

**PSYCHOLOGICAL EXPERIENCES OF FAMILY CAREGIVERS OF
CHILDREN WITH INTELLECTUAL DISABILITY**

BY

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DECLARATION

I, Tshimangadzo Getrude Sadiki, declare that this dissertation hereby submitted to the University of Limpopo for the degree of Master of Arts in Research Psychology is the result of my independent work, and that all the sources used have been acknowledged by means of complete references.

Signed at the University of Limpopo on the _____2016

T.G. Sadiki

DEDICATION

This dissertation is dedicated to all families with children with an intellectual disability.

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ABSTRACT

The aim of this study was to determine the psychological experiences of family caregivers of children with an intellectual disability. The study was conducted along the lines of an exploratory sequential mixed-method design. Firstly, 15 family caregivers were purposively sampled as participants. They described their experiences of caring for children with a formal diagnosis of mild intellectual disability. The research question, which was used as a “grand-tour” question, was: “What are the psychological experiences of family caregivers of children with an intellectual disability?” Themes that emerged included the following: understanding intellectual disability; disclosure of the disability as a result of schooling difficulties; reaction to the disclosure of the disability; challenging behaviour of the child’s integration into the family system, unemployment and financial strains due to the child’s condition and community reaction; social support and stigmatisation. In the quantitative aspect of the study, the researcher used a close-ended questionnaire to collect data from one hundred self-declared primary family caregivers (one per household) of children with an intellectual disability. Results of regression analysis indicated that psychological wellbeing as measured by the Psychological General Well Being Index and its dimensions was predicted mainly by psychological stress and family support. Significant other support and support from friends only predicted life satisfaction. Policy recommendations are advanced based on the findings of the study.

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CHAPTER 1

Chapter 1: General Introduction and Background

1.1 Introduction

Today there are many competing demands and alternative roles for caregivers. Caregivers of children with intellectual disability have a great responsibility that may be stressful (Mbugua, Kuria, & Ndeti, 2014). Parents of children with mental disability have been found to experience more stress and adjustment problems than parents of typically developing children (Dervishaliaj, 2013; Dyson, 1997). Raising a child with mental disability can have a profound impact on the family (Dyson, 1997). Parents come to acknowledge that the “normal” child they thought they had does not exist, and they are instead left with a child who may never be able to lead a normal life and who may exhibit behavioural problems. As a result, parents have to first deal with the fact that their child is different to other children, and will require special attention throughout his/her life. Indeed, raising a child with mental disability is arguably one of the greatest stressors any parent has to face (Sanders & Morgan, 1997).

Parents of intellectually disabled children eventually experience stress due to a number of stressors, including financial problems that makes it difficult for them to provide all the demands for such children, spending more time at therapeutic facilities or travelling to and from them, possible isolation due to the child's physical challenges or behavioural problems, and strained family relationships (Beckman, 1991). A study conducted in South Africa found that caregivers of children with disability consumed as much as 5% of the average family's income on transport cost for one return trip for therapeutic facilities (Saloojee, Phohole, & IJsselmuiden, 2006).

Intellectual disability is considered the single largest category of life-long handicaps affecting populations of developing countries (Louw & Edwards, 1997). Often times, intellectual disability is accompanied with environmental

deprivation, either as a source or consequence. The majority of the children come from families that are poor, unstable, lacking in cognitive stimulation and poor social interaction (Louw & Edwards, 1997). Living in an impoverished environment where unemployment rates are high, where many children live in single-parent families with little or no support from fathers, and where household incomes are very low, adversely affects a caregiver's ability to prioritise the care that a child with disability needed in South Africa (Saloojee et al., 2006).

Family caregivers play an important role in helping intellectually disabled children cope in their everyday lives as some cannot take care of themselves. Certain patterns of findings are becoming common. For instance, most caregivers are women (Heller, Hsieh, & Rowitz, 1997), and parents of children with mental disabilities show significantly more stress and strain within the family system as compared to parents of typically developing children (Pinquart & Sörenson, 2003a, 2003b; Smith, 2007). The results emanate from studies conducted mostly in the West. However, their findings are yet to be replicated in South Africa. The purpose of this study was to investigate the experience of caregivers in the Makhado Municipality, Vhembe District, Limpopo Province. The study is also aimed at adding the African dimension to existing knowledge about caregiver experiences.

1.2 **Background of the study**

Family caregivers of individuals with intellectual disabilities have been found to experience mental health difficulties of their own. Attitudes surrounding the attributes and place of children with intellectual disabilities in families and communities have undergone significant changes over the last 100 years. In the past, children with intellectual disabilities were expected to live in institutions, away from their families and communities. Now the approach is to deinstitutionalize care, and the majority of mentally disabled children are able to live with their parents and families (Seltzer & Heller, 1997).

During the 1930s and 1940s, parents often had little choice about whether to keep their child at home or not. If a child was born with some intellectual

disability, doctors often discouraged the mother from seeing the child, or taking the child home. A common attitude from medical professionals was to simply put the child in an institution and forget about the family. If the parents chose to take their child home, no services were provided to help the mother or family as it was generally believed that such services would encourage families to keep their children whereas medical professionals felt it was their duty to control and limit any such inclination. Parents were also discouraged from keeping contact with their children, who were kept at a facility as they believed that any involvement would promote a breakdown within the family (Baxer, Cummins, & Yiolitis, 2000).

In modern times the concept of intellectual disabilities is becoming increasingly normalized and children are no longer segregated from their peers. Their families have increasing access to community services and facilities not previously available to them (Baxer, et al., 2000). The majority of parents are able to keep their child at home with the family, whereas other children may be brought up by grandparents and other family members (Seltzer & Heller, 1997). However, improving conditions of children with intellectual disability and their placement under family care have their downside for caregivers.

According to Seltzer and Heller (1997), parents of children with mental disabilities have many issues to face. They may come to the realization that their child is not developing normally. They also begin to face issues and ask questions such as: the kind of treatment available for them, the possibility of parents or child being entitled to government grants and assistance, where the child will attend school. Many parents also face the question of whether they are able to care for their child themselves, or whether they feel they do not have the necessary skills or resources and that it may be better for someone to care for their child (Seltzer & Heller, 1997). Moreover, the stress accompanying home care of children with intellectual disability is enormous.

1.3 Statement of the problem

Raising a child with some mental disability has a profound impact on the family and its members, especially those who are the primary caregivers. Parents of children with mental disabilities experience more stress and adjustment problems than parents of normal developing children (Dyson, 1997; Pinguart & Sörenson, 2003a). Caring for intellectually disabled children is a burden to the family. Behaviour problems of intellectual disabled children apparently are the most critical element of the family burden (Floyd & Gallagher, 1997). These behaviours eventually are problematic for caregivers. Khamis (2007) further argues that the continuing care of children with intellectual disability is often stressful for parents as these children's difficulties inevitably affect many aspects of the parents' lives. Therefore, the more problematic or difficult the child is to manage, the greater the likelihood of experiencing parenting stress (Fisher, 1990).

Several studies have found higher subjective caregiving burden among mothers than fathers (Beckman, 1991; Hallum & Krumboltz, 1993; Heller et al., 1997). Marcenko and Meyer (1991) found that in two-parent families, in which all the women had been employed prior to the birth of their child, only 8% of women returned to work after having a child with a disability. However, some studies have found little differences in burden or only in some aspects of burden (Greenberg, Seltzer, Krauss, & Kim, 1997).

Although family caregivers of individuals with mental disorders have been found to experience mental health difficulties of their own, little has been done about caring for children with intellectual disability. Previous studies focused on other mental disorders, or disabilities, such as schizophrenia, autism, attention deficit hyperactive disorder, and so on. The few studies that focused on intellectual disability applied mainly quantitative methodologies, and their focus was mostly on family members who care for adults with an intellectual disability (such as the differential effects of social support on the well-being of aging mothers of adults with mental illness or intellectual disability (Greenberg et al., 1997); maternal and paternal caregiving of persons with an intellectual disability across

the life span (Heller et al., 1997); parenting stress in mothers of adults with an intellectual disability (Hill & Rose, 2009)); and parental cognition in relation to child characteristics and family support. It is not clear if the findings will apply to younger children who have an intellectual disability. Therefore, this study focused on children with intellectual disability and used both a qualitative and a quantitative approach.

1.4 Aim of the study

The aim of this study was to determine the psychological experiences of family caregivers of children with intellectual disability, using a method triangulation approach in the context of an exploratory sequential mixed-method design

1.5 Objectives of the study

- 1.5.1 To investigate the challenges faced by family caregivers of intellectually disabled children; and
- 1.5.2 To find out what support systems are used by family caregivers of intellectually disabled children.

1.6 Research question

What are the psychological experiences and ways of coping used by family caregivers of children with intellectual disability?

1.7 Scope of the study

The study was conducted within the Vhembe District, Limpopo Province. The population from which the sample was drawn consists of African (mainly Tshivenda and Xitsonga-speaking) family caregivers of intellectually disabled children.

1.8 Research design

The research design followed in this study is exploratory sequential mixed-method design. Two studies were conducted, and in each instance, the method of data collection was cross-sectional, that is, it was collected at one point in time, with no follow-up data collection plan. Triangulation of method was used in this study. This involves the combination of more than one research methodology in the study of the same phenomenon. The first study was qualitative and the second was quantitative. This study combined methods in order to overcome the weakness or intrinsic biases and the problems that come from a single method approach (Guy, 1987).

1.9 Operational definition of terms

- (a) **Intellectual Disability** – Sub-average general intellectual functioning that originates during the developmental period and is associated with impairment in adaptive behaviour. Intellectual disability affects about 2 to 3% of the population. Following psychological testing, individuals who are intellectually disabled can be classified into any of the four categories, namely: (1) mild, (2) moderate, (3) severe, and (4) profound intellectual disability. Based on the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (2013), the diagnosis of intellectual disability is done on the basis of an IQ score, and failure to function successfully in areas of adaptive functioning. Adaptive functioning refers to common skills such as taking care of oneself, functioning at home and at school, and so on. All categories of intellectual disability function at a below average level of intellectual or cognitive functioning. However, they differ in the extent that they are trainable. The mildly disabled are trainable in some basic and adaptive skills, and the profoundly disabled require constant supervision since they cannot be trained.

Signs that may suggest intellectual disability include, among others, the child's inability to do everyday things for himself or herself, delayed speech, and minor physical and cognitive anomalies.

- (b) **Family caregiver** – A “family caregiver” is anyone who provides any type of physical and/or emotional care for an ill or disabled loved one at home. In this study, the term refers to any person who has the responsibility of taking care of a disabled child. He or she may be a parent, relative friend or paid worker.

- (c) **Child** – In this study, the term “child” refers to a person under the age of 18 years as defined in the Children's Act 38 of 2005.

1.10 List of Abbreviations

ANX	:	Anxiety
DEP	:	Depressed Mood
GH	:	General Health
ID	:	Intellectual Disability
MSPSS	:	Multidimensional Scale of Perceived Social Support
PWB	:	Positive Well-Being
PGWBI	:	Psychological General Well-being Index
PSS	:	Perceived Stress Scale
SC	:	Self-Control
SWLS	:	Satisfaction with Life Scale
VT	:	Vitality

CHAPTER 2

Theoretical perspective and literature review

2.1 Theoretical perspective

The stress process model was used as this study's theoretical reference for understanding caregiving stress. The study was not designed to test the model. Thus, it is empirical in its focus on caregivers' own experiences of taking care of children with intellectual disability. The theory was only used as reference rather than the study's theoretical framework. Here, it is briefly explained.

The stress process model

The stress process model, a highly influential model that evolved out of the theory of strain, was developed by Pearlin, Mullan, Semple and Skaff (1990). Pearlin and colleagues introduced this model in the study of stress among 555 non-paid dementia caregivers across the United States. The model was designed to assess the informal caregiving processes affecting caregiver health. It proposes that caregiving is a stressor which if appraised as a burden, can result in psychological distress. The impact of caregiving however is influenced by a variety of context variables such as age, gender, socio economic status, relationship to the care recipient, social support, coping behaviours and culture (Aranda & Knight, 1997; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Pearlin et al., 1990).

The stress process model argues that the four major contributing factors to caregiving stress include the caregiver's background and context, stressors, mediators, and outcomes (Pearlin et al., 1990). The caregiver's background and context may include factors such as gender, socio-economic status and age (Pearlin et al., 1990). This model proposes two categories of stressors: primary stressors and secondary stressors. The primary stressors are those related to the role of caregiving, such as providing assistance and supervising the care receivers, such as feeding, bathing et cetera. Secondary stressors

may include the negative emotional, social, and economic effects of caregiving (Pearlin et al., 1990). With regards to the primary stress factors, the influence of behavioural problems generated by mental disorders can appear in a severe way, as opposed to the cognitive deficiencies and dependence for the activities of daily life, as generators of excessive burden in the caregiver, emotional, discomfort, exhaustion and emotional mood disorders (Dunkin & Anderson-Hanley, 1998; Hawranik & Strain, 2000).

Mediators are variables that may lessen the effect of the stressors, or outcomes. Mediators of stress are also divided into two categories. These include social support and coping (Pearlin et al., 1990). Social support has appeared as another mediator variable of the stress process, either by means of emotional system or the formal resources. Mockus and Noveilli (2000) found that the assistance of emotional type supplied by family members, neighbours to the informal caregiver is efficiently, respectively, to reduce the excessive burden. Caregivers who report higher levels of social support are less likely to report burden (Majervotiz, 2007). In the stress process model, the outcomes of caregiving stress in the caregiver may include disturbances in mood (depression or anxiety) or a decline in the physical health (Pearlin et al., 1990).

The stress process model as a theoretical reference for this study provides some understanding of caregiving processes affecting caregiver health and highlights some of the contributing factors to caregiver stress. However, the stress process model obviously consists of multiple conceptual components and each components potential has multiple aspects of dimensions.

2.2 LITERATURE REVIEW

2.2.1 The Concept of Caregiving and Experiences

The process of caregiving was originally proposed by Bowers (1987), who defined five categories of roles that provide meaning or purpose for the caregiver: anticipatory, preventive, supervisory, instrumental and protective. Thus family caregivers are primarily anticipatory of possible needs for the child,

preventers of possible injuries or complications and provided supervisory and protective caregiving. Nevertheless, Hermanns and Mastel-Smith (2012) argue that the development of the concept of caregiving for use in research lacks consistent conceptualization and operational definition. Therefore, the literature review highlights that there is a lack of a universal definition of caregiving. The caregiving literature generally has considered family caregivers to be independent actors who provide unilateral assistance to dependent recipients (Wolff & Kasper, 2006).

Glendy and Mackenzie (1998) indicated that caregiving is mainly defined in terms of the amount and extent of help provided to the care recipient. The Merriam Webster online dictionary (2010) defines the caregiver as “a person who provides direct care for children, elderly people, or the chronically ill”. Drentea (2007) refers to caregiving as “the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological or developmental needs”. In the disciplines of psychiatry and psychology, the psychological ramifications of the act of caregiving, that is, caregiving burden and stress have been studied, but caregiving is not explicitly defined in this area (Hermanns & Mastel-Smith, 2012). In this study, the term refers to any person who has the responsibility of taking care of an intellectually disabled child. He or she may be a parent, relative or friend.

In the area of psychiatry and psychology, literature has seldom prioritised the well-being of carers or relatives. The situation has changed somewhat, since some caregiving literature is emerging. It is generally agreed that carers experience a wide range of problems and that caregiving is best seen as multidimensional. Parents of intellectually disabled children face a lifetime of caregiving responsibilities and the length of active caregiving often extends for many decades (Kim et al., 2003). Thus, caring for children with any form of mental disability, including intellectual disability, is experienced in a particular way by parents.

Generally, a child’s diagnosis of an intellectual disability is considered a traumatic experience for families (Blacher, Baker & Braddock, 2002). The

process is characteristically shocking, and sometimes accompanied by feelings of embarrassment, sorrow and helplessness (Szmukler et al., 1996). During the time that the child is cared for, the family also undergoes change, necessarily transforming in activities and relationships through the life cycle. Such normal changes are often erroneously ascribed to the illness. Yet, in some instances, the family structure does experience problems related to the child's condition.

Indeed, family member roles have to change due to the different and demanding responsibilities (Bumin, 2008), and parents or other caregivers are always at increased risk of anxiety and depression (Dave, Mittal, Tiwari, Parmar, Gedan & Petal, 2014). Mbugua et al. (2011) suggest that social isolation, loss of previous close friendships, and stigma associated with taking care of an intellectually disabled person may further predispose caregivers to the risk of depression. Caregivers often neglect their own chronic conditions and psychological well-being in favour of the disabled child. Aside from worrying about the disabled child, strained caregivers also worry about the rest of the children. Most caregivers become concerned that their worsening psychological well-being would jeopardize their ability to meet the long-term needs of their children (Murphy, Caplin, & Young, 2006).

Researchers have indicated that family caregivers of children with intellectual disability are generally at risk for a variety of family life problems and emotional difficulties (Khamis, 2007). Caregivers may experience lack of control of what happens in their lives and over day-to-day events (Mbugua et al., 2011; Murphy et al., 2006). The most affected person in the family is usually the mother in such a situation. Mothers of children with disabilities often experience greater stress and emotional demands compared to other mothers. They experience more caregiver burden and stress because they are the ones who spend most of the time with the children and carry out most of the caregiving tasks (Bumin, 2008).

Glendy and Mackenzie (1998) found that family caregivers also express fear for the well-being of the intellectually disabled relative and of the other family members, in particular, that of the children. Fear arises because of the

unpredictability of the relative's emotions and behaviour. A sense of loss was another emotional experience of family caregivers; especially the mothers. Szmukler et al. (1996) also found that family caregivers had a poor understanding of the relative's diagnosis and the management of the associated problems. Madianos, Economou, Dafni, Koukia, Palli and Rogakou's (2004) findings indicate that families of a member with severe and chronic mental disorders experience psychological distress and situations related to change of social activities and financial strain. They also experience social isolation which is probably caused by the fear of stigma and societal attitudes.

However, Burke (2004) intimates that caring can also be a positive experience providing opportunities for growth-related challenges. Burke further points out that some caregivers express greater marital satisfaction, a feeling of self-worth, a pride in their ability to meet challenges and a meaning in their lives. In some instances, while caring for a child with mental disability, parents gain positive experience such as improved in relationship with other, personal growth and increase patience and empathy (Hastings & Taunt, 2002; Pakenham, Sofronoff, & Samios, 2005; Scorgie & Sobsey, 2000).

2.2.2 Family Caregivers Stress

Stress has long been identified as an important determinant of family functioning and family relationships (Gerstein, Crnic, Blacher, & Baker, 2009). Raising a child with an intellectual disability is arguably one of the greatest stressors any parents have to face. They often experience stress in relation to caring for children with intellectual disability (Syeda, Weiss, & Lunskey, 2011). Parents of children with a mental disability have been found to experience more stress and adjustment problems than parents of typically developing children (Dyson, 1997; Herring, Gray, Tonge, Sweeney, & Einfeld, 2006). Khamis (2007) said that the continuing care of children with intellectual disability is often stressful for parents as these children's difficulties inevitably touch their lives. Stressors associated with taking care of individuals with intellectual disability

often have a significant negative impact on families and in some cases lead to crisis (Weiss & Lunskiy, 2011).

Fischer (1990) investigated the parenting stress of parents of children with mental disabilities, and concluded that research looking at parent-child interaction patterns is more indicative of a child-to-adult direction of effect with regard to parenting stress, more so than the reverse. This would seem to suggest that the more problematic or difficult the child is to manage, the greater the likelihood of experiencing parenting stress (see also Herring et al., 2006; Ki & Joanne, 2014). Fisher (1990) further indicated that other studies in this area have suggested that the stress resulting from parenting difficult children is associated with parents' psychological distress, life satisfaction, and marital relationship.

Blacher and Baker (2007) suggest that child characteristics, social support, personal and family resources and other life stressors may also play an important role as stressors. Beckman (1991) found that parents experience stress due to economic problems of providing for an intellectually disabled child, time demands related to seeking therapists, possible isolation due to a child's limited mobility, behavioural problems, and the development of strained family relationship. Financial and employment troubles are significant stressors for families of individuals with intellectual disability (Syeda et al., 2011). Khamis (2007) found that in addition to child characteristics such as age, parental unemployment predicts parental stress over time.

However, Dyson (1997) found that it is not always the case that parental stress associates with family dysfunction. It is possible for families to respond to the stress of caring for their child with resilience and adaptive functioning. Family caregivers who made greater use of coping strategies that involved learning about and understanding their child's medical problems had lower parenting stress related to difficult child characteristics (Auslander, Bubb, Rogge, & Santiago, 1993). It turns out that parents with a better physical well-being and who can maintain a more positive mental health status able to better cope with the stressful demands of caregiving (Gerstein et al., 2009).

Although there is considerable evidence to support the notion that family caregivers of people with mental disabilities and chronic disorder suffer from psychological and physical stress, various studies suggest that the extent to which this is true is doubtful (Burke, 2004). Burke also said that caring is stressful and can be a burden to the caring family, but at the same time it should be seen in a positive perspective rather than solely in negative terms. Burke (2004) recognizes that although stress is an inevitable part of caring, and indeed life in general, it can also be a positive experience providing opportunities for growth and challenges. Some caregivers express greater marital satisfaction, a feeling of self-worth, a pride in their ability to meet challenges and a meaning in their lives. Caregiving can thus be a satisfying and rewarding experience, characterized by bringing the family closer together and even salvaging relationships that are on the verge of disintegrating.

2.2.3 Caregivers Coping Strategies

Seltzer and Heller (1997) said that family caregiver's capabilities in coping with stress of parenting a child with disability are dependent on their personal strength and their social resources and support system. Intellectual disability was found to generally mean lifetime care giving (Cook, Lefley, & Cohler, 1994). For family caregivers of children with intellectual disability, depressive symptoms were a function of their child's behaviour problems, although this source of stress was buffered by coping (Greenberg et al., 1997).

Although challenging behaviours have been identified as a source of family caregiver stress, few researchers have directly addressed this relationship. In a study about challenging behaviour, 55 educators and support staff in special schools for children with intellectual disability completed questionnaires assessing burnout, coping strategies for challenging behaviour, and their exposure to challenging behaviour (Hastings & Brow, 2002). Results showed that the use of maladaptive coping strategies for challenging behaviours constitutes a risk for staff burnout. This risk is in addition to that associated with exposure to challenging behaviour. The use of maladaptive coping strategies moderated the impact of exposure to challenging behaviours on emotional

exhaustion burnout (Hastings & Brow, 2002). Magliano et al. (1998) found that the adoption of problem-focused coping resources (for example, seeking information and maintenance of social interests) was more frequent among younger relatives, relatives of younger patients, and those who received higher levels of social support and professional help. In contrast, relatives who had been living for a longer period of time with the patient, and those who had poorer social support, more frequently adopted emotion-focused strategies (for example, resignation and avoidance). Kim et al. (2003) found that mothers of individuals with an intellectual disability used problem-focused coping, a coping strategy that predicts enhanced well-being. Kim et al. further indicated that it is possible that problem focused coping efforts may increase maternal involvement with a child, and enhance caregiver understanding of the struggles which a child encounters in seeking mental health treatment.

In the study about caring for relatives with mental illness at home, Glendy and Mackenzie (1998) found that family caregivers had developed a wide range of strategies to cope with the long-term caregiving situation. Acceptance and taking positive action were the two important strategies identified. Carers had learned to accept and reconcile the disabilities in the chronically mentally ill relatives over time and to avoid the dissatisfaction and disappointment that would have resulted from unrealistic expectations of their relatives. Care took positive action by undertaking problem-solving activities to cater for their relatives' practical, psychological, and emotional needs to help overcome the illness.

2.2.4 Behaviour Challenges Confronting Family Caregivers

Floyd and Gallagher (1997) said that child intellectual disability is a risk factor for behaviour problems, but familial stress is associated with behaviour problems rather than with intellectual disability (Gerstein et al., 2009). Most researchers found behaviour problems as a significant predictor of parenting stress (Baker et al., 2002; Hassal, Rose, & McDonald, 2005; Lecavalier, Leon, & Wiltz, 2006). Even teacher burnout was associated with behaviour problems in children with intellectual disability (Hastings & Brown, 2002). The family

caregiver copes better when they do not have to put up with difficult behaviours. A relatively large proportion of persons with intellectual disability show problematic behaviour like self-injurious behaviour, aggression towards others, destruction of property, inappropriate social and sexual conduct, screaming, non-compliance, and eating inedible objects (Moss, Emerson, Kiernan, Turner, Hatton, & Alborz, 2000). These behaviours may be dangerous to the individual and problematic for family caregivers.

Several studies have investigated the prevalence of challenging behaviour among persons with intellectual disability. Borthwick-Duffy (1994) identified 14% of the population with intellectual disability as having challenging behaviour. Quereshi and Alborz (1992) found that 5.7% of the population with intellectual disability manifested severe challenging behaviour. Emerson (2001) concluded that challenging behaviours are shown by 10-15% of people with intellectual disability who receive educational, health or social care services, and most challenging behaviour are shown by 5-10% of these people.

Family caregivers also show symptoms of depression that are often correlated with challenging behaviour and symptoms of anxiety correlated with self-injurious behaviour (Moss et al., 2000). However, from both theoretical and practical perspectives, family caregiver beliefs are likely to have a significant impact on the process of care for children with an intellectual disability who engage in challenging behaviours. According to family caregivers, challenging behaviours are actions that are difficult to manage, as the causes of those behaviours are unknown (Berryman, Evans, & Kalbag, 1994).

2.2.5 **Family Burden**

Family caregiver burden is a complex issue involving many factors. Living with the patient, patient behaviours, demographic characteristics, and socio-economic status have all been associated with differing levels of burden (Szmukler et al., 1996). Floyd and Gallagher (1997) said that child behaviour problems apparently are the most critical element of family burden. Dave et al. (2014) found that family caregivers (especially divorced and separated

caregivers) may be depressed due to the burden of caring. Heller et al. (1997) said that older parents scored significantly higher in feelings arising from the burden associated with on-going responsibility for their child and worries about the future while younger parents were significantly more burdened by behavioural problems and control and management issues. The study carried out by Raj, Kulhara and Avasthi (1991) on experiences of burden by relatives who have a family member with intellectual disability, burden was found lower at 6-month follow-up in relatives of patients with predominantly positive symptomatology, and stable among those of patients with predominantly negative symptomatology. Brown and Birtwistle (1998) also found burden to be stable at 15-years follow-up in a sample of relatives who had not received any specific intervention. Brown and Birtwistle (1998) suggest that levels of family burden can change over time, are influenced by the nature of the patient's symptomatology and are unlikely to improve in the absence of specific interventions.

Magliano et al. (1998) carried out a study in five European centres on 236 relatives of patients with intellectual disability, and highlighted the fact that relatives experience higher levels of burden when they mainly adopt emotion-focused coping resources (for example, avoidance of the patient and resignation), and receive poor practical and psychological social support. In a retrospective study of older family caregivers, Roberto (1993) found that 40% reported increased physical burden and 41% reported emotional burden over a period of 10 years. On the other hand, in an earlier cross-sectional study of 489 family caregivers of family member with intellectual disability, family caregivers of adults over the age of 30 experienced fewer burdens in comparison to family caregivers of younger members with mental disability (Heller et al., 1997).

Studies have indicated that in order to reduce family burden, the intellectually disabled patient and his family should, ideally, be subjected to family-based interventions (Fallon & Shanahan, 1990; McFarlane, 1994; McFarlane, Dushay, Stastny Deakins, & Link, 1996; Mueser et al., 2001). Such interventions include elements of stress management, communication strategies, problem solving, goal achievement, and receiving knowledge about the psychotic disorder and

early warning signs (Falloon & Fadden, 1993; Hahlweg & Wiedemann, 1999; Randolph & Glynn, 1994). In a recent study by Mueser et al. (2001) the addition of behavioural family therapy to supportive family management did not, however, influence family burden. The study carried out by Madianos et al. (2004), which examined the dimensions of burden perceived by key-relatives of patients suffering from mental disability highlighted the fact that variables such as gender and age, both of caregivers and patients, number of family members, duration of illness and the employment status of the patients, were not found to have an effect on dimensions of family burden.

Szmukler et al. (1996), in an effort to include some of the more positive aspects of caregiving, replaced the concept of burden with the 'Experience of Caregiving'. This approach was based on a 'stress-appraisal-coping' framework. They said that more than being simply unhelpful, one could further suggest that the term 'burden' is damaging. It is pejorative, connoting a passive 'load' borne by carers, one easily seen as unchangeable. In an era when patients are encouraged to participate actively in their own care, the inertia implied by the term is offensive. Caregiving is surely a dynamic process to which the carer, patient, friends, community agencies, and the mental health services contribute. It is unhelpful in yet another way: it restricts carers' reactions to the negative. Rewarding aspects of caregiving and valued aspects of the relationship with the patient are excluded even though carers, if asked, commonly report them. A more appropriate term for what is being described is 'caregiving'. It is neutral in tone, allows for both negative and positive aspects, and has no built-in preconceptions. Negative aspects of caregiving could be termed 'caregiver distress', and positive aspects, 'caregiver rewards'. The term 'burden' expresses negative stereotypes of mental disorder.

2.2.6 Social Support as a Moderator of Parenting Stress

Rivers and Stoneman (2003) said that access to social support has been related to positive family and child outcomes in families of children with intellectual disability. Allowing caregivers to regularly socialise with family and friends may thus alleviate the stress experienced by caregivers of children with

intellectual disability (Cramm & Nieboer, 2011). Boyd (2002) said that stress and depression are two main factors that lead parents to seek social support. Family assistance can be one of the most useful sources of support, as families may be more willing and able to provide instrumental and financial assistance. Family respite care and financial support are some of the most frequently identified services that family support networks provide (Herman & Thomson, 1995). The stress involved in raising a child with mental disability can be exacerbated by a lack of social support and can have effects on how the family is able to function and on the psychological adjustment of other children in the family (Beckman, 1991). However, families who report higher levels of social support, report lower levels of stress (Boyd, 2002; Hassal et al., 2005; Hill & Rose, 2009).

The relationship between positive psychological adjustment and social support has been widely reported, as have the buffering effects of social support on stress. In a study of moderators of stress in parents of children with autism, Dunn, Burbine and Bowers (2001) found that parents with greater social support show better psychological adjustment. They further showed that poor social support and more problematic behaviours were associated with increased psychological morbidity in parents caring for child with an intellectual disability. In a study on examining the relationship between stress and lack of social support in mothers of children with autism, Boyd (2002) found that mothers who perceived greater support also reported significantly fewer depressive symptoms. Social support was generally found to minimize the impact of caregiving on parental distress; eventuating in those with greater social support showing better psychological adjustment (Dunn et al., 2002; Gray & Holden, 1992).

Like parenting stress, social support has received a great deal of attention with respect to operationalizing and choosing a useful way to measure the phenomenon. The bigger the numbers of supports in the social network the better. However, negative consequences related to the presence of others in the social network system is possible. Melson, Windecker-Nelson and Schwarz (1998) found that for fathers of young children, a greater number of supporters

predicted more hassles, which are considered contributors to parents' general, non-parenting stress. Melson et al. (1998) further suggest that an optimal number of supporters may exist, with too many being as problematic as too few. Thus, the most important element of support is how helpful the mother perceives the help to be, rather than the amount of help available (Hassal et al., 2005; Hill & Rose, 2009).

Researchers have discussed different types of support such as informal (for example, family, friends, and neighbours), formal (institutions, agencies and professionals), and informational (books, TV, magazines) and their influence on parenting stress (Beckman, 1991). Melson et al. (1998) found that kin support in particular, predicted fewer general hassles for mothers and fathers, and fewer negative life events for fathers specifically. Perceived helpfulness of total social support was found to be negatively related to parenting stress reports for both mothers and fathers. In essence, family caregivers who reported greater helpfulness with the social support they received from family and friends also reported experiencing less parenting stress. This was true also for parents' perceived helpfulness of total support, which included all forms of support (that is, informal, formal, and informational).

Dyson (1997) found that mothers are more likely to seek support from families and friends as a source of informal support are more effective at reducing stress than sources of formal support. Dyson (1997) observed in her study between mothers and fathers of developmentally disabled children that mothers' stress was moderately and inversely related to fathers' report of family social support. Glendy and Mackenzie (1998) found that some care sought religious support and said that religious practice gave them peace of mind and helped them endure the caregiving situation. Family caregivers believed that praying was likely to reduce the suffering on the part of the ill relative as well.

2.2.7 Caregiver Gender Differences

Mbugua et al. (2011) indicated that in the African context, it is more acceptable and indeed common for women to take up the role of caregiving. Heller et al. (1997) found highly disparate contributions from mothers and fathers of children and adults with intellectual disability. Mothers invested more time and more types of support than fathers to the wellbeing and health of their offspring. Several studies have found higher subjective caregiving burden among mothers than fathers of children (Beckman, 1991) and of young adults with some disability (Hallum & Krumboltz, 1993). Mothers are more stressed and their increasing stress may reflect the greater amount of time they spend with the children relative to the father (Gerstein et al., 2009). In a study of two-parent families in which all the women had been employed prior to the birth of their child, Marcenko and Meyer (1991) found that only 8% of women returned to work after having a child with disability.

Fathers of children with an intellectual disability were less likely to be involved with child care than were the mothers (Willoughby & Glidden, 1995). Essex et al. (1993; in Greenberg et al., 1997) studied older fathers of children with intellectual disability, and found that the fathers' retirement was not associated with increased involvement in the care of the child with a mental disability. Willoughby and Glidden (1995) found that the only task in which fathers participated almost equally with mothers were those of play and helping activities. Mbugua et al. (2011) suggested that female caregivers are more affected than male caregivers while caring for their intellectually disabled.

Although evidence is overwhelming that mothers are the ones who carry the load of caregiving, some studies have found little differences, or only in some aspects, of burden between mothers and fathers (Essex et al., 1993; in Greenberg et al., 1997). Dave et al. (2014) found that regardless of the gender, caregivers are equally affected while caring for disabled child.

2.2.8 Summary and Conclusion

The chapter covered the theoretical perspective and literature review. The theory used in the study is the stress process model emanating from Pearlin and colleagues (1990). The literature covered in the review ranged from studies of caregiver stressors and the related coping strategies. Coping strategies were also explained as moderator variables in the relationship between stressors and their consequences. The review also covered the role of gender in the experience of caregiver stress. It is clear from the literature review that family caregivers of children with intellectual disability are likely to experience some form of stress.

CHAPTER 3

STUDY ONE: QUALITATIVE RESEARCH APPROACH

3.1 INTRODUCTION

The study used an exploratory sequential mixed-method approach to design (Caruth, 2013). Each of the methods will be explained. First, the qualitative section of the study. Chapter 3 will provide results of the first and qualitative study. A qualitative approach was used to assess the psychological experiences of family caregiver's of children with intellectual disability. Interviews were conducted with a sample of family caregivers. First, the research methodology of the study will be described, including the sampling method used; then data collection, capturing, and analysis will follow. The penultimate aspect covered will be the findings, which will be presented by themes. Lastly, the findings will be discussed, mainly related to existing literature.

3.2 RESEARCH METHODOLOGY

3.2.1 Population and Sampling Method

The population targeted in the qualitative component of the study consisted of family caregivers of children with some intellectual disability enrolled in a care centre in Makhado Municipality, Vhembe District, Limpopo province. The participants were defined as any family caregivers (for example, biological parents, foster parents, or guardians) who were responsible for taking care of children with an intellectual disability. According to the World Health Report (2001), it is estimated that the overall prevalence of intellectual disability in a population is between 1 and 3%. It is more common in developing countries because of frequent incidences such as deprivation of oxygen at birth, early childhood brain infections and head injuries. The White Paper on an Integrated National Disability Strategy (1997) indicated that there is a serious lack of reliable and relevant information on the nature and prevalence of disability in

South Africa. However, Statistics South Africa Population census (2011) estimated that 7.5% (2, 870 130) of South Africans are classified as disabled. The report shows that there were 260 138 persons with a mental handicap in Limpopo Province, and 2, 499 171 in the Republic of South Africa as at October 2011. The census further shows that as compared to other provinces, Limpopo represented 10% of people with mental handicap and 23% (59 037 persons) of those mentally handicapped individuals reside in the Vhembe District. Twenty eight percent (16 526 persons) of the mentally handicapped individuals in the Vhembe district were aged between 5 to 19 years.

In the qualitative component of the study, the purposive method of sampling was used to recruit participants. This type of sampling is based entirely on the judgment of the researcher. An advantage of purposive sampling is that the participants selected were qualified to assist in the study.

The researcher sought assistance from a primary care medical clinic in the area to identify prospective participants. The health practitioners referred the researcher to the day-care centres for children with an intellectual disability around the area. It turned out that intellectually disabled children register and attend stimulation classes at any of the three day-care centres in Makhado Municipality, Vhembe District. The researcher used the list of registered children with an intellectual disability at the day-care centre to identify the participants. The researcher randomly selected five intellectually disabled children per day-care centre to constitute the sample. All intellectually disabled children who were sampled were given letters to inform their caregivers about the study and requested to participate in the study. Therefore, 15 primary family caregivers (one per household, who spent most of their time with the child) were sampled.

3.2.2 Data collection

The interviews were conducted using a face-to-face format. All the resultant verbalizations were captured using a *SONY* digital recorder. The researcher also took observational notes based on participant factors such as general body

language and gesturing resulting from certain types of questions or topics discussed. Although the interview schedule was written in English, the interviews were conducted using the Tshivenda and Xitsonga translations, since the interviewees were Tshivenda and Xitsonga speakers. The interviewer herself is fluent in both dialects, and is in fact a first-language speaker of Tshivenda, a predominant dialect in the catchment area of the study.

The interviews were conducted in each of the participants' home. Although the interviewees were briefed about the study upon recruitment, they received further clarifications about the study, their rights as participants, and they were made aware about the need to assent in writing before participating. Thus, each participant signed the consent form before taking part in the study. Briefly, they were informed, among other things, that participation was voluntary, that the information they provided would be considered confidential, that their names would not be linked to any of the information analysed and reported, and that they have the right to withdraw from participating at any time if they felt so without having to give a reason for it.

Interview guide

The information obtained from some of the studies in the literature review helped in structuring the interview guide (see appendix 2). The common probing questions used in case insufficient information was provided by the respondents are as follows:

- How do family caregivers of children with an intellectual disability take care of their own needs while taking care of the intellectually disabled child?
- What motivates family caregivers to provide care?
- What forms of social support are received by family caregivers?
- What other support do family caregivers think would be beneficial to them?

3.2.3 Data analysis

Thematic analysis was used in this study. Since the data were collected using a digital recorder to record responses, after each interview, the researcher listened to the interview to familiarize herself with its content, and then transcribed it verbatim. Each interviewee was assigned a number for identification purposes, for example, respondent number 1, respondent number 2, respondent number 3, as the case may be.

Once transcription was done, each interview was subjected to a hybrid data analytical procedure derived from Braun and Clarke (2006), Groenewald (2004) and Marshall and Rossman (1999). The procedure was done as follows:

- Organizing the data

The researcher read and re-read the transcripts one by one in order to become familiar with the content of each. The researcher engaged with the data to familiarise herself with the depth and breadth of the content. That involved repeated reading of the transcribed data in order to be familiar with all the data aspects. During this phase the researcher took notes on key information from the data.

- Generating initial codes

The researcher began this phase by generating a list of ideas based on what was interesting in the data, and then produced initial codes from the data. Therefore, the data were coded while reading the transcripts by categorizing statements with similar meaning. Statements with the same meaning were grouped together to form potential themes or patterns.

- Searching for themes

The researcher sorted the different codes into potential themes and collated all the relevant coded citations within the identified themes. The researcher

generated the themes by reading the transcripts and identifying statements that enhanced the research focus. The themes were identified depending on the responses of the participants. However, some of the codes were related and therefore were combined to form primary themes.

- Testing emergent understandings

While phases two and three were under way, the process of evaluating the credibility of understanding and exploring themes through the data were done. Therefore, the researcher looked at how the themes derived from the data and were representative of it, and whether the research question has been well supported by the data.

- Defining and naming themes

The researcher defined and further determined what aspects of the data each theme captured. For each theme, the researcher identified what is of interest about the theme, the story that each theme tells considering that it is in relation to the research question and then wrote a relatively more detailed analysis within those themes.

- Producing the report

The researcher wrote a final report based on the findings from the data.

3.2.4 Enhancing the objectivity of the research process

The researcher was fully aware of her pivotal role in the research process. She was aware that her personal preferences or biases may interfere with the fair reception and treatment of the data. Thus, she remain close to the data by making sure that only the information provided by the participants was at the centre of interpretation. The researcher's supervisor inspected the data and the process of interpretation to ensure that the authentic voice of the respondents was the main source of information.

The researcher attempted to increase the validity of the research process by engaging in a number of activities already listed in 3.2.1-3.2.3. These are: (1) conducting the interviews in an environment that the respondents are familiar and comfortable with; (2) ensuring that the respondents are well aware of the nature of the research they are about to take part in; (3) making sure that field notes are made immediately after the interview whilst their memory was still fresh, and ensuring that the field notes reflect the interview accurately; and having the research supervisor to serve as an inspector of the information. Besides the supervisor, the researcher returned to some of the interviewees to verify and confirm some of the points. Although this practice is risky, since some respondents may suddenly change their utterances based on what they perceive to be what the study was about, it was nevertheless done. The researcher was careful to inspect the additional information for credibility.

In this section, the researcher was declaring *post facto* the role of reflexivity in the unfolding of her research. Elements of the method were introduced in an unsystematic way, although the intention was to render them effective in the research.

3.3.1 RESEARCH FINDINGS

The findings of the study will be presented in two sections. The first section briefly describes the demographic details of the sample, and the second provides the core results of the interview. Six themes were identified and they are as follows: (a) Participants' understanding of intellectual disability; (b) Disclosure of the disability as a result of schooling difficulties; (c) Reaction to the disclosure of the disability; (d) Challenging behaviour a child's integrated into the family system; (e) Unemployment and financial strains due to the child's condition; and (f) Community reactions: Social support and stigmatization.

3.3.2 Demographics

According to Table 1, respondents in this study consisted of 15 family caregivers, 14 of whom were females and one was male. The mean age of the respondents was 48 years with a range of 35 to 68 years. The mean age of children with an intellectual disability was 13 years with a range of 6 to 18 years. The family caregivers who participated in the study were mostly mothers, followed by grandmothers. All of the 15 family caregivers were living with their intellectually disabled children when the data were collected. On average the family structure consisted of five family members (mostly the primary caregiver and her care recipients). Eight (53%) of the 15 family caregivers were unemployed and only volunteered at the day care centre where their intellectually disabled children were enrolled. They were compensated with a stipend once in a while. Eight (53%) of the respondents were single mothers, and only three (20%) were married and living with their partners. Almost all (14 or 93%) of the respondents were each caring for at least one child with an intellectual disability. Some of the respondents (46%) mentioned that their intellectually disabled children also suffered from other illness such as epilepsy, attention deficit hyperactivity disorder (ADHD), Down syndrome, and others. All the intellectually disabled children were under the age of 18 years (see Table 1).

Table 1

Demographic information of the respondents (qualitative study)

Respondent no.:	Gender	Age	Relationship with child	Employment	No: of ID children in the households & their age & Gender	Marital status	Family size	ID children's Other illnesses
1	Female	52 years	Mother	Unemployed	1 child;18 years; Female	Single	5	n/a
2	Female	35 years	Mother	Employed	1 child;12 years; Male	Single	4	Epilepsy
3	Female	68 years	Grand mother	pensioner	1 child; 6 years; Male	widowed	3	Down syndrome
4	Female	65 years	Grand mother	pensioner	2 children; 8 & 12 years; Females	widowed	4	n/a
5	male	45 years	Father	Unemployed	1 child; 7 years; Male	Married	5	n/a
6	Female	38 years	Mother	Unemployed	1 child; 18 years; Male	Single	5	Epilepsy & ADHD
7	Female	65 years	Grand-mother	pensioner	1 child; 15 years; Male	Widowed	5	n/a
8	Female	46 years	Mother	Unemployed	1 child; 11 years; Female	Single	6	n/a
9	Female	68 years	Grand-mother	pensioner	1 child; 17 years; Male	Widowed	7	Epilepsy
10	Female	38 years	Mother	Unemployed	1 child 12 years; Female	Single	3	n/a

Respondent no.:	Gender	Age	Relationship with child	Employment	No: of ID children in the households & their age & Gender	Marital status	Family size	ID children's Other illnesses
11	Female	48 years	Mother	Employed	1 child; 16 years; Male	Single	4	Epilepsy & ADHD
12	Female	38 years	Mother	Employed	1 child; 17 years; Male	Single	5	n/a
13	Female	37 years	Guardian	Unemployed	1 child 14 years; Female	Single	5	n/a
14	Female	48 years	Mother	Unemployed	1 child; 17 years; Female	Married	7	Physical impairment
15	Female	42	Mother	Employed	1 child; 9 years; Male	Married	5	Epilepsy & Down syndrome

Note: ID = intellectually disabled

3.3.3 Participants' understanding of intellectual disability

When the respondents were asked to describe their psychological experiences of caring for their intellectually disabled children, the descriptions showed some understanding of intellectual disability. The knowledge was apparently gained through experience with their own intellectually disabled children. The respondents spontaneously referred to delayed milestones in areas of speech and walking. Some of them (33%; respondents №: 2, 3, 6, 7, & 15) indicated that their children started to walk at a later age, such as ages 2 and 3 years, with one citing the age of 9 years. They also indicated that there was impairment in adaptive behaviours, such as failure to take care of oneself, and limited adaptive functioning at home and at school. Some respondents (20%; respondents №: 2, 3, & 7) reported children experiencing a major problem with toilet training. Statements made by some of the family caregivers indicated the awareness of intellectual disability and the problems associated with caring for a child who is affected by the condition. For instance, one respondent put it as follows:

“My grandson started to walk at the age of 9 years; he was not able to do anything for himself. I was doing everything for him including taking him to the toilet, bathing him and carrying him wherever I go”
(Respondent №: 7, 65 years old).

Another respondent was even aware that her child has particular limitations and this was uncommon for the child's age. She said that her “... child is very slow to think and to understand, forgets easily and his mental capacity is not well-suited for his age” (Respondent №: 11, 48 years old).

The consequence of the children's condition, which the caregivers were aware of, was that some of them were not functioning well at school. They tended to repeat the same class several times because they lacked reading and writing skills. It became obvious during the course of the interviews that the respondents' understanding of the concept of intellectual disability was not based on any formal definition taught to them by professionals. They learnt

about the condition from observing and then interpreting the behaviour of their own children, something they learned over time.

3.3.4 Disclosure of the disability as a result of schooling difficulties

The majority of the respondents were not aware of their children's intellectual disability until later when the children went to school. The respondents were not informed or hinted about the condition of their children immediately following birth and earlier on. The formal disclosure of the mental disability was done after the family caregivers communicated suspicion and uncertainty about the child's cognitive condition and adaptability. In most cases the disclosures were done after the family caregivers took their children to school where educators noticed that the child was not performing well and advised parents to seek help from health professionals. A statement by respondent number 11 (48 years old) encapsulates this observation:

"I was not aware that my child is intellectually disabled until he went to (began attending) school. The school principal called me complaining that my child was not coping at school; he repeated one grade for several times. He does not even know how to read, write and copy what the educators write on the (writing) board. The principal recommended that we take the child to hospital, and the hospital psychologist confirmed that my child is intellectually disabled ... and that I am not responsible for any of the abnormal behaviours he exhibits".

3.3.5 Reaction to the disclosure of the disability

The respondents described their own and their extended family members' psychological reaction towards the disclosure of their children's mental disability. The respondents described a state of shock (Respondent no:15), frustration (Respondents №: 3, 4, 5, 8, 10 & 11), disappointment (Respondent no: 15), denial (Respondents №: 1, 3, 5, 6, 8, 11, 12 & 13), distress (Respondents №: 3, 4, 5, 7, 8, 9, 10, 13 & 15), fear (Respondents no: 4; 10 & 14) and confusion (respondents №: 3, 10 & 11) regarding the disability of their

children. One of the respondents also mentioned that she consulted “sangomas” (African traditional healers) thinking that her child’s condition was as result of bewitchment. She put it as follows:

“Finding out about the condition of my child was the most stressful situation I ever had. I used to shout at people, telling them not to look at my child. I even consulted with sangomas thinking that my child has been bewitched, hoping that if she got help in time she would be fine” (Respondent №: 8, 46 years old).

Confusion and being stressed out was described as follows:

“I was very confused, frustrated and stressed; not knowing what went wrong with my grandchild. I used to cry almost every day looking at my daughter and her intellectually disabled son, asking myself why it happened to my family and also what used to worry me is because he is my first grandson. What if I will never get another grandchild” (Respondent №: 3, 68 years old).

And another said:

“I was 18 years old when I gave birth to my child and do not even know the father. When I found out that my child is intellectually disabled, I became confused, frustrated and stressed because I was afraid that my friends would laugh at me. I decided to drop out of school because my mother was the only one who was keeping a job and looking after us at home. Therefore, my mother could not resign from work to look after my child. I used to fight with people if I heard that they were talking about my child. Having an intellectually disabled child derailed all my future and career plans, and changed my whole life” (Respondent №: 10, 38 years old).

The findings also revealed that most of the family caregivers also began to face issues such as: What kind of assistance is available for them? What will happen

to them and their children, and what other family members, friends and community members will say to them?

Most of the respondents (73%; respondents №: 1, 2, 3, 5, 6, 8, 9, 10, 11, 12, & 14) indicated that their extended families were very touched by the condition of the cognitively challenged children. However, some of them added that disclosure of the child's disability caused tension and conflict in the families. In some cases the extended family members were not happy and some went as far as blaming the mother for the condition of the child:

“When my parents found out that my child is intellectually disabled, they blamed me for it. They were saying that had I listened to them when they warned me about getting married to a man from a different ethnic group, my child would not be the way he is. I got married to a Venda man and I am originally Zulu. My in-laws also blamed me for the condition of the child. They did not want to have anything to do with my intellectually disabled child; during conversations they only wanted to know how my other children were doing and avoided mentioning the intellectually disabled one” (Respondent № 15: 42 years old).

However, it was not always the case that the mothers would be blamed and the children neglected. There were instances where family members volunteered to act as caregivers of the children. For instance, the sample of the study includes grandparents and a child's father. One respondent explained how her own mother expressed support for the child:

“When I told my mother about the condition of my child, she was very supportive and even encouraged me to go back to school and volunteered that she would look after my child while I'm at school.” (Respondent №: 11, 48 years old).

However, in some cases disclosure of the disability was met with shock and sadness, but also elicited support from some of the members of the extended

family. Statements made by some of the family caregivers during the interview support the conclusion:

“When members of my family found out that my grandson was intellectually disabled, everyone at home used to cry every-day when they looked at him. My daughter-in-law started to fight with me believing that I knew what was happening to her son. She never accepted that it is the will of God, she ended up divorcing my son and left me with the child”. (Respondent №: 9, 68 years old)

3.3.6 The challenge of integrating a child into the family system

Family caregivers who participated in the study expressed a view that their lives have been immensely affected due to the challenging behaviour of their intellectually disabled children, and also by the child’s presence in the household. The majority of the respondents (80%) isolated for special mention social and financial effects. The two effects were intertwined. Caregivers were compelled to take up the caregiving role on fulltime basis. Simultaneously, it meant that they could no longer visit with friends and relatives. Nevertheless, the reason for not visiting with the child was also related to practical considerations. Caregivers were concerned that taking their intellectually disabled children to relatives would affect them (relatives) because of the care that their children needed. Statements made by some of the family caregivers during the interview support this point:

“My child is 18 years old. She tends to be involved in intimate relationships and men take advantage of her and uses her for their sexual satisfaction. I have to go with her everywhere I go and I am no longer regularly going to community activities such as funerals, stokvels and even travelling far from home because I cannot afford to pay the taxi fare for both of us. My life changed since I gave birth to this child. I am no longer living the normal life that I used to live and sometimes this causes me stress” (Respondent № 1, 52 years old).

At the same time, arranging to leave the child at home presents a mammoth task for those who must take care of him. The caregiver has to take all this into consideration when arranging to be away from the child. This is how one of them put it:

“My child is not a person that you can leave alone at home. If there is no one at home, he just goes without informing anyone where he is going And then there are some of the community members who would give him drugs and alcohol. That’s the reason why I do not want to leave my son alone. When I have to go someplace I ask my mother to take care of him but I don’t have to spend much time away because my mother is also old” (Respondent № 6, 38 years old).

Everything boils down to making sure that the child fits into the family system in a manner that will suit all parties concerned.

3.3.7 Unemployment and financial strains due to the child’s condition

The study also found that in cases where parents were a married couple, one would have to sacrifice employment to accommodate the presence of a cognitively challenged child who requires extensive caretaking. The sacrifice is almost always taken by the mother, who will assume the care-taking role. In turn, the arrangement affects family income. Although some of the participants mentioned that their children were beneficiaries of a child disability grant offered by the Department of Social Development, it was not enough. It appeared as though a family could not depend on the grant only. The condition of the child was of such a nature that it put additional strain on the family, including financial difficulties. This is how the parents described it:

“My child’s condition needs special treatment and he is also allergic to some of the foods. I do not have enough money to provide him with everything that he needs. Nevertheless, he remains my first priority. After giving birth I decided to resign from work since there was no one to take care of my child” (Respondent №: 11, 48 years old).

Respondent number 11 went on to explain that because of her caregiving responsibilities, the financial situation of the family worsened, to a point that they had to depend on the child's disability grant and her mother's pension grant. In spite of having a source of income, they still would find themselves with little to eat. Respondent number 11 said she would then feed the cognitively challenged child first and whatever was left would then go to the other children.

Another respondent highlighted difficulties of having a cognitively challenged child in the family and its impact on her employment status and financial situation:

“My child suffers from epilepsy too. After giving birth I went back to work and hired a nanny to look after her. Almost every day the nanny would call me, saying that she was frightened. She was concerned that my child's development was irregular, and placed a great demand on her especially during epileptic attacks. I fired the nanny and got another to take over the caregiving task. She too complained. I then decided to resign from my employment to take care of my child” (Respondent № 15, 42 years old).

Almost half of the respondents mentioned that they volunteer at the day care centre where their children are cared for during the day. They say they do it so they can be able to monitor their own children while working. Respondents mentioned that although they are not getting much at the day care centre, at least they were able to buy some basic necessities for their families. Other essentials they have to cater for include: Fees for the day care centre, financing regular hospital visits, and special equipment to suit the needs of the child. Their unemployed status makes it difficult to meet the requirements.

3.3.8 Community reactions: Social Support and Stigmatization

Respondents mentioned that certain forms of social support were available while others were not. Most of the respondents (73%) received social support

from sources that include their extended family members, members of their church, neighbours and family friends (Respondents № 1, 2, 3, 5, 6, 8, 9, 10, 11, 12 & 14). Family members assisted with taking care of their intellectually disabled children. Some of the respondents (Respondents №: 5, 8, 10, 12 & 14) also reported that they were able to attend other family and community commitments because grandparents or neighbours looked after their children in their absence. The study found that respondents appreciated the way their extended families or family friends treated their intellectually disabled children.

“I am pleased that my neighbours and family friends do not discriminate against my children. They treat them as their own and they do not have any problems with my child playing with their children and it makes me believe that there is nothing wrong with my child, only that he is intellectually disabled” (Respondent №: 4, 65 years old).

Most of the respondents (11 out of 15) also reported that members in their respective churches supported them with prayers so that they can have strength to take care of their intellectually disabled children, and also encouraged them to accept and believe that having a child with an intellectual disability is the will of God.

“I receive support from the church. The pastor is concerned about the condition of my grandson. He once asked me why I always carried my grandson. I explained to him that he cannot walk and I do not have money to buy him a wheel chair. The pastor donated the wheel chair for my grandson ... and he even supports us with food every month” (Respondent №: 3, 68 years old).

Community members were found to be partially supportive. Almost half (47%) of the respondents (Respondents №: 1, 2, 3, 5, 12, 13 & 14) mentioned that some community members labelled their children, giving them offensive names, and unacceptable descriptions such as “crazy” or “mad”. They even said that since they had children with intellectual disability, some of the community members are no longer socializing with them and do not even pay them

visitations at their homes; those who still visit no longer bring along their children, mentioning that they (their children) will “be infected” with the intellectual disability.

The common view is that parents, caregivers and the children with intellectual disability live under stress because of being humiliated and stigmatized by some community members. The respondents left an impression that some of the people who do not have children with intellectual disability do not understand what parents with intellectually disabled children go through. Instead of being supportive, they add to their stress. Statements made by some of the family caregivers during the interview support this view:

“Some of the community members take advantage of our children by giving them heavy work, like fetching water for them from the community’s common tap, which is far from home, fixing their fences, digging trenches, and so on, justifying it by saying that the children do not get tired because they are ‘crazy’” (Respondent №: 6, 38 years old).

“The other day I was walking behind my child. I overheard these two women gossiping about my child, saying that she suffers from mental illness, unaware that I’m her mother. They even went on to ask her why she was not attending school with other normal children. When she replied that it was because at her school they taught her technical work, they just laughed at her and quipped: “That’s not true; it is because you’re crazy”. My child started to cry and ran to me” (Respondent №: 14, 48 years old).

Although family caregivers of children with intellectual disability mentioned certain forms of support that are available while taking care of their children, the study revealed that respondents in this study did not receive any clear information on how to look after their children and how to meet their specialized needs. There was no training offered on how to take care of the children. They reported that they acquired knowledge and skills on how to cope with their

intellectually disabled children through their interactions with the children themselves.

“I understood my child’s behaviour through the interaction with him. I also found out that my child needs attention all the time, and he gets angry easily. In order for me to make him happy, I have to give him what he want and if I do not have what he wants, I sit down with him and explain to him. By doing that it makes my situation easier” (Respondent №: 11, 48 years old).

The respondents indicated that although they were worried about the future of their intellectually disabled children and what will happen to them if they passed on, they are motivated to continue taking care of them because they want people to realize that intellectually disabled children are also human beings just like anyone else. They want the children to be happy, and attached to them. They say that the one thing that motivates them in their effort is the love that any parent has for her offspring.

“I love my child and if I do not take care of her who is going to?”
(Respondent №: 14, 48 years old).

3.4 DISCUSSION

3.4.1 Introduction

The qualitative component of the study was designed to determine the psychological experiences of family caregivers caring for children with intellectual disability, doing this from the point of view of the caregivers themselves. It investigated and analysed the challenges faced by family caregivers of intellectually disabled children and the support systems at their (family caregivers) disposal. A number of themes emerged from the open-ended, phenomenological interviews, including the caregivers’ understanding of intellectual disability, how the disability was disclosed by school authorities, the caregivers’ reaction to the disclosure, unemployment and financial

difficulties emanating from the condition, integrating the child into the family system, and the community's reaction to the intellectual disability of the child. Each of the themes will be discussed in the following subsections.

3.4.2 Participants understanding of intellectual disability

The current study concurs with Pilusa's (2006) findings regarding caregivers' understanding of the notion of intellectual disability. Respondents in this study understood the concept of intellectual disability from the interpretation of the behaviour of their own children over time. This was different to what Mbwilo, Smide and Aarts (2010) found in Tanzania, where the parents they interviewed did not have a good understanding of intellectual disability. A study conducted by Mohamed (2007) about the psychological health of mothers caring for mentally disabled children, found that receiving information on the disability and training in caring for a mentally disabled child reduces the risk of developing psychiatric morbidity in mothers of mentally disabled children. Mohamed (2007) further argues that many studies showed that providing adequate information on child disability and the availability of services along with caring skills training of dealing with a disabled child has a great impact on reducing the psychological distress among mothers of disabled children.

3.4.3 Disclosure of the disability as a result of schooling difficulties

Results of the present study were in line with research regarding the process of disclosing the child's illness to the parents. Many problems are not noticeable at birth but only develop or become noticeable as the child grows older (Kimpton, 1990). So was the case with parents in this study, who did not notice their children's cognitive limitations until the children were exposed to schooling. The discovery itself is not easy to accept (Dervishaliaj, 2013). Parents rarely expect their children to have a disabling condition or life-threatening illness (Dale, 1996). Wicks-Nelson and Israel (1997) observe that most parents expect their children to be attractive, witty and socially successful. Therefore, breaking the news about the child's disability, or parents discovering it themselves, can destroy their expectations and hopes for the children. The

diagnosis, whether early or later, is an immense crisis, necessitating a radical change of expectations, and is often accompanied by parents' intense reaction at first (Dale, 1996; Madala, 2014).

Other researcher (Pilusa, 2006) indicate that in some cases professionals do not inform parents about the disability of their children and leave it to the parents to discover for themselves. Similar results were observed in this study as it was found that some parents of children with intellectual disability were not informed early enough about the condition of their children. The formal disclosure of the disability was done after the parents and family caregivers communicated suspicion and uncertainty about the condition of the children. In some cases, it was educators raised the alarm and advised parents to seek help from health professionals. The diagnosis, whether at early or later, often creates an immense crisis, a radical change of expectations and hopes, often accompanied by parents' intense reaction at first (Dale, 1996).

3.4.4 Reaction to the disclosure of the disability

The initial discovery of the status (diagnosis) of a cognitively challenged child is stressful (Fortier, & Wanlass, 1984; Kromberg & Zwane, 1993). The discovery of a child's diagnosis was construed by some parents as "symbolic loss" worthy of being grieved (Madala, 2014; Negota & Mashegoane, 2012). Parent's reactions at the birth of a child with disabilities are based upon the belief that the grief they experience is the result of the loss of an expected "normal" child (Alper, Schloss & Schloss, 1994). In fact, parents go through a complex emotional process (Dervishaliaj, 2013). The reaction commences with surprise and shock, followed by frustration, confusion, denial and disappointment. Sometimes there are feelings of guilt, sorrow and helplessness (Szmukler et al., 1996). More or less similar reactions were found by Kromberg and Zwane (1993) in their study of Down syndrome among black mothers in South Africa. Indeed raising a child with mental disability has a profound impact on the family (Dyson, 1997).

Family caregivers come to acknowledge that the “normal” child they thought they had does not exist, and they are instead left with a child who may never be able to lead a normal life and, in some cases, who displays behavioural problems. Parents thus have to first deal with the fact that their child is different to other children, and will require special attention throughout his/her life. In Madala (2014), all respondents felt that, with their child’s abnormality, they had lost a perfect child. Thus, parents tend to mourn the loss of a desired normal child before accepting their real defective child (Fraser, Sines & Kerr, 1998).

Moreover, the persistence of an illness raises doubts as to what could be the cause, and hence a supernatural cause is eventually suspected which could either be God, evil spirits, ancestors or witches (Kromberg & Zwane, 1993). Pilusa (2006) indicated that parents interpret the event positively or negatively, that is, either being blessed or punished by God depending on their frame of reference. For those who suspect the play of malevolent forces, traditional healers become a natural destination (Pilusa, 2006). Moreover, Madala (2014) found that respondents paid a lot of money to traditional healers regarding their children, in spite of not realising healing or improvement to the condition of their children.

One of the parents’ concerns upon finding out about the child’s condition is the future. Although studies concur on this point, they nevertheless differ regarding the importance of the parents’ age. Heller et al., (1997) found that older parents scored significantly higher on measures of burden and concern about on-going responsibility and worries about the child’s future, while younger parents were significantly more burdened by behavioural problems and control and management issues. Divergent results were observed in this study as it was found that both younger and older respondents expressed similar feelings and concerns.

3.4.5 Unemployment and financial strains due to the child's conditions

Researchers have indicated that family caregivers of children with intellectual disability generally experience a variety of life problems and emotional difficulties. Beckman (1991) found that parents of intellectually disabled children experience stress due to economic problems of providing for a disabled child. It is not uncommon that a parent, especially the mother, may have to leave employment and assume the caring role on a full-time basis (Bumin, 2008; Marcenko & Meyer, 1991). Pilusa (2006) found that this affects family income and causes difficulties in caring for the child with a cognitive disability and other children, if there are any. In the South African context, unemployed caregivers may have to rely on the disability grant paid to the children by the state.

3.4.6 The challenge of integrating the child into the family system

Sanders and Morgan (1997) noted that raising a child with a mental disability is arguably one of the greatest stressors any parent can face. The respondents in this study expressed the fact that their lives have been affected due to the challenging behaviour that their intellectually disabled children have, and also by the presence of the child with intellectual disability in the family. However, Floyd et al. (1997) indicated that though the child's mental disability is a risk factor for behaviour problems, familial stress is associated with behaviour problems rather than with the disability itself. Other researchers (e.g., Berryman et al., 1994) found that caregivers are of the opinion that challenging behaviours are actions that are difficult to manage, as their causes (the behaviour) are unknown. The findings support Moss et al. (2000), in that a preponderance of problematic behaviours like self-injurious acts, aggression towards others, screaming, and inappropriate social and sexual conduct were present. The presence of the behaviours require that the caregiver's role change (Bulmin, 2008). Family caregivers' abilities in coping with the stress of caring for a child with mental or intellectual disability depends on their personal strength, social resources and support system. In addition, their beliefs are likely to have a significant impact on the process of care for children with intellectual disability

who engage in challenging behaviours (Moss et al., 2000). All of these may have to be adapted to the problem behaviours of the child. Other family members too may have to be prepared for the behaviour of the child.

3.4.7 Community reaction: Social support and stigmatization

Boyd (2002) contends that stress and depression are two main factors leading parents to seek social support. Family assistance can be one of the most useful sources of support, as family members may be more willing and able to provide influential and financial assistance. Most family caregivers in this study who receive social and financial support from their families, extended family members, church members and family friends coped better than those who did not receive any social support.

Institutions such as the church offer immense supportive benefits. Walsh and Pryce (2003; cf. Madala, 2014) state that advantages accruing from involvement in a faith community includes health and social benefits and support during difficult times. Caregivers in Glendy and Mackenzie's (1998) study stated that they deliberately sought out religious support, and that religious practices gave them peace of mind and helped them endure the caregiving situation. Family caregivers believe that prayer gives them strength to deal with caregiving challenges (Glendy et al., 1998). Family caregivers who reported greater helpfulness from sources of support report less parenting stress (Boyd, 2002).

In spite of the usefulness of social support and accompanying support networks, risks involved in placing faith in the supportiveness of communities and support systems are many. For instance, neighbours may not necessarily be forthcoming with social support (Pariante & Carpinello, 1996). The White Paper on an Integrated Disability Strategy (1997) mentions that experiences in the United States, United Kingdom and Europe have shown that a move away from institutionalization often results in people with mental disabilities becoming homeless and living on the streets with little or no community support. The public has a tendency to stereotype all people with a mental handicap as

completely lacking in social competence (Fraser, MacGillivray, & Green, 1991). In the worst case scenario, children with mental disabilities and their families are humiliated and stigmatized by community members (Corrigan, Watson, & Miller, 2006; Pilusa, 2006). That is why the White Paper for Social Welfare (1997) suggests that families in need should receive comprehensive protection and support from the state and civil society.

3.5 CONCLUSION

Available studies suggest that disclosure of the diagnosis of intellectual disability, and the subsequent caring is a strain, especially to mothers. In most cases caregivers have to change their roles and responsibility in order to accommodate the demands of caring for their child. It must not be assumed that there will be social support available for the child and caregiver. It is possible for them to be exposed to humiliation and stigmatisation in their respective communities. The respondents left an impression that people who do not have children with intellectual disability do not understand what parents with these type children go through. Instead of being supportive, they add to their stress.

CHAPTER 4

STUDY TWO: QUANTITATIVE RESEARCH APPROACH

4.1 INTRODUCTION

Study two used a quantitative, cross-sectional design to assess whether perceived stress measured with the perceived stress scale (PSS; Cohen & Williamson, 1988) and the multidimensional scale of perceived social support (MSPSS; Zimet, Dahlem, Zimet & Farley, 1988), could predict psychological well-being and life satisfaction, measured by the psychological general well-being index (PGWBI; Bech, 1993) and the satisfaction with life scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985) among family caregivers of children with an intellectual disability. All relevant instruments were included in a comprehensive questionnaire which was used to collect data.

4.2 POPULATION AND SAMPLE

The population of the study consisted of children enrolled at three day-care centres in the Makhado municipality, Vhembe district. Each of the first two centres had a total enrolment of children just below 40 and the third had 70 children. The researcher selected 100 participants who are caregivers of intellectually disabled children registered and attending stimulation classes at either one of the three day-care centres in Vhembe district. Those who participated in individual interviews were also included. Thirty parents each were recruited from the smaller day-care centres and 40 were recruited from the largest. The selection of the parents was also facilitated by the centre managers, who also hinted that they were making sure that the parents selected will be in a position to provide feedback, based on their cooperation and participation in the activities of the centres.

4.3 INSTRUMENTS

4.3.1 The data collection questionnaire

A questionnaire was constructed from established scales, incorporating a demographic component, and used to collect data. The questionnaire was translated into Tshivenda and Xitsonga languages by individuals who are competent speakers of both the vernaculars and English. The researcher, who also speaks the three languages, checked the translations and finalized them. The questionnaire consisted of two sections. The first included items asking for demographic details such as age, gender, number of siblings, highest level of education, occupation for family caregiver, relationship with the intellectually disabled child. The second section included established scales. Four scales were used to construct the final questionnaire used to collect data. They are each listed and discussed in the following subsections.

4.3.2 Psychological general well-being Index (PGWBI)

The PGWBI (Bech, 1993) was used to determine the level of psychological well-being and distress experienced by family caregivers of children with intellectual disability. The scale targets peoples' self-representations of an aspect of their general well-being. The PGWBI has 22 items rated on a Likert scale from 0 (most negative) to 5 (most positive). The 22 items instrument includes six dimensions: Anxiety, Depressed mood, Positive Well-being, Self-Control, General Health and Vitality. For each dimension, score is given by the sum of the relevant items and global score is calculated by the sum of the six dimension scores. The 22 items are frequently used to generate an overall index or total score for general well-being. No items score needs to be reversed because the direction of the score is the same for all, whatever the direction taken by the wording of the options (that is, a higher score is always positive).

Different scoring algorithms have been used. The original scoring for each item was 0—5, giving a possible global PGWBI score ranging of 0 (poor quality of

life) to 110 (good quality of life). The range for the dimensions score was also calculated. Anxiety score range from 0 to 25, depressed mood range from 0-15, Positive well-being range from 0-20, Self-control range from 0-15, General health range from 0-15 and Vitality range from 0-20. Furthermore, if the scores for 3 or more items are missing from anxiety, positive well-being or vitality, the score of the dimension as a whole is missing. For depressed mood, self-control and general health, the score of the dimension is missing if the scores for 2 or more items are missing. In clinical and health services research since the 1970's, there is substantial and consistent evidence for reliability and validity of the PGWBI as a measure of the intended concepts. The scale is reliable (Bech, 1993). The current study found a Cronbach's alpha value of 0.85 of the total PGWBI.

4.3.3 Perceived Stress Scale (PSS)

The PSS was developed by Cohen and Williamson (1988). There are three versions of the PSS. The original instrument is a 14-item scale (PSS-14) with 7 positive items and 7 negative items. Five years after the introduction of PSS-14, the scale was shortened to 10 items (PSS-10) using factor analysis based on data from 2,387 U.S. residents. A 4-item (PSS-4) version was also introduced as a brief version for situations requiring a very short scale or telephone interviews. The PSS-10 version was used in this study. The scale uses 10 self-appraisal items to evaluate the stressfulness of the respondent's life situation in the past month. Responses for each item is done on a five-point response scale, ranging from 0 (never) to 4 (Very often). PSS-10 scores are obtained by reversing the scores on the four positive items (4, 5, 7 and 8), for example, 0 = 4, 1 = 3, 2 = 2, and then summing across all 10 items. Scores can range from 0 to 40, with higher scores indicating greater stress.

The psychometric properties of the PSS were investigated by confirmatory factor analysis (construct validity), coefficient alpha (reliability) and by investigating relations with other measures of appraised stress. Cohen and William (1988) found a satisfactory coefficient alpha of 0.78 and the PSS scores were moderately related to responses on other measures of appraised stress,

as well as to measures of potential sources of stress as assessed by event frequency. Andreou et al. (2011) assessed the psychometric properties of the different versions of the PSS (PSS-4, PSS -10 and PSS -14) and investigating the relations with the Depression Anxiety and Stress scale (DASS-21 version) in a sample of the general Greek population. The study found a Cronbach's alpha value of 0.82 for the full scale for PSS-10 and PSS-14 and marginally satisfactory values of 0.69 for PSS-4. The current study found a Cronbach's alpha value of 0.58.

4.3.4 **Multidimensional Scale of Perceived Social Support (MSPSS)**

The MSPSS was developed by Zimet, Dahlem, Zimet and Farley (1988). The scale has 12 items that measure perceived support from three domains: family, friends and significant other. Respondents reported each item on a seven-point scale, ranging from 1 (very strongly disagree) to 7 (very strongly agree). Each item is scored 1-7 and the total score obtained by summing all 12 items, possible range for total is 7-84.

Adequate psychometric properties have been found with the MSPSS in several studies. Canty-Mitchell and Zimet (2000) investigated the MSPSS with a sample of urban adolescents and found internal reliability estimates of 0.93 for the total score and 0.91, 0.89 and 0.91 for family, friends and significant other subscales (respectively). Factor analysis confirmed the three-factor structure of the measure. The study conducted by Edwards (2004) showed that both the family and friends subscales demonstrated high internal consistency (0.88 and 0.90, respectively). The total MSPSS score demonstrated high internal consistency with an alpha of 0.86. Support for construct validity was found by evaluating correlation from a perceived family support subscale as well as a satisfaction with family measure. MSPSS was found to be a useful measure for assessing perceived social support (Edwards, 2004). The current study found a Cronbach's alpha value of 0.75, 0.72 and 0.79 for family, friends and significant other subscales (respectively).

4.3.5 **Satisfaction with Life Scale (SWLS)**

The SWLS developed by Diener et al. (1985) SWLS was used to measure family caregivers' life satisfaction. SWLS has 5 items scale designed to measure global cognitive judgements of one's life satisfaction. The participants indicate how much they agree or disagree with each 5 items using a 7-point scale that ranges from 1 (strongly disagree) to 7 (strongly agree). The reliability and validity of the SWLS have been assessed in several investigations. The exploratory and confirmatory factor analyses have indicated that the five elements of this scale provide a one factor solution (Arrindell, Meeuwesen & Huyse, 1991; Diener et al., 1985; Pavot, Diener, Colvin & Sandvik, 1991). The reliability estimate (Cronbach's alpha) in various studies range between 0.79 and 0.89 (Pavot et al., 1991). As expected, the SWLS has shown a negative correlation with depression, anxiety and general psychological disorders, and a positive correlation with other measures of well-being. Therefore, these results indicate that this scale is a reliable and valid measure of the cognitive component of judgments of subjective well-being. The results of a series of studies in Brazil confirmed the single factorial structure and reliability of the SWLS (Gouveia, Milfont, Nunes da Fonseca, & Pencan ha de Miranda Coelho, 2009). The current study estimated internal consistency reliability at a Cronbach's alpha value of 0.69.

4.4 **PROCEDURE**

The researcher obtained permission to access the day-care centres from the hospital where they were affiliated. Once permission was granted, the centre managers were approached and requested to provide access. The managers were willing to assist the researcher to contact the primary caregivers of the intellectually disabled children and helped to facilitate meetings with the caregivers. They made available lists of children enrolled at the day-care centres for activities such as stimulation classes. Letters of information and consent were directed to the identified primary caregivers of the enrolled children. All primary caregivers identified were willing to provide data for the study.

4.5. RESULTS

4.5.1 Introduction

This section will be presented in four sections. The first section will briefly describe the sample, the second is a preliminary analysis of the data, the third will report the outcomes of regression analysis, and the final section is a discussion and conclusion of the overall findings of the study.

Data were first prepared for analysis, and the Statistical Package for the Social Sciences (IBM SPSS-22) was used to analyse it. For instance, the four positive items (items 4, 5, 7, and 8) of the PSS were reverse scored based on Cohen and Williamson's (1988) directions. Once that was done, the final score was obtained by summing across all ten items. Composite scores for the PGWBI were computed for the six dimensions, namely: Anxiety, Depressed Mood, Positive Well-Being, Self-Control, General Health and Vitality. Additionally, an overall score was also computed as the sum of scores on the six dimensions. A composite score for the SWLS was also computed by summing all the items of the scale.

In order to explain the relationships between dependent variables (PGWBI and SWLS) and independent variables (PSS and MSPSS) a correlational analysis was done. The relationship observed between the dependent variable and independent variables suggest that there is a linear relationship between variables. Based on the relationship, regression analysis was deemed appropriate. Thus it was used to predict psychological wellbeing (PGWBI and SWLS) from stress and social support variables (PSS and MSPSS).

4.5.2 Demographics

The respondents in this study consisted of 100 family caregivers, of which 72% were female and 28% male (see Table 2). Most of the respondents (21%) were of the age 53-59 years, followed by 19% who were between the ages of 39-45 years and only 6% were of aged between 60-64 years. Most of the respondents (43%) had secondary level (Grade 8-12) as their highest level of education. The

majority of the respondents reported caring for at least one intellectually disabled child. The mean age of the children with an intellectual disability was 11.83 years with a range of 4 to 18 (Table 2).

Table 2
Sample demographics (quantitative study)

		Frequency	Percentage
Respondents' ages	18-24 years	14	14.0
	25-31 years	8	8.0
	32-38 years	13	13.0
	39-45 years	19	19.0
	46-52 years	10	10.0
	53-59 years	21	21.0
	60-66 years	6	6.0
	Above 66 years	9	9.0
Gender	Female	72	72.0
	Male	28	28.0
Highest education completed	No schooling	20	20.0
	Grade R—7	28	28.0
	Grade 8—12	43	43.0
	Diploma/Degree	8	8.0
		Mean	Range
Number of people in the household		5.86	2—11
Average age of intellectually disabled child		11.83 yrs.	4—18 yrs.
Number of intellectually disabled children		14	1—2

Note: Numbers in columns for each variable do not always add up to 100 because of missing values.

Skewness, kurtosis, mean and Cronbach's alphas of the study scales

The normality of the data and the psychometric properties of the scales were determined. This was done to ensure that the analysis is based on acceptable and good data. The skewness and kurtosis for each of the individual scales are within range. The standardized method was also used to detect outliers. Variables were transformed, and the standardized values inspected. None of them were ± 3 , meaning that there were no outliers. Scale reliability was also determined. The reliability levels of three of the PGWBI subscales were not acceptable. Items with low item-to-total correlations were identified and their removal improved reliability coefficient values. For the PGWBI scales, the full scale version had a high reliability estimate. The social support scales also recorded relatively high reliability coefficients (see Table 3).

Table 3**Skewness, kurtosis, mean and Cronbach's alphas of the study scales**

	Skewness	Kurtosis	Mean	SD	A	№ of items	α after correction
1. ANX	-0.369 (0.241)	0.481 (0.478)	10.190	3.760	0.567	5	
2. DEP	-0.430 (0.241)	-0.213 (0.478)	6.170	2.839	0.523	3	
3. PWB	-0.446 (0.241)	0.065 (0.478)	†6.660	2.413	0.312	‡4(3)	0.416
4. SC	-0.587 (0.241)	-0.240 (0.478)	†4.900	2.195	0.390	‡3(2)	0.501
5. GH	-0.751 (0.241)	0.323 (0.478)	†4.630	2.200	0.371	‡3(2)	0.428
6. VT	-0.422 (0.241)	-0.120 (0.478)	9.450	3.276	0.526	4	
7. PGWBI	-0.800 (0.241)	0.800 (0.478)	49.270	14.077	0.856	22	
8. Life Satisfaction	-0.608 (0.241)	0.061 (0.478)	24.180	5.345	0.690	5	
9. PSS	-0.741 (0.241)	0.760 (0.478)	18.780	5.293	0.584	10	
10. MSPSS Significant Other	-0.186 (0.241)	-0.563 (0.478)	20.070	4.804	0.791	4	
11. MSPSS Family	-0.294 (0.241)	0.570 (0.478)	21.320	4.320	0.752	4	
12. MSPSS Friend	-0.729 (0.241)	-1.057 (0.478)	18.889	4.551	0.727	4	

Note: α = Cronbach's Alpha

ANX = Anxiety, DEP = Depressed Mood, PWB = Positive Well-Being, SC = Self-Control, GH = General Health, VT = Vitality, PGWBI = Psychological General Well-Being Index, PSS = Perceived Stress Scale, MSPSS = Multidimensional Scale of Perceived Social Support.

† = The means and standard deviations after item-to-total correlation analysis.

‡ = Values in brackets are the number of items after removal of problematic items.

4.5.3 Preliminary analysis

Analysis began by correlating all the major variables of the study against each other. The results of the analysis are in the direction that the researcher expected. For instance, scales of the PGWBI are highly correlated with each other and the correlations with the total scale are even higher ($p \leq 0.05$; see Table 4). PSS-10 was positively related to PGWBI ($r = 0.744, p \leq 0.001$) and its subscales ($r = 0.506\text{--}0.647, p \leq 0.001$). On the other hand, PSS-10 was negatively related to life satisfaction, and the relationship was statistically significant ($r = -0.251, p \leq 0.05$). Nevertheless, the MSPSS Friend subscale was unrelated to PGWBI and its factors, but it was related to life satisfaction. MSPSS Significant Other and Family subscales led to lower experiences of PGWBI as expected. The relationships observed between the dependent variables (PGWBI and its subscales and life satisfaction) and the independent variable (PSS-10 and MSPSS), suggest that there is a linear relationship between the variables and regression analysis is appropriate.

Table 4**Correlation analysis between all the major variables of the study**

	1	2	3	4	5	6	7	8	9	10	11
1. ANX	1										
2. DEP	0.559***	1									
3. PWB	0.590**	0.498***	1								
4. SC	0.475***	0.476***	0.603***	1							
5. GH	0.531***	0.601***	0.506***	0.390**	1						
6. VT	0.530**	0.519**	0.531***	0.503***	0.578***	1					
7. PGWBI	0.813***	0.776***	0.795***	0.725***	0.762***	0.791***	1				
8. Life Satisfaction	-0.317***	-0.174†	-0.363***	-0.306***	-0.135	-0.303***	-0.348***	1			
9. PSS-10	0.647***	0.506***	0.611***	0.535***	0.517***	0.630***	0.744***	-0.251**	1		
10. MSPSS Significant Other	-0.365***	-0.344***	-0.338***	-0.347***	-0.267***	-0.485***	-0.465***	0.545***	-0.452***	1	
11. MSPSS Family	-0.417***	-0.383***	-0.397***	-0.400***	-0.366***	-0.406***	-0.509***	0.463***	-0.385***	0.742***	1
12. MSPSS Friend	0.124	0.112	-0.040	0.087	0.056	0.112	0.100	0.435***	0.084	0.289**	0.302***

Note: ANX = Anxiety, DEP = Depressed Mood, PWB = Positive Well-Being, SC = Self-Control, GH = General Health, VT = Vitality, PGWBI = Psychological General Well-Being Index, PSS = Perceived Stress Scale, MSPSS = Multidimensional Scale of Perceived Social Support.

† p -value ≤ 0.10 ; * p -value ≤ 0.05 ; ** p -value ≤ 0.01 , *** p -value ≤ 0.001

4.6 MAIN ANALYSES OF THE STUDY: THE PREDICTION OF WELLBEING AS MEASURED BY THE PGWBI (FULL-SCALE) AND ITS DIMENSIONS OF ANXIETY, DEPRESSED MOOD, POSITIVE WELL-BEING, SELF-CONTROL, GENERAL HEALTH AND VITALITY

4.6.1 The prediction of Anxiety (ANX)

Table 5a shows that perceived stress, as measured by the PSS-10, predicted Anxiety on its own in the first model ($\beta = -0.647, p \leq 0.001$). In the second model, Anxiety was predicted by both the PSS-10 ($\beta = -0.572, p \leq 0.001$) and the MSPSS Family support scores ($\beta = -0.197, p \leq 0.05$). The R^2 , which is considered a coefficient of determination, suggests that 45% of variation in Anxiety can be explained by PSS-10 and MSPSS Family support. However, the direction of influence of the independent variables differs. Whereas high PSS-10 scores tended to lead to the experience of elevated Anxiety experiences, high MSPSS Family support scores were associated with the experience of low Anxiety.

Table 5a
The prediction of Anxiety

Variables	Model 1	Model 2
Step 1:		
PSS-10	0.647***	0.572***
Step 2:		
MSPSS Family support		-0.197*
R ² (Adj. R ²)	0.419 (0.413)	0.452 (0.441)
ΔR ²	0.419	0.033
F	70.679	40.005

Note: * p -value ≤ 0.05 ; *** p -value ≤ 0.001

PSS = Perceived Stress Scale

MSPSS = Multidimensional Scale of Perceived Social Support

4.6.2 The prediction of Depressed Mood (DEP)

Depressed Mood was predicted by the PSS-10 scores ($\beta = 0.421, p \leq 0.001$) and the MSPSS Family support scores ($\beta = -0.221, p \leq 0.05$). The R^2 value means that 30% of the variation in Depressed Mood can be explained by perceived stress and MSPSS Family. However, the direction of the independent variables is not the same. Perceived stress contributes positively and MSPSS negatively to the equation. Put differently, whereas high PSS-10 scores tended to lead to the experience of elevated depressed mood experiences, high MSPSS Family support scores were associated with the experience of low depressed mood.

Table 5b**The prediction of Depressed Mood**

Variables	Model 1	Model 2
Step 1:		
PSS-10	0.506***	0.421***
Step 2:		
MSPSS Family support		-0.221*
R ² (Adj. R ²)	0.256 (0.248)	0.298 (0.283)
ΔR ²	0.256	0.042
F	33.722***	20.564***

Note: * p -value ≤ 0.05 ; *** p -value ≤ 0.001

PSS = Perceived Stress Scale

MSPSS = Multidimensional Scale of Perceived Social Support

4.6.3 The prediction of Positive Well-Being (PWB)

Positive Well-Being was predicted by both the PSS-10 ($\beta = -0.538, p \leq 0.001$) and the MSPSS Family support scores ($\beta = -0.190, p \leq 0.05$). The R^2 , which is considered a coefficient of determination, suggests that 41% of variation in Positive Well-Being can be explained by PSS-10 and MSPSS Family support. The observation implies that whereas high PSS-10 scores tended to lead to the experience of elevated Positive Well-Being experiences, high MSPSS Family support scores were associated with the experience of low Positive Well-Being.

Table 5c**The prediction of Positive Well-Being**

Variables	Model 1	Model 2
Step 1:		
PSS-10	0.611***	0.538***
Step 2:		
MSPSS Family support		-0.190*
R ² (Adj. R ²)	0.374 (0.367)	0.405 (0.392)
ΔR ²	0.374	0.031
F	58.492***	32.961***

Note: * p -value ≤ 0.05 ; *** p -value ≤ 0.001

PSS = Perceived Stress Scale

MSPSS = Multidimensional Scale of Perceived Social Support

4.6.4 The prediction of Self-control (SC)

Self-control was predicted by the PSS-10 scores ($\beta = 0.447, p \leq 0.001$) and the MSPSS Family support scores ($\beta = -0.228, p \leq 0.05$). Whereas high PSS-10 scores tended to lead to the experience of elevated Self-control experiences, high MSPSS Family support scores were associated with the experience of low Self-control.

Table 5d**The prediction of Self-control**

Variables	Model 1	Model 2
Step 1:		
PSS-10	0.535***	0.447***
Step 2:		
MSPSS Family support		-0.228*
R ² (Adj. R ²)	0.286 (0.279)	0.330 (0.317)
ΔR ²	0.286	0.044
F	39.286***	23.934***

Note: * p -value ≤ 0.05 ; *** p -value ≤ 0.001

PSS = Perceived Stress Scale

MSPSS = Multidimensional Scale of Perceived Social Support

4.6.5 The prediction of General health (GH)

General Health was predicted by the PSS-10 scores ($\beta = 0.441, p \leq 0.001$) and the MSPSS Family support scores ($\beta = -0.196, p \leq 0.05$). Whereas high PSS-10 scores tended to lead to the experience of elevated General health experiences, high MSPSS Family support scores were associated with the experience of low General Health.

Table 5e**The prediction of General health**

Variables	Model 1	Model 2
Step 1:		
PSS-10	0.517***	0.441***
Step 2:		
MSPSS Family support		-0.196*
R ² (Adj. R ²)	0.267 (0.259)	0.300 (0.285)
ΔR ²	0.267	0.033
F	35.690***	20.768***

Note: * p -value ≤ 0.05 ; *** p -value ≤ 0.001

PSS = Perceived Stress Scale

MSPSS = Multidimensional Scale of Perceived Social Support

4.6.6 The prediction of Vitality (VT)

Table 5f shows that perceived stress, as measured by the PSS-10, predicted Vitality on its own in the first model ($\beta = 0.630, p \leq 0.001$). In the second model Vitality was predicted by both the PSS-10 ($\beta = 0.516, p \leq 0.001$) and the MSPSS Significant other support scores ($\beta = -0.252, p \leq 0.01$). The R^2 , which is considered a coefficient of determination, suggests that 45% of variation in Vitality can be explained by PSS-10 and MSPSS Significant other support. However, the direction of influence of the independent variables differs. Whereas high PSS-10 scores tended to lead to the experience of elevated Vitality experiences, high MSPSS Significant other support scores were associated with the experience of low Vitality.

Table 5f
The prediction of Vitality

Variables	Model 1	Model 2
Step 1:		
PSS-10	0.630***	0.516***
Step 2:		
MSPSS Significant Other		-0.252**
R ² (Adj. R ²)	0.396 (0.390)	0.447 (0.436)
ΔR ²	0.396	0.051
F	64.367***	39.198***

Note: **p*-value ≤ 0.05; ***p*-value ≤ 0.01; ****p*-value ≤ 0.001

PSS = Perceived Stress Scale

MSPSS = Multidimensional Scale of Perceived Social Support

4.6.7 The prediction of psychological wellbeing as measured by the full-scale PGWBI

Table 5g shows that perceived stress, as measured by the PSS-10, predicted the full-scale PGWBI on its own in the first model ($\beta = 0.744, p \leq 0.001$). In the second model the full-scale PGWBI was predicted by both the PSS-10 ($\beta = 0.644, p \leq 0.001$) and the MSPSS Family support scores ($\beta = -0.261, p \leq 0.001$). The R^2 suggests that 61% of variation in the full-scale PGWBI can be explained by PSS-10 and MSPSS Family support. However, the direction of influence of the independent variables differs. Whereas high PSS-10 scores tended to lead to the experience of elevated general wellbeing as measured by the full-scale PGWBI, high MSPSS Family support scores were associated with the experience of low PGWBI.

Table 5g**The prediction of full-scale PGWBI**

Variables	Model 1	Model 2
Step 1:		
PSS-10	0.744***	0.644***
Step 2:		
MSPSS Family		-0.261***
R ² (Adj. R ²)	0.554 (0.549)	0.612 (0.604)
ΔR ²	0.547	0.058
F	121.732***	76.475***

Note: **p*-value ≤ 0.05; ****p*-value ≤ 0.001

PSS = Perceived Stress Scale

MSPSS = Multidimensional Scale of Perceived Social Support

4.6.8 The prediction of life satisfaction

In Table 5h, the “usual suspect” did not feature in the model; life satisfaction was predicted by social support variables in exclusion of perceived stress. The table shows that MSPSS Friend measured social support predicted life satisfaction on its own in the first model ($\beta = 0.435$, $p \leq 0.001$). In the second model, life satisfaction was predicted by both the MSPSS Friend ($\beta = 0.303$, $p \leq 0.001$) and the MSPSS Significant Other support scores ($\beta = 0.457$, $p \leq 0.001$). The R^2 suggests that 38% of variation in life satisfaction can be explained by MSPSS Friend and MSPSS Significant other support. The direction of influence of both of the independent variables was the same; it was positive. This means that MSPSS Friend and MSPSS Significant other scores tended to lead to higher levels of life satisfaction.

Table 5h**The prediction of life satisfaction**

Variables	Model 1	Model 2
Step 1:		
MSPSS Friend	0.435***	0.303***
Step 2:		
MSPSS Significant other		0.457***
R ² (Adj. R ²)	0.189 (0.181)	0.381 (0.368)
ΔR ²	0.189	0.192
F	22.875***	29.821***

Note: **p*-value ≤ 0.05; ****p*-value ≤ 0.001

MSPSS = Multidimensional Scale of Perceived Social Support

4.7 DISCUSSION

The quantitative study examined the predictors of psychological general well-being and life satisfaction experiences of family caregivers of children with intellectual disability. Based on the stress process model (Pearlin et al., 1990), this study assessed the extent to which caregiver's psychological general well-being and satisfaction with life are predicted by perceived stress and social support. In general, correlation results found that the PSS-10 measured perceived stress was positively associated with the PGWBI General well-being and its components, and negatively associated with life satisfaction. It was negatively associated with the significant other and family components of the MSPSS and unrelated to the friends' component. The MSPSS significant other and family supports were negatively related to stress and general well-being and its components, and positively related to life satisfaction. MSPSS friends was not related to general well-being and any of its components, but was positively related to life satisfaction. The associations are mostly in the expected direction.

When all the variables of the study are entered into regression models, psychological general well-being and most of its components (Anxiety, Depressed mood, Positive well-being, General health and Self-control) are predicted by perceived stress and MSPSS family support. The exceptions were Vitality and life satisfaction. Vitality was predicted by perceived stress in the first step and Significant other in the second step. Life satisfaction was the only dependent variable that featured Friends support in its model, the latter acting as the predictor in the first step, and significant other was added as a predictor in the second step of the regression model. The discussion addresses the prediction of PGWBI and its components and life satisfaction as follows:

A number of studies have shown that in most cases, caregivers of children with developmental disabilities, including intellectual disability, experience stress because of their caregiving role (Azar & Badr, 2006; Dervishaliaj, 2013; Duvdevany, & Abboud, 2003; Floyd & Gallagher, 1997; Weiss, Sullivan, &

Diamond, 2003). The stress is attributed to factors such as problem behaviours among the children (Baker, McIntyre, Blancher, Crnic, Edelbrock, & Low, 2003; Ki & Joanne, 2014). Most caregivers eventually succumb to considerable physical and psychological strains, including depression and anxiety (Baker et al., 2003; Emerson, 2003, Glidden & Schoolcraft, 2003; Piquart & Sörenson, 2003a, 2003b; Yiengprugsawan, Harley, Seubsman, & Sleight, 2012). One of the variables found to ameliorate the experience of strain is social support. However, not all types of social support are useful.

In this study the role of social support in the relationship between stress and psychological wellbeing was investigated among caregivers of children who have intellectual disability (Boyd, 2002). The MSPSS was used since it measures social support as provided by three sources, namely, significant others, family and friends. The results showed that social support does have an inverse relationship with distress among caregivers, as found in previous studies (Gray & Holden, 1992; Weiss, 2002; White & Hastings, 2004). However, not all forms of social support featured prominently. The family type of support (MSPSS family) featured in most of the regression models involving PGWBI dimensions.

Two types of support, namely, significant other and friends, did not feature consistently as factors reducing the impact of stress on negative outcomes. It seems that the responsibility of caretaking often falls on one parent, most often the mother. Thus, a significant other does not feature as a source of support. Regarding friends, it is possible that caregivers do not solicit support from friends, and they do not perceive them to be a source of support. Studies conducted in non-Western countries suggest that caregivers tend to perceive others as judgemental of their situation (Ambikile, & Outwater, 2012; Mbwilo et al., 2010). For that reason, they experience self-stigma (Corrigan et al., 2002) and keep their cared-for children away from the view of others. It is likely that they may tend to perceive friends with suspicion when it comes to their children who are intellectually disabled.

Significant others did not feature in the prediction of most aspects of psychological wellbeing. Mothers are likely to see their partners as not involved in the care of their intellectually disabled children, since they are the ones who mainly carry the burden of caring. Nevertheless, significant other support, together with support from friends, predicted life satisfaction. It seems that the two types of support are not completely useless in the context of caregiving to intellectually disabled children.

4.8 **General Discussion**

The qualitative study was conducted first to explore the subjective experiences of providing care to a child who has an intellectual disability. The quantitative study was meant to explore specific aspects of caregiving, mainly the consequences of caregiving and the possible mediating role played by social support. Family support emerged as an important factor in the relationship between the stress experienced by caregivers and aspects of psychological well-being. Quantitative results seem to confirm the findings of the qualitative study. Friends did not feature much in the quantitative study as a moderating factor, seemingly reflecting the lack of social support from friends articulated by family caregivers. This is not uncommon in the African context, where observations are made to the effect that not all sources of social support are helpful to the recipient (Ambikile, & Outwater, 2012; Mbwilo et al., 2010). Social support systems can be seen as negative and detrimental. This idea is not new in the studies of social support systems (Pariante & Carpinello, 1996).

Surprisingly, support from friends, together with support from significant others, predicted life satisfaction in the quantitative study. It could be because life satisfaction can be influenced by many factors, including social support systems (Diener, Inglehart, & Tay, 2013). This means that it might be premature to disregard social support systems in the context of intellectual disability caregiving. Most likely, the concept needs to be re-conceptualized in a manner that it will suit the context.

4.9 **Conclusion**

The results of the quantitative study show that PSS-10 predicted psychological wellbeing, as measured by the PGWBI and its subscales, and predicted mainly by social support emanating from the family. Significant other support and support from friends are limited in their prediction, having only featured in the prediction of life satisfaction only.

4.10 **Limitations**

The sample used in this study was ethnically limited since respondents were only blacks from only two ethnic groups, namely, Tshivenda and Xitsonga speakers. Thus, the findings cannot be generalised to other 'race' or ethnic groups in South Africa.

Furthermore, another limitation was that respondents were recruited in the special school setting, as opposed to the clinical or community setting. This means that the experiences of family caregivers of children with intellectual disability who are not enrolled in special schools have not been tapped. Therefore, in interpreting results, this has to be borne in mind. Also, only one male family caregiver was included in the qualitative sample of the study. According to Heller et al. (1997), most caregivers are women, and in some conditions, female caregivers experience more stress than males (Boyd, 2002). Thus, with only a single male caregiver interviewed, comparison of family caregivers' experiences by gender could not be explored.

Of course the model of the quantitative study was basic, having excluded some of the variables that could have provided even better clarity about variables at play. Factors such as parenting style, caregiver-care-recipient interactions would have provided an even better understanding of the relationships between variables.

The quantitative study used the PSS-10 to measure stress among caregivers. Scales measuring stress specific to caregivers would be the best option in future studies.

4.11 Recommendations

Aside from the recommendations related to study designs, there are policy aspects that have to be highlighted in the recommendations. They are as follows:

- There is a need for health professionals to consider disclosing and communicating the mental disability of the child with the parents immediately after birth.
- The Department of Social Development should communicate more effectively the financial assistance available for caregivers and children with cognitive disabilities.
- Relevant health professionals (for example, psychologists and social workers) need to educate and train caregivers of children with an intellectual disability on the technical aspects of caring for children with the condition.
- Relevant government departments such as the Departments of Health and Social Development need to work with relevant non-governmental organizations (NGO's) to raise more awareness and outreach programmes, especially at a community level in order to educate and sensitize the public about intellectual disability, its causes and implications of stigmatizing and isolating children with intellectual disability and their families.
- Relevant health professionals should facilitate and encourage the establishment of home-based care and caregiver support groups in order to support and monitor the progress of coping with caring for children with intellectual disability.

REFERENCES

- Alper, S. K., Schloss, P. J., & Schloss, C. N. (1994). *Families of students with disabilities: Consultation and advocacy*. Needham Heights, MA: Allyn and Bacon.
- Ambikile, J. S., & Outwater, A. (2012). Challenges of caring for children with mental disorders: Experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam—Tanzania. *Child & Adolescent Psychiatry & Mental Health*, 6(16), 1-16. Retrieved on 24 May 2014 from <http://www.capmh.com/content/6/1/16>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Arlington, VA: Author.
- Andreou, E., Alexopoulos, E. C., Lionis, C., Varvogli, L., Gnardellis, C., Chrousos, P. G., & Darviri, C. (2011). Perceived Stress Scale: Reliability and validity study in Greece. *International Journal of Environmental Research & Public Health*, 8(8), 3287-3298.
- Aranda, M. P., & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *Gerontologist*, 37(3), 342-354.
- Arrindell, W. A., Meeuwesen, L., & Huyse, F. J. (1991). The Satisfaction with Life Scale (SWLS): Psychometric properties in a non-psychiatric medical outpatients sample. *Personality & Individual Differences*, 12, 117-123.
- Auslander, W. F., Bubb, J., Rogge, M., & Santiago, J. V. (1993). Family stress and resources: Potential areas of intervention in children recently diagnosed with diabetes. *Health & Social Work*, 18, 101–113.

- Azar, M., & Badr, L. K. (2006). The adaptation of mothers of children with intellectual disability in Lebanon. *Journal of Transcultural Nursing*, 17(4), 375-380.
- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47(4/5), 217-230.
- Baxter, C., Cummins, R. A., & Yiolitis, L. (2000). Parental stress attributed to family members with and without disability. A longitudinal study. *Journal of Intellectual & Developmental Disability*, 25(2), 105-118.
- Blacher, J., & Baker, B. L. (2007). Positive impact of intellectual disability on families. *American Journal of Mental Retardation*, 112, 330-348.
- Bech, P. (1993). *Rating scales for psychopathology, health status and quality of life*. New York, N.Y.: Springer-Verlag.
- Beckman, P. L. (1991). Comparison of mothers' & fathers' perceptions of the effect of young children with and without disability. *American Journal of Mental Retardation*, 95(5), 585-595.
- Berryman, J., Evans, I. M., & Kalbag, A. (1994). The effects of training in non-invasive behaviour management on the attitudes & understanding of direct care staff. *Journal of Behaviour Therapy & Experimental Psychiatry*, 25(3), 241-250.
- Borthwick-Duffy, S. A. (1994). Prevalence of destructive behaviors: A study of aggression, self-injury and property destruction. In T. Thompson and D. B. Gray (Eds.), *Destructive behaviour in developmental disabilities: Diagnosis and treatment* (pp. 3-23). Thousand Oaks, CA: SAGE.
- Bowers, B. J. (1987). Intergenerational caregiving—Adult caregivers and their aging parents. *Advances in Nursing Science*, 2(2), 20-31.

- Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism & Other Developmental Disabilities*, 17(4), 208-215.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Brown, S., & Birtwistle J. (1998). People with schizophrenia and their families: Fifteen-year outcome. *British Journal of Psychiatry*, 173,139-144.
- Bumin, G., Gunal, A., & Tukul, S. (2008). Quality of life in mothers with disabled children. *Medical Journal of Suleyman Demirel University*, 15(1), 6-11.
- Burke, M. M., & Laramie, J. A. (2004). *Primary care of the older adult: A multidisciplinary approach (2nd ed.)*. St. Louis, MO: Elsevier Mosby.
- Canty-Mitchell, J., & Zimet, G. D. (2000). Psychometric properties of the Multidimensional Scale of Perceived Social Support in urban adolescents. *American Journal of Community Psychology*, 28, 391-400.
- Caruth, G. D. (2013). Demystifying mixed methods research design: A review of the literature. *Mevlana International Journal of Education*, 3(2), 112-122.
- Cohen, S., (1988). Perceived stress in a probability sample of the United States. In S. Spacapan & S. Oskamp (Eds.), *The social psychology of health: Claremont symposium on applied social psychology* (pp. 31-67). Thousand Oaks, CA: SAGE.
- Cook, J. A., Lefley, S. A., & Cohler, B. J. (1994). Age and family burden among parents of offspring with severe mental illness. *American Journal of Orthopsychiatry*, 64, 435-447.

- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science & Practice*, 9, 35–53.
- Corrigan P. W., Watson A. C., & Miller F. E. (2006). Blame, shame, and contamination: The impact of mental illness and drug dependence stigma of family members. *Journal of Family Psychology*, 20, 239–246.
- Dale, N. (1996). *Working with families of children with special needs: partnership and practice*. London, England: Routledge.
- Dave, D., Mittal, S., Tiwari, D., Parmar, M., Gedan, S., & Petal, V. (2014). Study of anxiety and depression in caregivers of intellectual disabled children. *Journal of Research in Medical & Dental Science*, 2(1), 8-13.
- Dervishaliaj, E. (2013). Parental stress in families of children with disabilities: A literature review. *Journal of Educational & Social Research*, 3(7), 579-584.
- Diener, E., Inglehart, R., & Tay, L. (2013). Theory and validity of life satisfaction scales. *Social Indicators Research*, 112, 497-527.
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment*, 49, 71-75.
- Drentea, P. (2007). Caregiving. In G. Ritzer (Ed.), *Blackwell encyclopaedia of sociology*. [Caregiving]. Blackwell Reference Online. Retrieved on 24 May 2014 from: <http://www.blackwellreference.com/subscriber/book>.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37(1), 39-52.

- Dunkin, J. J., & Anderson-Hanley, C. (1998). Dementia caregiver burden: a review of the literature and guidance for assessment and intervention. *Neurology*, *51*, 53-60.
- Duvdevany, I., & Abboud, S. (2003). Stress, social support and well-being of Arab mothers of children with intellectual disability who are served by welfare services in northern Israel. *Journal of Intellectual Disability*, *47*, 264-272.
- Dyson, L. L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning, and social support. *American Journal of Mental Retardation*, *102*(3), 267-279.
- Edwards, L. (2004). Measuring perceived social support in Mexican American youth: Psychometric properties of the Multidimensional Scale of Perceived Social Support. *Hispanic Journal of Behavioural Science*, *26*(2), 187-194.
- Edwards, L. M., & Lopez, S. J. (2006). Perceived family support, acculturation, and life satisfaction in Mexican American youth: A mixed-methods exploration. *Journal of Counselling Psychology*, *53*(3), 279-287.
- Emerson, E. (2003). Mothers of children and adolescents with intellectual disabilities: Social and economic situation, mental health status and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disabilities Research*, *47*(Pt. 4-5), 385-399.
- Emerson, E. (2001). Challenging behaviour. *Analysis & intervention in people with severe intellectual disabilities*. (2nd ed.). Cambridge, England: Cambridge University.
- Greenberg, J. S., Seltzer, M. M., Krauss, M. W., & Kim, H.-W. (1997). The differential effects of social support on the well-being of aging mothers of adults with mental illness or mental retardation. *Family Relations*, *46*, 383-394.

- Falloon, I. R., & Shanahan, W. (1990). Community management of schizophrenia. *British Journal of Hospital Medicine*, *43*, 62–66.
- Falloon, I. R., & Fadden, G. (1993). *Integrated mental health care*. Cambridge, England: Cambridge University.
- Fischer, M. (1990). Parenting stress and the ADHD child. *Journal of Clinical Child Psychology*, *19*, 337-346.
- Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-aged children with disabilities and behaviour problems. *Family Relations*, *46*(4), 359-371.
- Fortier, L. M., & Wanlass, R. L. (1984). Family crisis following the diagnosis of a handicapped child. *Family Relations*, **33**, 13-24.
- Fraser, W. I., MacGillivray, R. C., & Green, A.M. (1991). *Hallas'- Caring for people with mental handicaps* (8th ed.). Oxford, England: Butterworth Heinemann.
- Fraser, W., Sines, D., & Kerr, M. (1998). *Hallas'- The care of people with intellectual disabilities* (9th ed.). Oxford, England: Butterworth Heinemann.
- Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disabilities Research*, *53*(12), 981-997.
- Glendy, S. H. I., & Mackenzie, A. E. (1998). Caring for relatives with serious mental illness at home: The experiences of family cares in Hong Kong. *Archives of Psychiatric Nursing*, *12*(5), 288-294.
- Glidden, L. M., & Schoolcraft, S. A. (2003). Depression: Its trajectory and correlates in mothers rearing children with intellectual disability. *Journal of Intellectual Disabilities Research*, *47*(Pt. 4-5), 250-263.

- Gouveia, V., Milfont, T., Nunes da Fonseca, P., & Pencan ha de Miranda Coelho, J. (2009). Life satisfaction in Brazil: Testing the psychometric properties of the Satisfaction with Life Scale (SWLS) in five Brazilian samples. *Social Indicators Research, 90*, 267-277.
- Gray, D. E., & Holden, W. J. (1992). Psycho-social well-being among the parents of children with autism. *Journal of Intellectual & Developmental Disability, 18*, 83-93.
- Greenberg, J. S., Seltzer, M. M., & Krauss, M. W. (1997). The differential effects of social support on the well-being of aging mothers of adults with mental illness or mental retardation. *Family Relations, 46*, 383-394.
- Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods, 3*(1). Article 4. Retrieved on 23 April, 2014 from <http://www.ualberta.ca/~iiqm/backissue/3-1/pdf/groenewald.pdf>
- Guy, R. F. (1987). *Social research methods: Puzzles and solutions*. London, England: Allyn & Bacon.
- Hahlweg, K., & Wiedemann, G. (1999). Principles and results of family therapy in schizophrenia. *European Archives Psychiatry Clinical Neuroscience, 249*, 108–115.
- Hallum, A., & Krumboltz, J. D. (1993). Parents caring for young adults with severe physical disabilities: Psychological issues. *Developmental Medicine & Child Neurology, 35*, 24-32.
- Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405-418.

- Hastings, R. P., & Brown, T. (2002). Behavioural knowledge, causal beliefs and self-efficacy as predictors of special educator's emotional reactions to challenging behaviours. *Journal of Intellectual Disability Research*, 46, 144–150.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with development disabilities. *American Journal of Mental Retardation*, 107, 116-127.
- Hawranik, P. G., & Strain, L. A. (June, 2000). *Health of informal caregivers: Effects of gender, employment, and use of home care services*. Accessed from www.pwhce.ca/pdf/informal-care/informal_report.PDF
- Heller, T., Hsieh, K., & Rowitz, L. (1997). Maternal and paternal care giving of persons with mental retardation across life span. *Family Relations*, 46(4), 407-415.
- Hermanns, M., & Mastel-Smith, B. (2012). Caregiving: A qualitative concept analysis. *The Qualitative Report*, 17(Art. 75), 1-18.
- Herman, S. E., & Thompson, L. (1995). Families' perception of their resources for caring for children with developmental disabilities. *Mental Retardation*, 33, 73-83.
- Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, 50, 874-882.
- Hill, C., & Rose, J. (2009). Parenting stress in mothers of adults with intellectual disability: parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 53(12), 969-980.

- Khamis, V. (2007). Psychological distress among parents of children with mental retardation in the United Arab Emirates. *Social Science & Medicine*, 64(4), 850–857.
- Ki, Y. W., & Joanne, C. C. Y. (2014). Stress and marital satisfaction of parents with children with disabilities in Hong Kong. *Psychology*, 5, 349-357. <http://dx.doi.org/10.4236/psych.2014.55045>
- Kim, H. W., Greenberg, J. S., Seltzer, M. M., & Krauss, M. W. (2003). The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research*, 47(4), 313-327.
- Kimpton, D. (1990). *A special child in the family—Living with your sick or disabled child*. London, England: Sheldon.
- Kromberg, J. G. R. & Zwane, E. (1993). Down syndrome in the black population in the Southern Transvaal. *Southern African Journal of Child & Adolescent Mental Health*, 5(1), 30-33. **Doi:**[10.1080/16826108.1993.9631498](https://doi.org/10.1080/16826108.1993.9631498)
- Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontologist*, 44, 61-71.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50(3), 172-183.
- Louw, D. A., & Edwards, D. J. A. (1997). *Psychology: An introduction for students in Southern Africa*. (2nd ed.). Johannesburg, South Africa: Heinemann.
- Madala, S. T. M. (2014). *Resilience factors in low-income African families of children with Down syndrome* (unpublished dissertation). Polokwane, South Africa: University of Limpopo.

- Madianos, M., Economou, M., Dafni, O., Koukia, E., Palli, A., & Rogakou, E. (2004). Family disruption, economic hardship and psychological distress in schizophrenia: Can they be measured? *European Psychiatry, 19*(7), 408-414.
- Magliano, L., Fadden, G., Economou, M., Xavier, M., Held, T., Guarneri, M., ... & Maj, M. (1998). Social and clinical factors influencing the choice of coping strategies in relatives of patients with schizophrenia: Results of the BIOMED I study. *Social Psychiatry & Epidemiology, 33*, 413-419.
- Majerovitz, S. D. (2007). Predictors of burden and depression among nursing home family caregivers. *Aging & Mental Health, 11*(3), 323-329.
- Marcenko, M. O., & Meyer, J. C. (1991). Mothers of children with developmental disability: Who shares the burden? *Family Relations, 40*, 186-190.
- Marshall, C., & Rossman, G. B. (1999). *Designing qualitative research* (3rd ed.). London, England: SAGE.
- Mbugua, M. N., Kuria, M. W., & Ndetei, D. M. (2011). The prevalence of depression among family caregivers of children with intellectual disability in a rural setting in Kenya. *International Journal of Family Medicine, 1*, 1-5.
- Mbwilo, G. S. K., Smide, B., & Aarts, C. (2010). Family perceptions in caring for children and adolescents with mental disabilities: A qualitative study from Tanzania. *Tanzania Journal of Health Research, 12*(2), 1-12. Accessed from www.ajol.info/index.php/thrb/article/view/56400
- McFarlane, W. R. (1994). Multiple-family groups and psychoeducation in the treatment of schizophrenia. *Mental Health Services, 62*, 13–22.
- McFarlane, W. R., Dushay, R. A., Stastny, P., Deakins S. M., & Link, B. (1996). A comparison of two levels of family-aided assertive community treatment. *Psychiatry Service, 47*, 744–750.

- Melson, G. F., Windecker-Nelson, E., & Schwarz, R. (1998). Support and stress in mothers and fathers of young children. *Early Education & Development, 9*(3), 263-281.
- Merriam-Webster. (2010). Caregiving. Retrieved from <http://www.merriam-webster.com/dictionary/caregiver>
- Ministry for Welfare and Population Development. *White paper for Social Welfare. Notice 1108 of 1997. Government gazette, 386*(18166). Pretoria, South Africa: Government Printer.
- Mockus Parks, S., & Novielli, K. D. (2000). A practical guide to caring for caregivers. *American Family Physician, 16*(12), 2613-2620.
- Mohamed, G. (2007). Psychological health of mothers caring for mentally disabled children in Qatar. *Journal of Neurosciences, 12*(4), 312-317.
- Moss, S., Emerson, E., Kiernan, C., Turner, S., Hatton, C., & Alborz, A. (2000). Psychiatric symptoms in adults with learning disability and challenging behaviour. *British Journal of Psychiatry, 177*(5), 452–456.
- Mueser, K. T., Sengupta, A., Schooler, N. R., Bellack, A. S., Xie, H., Glick, I. D., & Keith, S. J. (2001). Family treatment & medication dosage reduction in schizophrenia: Effects on patient social functioning, family attitudes, and burden. *Journal of Consulting & Clinical Psychology, 69*, 3–12.
- Murphy, N. A., Caplin, B., & Young, P. C. (2006). The health of caregivers for children with disabilities: caregiver perspectives. *Child: Care, Health & Development, 33*(2), 180-187.
- Negota, A. J., & Mashegoane, S. (2012). Mothering children with schizophrenia in a village setting: A multiple case study. *Journal of Psychology in Africa, 22*, 259–262.

- Pakenham, K. I., Sofronoff, K., & Samios, C. (2005). Adjustment in mothers of children with Asperger syndrome. *Autism, 9*, 191-212.
- Pariante, C. M., & Carpiniello, B. (1996). Family burden in relatives of schizophrenics and of people with mental retardation: A comparative study. *European Psychiatry, 11*, 381-385.
- Pavot, W. G., Diener, E., Colvin, C. R., & Sandvik, E. (1991). Further validation of the Satisfaction with Life Scale: Evidence for the cross-method convergence of well-being measures. *Journal of Personality Assessment, 57*, 149-161.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process. An overview of concepts and their measures. *The Gerontologist, 30*, 583-594.
- Pilusa, N. E., (2006). *The impact of mental retardation on family functioning* (Unpublished dissertation). Pretoria, South Africa: University of Pretoria. Retrieved from: www.google.com
- Pinquart, M., & Sörensen, S. (2003a). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology & Aging, 18*, 250-267.
- Pinquart, M., & Sörensen, S. (2003b). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences & Social Sciences, 58*, 112-128.
- Quereshi, H., & Alborz, A. (1992). Epidemiology of challenging behaviour. *Mental Handicap Research, 5*, 130-145.

- Randolph, E. T., & Glynn, S. M., (1994). Behavioural family management in schizophrenia: outcome of a clinic based intervention. *British Journal of Psychiatry*, 164, 501–506.
- Raj, L., Kulhara, P., & Avasthi, A. (1991). Social burden of positive and negative schizophrenia. *International Journal of Social Psychiatry*, 37, 242-250.
- Rivers, J. W., & Stoneman Z. (2003). Sibling relationship when a child has autism: marital stress and support coping. *Journal of Autism & Developmental Disorders*, 33(4), 383-394.
- Roberto, K. A. (1993). Older caregivers of family members with development disabilities: Changes in roles and perceptions. In K. A. Roberto (Ed.), *The elderly caregiver: Caring for adults with developmental disabilities* (pp. 39-50). Newbury Park, CA.: SAGE.
- Saloojee, G., Phohole., M., Saloojee, H., & Ijsselmuiden, C. (2006). Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child: Care, Health & Development*, 33(3), 230-235.
- Sanders, J. L., & Morgan, S. B. (1997). Family stress and management as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child & Family Behavior Therapy*, 19, 15-32.
- Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation*, 38, 195-206.
- Seltzer, M. M., & Heller, T. (1997). Families and care giving across the life course. Research advances on the influence of context. *Family Relations*, 46, 321-323.
- Smith, A. L. (2007). *Parental stress and its relation to parental perception of communication following language intervention* (unpublished dissertation).

Atlanta, GA: Georgia State University. Retrieved from www.google scholar.co.za

South African Government. (1997). *Constitution of the Republic of South Africa Act 108 of 1996*. Section 28(3). Pretoria, South Africa: Government Printer.

South African Government. (2005). *Children's Act 38 of 2005*. Section 1. Pretoria, South Africa: Government Printer.

Statistics South Africa. (2011). *Population census. Statistical release P0301.4*. Pretoria, South Africa: Government Printer.

Syeda, M., Weiss, J., & Lunsky, Y. (2011). Brief report: Experiences of families of individuals with intellectual disability and psychiatric disorder. *Journal of Developmental Disability, 17*(2), 64-68.

Szmukler, G. I., Burgess, P., Herrman, H., Benson, A., Colusa, S., & Bloch, S. (1996). Caring for relatives with serious mental illness: The development of the Experience of Caregiving Inventory. *Social Psychiatry & Psychiatric Epidemiology, 31*, 137-148

Yiengprugsawan, V., Harley, D., Seubsman, S., & Sleight, A. C. (2012). Physical and mental health among caregivers: Findings from a cross-sectional study of Open University students in Thailand. *BMC Public Health, 12*(1111), 1-9.
Doi:[10.1186/1471-2458-12-1111](https://doi.org/10.1186/1471-2458-12-1111)

Madala, S. T. M. (2014). *Resilience factors in low-income African families of children with Down syndrome* (unpublished dissertation). Polokwane, South Africa: University of Limpopo.

Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism, 6*, 115-130.

- Weiss, J. A., & Lunsky, Y. (2011). The brief Family Distress Scale: A measure of crisis in caregivers of individuals with autism spectrum disorder. *Journal of Child & Family Studies, 20*(4), 521-528.
- Weiss, J. A., Sullivan, A., & Diamond, T. (2003). Parent stress and adaptive functioning of individuals with developmental disabilities. *Journal of Developmental Disabilities, 10*, 129-135.
- White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*, 181-190.
- White Paper on an Integrated National Disability Strategy (1997)*. Office of the deputy president. Pretoria, South Africa: Government Printer.
- Wicks-Nelson, R. & Israel, A. C. (1997). *Behaviour disorders of childhood* (3rd ed.). New Jersey: Prentice Hall.
- Willoughby, J. C., & Glidden, L. M. (1995). Fathers helping out: Shared child care and marital satisfaction of parents of children with disabilities. *American Journal of Mental Retardation, 99*, 339-406.
- Wolff, J. L., & Kasper, J. D. (2006). Caregivers of frail elders: Updating a national profile. *Gerontologist, 46*(3), 344-356.
- World Health Organisation. (2001). *ICD–10 Guide for mental retardation*. Division of Mental Health and Prevention of Substance Abuse. Geneva, Switzerland: Author.
- Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment, 52*, 30-41.

APPENDICES

APPENDIX 1

CAUSES OF INTELLECTUAL DISABILITY

Intellectual disability is not the result of a single or simple condition. It has many causes, including genetic problems and environmental factors. Scientist has identified more than 750 genetic problems that cause intellectual disability. The most common of these is Down syndrome, which is caused by the presence of an extra chromosome. The chromosomes in human body are made up of genes, which contain the chemical instructions for growth and development. Most people have 46 chromosomes in each of their cells. People with Down syndrome have 47 chromosomes. This gives them a distinctive physical appearance, including a small face and eye that slant upwards. A down syndrome is more likely to occur in a child who is born when the mother is over 40 years. Therefore, as women get older, there is an increased risk that the process of chromosomes separation will not take place normally (Danuka & Marvin, 2001).

The second common genetic cause of intellectual disability is Phenylketonuria (PKU). Children with PKU inherit a gene that causes problems with the enzyme that helps the body break down certain foods into the substances it needs to grow and develop. This leads to build-up of chemicals that poison the body. If left untreated, children with PKU suffer the effects of this gradual poisoning and by middle childhood are diagnosed as having intellectual disability (Louw & Edwards, 1997). Maternal infection with certain viruses, such as rubella, during early pregnancy can also lead to intellectual disability.

Intellectual disability can also be caused by health risk factors such as: consuming alcohol, smoking, or using illegal drugs during pregnancy can hurt a developing baby. Alcohol use during pregnancy can hurt the fetus by causing fetal alcohol syndrome (FAS). Children with FAS have a distinctive appearance, including a small head, widely spaced eyes, and thin lips. In addition to intellectual disability, they can have severe emotional problems.

There are other environmental factors that can cause intellectual disability after birth; these include exposure to lead and other poisons in the environment. Children can ingest this lead by eating peeling paint or by swallowing paint dust (Baltimore & Paul, 2004). Intellectual disability can also be caused after birth by head trauma from an accident, by a stroke, and by serious diseases, such as meningitis and encephalitis. There is a great deal of evidence that many intellectual disability cases are due to environmental deprivation. The majority of intellectual disabled children come from broken homes and families characterized by poverty, instability, lack of intellectual stimulation and poor social interaction (Louw & Edwards, 1997).

APPENDIX 2

Interview guide

The researcher gave an explanation about the nature and purpose of the study. She also obtained permission to use an audio-tape, from the participants. Furthermore, the researcher gave assurances with regards the issues of confidentiality and privacy of the information obtained during the interview with the participants. Once it was clear that the participants were fully informed and they understood what they were involving themselves in, the interview proper then began. The following areas of inquiry served to anchor the interview:

Grand-tour question:

- What are the psychological experiences of family caregivers of children with an intellectual disability?

Probes and/or prompts:

- How do family caregivers take care of their own needs while taking care of a child who is intellectually disabled?
- What motivates family caregivers to provide care?
- What forms of social support are available for family caregivers of children with an intellectual disability?