeting the emotional well-being of families need to be developed or modified, as well as further research efforts undertaken to understand how to best support these families in terms of their emotional well-being. Moreover, the potential vulnerability of families not receiving any disability-related support or services should not be taken lightly.

The relatively high mean of the satisfaction with family quality of life (*M* = 3.83, *SD* = 0.61) in this study is in contrast to other studies of the impact of ASD on families which use outcome measures such as stress or depression (Hayes & Watson, 2013). The present study found that the overall family quality of life satisfaction rating for 43% of the participants was between 4.0 (“moderately satisfied”) and 5.0 (“very satisfied”), while 48% of the participants was between 3.0 (“neither satisfied nor dissatisfied”) and 4.00 (“moderately satisfied”). However, the family quality of life construct is specifically conceptualised to be more balanced than measures of purely negative impacts such as stress and depression (Poston 2003). The FQOL Scale does allow for the expression of the negative emotional impacts in the Emotional Well-being subscale, as discussed in the previous section. Therefore, careful interpretation of the overall mean satisfaction rating of family quality of life should be considered. Also note that the family quality of life framework aims to understand and support families. Using a single family quality of life score (such as the mean satisfaction score) would not be helpful to identify strengths and weaknesses in the different areas of families’ lives (Park et al., 2003).

5.5. The influence of individual family member demographics and family unit characteristics on family quality of life

The way families were defined in this study allowed the researcher to have a broader understanding of the people who are closely involved in the day-to-day affairs of the household. Families reported other extended family members (such as grandparents, nieces, nephews, aunts, and siblings), close friends, and paid helpers as part of their family. This reflects the uniqueness of families in South Africa and underscores the importance of defining family broad enough to include the diversity of family members.

The diversity of families underpins the need to understand how different individual family member demographics (e.g., the parent and the child with ASD) and the family unit characteristics (e.g. the family income and family structure) affect a family's quality of life. Demographics and characteristics tend to be mostly static or unchanging concepts. However, an understanding of the influences of these concepts on family quality of life can help inform service providers to appropriately deal with a diverse range of families. The outcome is to enhance the family quality of life for all types of families.

5.5.1. *The influence of individual family member demographics*

The following section summarises the most important findings in this study about the influence of parent's demographics on the family's satisfaction about their quality of life:

(a) There were differences in the overall family quality of life for the different employment groups (i.e. parents who were employed full time reported the highest family quality of life, while parents who were not currently working reported the lowest family quality of life). Although these differences were not statistically significant, it might still be an important consideration for practitioners. Previous findings indicated that some parents put their career on hold to look after their child with ASD (Bayat, 2007). Similarly, it is reported that families with children with disabilities sometimes make specific accommodations regarding their employment, for example changing to a lower-paying job that offered more scheduling flexibility, going from full-time to part-time work, stopping work outside the home altogether, or purposefully finding a job with family-centred policies (Maul & Singer, 2009).

(b) There was an association between the age of parents (a mother or a father) and how satisfied they felt about their parenting. This association was statistically significant, however, it is considered to be a small effect. For practitioners it emphasises the importance of using a family systems perspective that recognises the life cycles and stages of families. Younger parents might feel less confident and satisfied with their parenting and might need some support, while older parents might feel more confident and satisfied with their parenting.

(c) The educational background of the parent had reliable associations with the satisfaction of parenting, physical/material well-being, and overall family quality of life domains. The association with the physical/material well-being indicated a medium effect, while the other associations showed a small effect. Again, this stresses the importance of getting to know the family, and finding out about their strengths and needs in various aspects of their family life.

In terms of the influences of demographics of the child with ASD on the family quality of life, the following was noted:

(a) The age of the child; the gender of the child; or having a co-occurring medical condition or an additional disability present, had no reliable associations with the family's quality of life.

(b) The level of the severity of ASD (as reported by the family) had reliable associations with how satisfied families felt about their family interaction, emotional well-being, disability-related support, and their overall family quality of life. These findings were similar to a previous study that found the severity of a child's disability to be a significant predictor of family quality of life, both for fathers and mothers (Wang et al., 2004). Although the associations found in this study are considered to have statistically small effects, it has important practical implications. The level of severity of the child's ASD was based on parental report. This highlights the importance of finding out how families perceive the level of their child's disability. Perceiving the child to have a severe level of disability can have a negative effect on the family's quality of life. This reflects the changing context of childhood disability, where the nature and severity of disability is not only a product of underlying medical conditions, but also a function of the demands, expectations, and social roles that children assume in their daily lives (Halfon, Houtrow, Larson, & Newacheck, 2012).

5.5.2. *The influence of family unit characteristics*

The study investigated whether the family income and the family structure had any associations with how satisfied families felt about their family quality of life. In terms of the family income, the data yielded that the monthly family income had a reliable, large effect on the families' material well-being. The monthly family income also showed reliable associations with the disability-related support and overall family quality of life domains, although these associations are considered to be small effects. These findings are similar to a previous study (Wang et al., 2004). However, in the current study, it was the family's appraisal of this income that was the more interesting finding. How families felt about their monthly income (struggling, just getting by, doing okay, managing well, or well off) showed reliable relationships with the family's emotional well-being, material well-being, disability-related support and overall family quality of life. The strengths of these associations ranged from medium associations (i.e. emotional well-being and disability-related support) to strong associations (i.e. material well-being and overall family quality of life). Supporting data from the FICD Scale in this study indicate that families rated the negative impact of additional financial cost as the most substantial family impact of ASD.

The findings about the effects of the family income and how families appraise this income provide further evidence that the financial situation of the family is a crucial area to consider when helping children with ASD and their families. This is particularly relevant in the South African context. The Social Assistance Act was amended in 2004 to remove the restriction that only children with "severe" disabilities requiring permanent "home" care are eligible for a Care Dependency Grant. This was to also include families of children with mild to moderate disabilities in need of care and support services. However, investigations found that the families of children with mild to moderate disabilities are still being economically excluded from the Care Dependency Grant (Proudlock, 2014). Pressure for the effective implementation of this Act is therefore paramount for families raising a child with ASD in South Africa. Receiving the Care Dependency Grant can decrease the economic stress of struggling families.

When investigating the family structure of the sample, it is noted that there was a wide range of diverse family systems – ranging from two person bonds to large complex family systems that include grandparents, extended family and paid helpers. Interestingly, the number of children in the household, having grandparent(s) or other family or friends living with the family, having a paid helper included in the family, or the ages of the youngest or the oldest children had no statistically significant effect on the family's quality of life. However, this does not mean that these concepts do not have any practical influences on the family's quality of life. A further investigation into how the family structure influences a family's quality of life is needed. The structural family unit characteristics that did indicate a reliable effect on the family quality of life were the following:

(a) Families who had a father living with them had a higher overall family quality of life compared to those families who did not have a father present.

(b) Families who had a working father had a higher overall family quality of life compared to families who did not have a working father, while a working mother did not indicate a significant difference.

(c) Two-parent families had a higher overall family quality of life compared to one-parent families. These findings show the broad range of factors that influence a family's quality of life and as noted before, should primarily be used by service providers to facilitate an optimal family quality of life for families with different characteristics.

The above mentioned findings have important implications for the South African context. To begin with, the proportion of fathers who are absent but living increased from 41.6 percent to 47.4 percent between 1996 and 2010 (Department of Social Development, 2012). This is a common and increasing phenomenon affecting families in contemporary South Africa. Secondly, among the major causes of poverty in South Africa is a lack of income. Employment creation has not transpired at the anticipated rate and many people are still unskilled. This inability of many people to secure employment has led to families facing additional burdens due to limited or no income to secure their family livelihood. The situation continues to place a huge dependency burden on families. And thirdly, more than 40 percent of all households in South Africa are headed by a single parent. In analysis of the characteristics of single parents in urban areas noted that the single parents were mostly African, female and between the ages of 25 and 34 (Department of Social Development, 2012). These findings paint a picture of the very real issues that many families are dealing with apart from raising their child with ASD.

5.6. The relationship between family routines, cognitive appraisal of the impact of ASD on the family, and family quality of life

The question under discussion in this section is whether there is a positive relationship between the regularity of a family's routines and family quality of life, and whether the positive and negative appraisal of the impact of ASD on the family mediates this relationship. The results from this study provide evidence of the positive relationship between the regularity of family routines and family quality of life, and that the positive and negative appraisal of the impact of ASD acts as partial mediators on this relationship (see Section 4.6.1 for the results of the multiple mediation model).

As illustrated in Figure 5.2, the findings suggest that more regular or frequent family routines (i.e. a rhythmic family life) are strongly related with a higher satisfaction level of the family's quality of life. Additionally, how families perceive the impact of ASD influence this relationship. This means that a more rhythmic family life is also related to a greater positive appraisal of the impact of ASD, which in turn, is related to a higher satisfaction level of the family's quality of life. Similarly, but in an opposite direction, a more rhythmic family life is related with lesser negative appraisal of the impact of ASD on the family, which in turn is related to a higher satisfaction level of the family's quality of life.

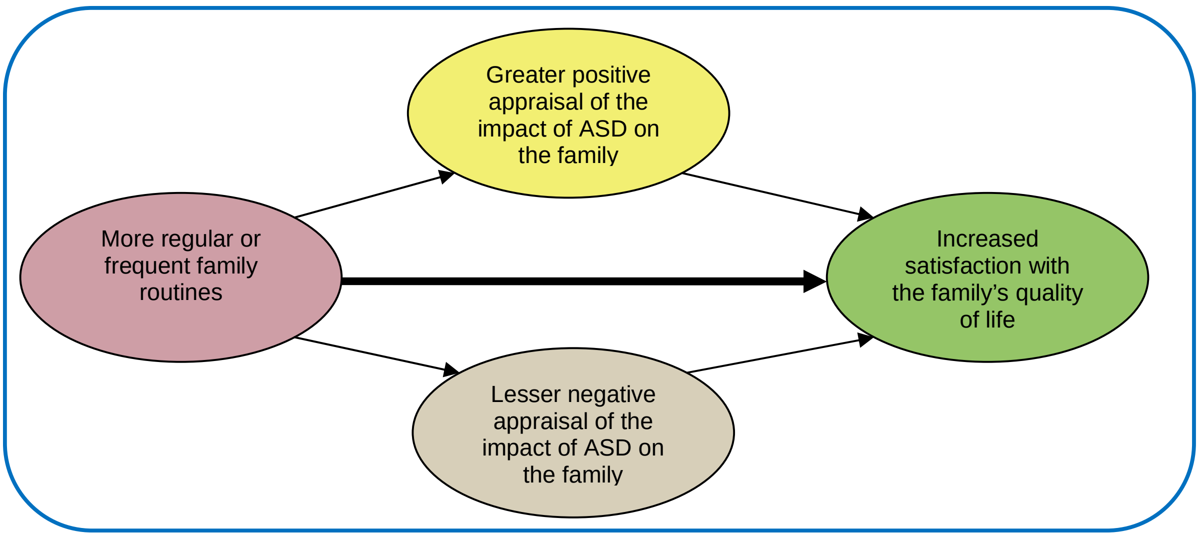


Figure 5.2 The relationship between regular family routines and family quality of life, and the mediation effect of positive and negative appraisal of the impact of ASD on the family.

The next section will focus on the implications of the relationship between the regularity of family routines and family quality of life, and subsequently discuss the implications of the partial mediation effect of positive and negative appraisal of the impact of ASD.

5.6.1. *The implications of the relationship between regular family routines and the satisfaction of family quality of life*

The evidence about the positive relationship between the regularity of family routines and family quality of life support a proposition of ecocultural theory, which proposes that the predictability or sustainability of family routines indicates a higher quality daily family routine and should enhance family well-being (Weisner, 2009). Moreover, the findings also provide supportive evidence for one of the propositions of the unified family quality of life theory – that a dynamic family unit concept directly influences or predicts family quality of life (Zuna et al., 2010).

The positive relationship between the regularity of family routines and family quality of life observed in this study has important implications. On the basis of the evidence, it seems fair to suggest that what families do together on a regular basis have an important influence on how satisfied they feel about their quality of life. The importance of creating and maintaining regular family routines implies that any supportive intervention to help a child with ASD should not intervene with the existing resources and capabilities required to sustain the family routines. Furthermore, it underscores the importance of supporting the families who are struggling to maintain regular family routines.

This means that practitioners should have a good understanding of the everyday lives of the families that they are helping. There are various tools available that can guide practitioners in conversing with families about their family routines. For example, the Ecocultural Family Interview (Weisner, 2011), the Routines-based Interview (McWilliam, Casey, & Sims, 2009), or the Family Routines Inventory (Jensen et al., 1983) used in this study. These conversations can illicit areas of family strengths (e.g. routines that are going well and are meaningful to the family members) and areas of family needs and concerns (e.g. routines that are difficult to create and maintain, challenges associated with the characteristics of ASD).

Families create routines that are compatible with their children's unique characteristics (Larson, 2006; Schaaf et al., 2011) and that are consistent with their own family goals and values. An assessment of the family’s routines may therefore be a manner to plan and deliver culturally sensitive interventions that are meaningful and relevant to families (Zisberg et al., 2007). This is especially important in the multicultural South African context, where a family’s daily routines may not necessarily require many of the activities that preoccupy families in other countries (Weisner, 2002a, 2009). Therefore it is important for practitioners to use a family-centred approach that allow families to be the ultimate decision-makers when considering suggestions for intervention and support of their family routines. Intervention strategies should facilitate the family’s sense of competence and confidence, and not interfere with the successful maintenance of family routines.

There are different approaches to helping families create and maintain successful routines. Spagnola and Fiese (2007) provide some helpful ideas for practitioners and suggest that when practitioners plan to educate families about the importance of routines, they have to question why there has been a lack of organisation in the first place. The authors suggest using the four R’s of intervention, namely remediation, redefinition, realignment, and reeducation. Realignment is a form of routine intervention warranted when there is conflict in the family over the relative importance of a routine. This happens when members of the family disagree about treatment parameters, which that can lead to disagreements about how to carry out daily routines. Helping families to realign their routines is an important aspect of early intervention, as they are often disrupted by the high demands of raising a child with a disability. The authors further note that reeduction might be the most difficult intervention to implement. In this situation, families have little or no history with creating and sustaining routines on a daily basis.

5.6.2. *The implications of the partial mediation effect of cognitive appraisal of the impact of ASD on the family*

The finding that positive and negative appraisal are partial mediators of the relationship between the regularity of family routines on family quality of life provide further evidence of the mediating role of cognitive appraisal (Folkman et al., 1986). The results support the postulation that the cognitive appraisal or the meaning ascribed to a crisis event or challenge, influences the outcome of the event. The findings are similar to other studies that detected the mediation effect of cognitive appraisal in families raising a child with ASD (Paynter et al., 2013; Plant & Sanders, 2007). Conversely, the mediating effect of cognitive appraisal is different than the postulation of the unified family quality of life theory. The unified family quality of life theory proposes that the beliefs of individual family members (such as the meaning ascribe to the impact of a child's disability) are a direct predictor of family quality of life (Zuna et al., 2010). Results of this study provide supporting evidence of "beliefs" as a mediating variable, rather than a direct predictor of family quality of life. The developers of this theory acknowledge that a larger theory is currently presented than what is supported by research data and that very limited research exists that utilised beliefs as a variable (Zuna et al., 2010). Therefore, further research on the influence of cognitive appraisal on family quality of life in families raising a child with a disability is necessary.

When examining the relationship between the regularity of family routines and cognitive appraisal (i.e. positive and negative appraisal), the findings of this study provides quantitative evidence to support the qualitative findings of Gray (1997). Daily routines were associated with the way families appraise the influence of ASD on the "normality" of their family. Subsequently, when looking at the relationship between cognitive appraisal (i.e. positive and negative appraisal) and family quality of life, the findings of this study are supported by previous findings. A study by Neely-Barnes and Dia (2008) found that positive appraisal lead to better family functioning, while Stuart and McGrew (2009) found that negative appraisal to be associated with higher levels of psychological distress in the family system.

A closer look at the data indicates an almost similar observance of the partial mediating effect of positive appraisal and negative appraisal. Apart from the directionality of the relationships, almost similar strengths were observed in the mediating effects (i.e. the regression weights of all the indirect effects were almost similar in strength). This finding is interesting because it can be inferred that increasing the positive appraisal of the impact of ASD will have a similar effect as decreasing the negative appraisal of the impact of ASD. This reflects what Larson (1998) suggested, that by embracing the paradox of disability – by balancing negative appraisal and positive appraisal, parents are able to regain a sense of control of the situation of taking care of a child with a disability.

Realising the potential of the positive appraisal of ASD implies that intervention efforts should aim to support families in making more positive, helpful appraisals. Positive reappraisal, or reframing a situation to see it in a positive light (Folkman & Moskowitz, 2000) is associated with positive emotions, or positive affect. Giving families the opportunity to reflect on potentially positive outcomes of ASD might help them to realise some of the positive impacts of ASD in their own family. The FICD Scale used in this study provides a way for families to reflect on positive outcomes of ASD such as an appreciation of the uniqueness of individuals, an increase awareness of the struggles of others, more tolerance of the differences between people, or the special pleasures from their child with ASD. As suggested by Paynter et al. (2013) it might also be helpful to expose families to other families with more positive appraisals. By interacting with other families that interpret the impact of ASD as a positive event, families might be able to reflect more positively and redefine their meaning of ASD (Tunali & Power, 2002). Those families who are struggling with stress and the negative impacts of ASD might benefit from cognitive behaviour therapy to assist them in reframing the meaning of ASD (Larson, 1998). Supporting emotion-focused coping strategies is crucial. A longitudinal study done by Gray (2006) found parents' coping strategies changed over time. As the children with ASD got older, parents used primarily more emotion-focused coping strategies and fewer parents cope through reliance on service providers and other coping strategies previously used.

As Zuna et al. (2010) explains that similar to person-first language for referring to an individual with a disability, families who have a member with a disability are a family first – a family that seeks similar aspects from life as all other families. Families want to have access and enjoy the benefits of their communities, live in a safe home and neighbourhood, experience the full range of emotions in life, and remain emotionally, physically and financially strong. The findings from this study indicate both the positives and the negatives that families experience when raising a child with ASD. Giving families the chance to reflect on and report on the positive impact of ASD, and not only the negative impact, provides for a more balanced interpretation of how these families function (Turnbull et al., 2007).

The concept of family quality of life has been presented throughout the thesis as a multidimensional construct that focus on the whole family and provides a way to explore various aspects of family life when raising a child with ASD. The outcome of family quality of life is to enhance the well-being of young children with disabilities and their family so that they can function optimally within their home and community (Brown, Schalock, & Brown, 2009; Turnbull, Summers, Lee, & Kyzar, 2007; Wang & Brown, 2009). As noted by Seligman and Darling (2007) – *All* families need a little help from time to time. This is a normal aspect of family life and is met by most families in informal ways, with the help of family and friends. However, sometimes families' capabilities and informal support systems are insufficient to address their concerns, and professional help is required. Viewing the family as a complex and interactive social system lies at the heart of this discussion. What families 'need' are increasingly defined by families themselves rather than by practitioners. Having a better understanding of the dynamics of family life, the families' beliefs, and their quality of life will guide practitioners to provide family-centred support that enhance the quality of life of *all* members of the family.

5.7. Summary

This chapter discussed and interpreted the results of the study. The results of each study construct were first interpreted and discussed individually. Thereafter, the influence of individual family member demographics and family unit characteristics on family quality of life were interpreted and discussed. Subsequently, the relationships between the study constructs were discussed by first discussing the relationship between the regularity of family routines and family quality of life, and secondly, by discussing the mediating effects of positive and negative appraisal on this relationship. The study concluded with the importance of a family quality of life outcome when families have a child with ASD.

CHAPTER 6
CONCLUSION

6.1. Introduction

This chapter concludes the study. A summary of the most important findings is provided. Secondly, the clinical implications of the study are discussed. The study is then evaluated in terms of its strengths and limitations. The chapter concludes with the recommendations for future research.

6.2. Summary of the findings

In attempting to find out more about families who are raising a child with ASD, the study looked at three different aspects of family functioning – the regularity of a family's everyday routines, the meaning ascribed to the impact of ASD on the family, and the family's quality of life. The study questioned whether the family quality of life of families raising a child with ASD is affected by the regularity of their family routines and whether this effect on family quality of life is mediated by the positive and negative appraisal of the impact of ASD on the family. When the four constructs were placed in a multiple mediation model to determine possible mediation effects, the results indicate that there was (a) a positive relationship between the regularity of family routines and family quality of life, (b) that the positive appraisal of the impact of ASD on the family acts as a partial mediator (in a positive direction) on this relationship, and (c) that the negative appraisal of the impact of ASD on the family acts as a partial mediator (in a negative direction) on this relationship. Other significant contributions of the study are:

To begin with, the results of the measurement of family quality of life in the South African context indicated that this unobservable construct was measured in an acceptable reliable and valid manner. This finding provides further evidence of the universal property of family quality of life across different countries and cultures. The preliminary evidence supports the suitability of using the FQOL Scale in the South African context.

Secondly, the results of this research support the idea that the rhythm or regularity of a family's routines has a positive relationship with how satisfied families feel about their quality of life. Correlation is a necessary (but not sufficient) condition for claiming that two variables are causally related (Iacobucci et al., 2007). Although the findings of this study cannot suggest, or imply, any causal effect between the regularity of family routines and family quality of life, it does provide supporting evidence to the idea that the regularity of family routines is an important factor contributing to a family's quality of life, and that the creation and maintenance of regular family routines might serve as a protective factor in families raising a child with ASD.

Thirdly, it was found that the meaning a family ascribes to the impact of ASD (positively and negatively) intervenes in a partial manner on the relationship between what families do (i.e. the regularity of their family routines) and the outcome of how they feel about their family quality of life. Evidence of the mediating effect of the cognitive appraisal of a potentially stressful situation supports the idea that how families interpret a stressful situation (i.e. the meaning they ascribe to a situation, whether positively or negatively) does affect the outcome of the situation.

Finally, the study proposed the utility of adopting a family systems perspective, where each family member influences and is influenced by the bigger system. The study also proposed that ASD represents more than a clinical diagnosis for families – it permeates the way families function in their home and in their community. As indicated by the findings, raising a child with ASD does not automatically imply that families have a less optimal family quality of life. By assessing the cognitive appraisal of the impact of ASD, a more balanced approached in portraying the impact of ASD was achieved, contributing to the small body of positive findings of the impact of ASD. Secondly, by assessing the family's quality of life, a more balanced portrayal of the satisfaction and needs in various domains of family life were achieved.

6.3. Clinical implications

An important implication for service providers is that it is indeed possible to make a difference for strengthening families who are raising a child with ASD by understanding the importance of their family routines. This study showed that what families do together on a daily basis is related to how satisfied they feel about their quality of life. This indicates that service providers should respect the uniqueness of each family's routines, and be cautious of recommending interventions that negative interferes with the regularity of existing family routines. It also means that there should be a greater emphasis on supporting families who are struggling to create and maintain their family routines during difficult times.

The finding that the meaning families' ascribe to the impact ASD (both positive and negative) partially mediate the effect of the regularity of family routines on the families' quality of life affirms the contention that by enhancing the positive family meaning of ASD and decreasing the negative family meaning of ASD will ultimately enhance the family's quality of life. Service providers are encouraged to examine their own interpretation of ASD in order to positively support families in constructing the family meaning of their child's ASD. Service providers can help families to redefine the family meaning of ASD more positively, while still acknowledging and supporting the negative impacts of ASD on the family.

The findings of the FQOL Scale in this study demonstrated that family quality of life measures can also be used as a needs assessment tool at a program level in the South African context. Practitioners can use the family-friendly instruments that measure family quality of life collaboratively with families. Using family quality of life as an intervention outcome aims to support young children with ASD and their families, but it also provides a way for professionals to think about and work toward what brings satisfaction and joy to families that they serve. The family quality of life instruments can be use to discuss the areas of strengths for the family and their needs. Family needs can then be further prioritised and help and support provided accordingly.

6.4. Evaluation of the study

6.4.1. *Strengths*

The study proposed a family systems perspective, and used a broad definition to define family. The study also approached the investigation of families raising a child with ASD in a balanced manner – by examining both the positive and negative aspects of the impact of ASD, as well as examining the multifaceted construct of family quality of life. Most importantly, it focused on family-level constructs that are amenable to change, such as the frequency of family routines, and the meaning families' ascribe to the impact of ASD. This allowed the researcher to do family-focused ASD research that not only adds to the theoretical knowledge in the family sciences, but also has a practical application to service providers, and ultimately, to families raising a child with ASD.

The survey methodology employed in this study allowed for a large number of families to participate in this study. Previous studies that investigated the family routines of families raising a child with ASD were mostly qualitative studies with small sample sizes, which limited generalisability. Similarly, studies that investigated the cognitive appraisal of ASD also had relatively small sample sizes. Furthermore, the participating families came from all of the municipal districts of the Gauteng province in South Africa, while the disability-related services that the child with ASD received included both public and private institutions. This increases the external validity to families who are raising a child with ASD that are receiving intervention services in Gauteng.

Using SEM allowed the researcher to test the relationships between multiple latent variables. SEM analysis recognised the prediction error in a dependent variable that is not perfectly explained by a set of predictors, as well as the measurement error in variables that are not completely reliable. Although the data obtained in this study does not allow for any causal attributions to be made, the hypothesised multiple mediation model was shown to be plausible given theory and the empirical findings.

6.4.2. *Limitations*

The data for this study was collected from families who are receiving disability-related services and support. This creates some limitations. Disability-related services and support plays an important role in how families perceive their family quality of life (Eskow et al., 2011; Summers et al., 2007). Data for this study was therefore specifically collected from families who did receive disability-related support and services. It is therefore extremely important not to draw conclusions of this study beyond the study population to families who are not receiving disability-related services and support, as these families might show different results.

Secondly, one of the participant criteria was that respondents had to be English literate. This resulted in a sample where more than 90 percent of the respondents had an education of Grade 12 or more. Although education levels are increasing, as of 2011 there were still 10.4 percent of persons aged 15 or older in Gauteng with no schooling or the highest level of education less than Grade 7. English is also not the most prevalent home language – most people in Gauteng speak isiZulu, followed by Afrikaans, Sesotho, and then English. Amongst the other home languages are isiXhosa, Sepedi, Setwana and others. Again, it emphasise the cautious interpretation of the findings and to not draw conclusions of this study beyond the study population.

Thirdly, there is a discrepancy between the stated unit of analysis (i.e. the family) and the respondent (i.e. the parent or primary caregiver). This is one of the most apparent weaknesses in family research (Hu et al., 2011). This study described the family perceptions of quality of life as viewed by the one of the primary caregivers who acted as a proxy for the whole family. Although it is desirable that all family members respond to their individual perceptions of family quality of life, the responses from the primary caregiver was more readily obtained, and reflects the issues that the carer is dealing with in relation to the family. Although in this study the child's mother was the most common respondent, the data is interpreted specifically to family issues and family concerns (Brown et al., 2006). Previous results have suggested that both mothers and fathers have similar perspectives of their family quality of life (Wang et al., 2006).

6.5. Recommendations for further research

Recommendation for future research stemming from this study is as follows:

- To explore the facilitating factors and possible barriers that influences the regularity of family routines in families raising a child with ASD. It fell beyond the scope of this study to examine the meaningfulness families ascribe to family routines or the specific accommodations families make to sustain their family routines. Exploring these aspects in a qualitative study might indicate additional protective mechanisms involved in the daily lives of families. The supporting evidence of this study about the importance of regular family routines in family functioning highlights the need to have a better understanding of the barriers and facilitators of families that might influence the regularity of a family's routines.

- The lower satisfaction scores of the emotional well-being of families raising a child with ASD identified a key area for researchers. Further research efforts to explore how to best support these families in terms of their emotional well-being are needed. Additionally, the emotional well-being of families not receiving any disability-related support or services should be investigated as well as the strategies to support these families. Having a better understanding of the emotional needs of these families and the strategies to support these families will help to enhance the overall family quality of life of these families.

- The finding of this study about the mediating role of the “beliefs” of family members is different to the current conceptualisation in the family quality of life field. The unified family quality of life theory proposes the way family members define the impact of disability on the family (i.e. “beliefs”) to be a direct predictor of family quality of life. However, the developers of this theory acknowledge the lack of empirical data for this proposition. Therefore, future research should investigate the role of cognitive appraisal and how that influences family quality of life in families of children with a disability.

6.6. Summary

The current chapter presented conclusions regarding the results of the study. The most important contributions of the findings were highlighted. Clinical implications of the results were also discussed, with reference to family routines, the cognitive appraisal of ASD, and the measurement of family quality of life. The strengths and limitations of the study were presented. Lastly, recommendations were made as to how future studies could further expand our knowledge on the family routines, and how to enhance the family quality of life of families raising a child with ASD.

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Appendices

Appendix A

Inclusion and Exclusion Criteria:

Studies that Investigated the Cognitive Appraisal of ASD

	Inclusion criteria	Exclusion criteria
Population	Families or family members of children with ASD.	Families with a child with a different type of disability.
Outcome	Cognitive appraisal of the parent or adult family member.	Cognitive appraisal of the child with ASD. Studies that focus on instrument development.
Design	All study designs.	No exclusions on type of study design.
Publication type and date	Articles published as full texts in peer review articles.	Abstracts, conference papers, theses, books and other grey literature. Published in languages other than English.

Appendix B

Permission to use the Beach Center's FQOL Scale

liezl schlebusch

From: Summers, Jean Ann [redacted]
Sent: 19 September 2011 02:53 PM
To: [redacted]
Subject: FW: Request for tool
Attachments: Eskow Summers Waiver Article 1 JPPID March 2011.pdf; FQOL JMF 2006.pdf; KS Impact Study.pdf; Zuna Confirmatory Analysis FQOL.pdf; Zuna et al., 2009- FQOL-Mvg frm Meas to Applic.pdf

Thank you for your interest in our Beach Center Family Quality of Life Scale. I am attaching the scale along with a few articles about its development and application.

You have our permission to use the scale free of charge as long as you appropriately reference the authors. Also, if you decide to use the scale in a research study, we would very much appreciate receiving a copy of your final report, so that we may continue tracking applications of our instruments.

Good luck in your work.

Jean Ann Summers, Ph.D.
Research Professor
Beach Center on Disability
[redacted]

Appendix C

Demographic Section of the Survey Booklet

This survey is about your life together as a FAMILY. Think of your family when you answer the questions. For this study, your family is those people living in the same household who support and care for each other on a daily basis and who think of themselves as part of your family. They may, or may not, be related by blood or marriage.

A. About you, your family and your child diagnosed with autism spectrum disorder (ASD)

First I want to ask you a few questions about yourself and your family. Remember, your answers will be kept confidential and only reported as a group, not as individuals or families.

1. What is your relation to the child with ASD in your family? ____________
(e.g. mother, father, grandparent)

2. Who are the people living in your household? Please check all that apply.

2.1. ☐ Father Year of birth ______ Working? ☐ Yes ☐ No

2.2. ☐ Mother Year of birth ______ Working? ☐ Yes ☐ No

2.3. The number of children in your household________________________________

2.4. ☐ Grandparent(s) living in your household

2.5. ☐ Any other family members living in your household, please specify____________

____

3. What is the date of birth of your oldest child?

3.1. dd/mm/yyyy

4. What is the date of birth of your youngest child?

4.1. dd/mm/yyyy

4.2. ☐ I only have 1 child

5. Which one best describes your family type?

5.1. ☐ Two-parent family - two parents and child(ren)

5.2. ☐ One-parent family - one parent and child(ren)

5.3. ☐ Blended or stepfamily - two separate families merging into one new family unit

6. What is the highest level of education that you completed?

6.1. ☐ Grade 11 or less
6.2. ☐ Grade 12
6.3. ☐ Diploma
6.4. ☐ Undergraduate degree
6.5. ☐ Postgraduate degree
6.6. ☐ Other, please specify____

7. What is your employment status?

7.1. ☐ Employed full-time
7.2. ☐ Employed part-time / Casual
7.3. ☐ Not currently working
7.4. ☐ Home executive / Housewife
7.5. ☐ Other, please specify____

8. What is your ethnic background?

8.1. ☐ Black
8.2. ☐ Coloured
8.3. ☐ Indian or Asian
8.4. ☐ White
8.5. ☐ I don't wish to say
8.6. ☐ Other, please specify____

9. What is your family's total household income per month?

9.1. ☐ Less than R4500 per month
9.2. ☐ Between R4 501 and R12 500 per month
9.3. ☐ Between R12 501 and R30 000 per month
9.4. ☐ Between R30 001 and R52 000 per month
9.5. ☐ Between R52 001 and R70 000 per month
9.6. ☐ More than R70 001 per month

10. When you think of the total income of your family, do you consider your family to be…

10.1. ☐ Struggling
10.2. ☐ Just getting by
10.3. ☐ Doing okay
10.4. ☐ Managing well with some extra money left over at the end of the month
10.5. ☐ Well off

11. Do you have more than one child diagnosed with autism spectrum disorder?

11.1. ☐ No
11.2. ☐ Yes. If yes, how many children? ____________

Now we would like to know a bit more about your child diagnosed with ASD. If you have more than one child with ASD, please consider the one who has the most impact on your family life.

12. What is his/her gender?

12.1. ☐ Boy
12.2. ☐ Girl

13. What is his/her date of birth? [dd/mm/yyyy]

14. How long ago was he/she diagnosed with ASD? [years] [months]

15. Does he/she have any <u>additional</u> disabilities or medical conditions beside ASD?

15.1. ☐ No
15.2. ☐ Yes, please specify____

16. How would you describe the level of his/her disorder?

16.1. ☐ Mild
16.2. ☐ Moderate
16.3. ☐ Severe

17. How many hours of schooling, intervention and/or therapy does he/she receive <u>per week</u>?

_____________total hours per week

18. Can you think of any life events (positive or negative) that your family experienced over the past year? Life events are significant events which occur throughout life. These can be any major event such as the birth of a child, getting married, getting a new job, losing a close family member or friend, or getting divorced.

____

____

____

____

____

Appendix D

Letter to Organisations to Request Permission for Recruitment of Participants

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

Date

Organisation's address

Dear Mr. or Ms

My name is Liezl Schlebusch and I am currently undertaking my doctorate in Early Childhood Intervention through the Centre for Augmentative and Alternative Communication at the University of Pretoria. I am writing to request permission to conduct a research study at your organisation.

Research topic - Families raising a young child with Autism Spectrum Disorder: Determining the relationship between family routines and family quality of life.
The purpose of my research is to find out more about the quality of family life when families raise a young child diagnosed with Autism Spectrum Disorder (ASD). Specifically, I want to have a better understanding of how everyday family routines influence the family's wellbeing. The study aims to use the construct of family routines to offer a positive approach to examine family quality of life. The outcome of my study will help inform service providers how to provide better support and services for these families.

Who are the participants for this study?
I hope that your organisation will allow me to recruit potential participants to take part in the study. The criteria for participants are as follows:

1. The parent/main caregiver of a child diagnosed with ASD.
2. The child has to be eight years old or younger (thus, under 9).

What will the participants have to do?
Potential participants will receive a survey packet – an envelope containing an information letter and a questionnaire. They will be asked to complete the survey at a place and time which is convenient for them. To complete the questionnaire will take approximately 20 minutes.

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
Communication Pathology Building
University of Pretoria, Lynnwood Road
PRETORIA, 0002
Republic of South Africa

Fax/Faks: +27 86 510 0841
Tel: +27 12 420 2001

alecia.samuels@up.ac.za
www.caac.up.ac.za

Participation in this research is completely voluntary and all responses will be treated confidentially. Participants will not be identified in any results, publications or presentations arising from this study. Furthermore, no costs will be incurred by either your organisation or the individual participants.

What will be expected of you as an organisation/institution?

Upon the favourable permission of your organisation, the following will be expected:

1. To identify children diagnosed with ASD who are eight years old or younger.
2. To distribute the survey packet (provided by the researcher) to the identified families.
3. To receive the completed questionnaires from participating families.
4. To safely keep the collected questionnaires for the researcher to collect at a prearranged date.

Will you have access to the research results?

I am happy to share the results from this study with your organisation. If you are interested to receive a free copy the results, please inform me. Alternatively, you are welcome to arrange for a feedback session in the form of a presentation should you prefer that.

Thank you for your time and consideration in this matter. I look forward to your favourable reply. If you have any further questions, you are welcome to contact me or my supervisor (see contact details below).

Sincerely,

Liezl Schlebusch
Doctoral Student
University of Pretoria

Dr Alecia Samuels
Supervisor, Centre for AAC
University of Pretoria

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
Communication Pathology Building
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Tel: +27 12 420 2001

alecia.samuels@up.ac.za
www.caac.up.ac.za

Appendix E

Reply Form: Permisson to Recruit Participants

To whom it may concern

On behalf of ____ *(name of school)*, I am writing to formally indicate our awareness of the research proposed by Ms. Schlebusch, a Ph.D. student at the University of Pretoria. We are aware that she intends to conduct her research by means of a self-administered survey handed out to the parents/main caregivers of children - eight years old or younger and diagnosed with Autism Spectrum Disorder. I am also aware that the parents/main caregivers will be informed about all aspects of the study, specifically about their voluntary participation and the confidential treatment of all information.

I grant her permission to conduct her research at our organization.

The number of children in our organisation/institution that are eight years old or younger, diagnosed with ASD are ________.

If you have any questions or concerns, please feel free to contact me.

Sincerely,

Signature ________________________________

Name ________________________________

Date ________________________________

Institution stamp/ Letterhead

Appendix F

Cover Letter of the Survey Booklet

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

Invitation to participate in a research study entitled:
"Families raising a young child with Autism Spectrum Disorder:
Determining the relationship between family routines and family quality of life"

Dear Parent or Caregiver

My name is Liezl Schlebusch and I am currently undertaking my doctorate in Early Childhood Intervention through the Centre for Augmentative and Alternative Communication at the University of Pretoria.

The purpose of my research study is to find out more about the quality of family life when families raise a young child diagnosed with Autism Spectrum Disorder (ASD). Specifically, I want to have a better understanding of how everyday routines influence the family's well-being. The results from my study will help to inform service providers, like therapists who work with your child, about how to provide better supports and services to families. I will share the results and practical outcomes of my study with various professional organisations, early intervention centres and support groups who are helping families of children diagnosed with ASD. I will also share the results of the study with you, should you prefer so.

If you are a parent or main caregiver of a child (eight years old or younger, diagnosed with ASD), you are cordially invited to participate in this study. Your participation is completely voluntary. All your responses will be kept confidential, which means that you or your family will not be identified in any results, publication or presentation arising from this study. You may also choose to withdraw from this study at any time without any negative consequences.

If you are willing to participate, please complete the survey questionnaire included in this packet. To complete the survey will require approximately 20 minutes of your time. Please return the completed questionnaire in the envelope provided to your child's educator/therapist as soon as possible, or at the latest before Tuesday, the 23rd of September 2014.

Finally, please know that I understand the many demands on your time and that I truly appreciate your help. Please contact myself or my supervisor if you have any questions. I thank you for your time and hope you will consider this request favourably.

Sincerely,

Liezl Schlebusch
Doctoral Student
University of Pretoria
[redacted]

Dr Alecia Samuels
Supervisor, Centre for AAC
University of Pretoria
[redacted]

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
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www.caac.up.ac.za

Appendix G

Thank you and Reminder Postcard

Dear Parent or Caregiver

Thank you for completing the Family Research Survey that I have recently sent you.
I truly appreciate your participation in this research study.

Sincerely,

Liezl Schlebusch
Doctoral Student
University of Pretoria
(contact details)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

If you have not had a chance to complete the survey yet, you are still welcome to do so before Wednesday, the *(date)*. If you have any questions or need another copy of the questionnaire, please call / send a SMS to *(number)*.

Appendix H

Pretesting the Survey Booklet –Questions for the Second Review Round

Thank you for your time to review the survey questionnaire. Below are a few questions about the survey questionnaire. Your expert opinion about these matters is very much appreciated.

1. **Does the questionnaire create a positive impression that motivates you to respond? Why?**

2. **Are the instructions meaningful and easy to follow?**

3. **Are the questions organised in a logical order? Would you change the order of any of the questions?**

4. **Are all questions worded in a clear, concise and unambiguous manner? If not, which questions are unclear?**

5. **Are there any words in the questionnaire that respondents might not understand?**

6. **Are the response choices appropriate for each question?**

7. **Do you think respondents will know or be able to recall the necessary information to answer the questions?**

8. **Any other comments or suggestions that might help to improve the quality of the questionnaire?**

Appendix I

Ethics Approval Obtained from the Ethics Committee of the Faculty of Humanities of the University of Pretoria

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

10 July 2014

Dear Prof Bornman

Project:	**Determining the relationship between family routines and quality of life in families with children with Autism Spectrum Disorder (ASD)**
Researcher:	**L Schebusch**
Department:	**Centre for Augmentative and Alternative Communication**
Reference number:	**28524960**

Thank you for your response to the Committee's communication of 30 October 2012.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** at an *ad hoc* meeting on 9 July 2014. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Karen Harris
Acting Chair: Postgraduate Committee &
Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:Karen.harris@up.ac.za

Appendix J

Registration of the Study Title

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

Our Ref: 28524960

17 July 2014

Mrs L Schlebusch
PO Box 19605
NOORDBRUG
2522

Dear Mrs Schlebusch

TITLE REGISTRATION : FIELD OF STUDY - PhD AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

I have pleasure in informing you that the following has been approved:

TITLE: **Families raising a child with Autism Spectrum Disorder: Determining the relationship between family routines and family quality of life**

SUPERVISOR: Dr AE Samuels

CO-SUPERVISOR: Dr S Dada

PLEASE TAKE NOTE OF THE FOLLOWING INFORMATION AS WELL AS THE ATTACHED REQUIREMENTS.

1. **PERIOD:**
   (a) You must be enrolled as a student for at least one academic year before submission of your thesis.
   (b) Your enrolment as a student must be renewed annually before 31 March, until you have complied with all the requirements for the degree. You will only be liable to have supervision if you provide a proof of registration to your supervisor.

2. **NOTIFICATION BEFORE SUBMISSION:**
   You are required to notify me at least three months in advance of your intention to submit your thesis for examination.

3. **APPROVAL FOR SUBMISSION:**
   On completion of your thesis enough copies for each examiner as well as the prescribed examination enrolment form which includes a statement by your promoter that he/she approves of the submission of your thesis, as well as a statement signed by you, must be submitted to Student Administration.

4. **DATE OF EXAMINATION:**
   If your doctoral examination is to take place after the submission of your thesis, please inform me of the date of the examination.

Yours sincerely

for **DEAN: FACULTY OF HUMANITIES**

Information Technology Building 2-9
Humanities Student Administration
University of Pretoria
Private Bag X20, Hatfield 0028
Republic of South Africa

Tel: +27 (0)12 4202959
Fax: +27 (0)12 4202698

Email: jana.bezuidenhout@up.ac.za
Website: www.up.ac.za

Appendix K

Permission Obtained from the Gauteng Department of Education

GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

For administrative use:
Reference no: D2015 / 239

GDE RESEARCH APPROVAL LETTER

Date:	30 July 2014
Validity of Research Approval:	30 July 2014 to 3 October 2014
Name of Researcher:	Schlebusch L.
Address of Researcher:	P.O. Box 19605
	Noordbrug
	2522
Telephone Number:	
Email address:	
Research Topic:	Families raising a young child diagnosed with Autism Spectrum Disorder: Determining the relationship between family routines and family quality of life
Number and type of schools:	FOUR LSEN Schools
District/s/HO	Gauteng West; Johannesburg Central and Tshwane South

Re: Approval in Respect of Request to Conduct Research

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

2014/07/31

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

1

Making education a societal priority

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

1. *The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.*
2. *The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.*
3. *A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.*
4. *A letter / document that outlines the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.*
5. *The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.*
6. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
7. *Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.*
8. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
9. *It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.*
10. *The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.*
11. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.*
12. *On completion of the study the researcher/s must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.*
13. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.*
14. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

Dr David Makhado

Director: Education Research and Knowledge Management

DATE: 2014/04/31

2

Making education a societal priority

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

Appendix L

Codebook: Families' Perspectives on Raising their Child with ASD

CODEBOOK: Families' perspectives on raising their child with Autism Spectrum Disorder						
Nr	**Question**	**Name**	**Description**	**Instructions**	**Value**	**Label**
1		Part ID	Participants ID	Assign your own identification nrs (start at 1)		
2		Site	Survey site	Enter the number that corresponds to one of the categories		
3		Date	Questionnaire received	Enter the date the survey was received - dd.mm.yyyy		
4		Results	Email address	Enter the email address		
5	1	REL	Relation	Enter the number that corresponds to one of the categories	1	Father
					2	Mother
					3	Caregiver
					4	Parent
					5	Both parents
6	2.1	FH	Father present in household	Enter the number that corresponds to yes or no	1	Yes
					2	No
7	2.2	MH	Mother present in household	Enter the number that corresponds to yes or no	1	Yes
					2	No
8	2.3	NRC	Number of children	Enter the number of children		
9	2.4	GPH	Grandparents present in household	Enter the number that corresponds to yes or no	1	Yes
					2	No
10	2.5	OFH	Other family present in household	Enter the number that corresponds to yes or no	1	Yes
					2	No
		PH	Paid helper present in household	Enter the number that corresponds to yes or no	1	Yes
					2	No
11	2.1	DoBF	Age of father	Enter year of birth		
12	2.2	DoBM	Age of mother	Enter year of birth		
13	2.1	FWO	Father working	Enter the number that corresponds to yes or no	1	Yes
					2	No
					0	Father not present in household

Nr	Question	Name	Description	Instructions	Value	Label
14	2.2	MWO	Mother working	Enter the number that corresponds to yes or no	1	Yes
					2	No
					0	Mother not present in household
15	3	DoBOC	Age oldest child	Enter date of birth - dd.mm.yyyy		
16	4	DoBYC	Age youngest child	Enter date of birth - dd.mm.yyyy		
17	5	FTYPE	Family type	Enter the number that corresponds to one of the categories	1	Two-parent family
					2	One-parent family
					3	Step-family
18	6	EDU	Respondent education level	Enter the number that corresponds to one of the categories	1	Grade 11 or less
					2	Grade 12
					3	Diploma
					4	Undergraduate degree
					5	Postgraduate degree
19	7	EMPL	Respondent employment status	Enter the number that corresponds to one of the categories	1	Employed full-time
					2	Employed part-time
					3	Not currently working
					4	Home executive / housewife
20	8	ETH	Respondent ethnicity	Enter the number that corresponds to one of the categories	1	Black
					2	Coloured
					3	Indian or Asian
					4	White
					5	I don't wish to say
21	9	FIN	Family income	Enter the number that corresponds to one of the categories	1	Less than R4500
					2	R4501-R12500
					3	R12501-R30000
					4	R30001-R52000
					5	R52001-R70000
					6	R70001+
22	10	SIN	Subjective family income	Enter the number that corresponds to one of the categories	1	Struggling
					2	Just getting by
					3	Doing okay

Nr	Question	Name	Description	Instructions	Value	Label
					4	Managing well with some extra
					5	Well off
23	11	ASDCh	Number of children with ASD	Enter the number of children with ASD in family		
24	12	ChGEN	Gender of child with ASD	Enter the number that corresponds to boy or girl	1	Boy
					2	Girl
25	13	DoBASD	Age of child with ASD	Enter date of birth - dd.mm.yyyy		
26	14	TIME	Time since diagnoses	Enter time in months only	0	awaiting diagnosis
27	15	ChADD1	Additional disability	Enter the number that corresponds to yes or no	1	Yes
					2	No
28	15	ChADD2	Specify additional disabilities	Enter description of additional disabilities		
29	16	LEV	Level of severity of ASD	Enter the number that corresponds to one of the categories	1	Mild
					2	Moderate
					3	Severe
30	17	HRS	Hours of services per week	Enter the amount of hours		
31	18	SLE	Significant life events	Enter description of life events		
32	19.1	N1	Increased time demands	Enter the number that corresponds to one of the categories	1	Not at all
33	19.2	N2	Disruptionof family routines		2	To a mild degree
34	19.3	P1	More spiritual		3	To a moderate degree
35	19.4	N3	Additional financial costs		4	To a substantial degree
36	19.5	P2	Do more for each other			
37	19.6	P3	Improved relationship with partner			
38	19.7	N4	Limitations in social contacts			
39	19.8	P4	What to value in life			
40	19.9	P5	Appreciate uniqueness			
41	19.10	N5	Cancel/postpone holidays			
42	19.11	N6	Hestitation to phone friends			
43	19.12	P6	Tolerant of differences			
44	19.13	N7	Decreased time for friends			
45	19.14	P7	Positive growth			
46	19.15	N8	Chronic stress			
47	19.16	P8	Awareness of disability			

Nr	Question	Name	Description	Instructions	Value	Label
48	19.17	N9	Tension with partner			
49	19.18	N10	Cancel major purchases			
50	19.19	P9	Special pleasures from child			
51	19.20	P10	Life is more meaningful			
52	20.1	RWD1	Talking to children	Enter the number that corresponds to one of the categories	1	Never / almost never
53	20.2	RWD2	Parents morning		2	Sometimes / 1-2 times a week
54	20.3	RWD3	Working parent playtime		3	Mostly / 3-5 times a week
55	20.4	RWD4	Working parent caretaking		4	Always / almost every day
56	20.5	RWD5	Children's mornings			
57	20.6	RWD6	Family play			
58	20.7	RWD7	Outside activity			
59	20.8	RWD8	Evening quiet time			
60	20.9	RL1	Go to special place each week			
61	20.10	RL2	Family time at home			
62	20.11	RC1	Read or tell stories			
63	20.12	RC2	Children play alone			
64	20.13	RC3	Therapy appointments			
65	20.14	RC4	School on the same days			
66	20.15	RC5	Therapy activities at home			
67	20.16	RP1	Parent hobby/sport			
68	20.17	RB1	Children bedtime routine			
69	20.18	RB2	Go to bed same time at night			
70	20.19	RM1	Dinner at the same time			
71	20.20	RM2	Breakfast together			
72	20.21	RM3	One meal together			
73	20.22	RF1	Parents talk to their parents			
74	20.23	RF2	Visit relatives or friends			
75	20.24	RLC1	Check in and out			
76	20.25	RLC2	Home from work same time			
77	20.26	RLC3	Greet working family			
78	20.27	RD1	Discipline			

Nr	Question	Name	Description	Instructions	Value	Label
79	20.28	RCC1	Children household chores			
80	21.1	QF1	Enjoy spending time together	Enter the number that corresponds to one of the categories	1	very dissatisfied
81	21.2	QP1	Teach children independence		2	dissatisfied
82	21.3	QE1	Support to relieve stress		3	neutral
83	21.4	QE2	Suportive friends		4	satisfied
84	21.5	QP2	Help with schoolwork		5	very satisfied
85	21.6	QM1	Transportation			
86	21.7	QF2	Talk openly			
87	21.8	QP3	Teach children to get along			
88	21.9	QE3	Time for own interests			
89	21.10	QF3	Solves problems together			
90	21.11	QF4	Support to accomplish goals			
91	21.12	QF5	Love and care for each other			
92	21.13	QE4	Outside help available			
93	21.14	QP4	Teach children good decisions			
94	21.15	QM2	Medical care			
95	21.16	QM3	Take care of expenses			
96	21.17	QP5	Know people in children's lives			
97	21.18	QF6	Handlelife's ups and downs			
98	21.19	QP6	Take care of individual needs of children			
99	21.2	QM4	Dental care			
100	21.21	QM5	Feels safe			
101	21.22	QD1	ASD support at school			
102	21.23	QD2	ASD support at home			
103	21.24	QD3	ASD support to make friends			
104	21.25	QD4	Good relationships with service providers		1	very dissatisfied
105	22	OQ	Overall family quality of life	Enter the number that corresponds to one of the categories	2	dissatisfied
					3	neutral
					4	satisfied
					5	very satisfied
			The End			

Appendix M

Correlations between Demographic Variables, Appraisal of the Impact of ASD on the Family, and Family Routines

	Number of children	Age of father	Age of mother	Age of the oldest child	Age of the youngest child	Education	Financial income	Appraisal financial income	Age of child with ASD	Time since diagnosis	Level of severity of ASD
Negative Appraisal	-.031	.042	.110	-.075	.050	.108	.095	-.113	-.162*	.015	.426**
Positive Appraisal	.040	.117	.061	.138	.038	-.003	-.067	-.030	.021	.026	.054
Workday Routines	-.101	-.006	-.011	-.101	-.040	.029	-.060	.053	-.007	.003	-.090
Leisure Routines	-.009	.041	-.058	-.109	-.110	.062	.059	.120	.039	.019	-.030
Child Routines	.054	.119	.078	-.043	-.103	.120	.164*	.156*	.034	.085	-.168*
Parent Routines	.030	-.086	-.088	-.046	-.008	.171*	.107	.189*	.062	.059	.045
Mealtime Routines	.248**	.023	.043	.162*	-.055	-.162*	-.275**	-.213**	.021	.070	-.074
Leaving & Homecoming Routines	-.013	.021	.061	-.044	.045	.059	.156*	.085	.055	.016	-.060
Disciplinary Routines	.101	-.090	-.112	.002	-.007	.039	.060	.002	-.080	.074	.002
Child Chore Routines	.181*	.059	.071	.150	.032	-.011	-.100	-.112	.096	-.010	-.136
Talking to Own Parents	-.109	-.135	-.065	-.157*	-.169	.043	.057	.126	-.103	-.007	.054
Visiting Family and Friends Routines	-.190*	-.005	-.085	-.089	.027	-.039	-.070	.115	.203**	.056	-.120
Regularity of Family Routines	.033	.011	.013	-.062	-.089	.072	.052	.081	.072	.083	-.111

*$p < 0.5$. ** $p < .01$.

Appendix N

Correlations between All the Latent Constructs

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
1	Workday Routines	-																		
2	Leisure and Weekend routines	.295**	-																	
3	Child Routines	.444**	.263**	-																
4	Parent(s) Routines	.198**	.342**	.225**	-															
5	Mealtime Routines	.226**	.152*	.218**	-.014	-														
6	Talking to Own Parents	.191*	.114	.163*	.039	.113	-													
7	Visiting Family and Friends Routines	.292**	.342**	.088	.214**	.147	.320**	-												
8	Leaving and Homecoming Routines	.351**	.217**	.278**	.128	.240**	.294**	.293**	-											
9	Disciplinary Routines	.128	.120	.207**	.116	.236**	.267**	.180*	.249**	-										
10	Child Chores Routines	.173*	.179*	.183*	.221**	.233**	.101	.208**	.254**	.238**	-									
11	Family Interaction	.300**	.219**	.182*	.139	.105	.264**	.372**	.360**	.184*	.190*	-								
12	Parenting	.276**	.198**	.314**	.308**	.113	.306**	.306**	.284**	.256**	.307**	.659**	-							
13	Emotional Well-being	.257**	.259**	.204**	.322**	.114	.156*	.441**	.241**	.145	.240**	.578**	.587**	-						
14	Physical/ Material Well-being	.164*	.156*	.177*	.064	-.070	.139	.221**	.332**	.101	.075	.528**	.502**	.485**	-					
15	Disability-related Support	.241**	.123	.241**	.200**	-.071	.150*	.252**	.194**	.176*	.248**	.456**	.615**	.449**	.571**	-				
16	Negative Appraisal	-.138	-.146	-.045	-.166*	-.125	-.113	-.244**	-.071	-.079	-.070	-.296**	-.218**	-.475**	-.156*	-.269**	-			
17	Positive Appraisal	.263**	.069	.120	.032	-.039	.155*	.129	.061	.165*	.222**	.312**	.295**	.113	.059	.234**	.081	-		
18	Regularity of Family Routines	.738**	.486**	.730**	.373**	.494**	.375**	.419**	.617**	.392**	.412**	.392**	.449**	.363**	.250**	.299**	-.146	.199**	-	
19	Overall Family Quality of Life	.298**	.238**	.275**	.251**	.056	.265**	.399**	.353**	.215**	.258**	.829**	.847**	.760**	.783**	.736**	-.336**	.254**	.439**	-

*p < 0.5. ** p < .01.