

Psychosocial experiences of caregivers of children with intellectual disability in

Limpopo Province, South Africa

by

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Declaration

I, Mpfariseni Chabalala declare that this mini-dissertation for the award of Master of Social Science in Clinical Psychology degree at the North-West University has not previously been submitted by me for a degree at this or any other institution. I hereby submit this mini-dissertation, and it is my own work in design and execution. All the reference materials contained herein have been duly acknowledged.

M. Chabalala

Date

Dedication

This research is dedicated to all those individuals who inspired me to study Master of Social Science in Clinical Psychology at the North-West University. These individuals include my parents, siblings, relatives, friends and lecturers.

Acknowledgements

To the almighty Lord, who pulled me through and provided me with strength and resilience.

Secondly, I would like to extend my sincere gratitude to all the participants that were amenable to the study. Without them, this study could not have been completed.

My heartfelt appreciation goes to my supervisor, Mrs P.S Kolobe for believing in my abilities.

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List of acronyms and abbreviations

AAIDD	American Association on Intellectual and Developmental Disabilities
AAMR	American Association of Mental Retardation
CDC	Centres for Disease Control
DSD	Department of Social Development
DSM	Diagnostic and Statistical Manual
DWCPD	Department of Women, Children and People with Disabilities
ID	Intellectual Disability
IQ	Intelligence Quotient
NADDC	National Association of Developmental Disability Councils
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organisation

Abstract

Research on caring for a person with an intellectual disability (ID) is well documented in the Western context but not in South Africa. The present study explored the lived experiences of caregivers caring for children with ID in the African context of Limpopo Province. The present study used a phenomenological design. Five female participants were recruited through purposive sampling. Data was collected via focus group interviews and was analysed thematically. The findings of the study revealed four themes namely positive experiences of caregiving, negative experiences of caregiving, common issues shared by the caregivers, and their coping strategies. This study concluded that the caregivers experienced a wide range of psychosocial processes that include pain, lack of support, strained relationships and limited engagement in social activities. However, through their religious beliefs, these caregivers manage to cope with the challenges of caring for children with ID. Recommendations and implications for future research on intellectual disability and caregiving are highlighted.

Keywords: *Caregivers, Experiences, Intellectual Disability, Psychological, Social, Limpopo*

CHAPTER 1

INTRODUCTION TO THE STUDY

1.1 Introduction

The delivery of a child is perceived with an excitement that also comes with great expectations by the parents. While waiting for the child's arrival, parents also hold an expectation regarding the child's potential in addition to how the child might look. The other thing that possibly strikes the parents' mind might be the gender of that child (Dhar, 2009). The birth of a normal child usually brings joy in the family. However, when parents realise that there are some disabilities in their child, that joy vanishes (Dhar, 2009; Kaur & Arora, 2010; Singh, Kumar, Sharma, & Kumar-Nehra, 2014).

Children could be born with congenital anomalies of physical and mental nature (Adnams, 2010; Karim et. al., 2015). One of the common mental abnormalities affecting most children is intellectual disability (ID) (Mckenzie, Milton, Smith, & Ouellette-Kuntz, 2016).

According to the DSM-5, intellectual disability (ID) is a disorder with an onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains. The following three criteria must be met:

A: Deficits in intellectual functions, such as reasoning, problem-solving, planning, abstract thinking, judgement, academic learning and learning from experience, confirmed by both clinical assessment and individualised standardised intelligence testing.

B: Deficits in adaptive functioning that result in failure to meet developmental and socio-cultural standards for personal independence and social responsibility. Without ongoing

support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.

C: Onset of intellectual and adaptive deficits during the developmental period (APA, 2013, p. 33).

A child with an ID often displays challenging behaviours that do not form any positive influence on his/her developmental phases of life. These challenging behaviours could range from but are not limited to undirected hand flapping, impulsive shouting at others, self-inflicted injuries and fast-finger hand motions (Cox, 2003; Rosenberg & Kosslyn, 2011; Schneiderman & Villagrana; 2010).

Globally, the general population has an ID prevalence of 10.5 per 1000 children. 10.8 per 1000 were found in rural areas, whereas 11/1000 were found in urban areas (Lakhan, Ekundayo, & Shahbazi, 2015). In African societies, 1/10 people are affected by either mental, sensory or physical disability (Milter, as cited in Shimelis, 2011). The prevalence of ID in Africa ranges between 0.2 % and 0.4% (Milter, as cited in Shimelis, 2011). Interestingly, the prevalence of ID is extensive in South Africa. There were reportedly 68550 children (both males and females) with ID according to the General Household Survey 2009 which was included in the Census of 2011. These children's ages ranged between 4–17 years old (DSD, DWCPD, & UNICEF, 2012). Limpopo Province was one of the provinces with the highest number of children diagnosed with ID according to statistics published by the Children with Disability in SA (2001-2011). There were 10164 children diagnosed with ID in Limpopo Province. Limpopo province was in 3rd place

behind Kwa-Zulu Natal in 2nd, and Free State in 1st place. This was according to the statistics that were published between 2001 – 2011 (DSD, DWCPD, & UNICEF, 2012).

Nurturing a child with an intellectual disability requires emotional capacity from the caregivers as the child's special needs are different from that of a normal child (Mudhovozi, Maphula, & Mashamba, 2012). Mudhovozi et.al. (2012) also found that caregivers of these children perceived their caring roles as a lifelong *pain* because their children functioned at the minimum intellectual level which was below expectation. Generally, these caregivers were mostly mothers and voluntary family affiliates. In some cases, it could be friends of the person suffering from any form of mental health condition (Sandy, Kgole, & Mavundla, 2013). By definition, caregivers are individuals who provide assistance and necessary support to a child, a relative, a family member or a friend who might be unable to care for themselves because of an illness or disability (Carers Northern Ireland, 2002).

The following studies state that caregivers of children with ID experience lots of psychosocial experiences (Emerson, 2003; Gupta & Kaur, 2010; Gallagher & Whiteley, 2013; Thompson, Kerr, Glynn, & Linehan, 2014). The psychosocial experiences could be accompanied by feelings of guilt for giving birth to a disabled child, and embarrassment in their own environment (Upadhyay & Singh, 2009). Psychosocial experiences refer to the psychological and social processes that caregivers experience when caring for a child with an ID. For example, psychological processes might include but are not limited to anger, pain, stress, anxiety, and depressive symptoms, while social processes might include stigma, discrimination, prejudices, labelling, strained friendships and social withdrawal. Caregivers often blame each other because of the arrival of a child with ID in the family (Mudhovozi et al., 2012; Ntswane & van Rhyn, 2007; Upadhyay & Singh, 2009). Sandy et al. (2013) reported that caregivers experience psychological-related problems especially

when they perceive their caring roles as challenging. Due to other parental responsibilities in their homes, caring roles are perceived as difficult and complex. The existing literature shows that caregivers often lack required skills and understanding of raising children with ID (Bourke-Taylor, Howie, & Law, 2010; Sandy et al., 2013).

However, in some societies, there are caregivers who are able to deal with the challenges of raising children with ID. Such challenges could possibly lead to experiences of certain difficulties regarding their own well-being (Greeff & van Der Walt, 2010). These challenges could also negatively impact on the family functioning. As such, coping mechanisms of these caregivers also form part of this research study because they are different coping styles that caregivers could use, as documented in Lazarus and Folkman (1984). Theoretically, coping is a constantly changing process and behavioural efforts that a person goes through in order to deal with internal or external challenges (Lazarus & Folkman, as cited in Friere, Del Mar Ferradas, Valle, Nunez, & Vallejo, 2016). Such challenges are seen as exceeding normal resources available to that person. These coping mechanisms are the abilities of the caregivers to survive and recover from any negative life experience (Walsh, 2012), in this case caring for children with intellectual disability.

1.2 Background of the study

Reportedly in 1961, there was a shift from the derogatory terms that were used to describe individuals suffering from mental retardation, now commonly known as intellectual disability. This shift highlighted an introduction of terms such as intellectual disability amongst others (Ward, 2002). The usage of the term 'intellectual disability' was recommended by the World Health Organisation in 1965. The DSM-5 also moved away from using the term 'mental retardation' by adopting the term 'intellectual disability' (APA, 2013). Before this recommendation by the WHO,

most populations across the globe lacked a good understanding of what intellectual disability entails. This often resulted in discrimination and labelling people with this condition, especially if they were seen as unable to conform to socially acceptable behaviours and norms. Although research studies and recent conceptions of 'disability' emerged, most people still lack a good understanding of the term 'ID' as compared to 'physical disability' (Ward, 2002).

On top of the recommendations to use the term such as ID, the development of psychological testing on levels of intellectual functioning reportedly began in early 1970. However, psychological testing increased institutionalisation even though it was designed to improve classification of these individuals. The likes of Alfred Binet and Simon developed a test for diagnosing French school children who were in need of special services. Goddard later adjusted and modified that specific test (Beirne-Smith, Patton, & Kim, 2006). The tests were designed because there was no simple way of diagnosing mild or severe forms of ID at that time until the development of different psychometric assessment tools.

The 'IQ' became a universal approach for identifying an ID and measuring the severity thereof. Major research studies on the topics of ID also began around 1962 when the special panel on former 'mental retardation' published its report which shaped a major turnaround in the history of 'mental retardation' in the United States (President's committee on Mental Retardation, 1977).

Currently, South Africa has also taken a stance of de-institutionalising the care of children with ID by shutting down large institutions. This was reportedly recommended in the South African legislation prior to 2002 (Burns, 2008; Lazarus, 2005, & Petersen, 2004) in order to facilitate improved development. Therefore, these children were being put back into their homesteads and communities (Cummins & Lau, 2003). These children might find themselves faced with the

challenges of stigma and isolation in these communities. When such negative events occur, these children look up to their caregivers for protection and comfort. These caregivers become the shield during the child's entire life (Cummins & Lau, 2003).

Even when the government was investing in possible adequate services for mental health care, there was still an increase in poor institutionalised care (Mkhize, 2007; Petersen & Lund, 2011) for people with ID including both children and adults (Oakes, 2012). Internationally and nationally, there had been an implementation by the nurses, community psychologists and other health care providers in various health care facilities to carry out assessment on individuals suffering from ID and how they managed their lives. As an outcome, this intervention placed the intellectually disabled into a 'patient' role like any other person with a disability or a mental health condition. This suggested that an ID was a form of mental illness (APA, 2013), like any other mental health condition. Therefore, the idea that an ID was not a 'curse' as regarded in ill-informed communities was better explained through describing it in the light of other mental health conditions (Oakes, 2012).

Caregivers of children suffering from ID were faced with an immense responsibility of providing adequate support throughout the children's entire life span. Generally, raising a child with a mental health problem was related to high levels of depression, grief, stress and anxiety. Caregivers also find the caring role as challenging due to the child's disruptive behaviours (Ambikile & Outwater, 2012; Bourke-Taylor et al., 2010; Nimbalkar, Raithatha, Shah, & Panchal, 2014; Sandy et al., 2013; Sen & Yurtsever, 2007). Just like a normal child, a child with ID generally perceive a successful life evolution as an embracement of several social roles such as adequate self-rule, ability to self-regulate, good education, and independence. Inability to achieve

these is associated with a period of stress and depression by their caregivers (Dyke, Bourke, Llewellyn, & Leonard, 2013).

Furthermost, research studies that focused on the psychosocial processes of caregivers raising children with disabilities had been mostly conducted in Western countries, with African studies still few (Sandy et al., 2013; Sen & Yurtsever, 2007). These studies focused on the following factors which included psychological well-being (Ambikile & Outwater, 2012; Bourke-Taylor et al., 2010; Nimbalkar et al., 2014), social support (Ntswane & van Rhyn, 2007; Qayyum, Lasi, & Rafique, 2013), and financial strain (Gona, Mung'dala-Odera, Newton, & Hartley, 2010; Pilusa, 2006; Sandy et al., 2013).

In the light of the above literature, the question that this study raised was: 'What are the psychosocial experiences of the caregivers in Limpopo Province and how do they cope'. Prior research on caregivers of children with intellectual disability had produced varied results. While some studies documented augmented stress among these caregivers, other studies had shown that caregivers had incredible resiliency and could assemble means to handle particular challenges (Bayat, 2007; Carr, 2005; Kulkhara, Kale, Grover, & Nehra, 2012).

In the light of this background, it was crucial to understand caregivers' psychosocial experiences when raising children with an intellectual disability.

1.3 Statement of the problem

Children with ID experience difficulties in age-appropriate functioning such as the ability to care for themselves and the ability to communicate with others in a language that a typical person can understand. Because of these impairments, children with ID struggle with independence and self-direction (AAIDD, 2011). This was both a global and national problem because Ali,

Ahlstrom, Krevens, and Skarsater (2012) found that in most social settings, children with ID were habitually deprived of equal involvement in the society and were treated in a different way compared to children without intellectual disability. According to Bourke-Taylor et al. (2010), most of these children require assistance to feed themselves and to dress themselves. As illustrated in Bourke-Taylor et al. (2010), some of the caregivers verbalised that they spend sleepless nights when the child needed gastrostomy feeding or change in sleeping position due to movement difficulties. Another challenge that caregivers experienced was in regard to toileting and protection from harming self or others (Bourke-Taylor et al., 2010).

Generally, in South Africa just like in other countries, caregivers play a crucial role in caring for these children. Studies reported that female caregivers suffer from high-stress level and are more vulnerable to develop depression (Greenberg, 2002; Sjoblom, 2010; Upadhyay & Singh, 2009). Sandy et al. (2013) found that Limpopo province was one of the poorest in the provision of adequate facilities that support and enhance the caregivers' lives. In this province, 30% of its population were children diagnosed with either mild or severe forms of ID. Reports showed that the figure might grow with the increase in the expectancy of life (Sandy et al., 2013).

When a caregiver learns that a child has ID, it causes an immeasurable stress (Hilliard, Monaghan, Cogen, & Streisand, 2011; Upadhyaya & Havalappanavar, 2008). However, few detailed descriptions of the severity of this condition have been illustrated in research studies. Instead, a few studies explored the neglect of the caregivers by mental health care service providers (Adnams, 2010; Ali et al., 2012). Further, there are few studies on caring for children with ID within the African context, as most emanate from the Western context (Bourke-Taylor et al., 2010; Nimbalkar et al., 2014).

Research studies which aim at exploring the lives of caregivers of children suffering from ID utilise quantitative methodology and quantitative research designs. The current study made an effort to employ a more phenomenological qualitative research design to reduce the research gap. The research gap that this study hoped to contribute to fill was based on the fact that most of the above-mentioned researches were conducted in a Western context, with African studies remaining few as mentioned previously. Research has identified few qualitative studies within the concept of caregiving in Limpopo Province, South Africa. Mudhovozi et al (2012) conducted a qualitative study on the topic of ‘caring for children with mental retardation: the experiences of vhavenda mothers’, while Sandy et al. (2013) explored a case study on ‘support needs of caregivers’. Pilusa (2006) studied the ‘impact of mental retardation on family functioning’, whereas Mavundla, Toth, and Mphelane (2009) investigated the ‘caregiver experience in mental illness’ which was from the perspective of a rural community in Limpopo Province.

1.4 Aim of the study

The aim of this study was to explore the lived psychosocial experiences of caregivers of children with an intellectual disability in the Limpopo Province, South Africa.

1.5 Objectives of the study

- To investigate positive psychosocial experiences of these caregivers.
- To explore negative psychosocial experiences of these caregivers.
- To identify common experiences that the caregivers shared.
- To explore the coping mechanisms of these caregivers.

1.6 Research questions

The study was guided by the following research question:

- What were the positive psychosocial experiences of these caregivers?
- What were the negative psychosocial experiences of these caregivers?
- What were the common experiences shared by the caregivers?
- How did the caregivers cope?

1.7 Significance of the study

This study will influence theory, practice and research methodology. Based on the existing literature, the prevalence of children with intellectual disability in South Africa, specifically in Limpopo Province, serves as a need for implementation of effective support structures and services to empower people with skills and knowledge about caregiving. This was because, although there seems to be some literature regarding intellectual disability, there were few African studies. Studies done on the similar topic in South Africa were few. Therefore, this study will provide more credibility and add value to the existing literature and another perspective to raising children with ID.

This study might open entries for studies on additional co-morbid conditions to the one used in this study. A descriptive examination of life histories of caregivers caring for children with ID might provide significant understanding for those who support them as well as those who find themselves in a related situation.

The study might possibly assist mental health care providers such as clinical psychologists to intervene not only with the affected children but also with the caregivers to ensure that their well-

being is also taken into consideration. Furthermore, awareness campaigns regarding ID could be introduced through this study.

Quantitative studies have been well documented regarding ID, while qualitative studies are few. This study would help in illustrating caregivers' experiences through a qualitative approach which would possibly add value to existing literature.

The research findings on psychosocial experiences of caregivers raising children with ID in Limpopo would assist government policy makers to develop intervention strategies that would help health care professionals to support the caregivers and the affected children. The study was aimed at discovering means to help caregivers and care-recipients. In other words, by supporting caregivers and their care receivers, the society composed of such individuals would be well equipped to care for them.

CHAPTER 2

THEORETICAL BACKGROUND

This chapter seeks to provide the operational definition of terms that were utilised in this study. It defined important concepts such as intellectual disability, caregivers, and psychosocial experiences. Additionally, the chapter further discusses theoretical frameworks and theoretical perspectives underlying the current study.

2.1 Operational definitions of terms

2.1.1 Psychosocial experiences

Egan, Tannahill, Petticrew, and Thomas (2008) state that there is a huge obstacle in the usage and the definition of the term *Psychosocial* in the research literature. Martikainen, Bartley, and Lahelma (2002) state that ‘psychosocial experiences’ describe an associating concept between a person and common structures. Hence, it comprises features such as support for social structures, occupational control, and independence. Similarly, Siegrist and Marmot (2004) define psychosocial experiences as the societal and traditional variety of opportunities that are accessible to a person. That person should be able to meet basic needs such as well-being, efficiency and constructive identity. In this study, psychosocial experiences refers to the psychological and social processes that caregivers’ experience when caring for a child with ID.

2.1.2 Caregivers

Swanson, Jensen, Specht, Johnson, Maas, and Saylor (1997) define caregivers as the providers of adequate health care to a family member suffering from a chronic illness. Carers Northern Ireland (2002) define caregivers as individuals who provided assistance and necessary support to

a child, a relative, a family member or a friend who may be unable to care for themselves because of an illness or disability, while Drentea (2007) describe caregivers as individuals who provided unpaid assistance and support to other family members suffering from physical, developmental and psychological conditions. Hermans and Mastel-Smith (2012) define caregivers as individuals who assist another person who is unable to do that for himself/herself “holistically” (emotionally, physically, socially and mentally). However, caregivers in this study refers to mothers/grandparents/guardians that serve as parental figures of children with intellectual disability. Such caregivers are responsible for daily care and maintenance of these children because some of these children are orphaned, while some are raised by a single parent.

2.1.3 Intellectual Disability (ID)

According to the DSM-5, intellectual disability (ID) is a disorder with an onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains. The following three criteria might be met:

A: Deficits in intellectual functions, such as reasoning, problem-solving, planning, abstract thinking, judgement, academic learning and learning from experience, confirmed by both clinical assessment and individualised standardised intelligence testing.

B: Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.

C: Onset of intellectual and adaptive deficits during the developmental period (APA, 2013, p. 33). The above-mentioned definition also applies to the current study wherein children with intellectual disability have difficulties in basic life routines such as but not limited to self-care, academic performance, and social interactions.

2.2 Theoretical framework

2.2.1 Social (dis)Empowerment Model

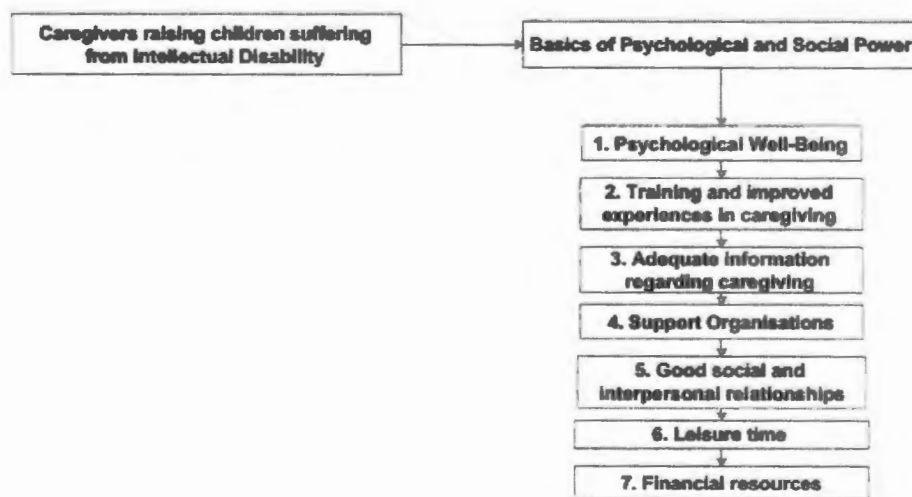
This model was developed by John Friedmann. It was published in the book titled *‘Empowerment: the politics of alternative development’* in 1992. Friedmann’s model was developed with the initial idea of describing how poverty in the communities should be seen in the light of social, political and psychological factors influencing such poverty (Friedmann, 1992). He said that when there was adequate social, political and psychological support, poor communities can find meaning in their lives and embrace healthy living, thus, excelling through poverty to be better individuals. However, when these social, political and psychological support needs were not met, one was poor (or disempowered). Friedmann called it (dis) empowerment model because he wanted to move away from the basics of social power only i.e social support, thus incorporating other factors that were seen as influential to human beings (Friedmann, 1992; Wilson, 2011).

However, some of the concepts in this model have been modified to suit the content of the current study. Friedman laid his model on the foundation of social, psychological and political empowerment, which he distinguished well. Additionally, Friedman explained social empowerment in terms of a community’s access to an adequate financial resource, supportive life space, surplus time, social networks, instruments of work and livelihood, knowledge and skills (Friedmann, 1992; 1996). In regards to psychological empowerment, Friedmann stated that when

people interact with a positive social and political structure, their sense of strength also improved, therefore, they became psychologically empowered (Friedmann, 1992). Lastly, when the community members were part of decision-making that affected their future and those around them, they were politically empowered (Friedmann, 1996).

In the context of this study, the main rationale behind this model is, but not limited to that, in order for caregivers to sustain a healthy meaningful life, they should be in the process of fulfilling the following basics of social and psychological strength. These basics of social power and psychological processes could be positively influential in their day-to-day life. The figure below illustrates how this model is applied to the current study.

Figure 1: *Social (dis) empowerment model: caregivers of children with ID*



Part of the ideology behind Friedmann's model, which has been modified, implies that an increased access to the above-mentioned factors would increase caregivers' psychosocial experiences. These factors included:

- Psychological well-being;
- Leisure time;
- Training and improved experiences in caregiving;
- Adequate information regarding caregiving;
- Financial resources;
- Support organisation,

(a) Psychological well-being

In this study, the psychological experiences of caregivers caring for children with ID will be explored. The factor of psychological processes had been widely researched, with several studies (Karasavvidis, Avgerinou, Lianou, Priftis, Lianou, & Siamaga, 2011; Merrifield, 2011; Mavundla, Toth, & Mphelane, 2009) showing a link between everyday negative experiences in caregiving and poor psychological functioning of the caregivers. Therefore, when caregivers were feeling stressed, painful, and exhausted, it might add to their caring burden and loss of fulfilment in raising children with ID (Karasavvidis et al., 2011; Merrifield, 2011; Mavundla et al., 2009).

(b) Leisure Time

There were quite a few studies which linked leisure time with improved psychosocial functioning of the caregivers (Bedini & Guinan, 1996; Gump, 2000; Hsieh & Van Puymbroeck, 2013). This model stipulated that an adequate amount of leisure time could be linked with a satisfactory caring role and quality of life (Friedmann, 1992).



(c) Training and improved experiences in caregiving

Training the caregivers was possibly the utmost important form of empowerment (Friedmann, 1996). ID is a condition that could be difficult for the caregivers to understand (Nel & Grosser, 2016). The work of Sen and Yurtsever (2007); and Sandy et al. (2013) argues that most caregivers lack knowledge and skills on how to handle a child who is often perceived as difficult. Caregivers might acquire a decent level of education and be in the possession of certain skills that would determine how they execute their caring roles. These include what the caregivers might attain in the future. This model related this as another long-term prospect of social power. Moreover, adequate information regarding caregiving should be provided to the caregivers (Friedmann, 1992).

(d) Support organisations and adequate information

It was further emphasised that caregivers should engage in social interactions and life supporting activities that could enhance their lives. These become an important coping mechanism when faced with comprehensive life challenges (Friedmann, 1992; Sjindjapkin & Johansson, 2015; Wilson, 2011). Interactions between the public, private and another civil organisation was another prospect which was important. Caregivers need to engage with different structures within their environment. This abstract space of interaction was seen as an important factor for support, comfort and guidance. When challenges arise in caregivers' lives, social interaction and interpersonal relationships that were solid might benefit the caregivers in maintaining a healthy life functioning (Friedmann, 1992; Sjindjapkin & Johansson, 2015). There were several studies (Yousafai, Farrukh, & Khan, 2010; Wang, Michaels, & Day, 2010; Bilgin & Kucuk, 2010) linking poor levels of social support with the poor psychosocial functioning of the caregivers. The needs

of the caregivers raising children with ID was to access resources (Barber, 2011). Furthermore, caregivers should be provided with adequate information regarding the child's condition and they should be part of decision-making regarding health care (Goodman, 2012).

(e) Financial resources

When raising a child with ID, caregivers require financial assistance (Nimbalkar, Raithata, Shah, & Panchal, 2014). Similarly, Eisenhower and Blacher (2006) also linked poor socio-economic status to high levels of financial strain. Financial support is also an important factor within this model because it determines the ability of one to work and earn an income in order to contribute to the household economy. In a study by Uksun and Gundogar (2010), the caregivers reported that financial support was one of the facilitators of their coping mechanisms.

2.3 Theoretical perspectives

2.3.1 Theory of Human Functioning

According to Luckasson, Coulter, Polloway, Reiss, Schalock, Snell, Spitalnik, and Stark (1992), this multi-dimensional theory was first announced by the American Association on Intellectual and Developmental Disorders (AAIDD). The AAIDD used to be called American Association of Mental Retardation (AAMR).

Two key parts of human functioning are the core of this theory. These two major parts include:

(1) Five human dimensions

- Intellectual capacities;
- Adaptive behaviour;
- Health (including the origin of intellectual disability);

- Participation;
- Context;

(2) An illustration of the major role that influence play in human functioning (Buntix & Schalock, 2010).

Interestingly, the AAIDD define ID as a disorder with the onset before 18 years of age. This disorder was mostly distinguished from others through a person's limitation in both intellectual and adaptive functioning as seen through difficulties in conceptual, social and practical skills (Schalock et al., 2010). Similarly, the DSM-5 define ID as a disorder with the onset during the developmental period. There is evidence of difficulties in intellectual and adaptive functioning. The deficits in adaptive functioning result in failure to meet developmental and socio-cultural standards for personal independence and social responsibility. Hence, children with ID display deficits in activities of daily life such as social participation, communication and independence (APA, 2013, p. 33).

An ID is described through severity such as mild (IQ between 50 & 70), moderate (IQ between 35 & 40), severe (IQ between 20 & 35), and profound (IQ less than 20) (CDC, 2012; O'Brien, 2001).

Applying this theory to the children with ID, the dimension of intellectual capacities includes reasoning, planning, thinking abstractly, and problem-solving to mention a few (APA, 2013; Cabbeh, Villafuerte, Ruiz, & Adanza, 2015). Hence, children with ID appear to have difficulties in the above-mentioned dimensions due to limited intellectual development. These difficulties could also be linked back to how caregivers came to terms with the limitations that the child portrayed given that the birth of a child with ID is often sad for the caregivers. Conceptual, social

and practical skills determine adaptive behaviour. This could also be explained as the capacity of a person to function in their day to day life (Arvidsson, 2013). Children with ID have difficulties in adaptive functioning. One could wonder how the caregivers experience this challenge, given that children without ID possibly function better than children with ID in most areas. Depending on the severity level, children with ID have difficulties, for example, communicating in clear language (Mudhovozi et al., 2012), walk or feed independently (Sullivan, 2008).

The World Health Organisation (2001) define health as a state of comprehensive bodily, intellectual and societal well-being. However, this is different in children with ID. Most of them, depending on the severity, display deteriorating health. This could be a burden for the caregivers as they also have to maintain their own well-being, and handle other household responsibilities.

In this theory, a human being is expected to participate in social life activities in order to be an integral member of the society (Arvidsson, 2013). However, children with ID have difficulties to be functioning members of the society. Hence, they possibly participate less in most social activities. This differs from one child to the other based on the severity level.

Lastly, there are environmental and personal factors that contribute to adequate human functioning. Community support and a positive attitude might contribute to the better adaptive functioning of children with ID. This might also lessen the caregiving burden. However, when there is evidence of stigma and other discriminatory practices, these children and their caregivers might remain in an uncomfortable situation (Arvidsson, 2013). Additionally, age, race, gender, habits, upbringing, socioeconomic status, and place of residence also play a role (Arvidsson, 2013). Children born in poor backgrounds with limited opportunities might struggle to adapt and function independently. As stated previously, most people in rural areas of Limpopo province live

in poor conditions with poor provision of services and facilities that cater for children with ID (Sandy et al., 2013). Therefore, this theory explained intellectual disability and why the children display certain cognitive-emotive reactions.

2.3.2 Stress and Coping Theory

This theory by Lazarus and Folkman (1984) has been widely used for guiding research studies aimed at exploring how caregivers adapt to their caring roles (Mackay & Pakenham, 2012). This theory implies that stress or a process is the result of perceived threat between an individual and the environment. That threat is seen as exceeding an individual's resources to cope (Mackay & Pakenham, 2012). This theory stipulates that caregiving adjustment is better explained through three intellectual, behaviour and social processes namely: cognitive evaluation, coping strategies and coping resources (Lazarus & Folkman, 1984). Additional to these, Mackay and Pakenham (2012) worked on background variables that were contributory to caregivers' adaptation.

(a) Background variables

Background factors that might influence how caregivers adapt to caregiving might include the characteristics of the caregiver and the characteristics of the child. These characteristics might include the caregiver's age, mental status, personality, gender, socio-economic status and level of education (Hill & Rose, 2009; Hassal, Rose, & MacDonald, 2005). In the context of this study, when the caregivers are older, this also means that their maturity level is possibly high. Thus, they might possibly be more knowledgeable on handling a difficult child in comparison to younger and less mature caregivers. Female caregivers are prominent in many rural societies because they are perceived as natural caretakers who are patient and understanding. However, people in these rural societies are usually struggling financially with little income, in addition to poor education

levels. These might have a negative impact on the caring roles. The child's characteristics could be his or her diagnosis of mental illness, age and gender (Mackay & Pakenham, 2012), characteristics associated with the diagnosis (Neely-Barnes & Dia, 2008), and the temperament of the child (Bostrom, 2012). Hill and Rose (2009) linked the child's characteristics with a poor level of caregivers' psychosocial functioning. Correspondingly, Gallagher and Whiteley (2013); Woodman and Hauser-Cram (2013) also linked the child's characteristics with the caregiver's poor level of psychological functioning. Thus, a diagnosis of intellectual disability and other co-morbid conditions are related to poor caregivers' psychosocial well-being. Apparently, when the child is older and male, the caregivers' struggle with caring for that child is high as a male child is more likely to display unruly behaviour towards others in his environment.

(b) Coping resources

The work of Taylor and Stanton (2007) define coping as action-oriented and intrapsychic efforts to manage the demand created by stressful events. In line with the coping resources, Hatton and Emerson (2009) argue that not only is social support influential in caregiver's adaptation, it also eliminates caregivers' stress and community attitudes. This means that when caregivers are surrounded by positive people in their communities, this could alienate negative attitudes and labelling regarding children with ID. Lastly, there could be joint support, understanding and guidance on caring for children of this nature in the future.

(c) Cognitive appraisal

In line with Lazarus and Folkman's theory, Friere et al. (2016) define the process of cognitive appraisal as an evaluative process that reflects the person's subjective interpretation of the event. Events are appraised in terms of threat and challenges (primary appraisal) and controllability

(secondary appraisal). A few studies stated that when caregivers appraised their caring experience in a negative way, that could lead to poor outcomes of psychological functioning (Baronet, 2003; Joyce, Leese, Kuipers, Schmukler, Harris, & Staples, 2003).

(d) Coping strategies

Coping is a constantly changing and behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of a person (Lazarus & Folkman, as cited in Friere et al., 2016)

According to Mackay and Pakenham (2012), coping has the following functions: dealing with the root of the stressor (problem-focused coping), and regulating emotive reactions (emotion-focused coping). Emotion-focused coping has an element of avoidant or emotional approach (e.g. acceptance) (Mackay & Pakenham, 2012). Park and Folkman (1997) further introduced other coping strategies (meaning-focused) which include reinstating, creativity and meaning-construction from difficult life events.

Lai and Oei (2014) distinguish between emotion-focused coping and problem-focused coping; active-avoidant coping and spiritual coping. Spiritual coping is mainly comprised of being optimistic, prayer, faith and divine relief, whereas active-avoidant coping includes denial, distancing, distraction, social withdrawal, ignoring the child and passive appraisal. Emotion-focused coping has to do with acceptance, hilarity, changing what to expect, shifting one's urgencies and life objectives, and appreciation, whereas solution-focused coping means integrating the family, seeking social support, setting out management strategies, seeking resources and active engagement with the child (Lai & Oei, 2014). In the context of this study, consistent findings

within the literature associate different coping strategies with positive outcomes of caregiving (Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010; Gona et al., 2010; Tsai & Wang, 2009).

Given the scarceness of theory driven qualitative research on caregivers of children with ID, the theoretical background provided in this research study enhance the understanding of how these caregivers adapt to their caring roles as illustrated through different behavioural, intellectual and social processes. Furthermore, this theoretical background offers a map for the integration of interventions and services for these caregivers and their children.

CHAPTER 3

LITERATURE REVIEW

Previous research done on intellectual disability had focused primarily on the children. While it was essential to look at these children, it was also necessary to look at how the child's condition affected their caregivers. This would highlight adequate ways to support the caregivers. Key topics would be discussed in the literature including the understanding of ID and its causes, caregivers' experiences (positive and negative, social experiences, experiences related to services and organisations), and coping mechanisms.

This study will highlight the literature on intellectual disability both nationally and internationally. Nationally, the literature is limited as compared to the internationally strengthened literature. From the literature reviewed it was clear that there was a considerable amount of work done internationally on these children that provided knowledge about their condition and their caregivers (Nimbalkar et al., 2014; Oruche, Gerkenmeyer, Stephan, Wheeler, & Hanna, 2012; Bourke-Taylor et al., 2010), although not within the context of Limpopo Province in South Africa.

3.1 Understanding intellectual disability: What is it?

A research study undertaken by Pusey-Murray and Miller (2013) showed that most caregivers had a different understanding regarding the concept of intellectual disability. This was apparent in caregivers' struggle and confusion in defining this concept. Caregivers defined ID using terms like 'brain malfunction, the person was befuddled, and disorientation'. There was no constant description of ID in most of these societies.

Generally, the research described ID as a condition in which there was a halt in the development of a human brain. Hence, this condition was supplemented by damage in cognitive capacity and other areas of social functioning (Johnson, 2007; Kale, 2011; WHO, 2001). In agreement with these, Hawkins-Shepard (1994); Smith (2005), and WHO (2001) stated that an ID is a cognitive state that impairs functioning that was unacceptable in the context of the community and social environment that the individual belonged to.

ID was often grouped in its severity: mild, moderate, severe and profound (Wilson, 2011). Pawlyn and Carnaby (2008) argued that individuals with profound ID usually performed low on intelligence tests - with a score as low as 20 on IQ. Moreover, APA (2013); AAIDD (2011); NADDCC (2003) term ID as the division of disabilities that suggestively and harmfully impacted intellectual functioning. For instance, a child suffering from ID could be impaired in areas of learning, reasoning and problem-solving. It also delayed adaptive performance in applied, societal and abstract realms. Signs and indications of ID constantly developed before the age of eighteen but were frequently evident much earlier (AAIDD, 2011).

Nel and Grosser (2016) acknowledge that operationalising and conceptualising ID in South Africa appear to be a difficult role. This was because there are a number of factors to consider before diagnosing someone with ID. In most African contexts, it is defined and named in relation to a person's body part. Therefore, such body part was highly dysfunctional to meet the expectations of societal norms. According to Stone-MacDonald (2014), East African idioms had limited room for classifications of people with physical disabilities from those with ID. In Kenya, children with speech impairments and ID were provided with names such as 'big head' and the 'one who stutters' (Ogechi & Ruto, 2002). Such idioms meant that the community had different 'names' that were attributed to ID and other form of disabilities (Stone-MacDonald & Butera,

2011). In Tanzania, the general term used was '*Watoto wenye ulemavu*' which simply means 'children with disabilities' (Stone-MacDonald, 2010).

Bayat (2015) conducted a qualitative ethnographic study of children with ID in Ghana. These children were often killed and abused. From this study, ID was understood as representative of an evil '*snake*'. Hence, these children were often referred to as *snakes*. The *snake* concept derived from the fact that during early childhood, these children were flaccid and they slinked on the ground. Additionally, these children could not sustain their heads straight for a long period. Therefore, they crawled like a *snake* (Bayat, 2015). Mudhovozi et al. (2012) conducted a qualitative study in South Africa. In this study, the concept of intellectual disability was understood as a superstitious condition. Caregivers were of the idea that the public bewitched them as a result of jealousy and rage, hence the birth of such a child in the family (Mudhovozi et al., 2012). Based on these concepts, the understanding and conceptualisation of intellectual disability in African societies was different from that of the Western context.

3.2 Symptoms and behaviours associated with intellectual disability

The literature was indicative that the behavioural indication of children with ID were similar internationally and nationally. In South Africa, Sandy et al. (2013) found that these children displayed behaviours that were interpreted as aggression and would lead to violence towards others. McClintock, Hall, and Oliver (2003) conducted a study in Birmingham on the risks associated with people suffering from intellectual disability. Findings of this study highlighted various challenging behaviours. These children displayed self-injurious behaviour such as aggression. Males were mostly at risk. Additionally, such children also displayed stereotypes and

could easily destroy properties in the house that they lived in. Stereotypes were behaviours that served little or no specific function to the child (McClintock, Hall, & Oliver, 2003).

Correspondingly, behavioural problems often displayed by these children included aggressiveness, throwing tantrums, not complying with instructions, and hyperactivity (Keller & Fox, 2009). Bourke-Taylor et al. (2010) also noted aggressiveness and self-injurious behaviours by these children. Similarly, McCann, Peppe, Gibbon, O'Hare, and Rutherford (2007); Oliver, McClintock, Hall, Smith, Dagnan, and Stenfert-Kroese (2003) quoted that these children often did not obey instructions, and they encountered challenges in expressing their desires and wishes. When their wishes and desires were not achieved, such children presented with acting out behaviours (Bourke-Taylor et al., 2010). Visible self-stimulative behaviours such as hand flapping, body rocking, looking for close visuals (i.e. TV) were noted (Kenny & Corkin, 2011). These behaviours were regularly considered as interfering with acquiring good educational performance, household unity, caregivers' well-being, and other family members' physical well-being (Eisenhower, Baker, & Blacher, 2009).

Other earlier studies contrasted challenging behaviours with other developmental disorders. These studies noted that children with ID had been linked to a range of challenging behaviours (Cox, 2003; Villagrana, 2010) such as conduct difficulties, obsessive-compulsive disorder, and attention deficit-hyperactivity disorder (Keller & Fox, 2009; Ambikile & Outwater, 2012). Moreover, Merrifield (2011) also agreed that children with ID displayed challenging behaviours such as aggression and self-harm.

3.3 Causal factors of intellectual disability

In Brazil, Karam et al. (2015) conducted a study on the genetic aetiological factors of ID. The findings of this study put the following factors as the causes of ID in children: Children who were diagnosed with a genetic disorder and presented with the dysmorphic syndrome and atypical behaviour. Children who suffered from birth complications, neonatal hypoxia, meningitis, intracranial haemorrhage and hypoglycaemia were at risk of suffering from ID (Karam et al., 2015). Karam et al. (2015) further stated that even though the child was delivered normally with no difficulties in the first days of life, if that child was diagnosed with epilepsy, visual or hearing problems, then such a child was likely to suffer from ID as well. Most importantly, there might be no diagnosis of a genetic disorder or any other condition, but due to poor socio-economic status and poor environmental stimulation, the child could develop ID (Karam et al., 2015). Similarly, Nicholas (2003) stated that genetic, biological and environmental factors were causal factors in ID. Edwardraj et al. (2010) studied perceptions of ID in Vellore, India. Most caregivers described medical, psychological, environmental and genetic causes. Caregivers verbalised lack of support from their family, traumatic events that occurred during pregnancy, and poor maternal health which exposed them to give birth to a disabled child (Edwardraj et al., 2010)).

Adnams (2010) conducted a study on the perspectives of ID in South Africa. This study highlighted several conditions that influenced the development of ID. Poor nutrition supplied to the unborn child and poor development lead to numerous organic and psychosocial risks, which further placed the child at risk of developing ID (Adnams, 2010). Adnams (2010) further stated that high levels of alcohol abuse by mothers during pregnancy were associated with ID in South Africa. Therefore, the majority of children diagnosed with Fetal Alcohol Spectrum Disorder functioned on the level of mild ID. This also meant that they had difficulties in regulating social,

behavioural and executive activities (Adnams, 2010). According to Adnams (2010), several authors depended on clinically derived reports that suggested that a number of causes of ID in South Africa were comparable to those in Asia, America, the United Kingdom and the Middle East. In Tanzania, Mbwilo, Smide and Aarts (2010) stated that poor conditions during foetal life and traumatic incidences during labour might play a role in the mental status of the unborn child. Biological influences such as abnormal central nervous system, genetics, infections, poor nutrition and exposure to toxins were also responsible. Moreover, when a child was born in a dysfunctional family - parents with mental illness themselves, large family size, poverty and poor parenting styles, there was the likelihood of developing ID (Mbwilo, Smide, & Aarts, 2010).

Ordinarily, intellectual disability was related to irrational behaviours and religious beliefs. Additionally, socio-cultural beliefs of the curse, bad luck and punishment from ancestors were associated with the birth of a disabled child (Ngatunga, 2004). Similarly, research studies with African populations established that a disability was observed as a curse, a punishment from God for wrongdoing by the parents, and possession by evil spirits (Gona, Hartely, & Newton, 2006; Dhar, 2009; Gona et al., 2010). In agreement, Mudhovozi et al. (2012) also found that caregivers believed that intellectual disability was the result of punishment from God and superstitious acts. Kisler and McConachie (2010) asserted that in most rural communities, intellectual disability was perceived to be caused by witchcraft. A study in Kenya reported that intellectual disability was caused by various factors that included physical abuse, superstitious acts, trauma during birth and the caregiver (mother) having contact with certain animals in the environment (El-Sharkawy, Newton, & Hartley, 2006). When a person laughed at intellectually disabled individuals, such a person could have an intellectually disabled child and the future generations in his or her family

would also be cursed (Ogechi & Ruro, 2002). In Ethiopia, a father accused his wife of giving birth to a disabled child as a result of exposure to people with 'distorted' body features (Teferra, 2003).

Penn, Watermeyer, MacDonald, and Moabelo (2010) researched on grandmothers as gems of genetic wisdom in order to explore South African traditional beliefs about the causes of childhood genetic disorders. The study concluded that eating culturally forbidden food was the cause of genetic disorders. The grandmothers ascribed foods such as eggs, tripe, animal innards, or duck as the cause of genetic disorders (Penn, Watermeyer, MacDonald, & Moabelo, 2010). This corresponded with Wessels and Penn (2008) who attributed disability to eating wrongly and craving foods, such as sugar. Ingstad, Bruun, and Tlou (1997) also found that traditional beliefs such as getting pregnant rapidly after a previous birth, and promiscuous behaviours were accountable for the birth of a child with ID in many African societies. The work of Solomon, Penn, Greenberg, and Vivian (2008) showed that through cultural beliefs, men were perceived as good, while women were seen as bad. Women were regarded as dirty. When a woman gave birth to a disabled child, she was accused of engaging in sexual intercourse with a man who had slept with another woman. This was attributed to giving birth to a child with mental deficits (Solomon, Penn, Greenberg, & Vivian, 2008). Additionally, most of the South African children lived in poor living conditions. These conditions were accompanied by underdeveloped environments, high crime rates, child abuse, and inadequate services (Muthukrishna & Schoeman, 2010; Nel, Nel, & Hugo, 2012). These factors could have had a significant impact on the healthy development of a child being raised in such poor conditions (Heward, 2010).

3.4 Caregivers' experiences

It was crucial to note that while there was evidence of psychosocial issues in caregiving, to give birth to a child with an intellectual disability could not automatically determine psychological and social problems in the caregivers. The work of Grant (2007) explained that a good relationship between the caregiver and care-receiver could bring about high satisfaction in caregiving. Additionally, the caregiver's sense of self could be well-established through such positive experiences (Grant, 2007). Similarly, Oruche et al. (2012) found that positive assertion became an important influence on the caregiver's emotional stability. Thus, when caregivers were recognised and acknowledged in their communities, they learnt to accept their children and constructed positive meanings from their caring experiences (Oruche et al., 2012). Tarlow, Wisniewski, Belle, Rubert, and Gallagher-Thompson (2004) reported that caregivers felt useful and appreciated when caring for these children. The caregivers' meaning of life increased. Their relationships strengthened in a positive way with a positive attitude towards life (Tarlow; Wisniewski, Belle, Rubert, & Gallagher-Thompson, 2004). Lastly, Pillay, Girdler, Collins, and Leonard (2012) stated that when caregivers came into contact with proper health care services and good support groups, they also learnt to adapt to their circumstance, thus accepting and acknowledging their roles, while Griffith and Hastings (2014) asserted that the experiences of caregiving were associated with love and acceptance towards the care-recipient.

The substantial psychological experience of caregivers had also been researched. Gallagher, Phillips, Oliver, and Carroll (2008) conducted a study in the UK and cited that caregivers of children with ID endured depression and anxiety. The work of Bourke-Taylor et al. (2010) also noted that caregivers had an increased risk of developing depression. Similarly, Nimbalkar et al. (2014) quoted feelings of anger, pain, suicidal ideations, stress and depression among caregivers

of children with special needs, while (Kerenhappachu & Sridevi, 2014; Sen & Yurtsever, 2007) also noted feelings of depression especially when the caregiver recognised the onset of the deficit. Pinquart and Sorensen (2003) quoted inferior levels of self-efficacy and individual well-being.

In India, a quantitative study by Gupta and Kaur (2010) showed that caregivers endured psychological stress when raising a child with ID, while Kalyanpur and Gowramma (2007) asserted that caregiving stress was also related to how the children were treated in their environment. Feelings of worry were also reported when the child could not perform developmental tasks such as feeding themselves, toiletry, bathing and dressing. Emotive reactions such as feeling sad and feeling deep instinctual pain were the psychological experiences that caregivers went through (Ambikile & Outwater, 2012). Moreover, in a rural area of Limpopo Province, Sandy et al. (2013) quoted stress, emotive reactions such as anger, and dissatisfaction when raising a child with ID. Correspondingly, raising such a child could create huge anxiety on caregivers (Mavunda, Toth, & Mphelane, 2009; Merrifield, 2011). McKenzie and McConkey (2015) also noted that caregivers raising children with ID developed depression, had frustration and suicidal ideations. As such, caregivers resorted to corporal punishment in order to reprimand the unruly child.

Hartley, Ojwang, Baguwemu, Ddamulira, and Chavuta (2005) conducted a study in Uganda. The study was based on how caregivers perceived their coping strategies when raising a child with ID. This study found that caregivers developed stress-related symptoms. Symptoms such as chest pains and backaches were displayed by these caregivers (Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005). In Ethiopia, Tilahun, Hanlon, Fekadu, Tekola, Baheretibed, and Hoesktra (2016) conducted a cross-sectional study with caregivers raising children with either autism

spectrum disorder (ASD) or intellectual disability (ID). This study found that caregivers became depressed as a result (Tilahun, Hanlon, Fekadu, Tekola, Baheretibed, & Hoesktra, 2016).

In regards to the caregivers' physical health, previous studies quoted that substantial strain could result in negative impacts on one's physical welfare. The strain could lead to high blood pressure (King, Oka, & Young, 1994), and a high risk of suffering from cardiovascular disease (Lee, Colditz, Berkman, & Kawachi, 2003). Generalised body ache was also reported as a result of travelling long distances to reach medical facilities with the child, resulting in sleep difficulties (Nimbalkar et al., 2014), and exhaustion (Oruche et al., 2012). In a study taken in Canada, caregivers stated a rise in physical health problems such as back pain (Brehaut, Kohen, & Raina, 2004), and a deprived sleep quality of caregivers was noted in a study that was conducted in England (Gallagher, Phillips, & Carroll, 2010).

3.5 Experiences related to social support

A descriptive qualitative study on the impact of disabled children on the lives of caregivers was conducted by Yousafai, Farrukh, and Khan (2010). This study found that caregivers experienced strained social support and satisfaction with life. Due to the stigma surrounding 'disability' in their communities, caregivers hardly achieved a positive social life (Yousafai, Farrukh, & Khan, 2010). A qualitative study by Edwardraj et al. (2010) in India found that caregivers had little support from their family members and their friends. Also, the community did not help them with resources to aid the caregivers in these caring roles. Further, the community became reluctant to visit the caregivers in their homes. According to Edwardraj et al. (2010) as in Yousafai et al. (2010), the contributory factors to the above-mentioned social isolations were stigma and myth surrounding ID. Wang, Michaels, and Day (2010) conducted a descriptive study with Chinese

families. In this study, Chinese caregivers (both females and males) experienced poor levels of social support from their friends and their family members (Wang, Michaels, & Day, 2010). Similarly, Shin and Nhan (2009) found that caregivers raising children with ID in Vietnam experienced poor social support, which negatively influenced their caring roles. Correspondingly, Scheidegger, Lovelock, and Kinebanian (2010) explored the experiences of Tibetan caregivers. Caregivers noted that they became socially isolated. Additionally, family members became reluctant to visit the caregivers' households (Scheidegger, Lovelock, & Kinebanian, 2010).

Qayyum et al. (2013) explored the perceptions of caregivers in Pakistan. In this study, caregivers rarely attended social functions. Thus, the social relationship between the caregivers and their respective community members became strained. To add to this, relatives also withdrew their support as well (Qayyum et al., 2013). Bilgin and Kucuk (2010) found that Turkish caregivers struggled with inadequate social support. Their partners did not support them. However, not all the caregivers reported strained social lives. In this study, some of the caregivers reported closeness and unity between them and their families which included shared caring roles and responsibilities (Bilgin & Kucuk, 2010). The negative impacts of stress further affected the caregivers' marital satisfaction, societal functioning, family adaptability, and siblings' functioning (Kogan, Strickland, Blumberg, Singh, Perrin, & van Dyck, 2008). Stigma has been quoted as part of the obstacles on delivering satisfactory services to populace with the prevalence of ID (Gill, Kroese, & Rose, 2002), causing reduced management, rejection, and diminished roles within the public (Corrigan, Markowitz, Watson, Rowan, & Kuniak, 2003; Mark & Cheung, 2008). Similarly, Jahoda and Markova (2004) showed that the society did not accept and include intellectually disabled individuals and their caregivers in the community activities due to stigma and discrimination.

In Tanzania, Ambikile and Outwater (2012) conducted a qualitative study on the challenges of raising a child with mental disorders. Caregivers in this study reported inadequate social support. The community's attitude towards the child meant that the caregivers were expected to manage their caring roles on their own (Ambikile & Outwater, 2012). In Katutura, Ntswane and van Rhyn (2007) found that few caregivers received social support from their relatives and their friends. Additionally, some of the relatives verbalised that they wanted nothing to do with the mother and her child. In this study, most of the fathers rejected the mothers and the children with ID (Ntswane & van Rhyn, 2007). In Tanzania, Mbwiolo et al. (2010) found that caregivers did not participate as much in social gatherings as they used to. Caregivers avoided interacting with people. Due to the birth of the child in the family, the relationship between caregivers, neighbours and relatives became poor (Mbwiolo, Smide, & Aarts, 2010).

In Uganda, Hartley, Ojwang, Baguwemu, and Chavuta (2005) found that the social life of the caregivers was negatively affected because the caregivers spent most of their time at home, with limited contact with people outside. In Limpopo, Mudhovozi et al. (2012) found that there was a lack of social support for caregivers of children with ID. The caregivers reported that those that were supposed to give them support gossiped about them. From this study, there was evidence of poor social support as relatives and friends did not consistently interact with the caregivers or the child (Mudhovozi et al., 2012).

However, not all the caregivers experienced poor social support. In Sudan, a study by Shabo, Mohammed, and El Tahir (2011) indicated that 65% of caregivers reported no difficulties with their social support, as they had great support resources. Caregivers reported instances of adequate support from family and friends (Shabo, Mohammed, & El Tahir, 2011). Similarly, McNally and Mannan (2013) found that caregivers felt respected and supported by the community members.

The support came in the form of words of encouragement to continue raising children with special needs (McNally & Mannan, 2013).

3.6 Experiences related to resources and support organisations

Discriminatory behaviours towards individuals with ID was noted through lack of adequate services and poor treatment within some of the hospitals. This treatment came in the form of humiliation through bathing in public, a very restraining environment, and the absence of privacy (Jahoda & Markova, 2004). Oruche et al. (2012) noted unskilled service providers and insufficient support as two of the contributors to the caregiving burden. Ali et al. (2012) cited stigmatisation, discrimination, and labelling through negative attitudes of the health care providers. Caregivers usually shared a distrust of a health care organisation that they perceived as insensitive, biased, careless, negative, although some also experienced positives from individual professionals providing care to the child and listening to them (Lam & Mackenzie, 2002; Lutenbacher, Karp, Ajero, Howe, & Williams, 2005). Other earlier studies also claimed high levels of dissatisfaction with the mental health care organisations, lack of information, unavailability of health care practitioners, support and advice (Bogren, 1997; Doornbos, 2002; Veltman, Cameron, & Stewart, 2002).

Coomer (2013) cited a study on the experiences of parents of children with a mental disability regarding access to mental health care in Namibia, which shared most societal and chronological attributes with South Africa. Using a focus group with 41 participants, he quoted poor service provision. Some of the service providers were reported to be difficult, sometimes unavailable, and sudden changes of service providers. In most cases, incorrect medication was prescribed for the child (Coomer, 2013). It was evident that raising these children raised stress, leading to

compromised well-being and financial problems, while caregivers dealt with financial implications on medications, travel expenses, marital problems, and anxiety (Tsai & Wang, 2009). The lower the socioeconomic status of the family, the higher the levels of financial strain the caregiver endured (Eisenhower & Blacher, 2006). Most of the caregivers were housewives, meaning their chances of having a job or earning an income were limited (Ambikile & Outwater, 2012). Similarly, Gona et al. (2010) noted that support resources that could assist in excellent caring practices were diminished by poverty, resulting in the poor provision of basic needs like food, clothing, transport, and medical needs.

It was well documented that money influenced different parenting styles. According to Nimbalkar et al. (2014), travelling expenses complicated the caregivers' lives as some were jobless. Similarly, caregivers in Limpopo province were from low economic backgrounds (Sandy et al., 2013). It could be deduced that their financial instability was a major blow to their caring roles as they were financially poor. While social grants were common in South Africa for people with mental health conditions, the money was not sufficient to meet all the financial needs (Sandy et al., 2013; Mavundla et al., 2009). The work of Pilusa (2006) asserted that most caregivers were unemployed. Those living with their spouse claimed that they had low paying jobs, and could not meet the financial demands of the whole household (Pilusa, 2006). Similarly, McKenzie and McConkey (2015) stated that caregivers experienced poor health care services. Health care services were not easy to access due to limited financial support to meet the transport needs. Inadequate facilities to care for these children were a concern for the caregivers. Hence, there was poor support from NGOs and the communities.

3.7 Coping mechanisms and resilience

Chen and Lukens (2011) argued that not all caring roles were negative, with Lloyd and Hastings (2009) stating that hope was the predictor of increased well-being of the caregivers. Hope further decreased psychosocial stress (Lloyd & Hastings, 2009). However, these positives depended on support resources that might include adequate financial stability, support from friends, family and health care facilities (Magliano, Fiorillo, Malangone, Marasco, Guarneri, Maj, & National Mental Health Project Working Group, 2003). Herbert (2010) reported that when the caregiver was involved in a mutual relationship with the child and perceived him or her as an important part of her life, she was more determined to continue providing care, which resulted in personal growth, strength and enjoyment.

A qualitative study by Ae-Ngisibe, Doku, Asante, and Owusu-Agyel (2015) in Ghana found that caregivers adopted different coping mechanisms. Some of the caregivers resorted to God, while some expected a new treatment approach to be initiated for the care recipients. Moreover, divine coaches and priests were often used for miracles of hope and deliverance (Ae-Ngisibe, Doku, Asante, & Owusu-Agyel, 2015). An earlier study stated that, despite the negatives to caregiving, some caregivers coped well despite all the challenges that they faced (Brehaut, Kohen, & Raina, 2004). According to Edwardraj et al. (2010) the majority of the caregivers found *faith* as an effective coping technique. When caregivers resorted to *faith*, they found comfort and hope, while Gona et al. (2010) indicated that caregivers sought *religious* involvement for emotional stability, as the children were often taken to the church for deliverance and prayers.

Tsai and Wang (2009) asserted that family resilience was a great force that drove the family to solve the frequent crises and stressors. Common beliefs and descriptions that nurtured a sense of

consistency, partnership, self-confidence and competence were important coping tools (Walsh, 1998; Lee, Lee, Kim, Park, Song, & Park, 2004). When talking to one another, caregivers shared advice and experiences to find ways to handle the child better (Gona et al., 2010). Amongst them, a societal support structure suggested a significant background for collective practice to nurture ideas, survival and adjustment (Chui & Chan, 2007). Few studies had worked towards interventions that possibly helped caregivers to raise these children. The work of Lloyd and Dallos (2008) cited that using positive cognition about the situation helped to increase self-efficacy and hope. Kenny and Corkin (2011) indicated that when effective coping strategies were considered, caregivers experienced a sense of control, low stress and depression levels. They further refrained from maladaptive coping mechanisms. Tilahun et al. (2016) found that caregivers coped well through engaging with health care professionals and through praying. The importance of religious faith in times of sadness was found to be helpful in this study (Tilahun et al., 2016). Correspondingly, McKenzie and McConkey (2015) found that religious faith and family support helped caregivers to continue striving for adequate care for themselves and their children.

3. 8 Summary and gaps in literature review

There was an adequate number of research studies that were done on caring for children with disabilities. These studies were mainly done in the Western context. However, studies that included African perspectives remained few. Most studies from the West found that caregivers experienced a variety of psychosocial processes when caring for children with disabilities. Those psychosocial processes included but were not limited to depression, stress, stigma, and discrimination. However, cultural, financial and societal issues that possibly influence caregiving were hardly noted. As much as research detailed psychosocial experiences that caregivers reported, these caregivers could assemble different means to cope with the challenges of

caregiving. In the context of intellectual disability, the severity of this condition amongst the children was hardly explored. Another important gap in the literature was the number of quantitative studies, which was more than the qualitative studies. In addition, these studies targeted female caregivers, excluding males.

CHAPTER 4

RESEARCH METHODOLOGY

4.1 Qualitative research

Qualitative research paradigm aided this study. The qualitative research focused on the informally assembled nature of reality. The relationship between the researcher and study participants was of paramount importance as such relations would underline the value-loaded nature of what was being investigated (Denzin & Lincoln, 2005). Qualitative research was used to explore the caregivers' psychosocial experiences when raising children with ID (Denzin & Lincoln, 2005; Ritchie & Lewis, 2009).

4.2 Study design

This study used a hermeneutical phenomenological research design. The rationale behind hermeneutical phenomenology was to explore how participants were making sense of their personal and social world. Therefore, this type of phenomenology studied how particular experiences and events hold for the participants. The data collection procedure was based on the hermeneutical phenomenological design which entailed that a researcher described the meaning of several individuals regarding their lived experiences (Creswell, 2007). The caregivers in the study told stories about the experiences they endured raising children with ID while the researcher described the meaning of those experiences (Creswell, 2007; Babbie, 2010).

4.3 Research context and participants

Kutama area is located within Makhado Local Municipality in Limpopo Province. This rural area had approximately 1871 population. Interestingly, 48.5 % of the households in this area were

headed by females, according to Statistics South Africa (2011). According to Bateman (2012), ID is the common disability affecting rural African children: 41 per 1000 children aged between 2 – 9 years old, while the General Household survey (2012) indicated that 5% of children aged 5 years and upwards had a disability in Limpopo Province. However, these statistics barely focused on Kutama area specifically, where the prevalence of ID was unknown. The closest hospital for the population in Kutama area is Louis Trichardt Memorial Hospital. The researcher initially sought contact details of adult female caregivers utilising the Department of Psychology in Louis Trichardt Memorial Hospital. There were five adult female caregivers who met the inclusion criteria during the recruitment process. The participants were primary female caregivers to children with ID and were dynamically involved in the child's needs, care and challenges as stipulated in Terre Blanche, Durrheim, and Painter (2006); Babbie, (2010).

These five participants were a hard-to-reach group. Research showed that this was a pattern wherein most qualitative studies were conducted with a minimum number of participants than expected as they were a hard-to-reach group. For example, Mudhovozi et al. (2012) conducted a study with six mothers on the topic of caring for children with mental retardation (the experiences of Vhavenda mothers), while Sandy et al. (2013) conducted a case study with three families comprising each parent of a child with a disability. Bourke-Taylor et al. (2010) used eight mothers in the study of the impact of caring for a school-aged child with a disability, while Heer, Larkim, and Rose (2015) had a number of five mothers and two fathers in the study of the experiences of British carers of children with developmental disabilities.

Caregivers in this study were telephonically contacted to arrange a briefing session in regards to the study. Home visits were done to ensure that what was written in the information leaflet sheet made sense to the caregivers in clear and understandable language. At the end, the focus

group was held with a number of five female caregivers as the sixth caregiver withdrew her participation, citing other responsibilities to attend to as her reasons for withdrawing.

The caregivers were predominately black females who reside in the Kutama area of Vhembe District in Limpopo Province, South Africa. Three out of these five participants used Tshivenda as their 1st language of communication, while the other two were Sotho-speaking. The focus group was held at a central point in Kutama High School with the consent of the Headmaster of the school. Four out of five participants were unemployed. These participants were between the ages of 30 – 60 years old.

4.4 Sampling

Participants were purposively sampled based on their capacity to offer rich information and their accessibility during data collection. This type of sample was based entirely on the judgement of the researcher in that the case was chosen as it illustrated a feature of interest of the study. Purposive sampling enabled the researcher to deploy participants who were well-informed and willing to provide the information and experiences desired by the researcher (Bernard, 2002).

4.5 Procedure and Data collection

Ethical approval was obtained from the institutional ethics committee in the university (Ref: NWU0028114A9). Furthermore, to screen for eligible caregivers, permission was requested from Vhembe District Research Committee to obtain contact details of caregivers utilising psychological services in the Louis Trichardt Memorial Hospital. All participants were informed of anonymity and confidentiality. A focus group consisting of semi-structured interview was scheduled with five participants that agreed to participate. A single appointment was set up accordingly. On meeting them, the participants were also provided with both an information sheet

and consent forms. The participants and the researcher used Tshivenda as the mode of communication. The data was translated into English. An information update on the sheet was held with all the participants to provide a clear understanding of the study purposes. The interview was audio-recorded with the participants' consent and ranged for approximately 50-60 minutes. Verbatim transcription was employed after data collection.

According to Babbie (2010), a list of suggested questions is advisable in which the questions would guide the research interview with participants. This is called semi-structured interview. The questions were developed based on the literature reviewed, and the process was iterative in that participants directed the flow of the interview.

4.6 Data analysis

Thematic analysis was utilised. All the data was analysed, transcribed, and organised to obtain sense from it (Dawson, 2002; De Vos, Strydom, Fouche, & Delpont, 2011). This type of analysis suited the research methodology chosen and the context of the study. The researcher was interested in determining how caregivers cope with their daily routine, using in-depth interviews. It was important to analyse the transcripts within the data using themes in order to understand the caregivers' psychosocial experiences in their caring roles for children with ID. Howitt and Cramer (2011) determined steps in the thematic analysis, which were as follows:

Step 1: Familiarisation with the data

This was the stage in which the researcher became actively involved with the data. The researcher began to formulate ideas about what was being said in the interview. Interview data had to be transcribed from the recording because this facilitated more intense processing of the

data and writing notes about what the researcher was reading. This was also the best way to familiarise oneself with the data (Howitt & Cramer, 2011).

Step 2: Initial coding generation

This was the process by which the themes were generated. The initial coding process involved working through the data systematically, making suggestions of what was happening in the data. Since we were analysing people's talk which did not have precise regularity, initial coding was intended to capture the essence of a segment of the text (Howitt & Cramer, 2011).

Step 3: Searching for themes based on the initial coding

In this step, themes were essentially obtained by joining together the coding in a meaningful way. Thus, the process of initial coding had involved the researcher in formulating descriptive suggestions for interesting aspects in the data they obtained. One way of identifying themes was to write each of the different initial codings onto a separate piece of paper or card, and then the initial coding was sorted into separate piles of coding which seemed to be related (Howitt & Cramer, 2011).

Step 4: Review of themes

In this step, a researcher had a set of themes which helped to facilitate the understanding of what was in the transcription. However, these themes needed to be tested against the original data again since they might not be refined at this stage (Howitt & Cramer, 2011).

Step 5: Theme definition and labelling

A researcher refined the themes in order for this step to be objective. At this stage, a researcher identified sub-themes which made it easy to define and label themes accurately. Defining and

labelling themes took place in relation to the data too. When a researcher did so, the encoded data was coded using refined themes which made it easy to understand the material (Howitt & Cramer, 2011).

Step 6: Report writing

The final report required that a researcher illustrates his analysis using extracts from his data. This was a stage of reflection on a researcher's analysis. The final report provided the opportunity to discuss the analysis in the light of the previous literature review. The researcher found innovative ways in which the analysis evaluated things beyond previous researchers (Howitt & Cramer, 2011).

4.7 Trustworthiness of the study

Crystallisation

Crystallisation helped with the provision of the deeper understanding of the phenomenon being studied. According to Ellingson (2009) crystallisation involves constructing the data into themes and patterns which further allows the researcher to analyse the participant's exact accounts. Crystallisation grants the researcher a chance to understand the research topic (Ellingson, 2009): Most importantly, crystallised texts feature an important level of spontaneous contemplation of the researcher's self in the technique of research design, data collection and analysis; by using in-depth interviews and field notes, the researcher ensures the trustworthiness of the study (Ellingson, 2009).

Dependability

Dependability entails that the applied techniques used to collect data under the same conditions would yield similar findings, with the same participants used, and same methods applied. The researcher ensured that the conclusion of the study was reported in detail, enabling future research in this area to produce consistent results (Creswell, 2003).

Confirmability

Shenton (2004) states that the concept of Confirmability is the qualitative researcher's equivalent concern to objectivity. The researcher ensures that the study has findings which were the result of the experiences and ideas of the participants, rather than the characteristics and preference of the researcher. To ensure Confirmability, transcripts were evaluated and tested against the original data in the audio-recordings. The researcher involved a second investigator and a peer researcher to assist with interpretation of the data at a different time, so as to improve the analysis and understanding of constructions by others.

4.8 Ethical considerations

For research study, approval to conduct the study was obtained from the ethics committee of North West University Mafikeng Campus (see attached Appendix A, Ref: NWU002814A9) under the central project title: The psychosocial experiences of caregivers raising children with intellectual disability in Limpopo province. The Department of Health, Vhembe District also approved the study (see attached Appendix C). Caregivers of children with ID were identified with the assistance of Louis Trichardt Memorial Hospital's Psychology Department. An informed consent form along with the information leaflet explaining the nature of the project and confidentiality was read and handed out to the caregivers in their own language, as stipulated in

Howitt and Cramer (2011), that participants had the right to be informed about the aims and purpose of the research. Informing participants was important so as to allow them to make an informed decision about participating or not.

Social research should never injure the people being studied, regardless of whether they volunteered for the study or not. Because participants could be harmed psychologically in the course of the study, the researcher looked for slight dangers and guarded against them. The researcher informed participants of their rights to terminate their participation in the study at any time they felt was necessary without any negative effect (Babbie, 2010).

Babbie (2010) states that research participation should be voluntary, and no one should be forced to participate. A researcher should inform participants about the nature and the possible dangers of the experiment, and that their participation is voluntary, and should not expect any reward for their participation (Babbie, 2010).

Privacy and confidentiality was addressed through interviewing the participants in a closed office which was used as a boardroom by the school. This was also done during the recess period, wherein the presence of learners and major staff members of the school was limited. Transcripts were kept safe in the researcher's possession. Participants were treated fairly, equally, with respect and dignity, as this was in line with Creswell (2007) who states that researchers are obliged to respect the rights, values, needs and desires of the participants.

During the end of the interviews, participants were debriefed to explore their experiences in taking part in the study. This was in line with Nestor and Schutt (2012) who emphasise that debriefing is important in evaluating participants' reactions to the study.

CHAPTER 5

FINDINGS

5.1 BACKGROUND INFORMATION OF THE PARTICIPANTS

Participant 1 was a widowed 52-year-old female. She did not have a formal education background, and she was unemployed. She was taking care of her own son with severe ID. Her son was seventeen years old, and he had been diagnosed with ID from an early age which the mother could not fully remember. She had been caring for this child for almost all his entire life span. The son was currently enrolled in one of the local special schools. She best described her socio-economic status as low. However, her child receives disability grant on a monthly basis.

Participant 2 was a 35-year-old female. She had two children of her own in addition to her sister with possible profound ID. The participant completed high school education. She was currently raising her sixteen-year old sister with other physical disabilities that accompanied ID. When the caregiver's own parents passed on in 2011, she had to leave her job in order to care for her disabled sister. The affected child is home-bound; she does not go to school. The caregiver described her socio-economic status as low but manageable. Although she is unemployed, she was currently cohabiting with the father of her two children who worked far from home. She also mentioned that her disabled sister receives disability grant monthly.

Participant 3 was a 56-year-old widowed female, and she was caring for her eighteen-year old daughter who was diagnosed with mild ID. She had been caring for her daughter since her early ages. However, during the day, she currently had limited contact with her daughter due to her occupational responsibilities, as compared to when she was still unemployed. The affected child used to attend a special school. However, she was currently not in school. The participant

completed ABET Training and she further did some courses in Basic Nursing. She described her socio-economic status as comfortable, as she could support her family.

Participant 4 was a 53-year-old widowed female. She was raising her seventeen-year old grandson suffering from severe ID and other co-morbid conditions such as epilepsy. The participant is currently unemployed, and she described her socio-economic status as low. The participant also verbalised that she did not have any formal educational background. Her grandson also receives disability grant as well. The grandson normally spends the early hours of the day at a local home-based care centre.

Participant 5 was a 39-year-old divorced female. She was caring for her seventeen-year old daughter suffering from mild ID. Moreover, the daughter was diagnosed with Down syndrome at an early age according to the mother. The affected child was enrolled in one of the local special schools. The participant completed high school education level. However, she is currently unemployed. She survives through the social grants of her children.

5.2 INTRODUCTION TO THE THEMES

Four major themes emerged from this study. These themes described the psychosocial experiences that the caregivers had endured when raising intellectually disabled children. The themes were: positive experiences of caregiving, negative experiences of caregiving, common issues shared by the caregivers, and coping.

Figure 2: Themes extracted during thematic analysis

THEMES	SUB-THEMES
1. POSITIVE EXPERIENCES OF CAREGIVING	Sense of growth and fulfilment • Acceptance • Unconditional positive regards • Happiness
2. NEGATIVE EXPERIENCES OF CAREGIVING	Emotional experiences • Pain • Feeling hurt • Feeling heavy and burdened • Pressure • Stigma
3. COMMON ISSUES SHARED BY THE CAREGIVERS	Difficulties that the child displays • Aggressive behaviours • Co-morbid conditions • Limited independence Community attitude • Labelling • Jealousy • Lack of understanding • Lack of knowledge Social experiences • Relative attitudes • Strained relationships

- Inadequate support
- Limited engagement in social activities

Experience related to services and organisations

- Finances
- Healthcare
- Adequacy and availability
- Support groups

4. COPING

Spiritual-religious coping

- Prayer
- Faith and religious beliefs
- Coping well with the situation
- Support
- Taking responsibility
- Acceptance
- Adapting
- Resilience

5.3 THEMES TO EMERGE FROM DATA ANALYSIS

5.3.1 Positive experiences of caregiving

Only God knows the situation

The majority of the participants demonstrated that through their acceptance, faith and love that they portrayed towards their children, they deduced strength from their caring responsibilities. The participants turned to their faith as a source of comfort and hope because only *God knows their situation*. Therefore, raising a child with ID was fulfilling for these participants. Their responses were further illustrated by the following statements:

Acceptance: *"I asked myself how I will be able to handle this role because I have two children of my own. Now I told myself that I don't have a choice, I should raise this other child too, indeed I managed through God" (P2).*

Love: *You always want her close to you, you feel that her condition is what God gave you, even when it hurts to see her in that condition" (P3).*

Unconditional positive regards: *"Myself I have two children of my own, but when I look at that one, I take her as my 1st child, I love her most" (P2).*

"He drools saliva all the time. Even when he eats, you will find him messy all over his clothes, but I can accept that, other people can't" (P4).

"There are times when she will be aggressive and angry, but you will be understanding towards her as a mother" (P3).

5.3.2 Negative experience of caregiving

Emotional experiences

A number of participants revealed experiences of pain in regards to raising a child with ID. The pain, with a feeling of being hurt and feeling heavy, feeling burdened and pressure was expressed in the form of the following statements:

Feeling heavy and burdened: *"This thing is very painful; it is very heavy. Because other people outside will be saying different things" (P5).*

Pain and Feeling hurt: *"I was saying raising a child with such a problem is very painful because for instance, that person when his condition comes, he poops and pees on himself" (P4).*

"To stay with a sick person is painful. It has pain and stress in it. Because you look at those children that she was born with, you see what they have achieved and what they are doing with their lives, and you look at her condition" (P3).

"The ways of living are different from other mothers; it can't be the same. Because it's like a swollen pain of the body with sores that do not disappear. It's like something you are always thinking that if you are not there around, someone won't treat her nicely" (P3).

Stigma: *"It is painful; people will say this child is not suitable to stay around people" (P5).*

"Small kids than her would say, 'this dumb', 'this crazy one" (P3).

Pressure: *"Even here in the house, when her siblings shout at her, I feel they are doing wrong because I always consider her condition. I am always on pressure.... I am in pain" (P3).*

5.3.3 Common issues shared by the caregivers

Difficulties that the child displays

The participants verbalised that the child's behavioural problems which could easily be interpreted as aggression, added to their experience of 'pain' and frustration. Below was what some of the participants said:

Aggressive behaviours: *“Even at school, she would come back ask for money to buy school things, I would say I do not have. The teachers would tell her that I took the money and gambled with it. Because she knows I don't gamble, she would beat up the teacher” (P5).*

“Because even when he plays with others, children are somehow, these small ones, since she is older than them, when the small ones talk badly to her, she will bully them and you will hear the small ones saying ‘this dumb, this crazy one’ there are times where she will be aggressive and angry, insulting others even when you talk to her. But you will have an understanding as a mother” (P3).

“It is too much difficult, because as we are like this when he goes and plays with others, they break neighbours’ windows with stones. All these children he was with are not held accountable, only he would be the culprit as they say he is stubborn” (P4).

In addition to the child’s inability to function independently, other conditions that came with the ID frustrated the caregivers even more. Therefore, caregivers together with other community members labelled their children due to confusion and frustrations of not knowing exactly what the child was suffering from.

Limited independence: *“The child cannot walk but can sit. She uses her knees to walk and when she walks, she stops and takes breaks. She does not speak. When she wants something, she will point it to me. I am not sure what her problem is” (P2).*

Comorbid conditions: *“The child does not talk; he is just a person. We went up and down with him. When he gets to school, he starts fainting, when the illness of fainting affected him, he would faint at any time without stopping. He can't talk, but he can hear. He drools saliva*

all the time and even to eat, you will find him with food all over his clothes. Eish I can't tell you really what he is suffering from I am not sure" (P4).

"At the hospital, they said she has problems with her eyes until they brought another doctor who said that the child is Down syndrome and this child has an abnormal backbone. He further said that this child is "under-rest" ... Her eyes, the child had a big head and a big stomach. She continued with her check-ups and they said she is a slow learner. She was not able to walk in the streets because people would say she look like a baboon" (P5).

"Yes, it is true because even when he plays with others, even when he gets to the neighbours, they chase him because of his saliva, he will come back home. But because his sickness affects him, his brains, the next day he will go back again where they chased him. My child is someone who suffers from falling, now he is suffering from falling, his life is hard" (P1).

"Since the child was born, she started coughing...she coughed and coughed until she started walking. It was not clear what is happening to her. At the hospital, they took me to a psychologist. They checked her and I went almost five times, but I spent several weeks going there. They checked her and concluded that this person will not be alright" (P3).

Community attitude

The participants illustrated experiences of jealousy from the community – they felt that the community was discriminating and rejecting their children and families sometimes. The community made many inappropriate remarks about the child's condition. Therefore, the community demonstrated a lack of understanding and lack of knowledge regarding ID. The participants' responses were illustrated through the following statements:

Lack of understanding and lack of knowledge: *"Because people on the outside will be saying different things, as a mother to give birth to such a child, you did not apply for it. It is the work and the wish of the Lord. Even though someone outside might say whatever they feel like saying, that child, you can call her names or you give birth to a disabled child, when it comes back, it will be said that it means your family practices witchcraft. Even neighbours around me, they call her like a baboon. I feel hurt because others will come and say lend me R2, when I say I don't have, they will say but your child gets a grant"* (P5).

"Yes, it is true because even when he plays with others, even when he gets to the neighbours, they chase him because he salivates" (P1).

"I don't have stress now like before. When I am with her, even when people say whatever they feel like saying words like she doesn't work, she quits her job, now her mum died and she is raising her mum's disabled child" (P2).

"Someone once passed my yard and my son was waving his hand at that men, those men showed a bad face, my son was not happy with that. I once went to the clinic, people looked badly at him" (P1).

Jealousy: *"Community complained when my child received clothes as she was tiny, those elders at the church would pick up clothes for her to bring home. People said 'why do you give her clothes; she has a grant'"* (P5).

Labelling: *"Even when she walks in the streets, people would say she look like a baboon, some call her a slow learner"* (P5).

“So she will say mom, that one said I am crazy, it leaves you hurt to hear such words being spoken about her” (P3).

Social experiences

The participants reported one common experience of limited engagement in social activities. Their responses were illustrated by the following statements:

Limited engagement in social activities: *“It is painful because even when you want to go somewhere you will be reluctant even when there are her sisters and brothers in the house. You won’t feel free even when you are far” (P3).*

“The person I am caring for can’t walk, it is true that people will talk and say whatever they want to say. She is someone that I can’t leave alone” (P2).

“No, not at all, it is difficult because you can’t seat and not attend gatherings, I can’t go far” (P4).

“I can’t leave the child alone, I am always there with her, and I can’t get a job far or outside home” (P5).

“I don’t even start unless my younger sister is around. If she is not here, I can’t attend those gatherings, I can’t enjoy with them knowing I left her alone” (P2).

“It is impossible. The child once followed me to a society gathering and embarrassed me. Even when I try to hide, he will expose me and say ‘no, mum is inside the house’ (P1).

While there was a report of relatives distancing themselves, some other relatives were supportive towards the caregivers and the child. Some of the participants said the following:

Relative attitudes: *“Because of even your own relatives, when that child comes near them, they chase her away and they say “hahaha this one” (P5).*

The participants further reported incidences of inadequate support and strained relationships. Their responses were illustrated through the following statements:

Strained relationships: *“He is around, but there is no marriage between us. The stop in marriage is because I would get married and have taken her along with me, so I will not go anywhere. The in-laws will not be pleased with a child with this condition” (P2).*

Inadequate support: *“I was married but I came back because of the in-laws and the child. The grandmother did not love us” (P5).*

Experiences related to service and organisations

There was evidence of difficulties related to organisations and health care services that were supposed to support the caregivers of children with ID. Due to limited finances, the participants demonstrated barriers in accessing adequate health care for their children. Moreover, the limited availability of adequate facilities that catered for children with ID added to the caregivers' frustrations. The participants also verbalised that there were limited support groups for caregivers raising children with special needs. The following statements illustrated their responses:

Health care: *“The child went as far as attending a school at a mainstream primary. They took her out to Roman Catholic Church. As a result of being unable to detect her problem, she was born at seven months. She underwent check-ups in the hospital. At the hospital, they said she has problems with her eyes. I continued taking her for check-ups. She goes to school by bus, the little money I get, I do little things like a shelter I am building for them now (P5).*

Adequacy and availability: *"I registered that she goes to school, when she went to school, it was difficult. She had difficulties even in writing her name. So, at school, they called me and advised that it is better that I take her to a school in 'Phithela' area. I started taking her to a Roman Catholic Church school thinking maybe there are people who would be able to talk to her. When it failed, I was sent to a social worker, the social worker advised that I take her to the hospital. At the hospital, they took me to a psychologist. They checked her and concluded that this person will not be okay" (P3).*

Finances: *"We went up and down with him, taking him to the doctors, we even to Roman Catholic Church. That school was demolished, so we took our children to 'Razwimisani' school. As he failed in that school, I decided to take him to this other one named 'thusalushaka. When he goes, and plays with others, they break neighbours' windows with stones. I am always in money situation paying for windows" (P4).*

"Even that little grant you get, you live and survive with that only. You even think back and ask yourself, how did I come out of that? The important thing is to ask God to not make me an alcoholic, a gambler. Lead me in the right direction" (P3).

Support groups: *"My relatives are also supportive, from the maternal side, they even sometimes ask to stay with her, but because I know her struggles, sometimes I would say no" (P3).*

"Other people are very supportive; they love him and can even touch him by his hand. I got married and my husband passed on. There was no problem in the marriage" (P1).

5.3.4 Coping

Spiritual-Religious Coping

The participants indicated that through God, they found satisfaction in their caring role. This belief system helped the caregivers to cope with the demands of caregiving. Further, the participants believed that God gave them these children for a purpose, and such purpose should be embraced by the caregivers. The following statements illustrated the caregivers' responses:

Faith and religious beliefs: *"Because God is there, I can pay all the debts. I don't know how it happened. I used to cry, saying I can't do these. Someone even offered to take the child, but I refused and say I will face this mountain. God made it possible, God is able. I pray a lot, my prayer helped me. I was sick, thin, thinking I am going to die. When I thought of bathing the child, I get stressed. But now I am doing well" (P2).*

Acceptance: *"You always want her close to you, you feel that her condition is what God gave you, even when it hurts" (P3).*

"As a mother to give birth to such a child, you did not apply for it, it is the work of and the wish of the Lord. All is known by the Lord" (P5).

Resilience and adapting: *"We are just living as we are, letting God take control, he knows, he above all" (P4).*

The majority of the participants were of the opinion that prayer helped them adjust and coped well with their caring roles. This could also be linked to resilience and coping strategies. Some of the participants said the following statements:

Prayer: *"Because God is there, I can pay all the debts. I don't know how it happened. I used to cry, saying I can't do these. Someone even offered to take the child, but I refused and say I will face this mountain. God made it possible, God is able. I pray a lot, my prayer helped me. I was sick, thin, thinking I am going to die. When I thought of bathing the child, I get stressed. But now I am doing well" (P2).*

Coping well with the situation: *"I was married, but I came back because of the in-laws, and this child. Her grandmother did not love us. Even when her father (the child) comes to visit, she would follow him all the way just to embarrass him. From the start, it was painful, but I gave it all to God" (P5).*

"We are just living as we are, letting God take control, he knows, he above all" (P4).

Some of the participants also believed that one should take responsibility in addition to prayer and receive support from some of their neighbours. Their responses were extracted as follows:

Support: *"Other women are very supportive of me, they will stand on my behalf in gatherings and social activities" (P2).*

"My neighbours are very supportive, even when I am not there, if they hear something wrong, they will pop in to ask what is happening. Even at gatherings, they do stand for me sometimes" (P4).

Taking responsibility: *"I am always incharge of taking care of my own household, because my own mother is also living in her own yard, she can't help" (P5).*

5.4 SUMMARY OF THE RESULTS

Themes that emerged from the collected data identified various findings. Although they were negatives affiliated to caregiving, the findings also revealed positive perceptions that the caregivers subjectively noted regarding caring for children with idea. Caregivers also shared common issues that they were faced with during their caring roles. Given the above mentioned core findings, there was also the dynamics of coping with these caring roles. Lastly, these findings will be discussed in relation to the literature reviewed and theoretical viewpoints.

CHAPTER 6

DISCUSSION

6.1 Introduction

The main aim of this study was to explore the psychosocial experiences of caregivers caring for children with ID in Limpopo Province, South Africa. The findings revealed four themes that described the lived experiences of caregivers raising children with ID. This discussion was done using these themes guided by the literature review and the theoretical perspectives.

Theme 1: Positive experiences of caregiving

In this current study, caregivers reported a range of positive experiences when caring for children with an intellectual disability. These positive experiences came in the form of acceptance. The finding is consistent with Pillay et al. (2012) and Tarlow et al. (2004) who found that acceptance was associated with satisfactory caring roles and happiness. Interestingly, a study by Griffith and Hastings (2014) found that love was also the main theme of caregivers. This concept of love was also mentioned in the current study by the caregivers. However, authors such as Grant (2007) and Oruche et al. (2012) argued a range of positive experiences that the current study did not identify. Oruche et al. (2012) reported that having the child at home, receiving support from family members, and positive affirmation were perceived as the positives of caregiving, while Grant (2007) emphasised that a good relationship between the caregiver and the child determined the positives of caregiving. The findings of Oruche et al. (2012) can be linked to a methodological viewpoint. This qualitative descriptive study had 20 participants and used five focus groups which had semi-structured interviews. Additionally, it emanated from the West, which might show many discrepancies in how caregivers experience their caring roles as compared to caregivers in African

cultures. The positive experiences that were identified herein could be associated with stress and the coping theory of Lazarus and Folkman (1984). This theory stipulates that when caregivers cognitively appraised their caring roles negatively, this could lead to poor outcomes. However, caregivers appraised the caring roles in a positive way, thus not only enhancing their psychosocial function but also bringing about positive feelings in their lives. Similarly, the theory of human functioning emphasised that when there was a constant positive attitude in the environment, caregivers' burden also lessened. Not enough research has been conducted on positive experiences such as happiness and unconditional positive regard that the current study identified. It is therefore suggested that studies of this nature are conducted. It may be necessary to consider exploring the positive experiences of caregivers in an African cultural context to have a deeper understanding of such experiences.

Theme 2: Negative experiences of caregiving

The finding revealed the most common negative experiences of pain. This is consistent with Nimbalkar et al.'s (2014) findings which reported feelings of anger and pain among caregivers of children with special needs. Correspondingly, Ambikile and Outwater (2012) reported emotive reactions such as feelings of sadness and pain that the caregivers went through. Sen and Yurtsever (2007) also reported feelings of anger, pain, suicidal ideations, stress and depression among the caregivers. However, the work of Sandy et al. (2013); Bourke-Taylor et al. (2010) and Merrifield (2011) could not agree fully with what this study identified. Although the experience of pain was noted in the current study which could link with what some of the studies identified, these studies further identified depression, stress, and anxiety (Sandy et al., 2013; Bourke-Taylor et al., 2010 & Merrifield, 2011). Sandy et al. (2013) used a case study design with three families, thus, the results of their study can be linked to methodology, which had two phases of data collection for a longer

period of time, whereas Bourke-Taylor et al. (2010) had four mothers and four professionals who went through a two-years-period of data collection within mixed method design. The results also included co-morbid conditions such as cerebral palsy and autism that affected the target group of children. Perhaps the findings of the current study could be linked to cultural inferences; some of the negative experiences of caregiving can be understood and experienced differently across cultures.

It is also important to note that depression, stress, and anxiety cannot be physically seen, just like pain and sadness. However, when one is detailing one's own subjective experiences to health care professionals, it could be deduced whether they are depressed, sad, painful, and anxious or stressed. Some cultures might assemble different strategies to deal with negative experiences of caregiving before they escalate, while other cultures might perceive it as something normal that might pass with time, thus perceiving the negative experiences on a superficial level. This might possibly be the case wherein African cultures have a different understanding of the negative experiences of caregiving as compared to Western cultures. Additional, caregivers' level of education might be of importance for understanding how they experience something and how they put meaning into it. Therefore, the findings highlight a need for studies that include a large sample size with different ethnic groups. Caregivers' level of education should also be taken into consideration together with a thorough assessment of the child, to determine a working diagnosis and the severity. In line with a theory, Friedmann's Social Disempowerment Model linked everyday negative experiences of caregiving to the poor psychological functioning of the caregivers. Importantly, when caregivers appraise their caring roles in a negative way, this could lead to the poor outcome of psychosocial functioning (Lazarus and Folkman, 1984). However, the participants further identified feeling hurt, feeling heavy and burdened, pressure, lack of

support and stigma. Although there is research that has been conducted on the burden, lack of support, and stigma, there is no further research supporting feeling hurt and pressure. It can be deduced that future qualitative and quantitative studies should be conducted to confirm the factors around these findings.

Theme 3: Common experiences shared by the caregivers

Firstly, there were revelations of other issues that the caregivers were faced with. These included the difficulties that the child displayed, which were also a burden for the caregivers. The participants verbalised that their children displayed uncommon behaviours such as aggressiveness. These results were consistent with Sandy et al.'s (2013) findings which reported that children with ID displayed behaviours that were interpreted as aggression and lead to violent behaviours. Bourke-Taylor et al. (2010) also noted aggressiveness and self-injurious behaviours by these children. Lastly, the children displayed limited abilities to be independent. The theory of Human Functioning attributes failure to meet independence as the result of deficits in adaptive functioning. Interestingly, the environment that the child belongs to may influence positive adaptive functioning if such environment is conducive. Therefore, the findings of the current study together with the previous study can be linked with a possible poor environment which is often not conducive for the development of children with ID. Therefore, there is a need for studies that incorporate community attitude or involvement towards intellectual disability within rural areas. Most of the children had other conditions such as epilepsy and Down syndrome. While there is evidence of a study on Down syndrome (Carr, 2005), there is no further study supporting epilepsy. However, according to Stress and Coping Theory, the diagnosis of another mental illness was also associated with poor outcomes of caregivers' psychosocial functioning (Lazarus & Folkman, 1984) as these caregivers were not well equipped to deal with the difficulties that the child

displayed (Friedmann, 1992). It is crucial for qualitative and quantitative studies that will explore whether caregivers experience challenges due to multiple diagnoses or the severity of the mental illness.

Secondly, it was found that caregivers encountered experiences related to their community. The community displayed a lack of knowledge and lack of understanding towards the caregivers. The lack of knowledge, especially around issues related to ID meant that the community at large often labelled, judged, and even rejected caregivers of children with ID. This also included the terminologies used to describe children suffering from this condition (e.g. 'crazy one', 'baboon'). The community further demonstrated jealousy when the caregivers were offered food parcels or clothes, and often labelled the child suffering from ID. The results of lacking understanding were consistent with Ambikile and Outwater (2012) who reported that the community's attitude towards the child with ID meant that the caregivers were expected to manage their caring roles on their own. While the study identified that most of the community members demonstrated jealousy when the caregivers received parcels, studies such as Edwardraj et al. (2010) reported that the community themselves did not help the caregivers with resources, while Jahoda and Markova (2004) reported that society does not accept and include the intellectually disabled into community activities. The findings of these studies can be linked to the environment which the child and the caregiver belong to, which is also the case in the current study. Hence, according to the Theory of Human Functioning, the environment that the caregiver and care-recipient find themselves in could cause strain. Community support and a positive attitude might contribute to the better adaptive functioning of children with ID. This might also lessen the caregiving burden. However, when there was evidence of stigma and other discriminatory practices such as lack of understanding and labelling, these children and their caregivers might remain in an uncomfortable situation

(Arvidsson, 2013). Bilgin and Kucuk (2010) reported incidences of closeness and unity between caregivers and their family. These included shared caring roles and responsibilities. The current results did not identify these, and such findings in Bilgin and Kucuk (2010) can be linked with the type of methodology that was used in addition to a larger sample size. Furthermore, the environment, the age of the children and the type of mental illness that Bilgin and Kucuk (2010) focused on were possibly influential in the findings. Therefore, it is emphasised that studies which might target a large sample and possibly consider children between 3–15 years of age who are in special schools should be considered. Additionally, perhaps there is also a need for different population groups in both urban and rural areas to be part of future qualitative and quantitative studies.

Thirdly, the results revealed experiences related to the social environment. These social experiences included relatives' attitude, strained relationships, inadequate support and limited engagement in social activities. These results corresponded with Mudhovozi et al.'s (2012) findings which reported a lack of social support for caregivers of children with ID. Similarly, Mbwilo et al. (2010) reported that caregivers did not participate much in social gatherings, while Qayyum et al. (2013) reported that the social relationship between the caregivers and their respective community members became strained. The findings in these previous studies were possibly the result of environmental factors such as community attitude, family attitude and limited understanding of mental illness in general. These factors possibly influenced the findings in the current study. As in the Social Disempowerment Model, when challenges arose in caregivers' lives, social interaction and interpersonal relationships that were solid may benefit the caregivers in maintaining a healthy life functioning (Friedmann, 1992). There were several studies (Yousafai, Farrukh, & Khan, 2010; Wang, Michaels, & Day, 2010; Bilgin & Kucuk, 2010) linking poor levels

of social support with the poor psychosocial functioning of the caregivers. There is a need for studies that might explore the community's attitude toward mental illness in general. Further, studies on siblings and extended family member's experiences of living with a child with ID should be considered within the African context.

Lastly, the study revealed experiences related to health care services and support organisations. These findings were reported in the form of finances, health care, adequacy and availability, and support groups. The results of health care services were consistent with Ourche et al. (2012) who reported that unskilled service providers and insufficient support contributed to the caregiving burden. Moreover, with adequacy and availability, Coomer (2013) and Veltman et al. (2002) reported inadequate services which were accompanied by difficult service providers who were often unavailable at times of need. Tsai and Wang (2009) and Sandy et al. (2013) reported financial implications of medication and travel expenses. Hence, the Social Disempowerment Model stipulated that the needs of the caregivers raising children with ID were to access resources (Barber, 2011). Furthermore, caregivers should be provided with adequate information regarding the child's condition and they should be part of decision-making regarding health care (Goodman, 2012). In line with these, there is a need for studies that might look at health care professionals' experiences of working with families of children with ID.

The recent findings also revealed that the caregivers became mostly confused and frustrated because they had limited knowledge of the condition that their children were suffering from. These results were consistent with Pusey-Murray and Miller (2013) who reported that most caregivers had a different understanding regarding the concept of ID, while Nel and Grosser (2016) acknowledged that conceptualising ID in South Africa could be difficult due to a number of factors that need to be considered before a diagnosis could be made.

Theme 4: Coping

Findings within this study also revealed the most common coping mechanism that the participants utilised to handle the caregiving challenges. The following accompanied the coping themes: prayer, faith and religious beliefs, support, taking responsibility, meaning construction, acceptance, adapting and resilience. The results of prayer, faith and religious beliefs were consistent with Ae-Ngisibe et al. (2015); Tilahun et al. (2016); McKenzie and McConkey (2015), who reported that some of the caregivers turned to God and other divine approaches. Edwardraj et al. (2010) reported that the majority of caregivers found faith an effective coping technique, while Gona et al. (2010) indicated that caregivers sought religious involvement for their own emotional stability. Tsai and Wang (2009) agreed with the concept of resilience when they mentioned that family resilience was a great force that drives the family to solve frequent crises and stressors, in this case caring for children with ID. Lastly, Lloyd and Dallos (2008) cited that positive cognition, which corresponded with meaning-construction, helped in increasing self-efficacy and hope. In Lazarus and Folkman's theory, Mackay and Pakenham (2012) said that coping had the following functions: dealing with the root of the stressor (problem-focused coping) and regulating emotive reactions (emotion-focused coping). Emotion-focused coping had an element of avoidant or emotional approach such as acceptance, escaping and denial (Mackay & Pakenham, 2012), altering anticipations, shifting objectives and urgencies, gratefulness in regard to the child's abilities and hilarity (Lai & Oei, 2014). Problem-focused coping had elements of seeking social support resources, ironing out the child's management strategies, conserving household support and household assimilation (Lai & Oei, 2014). Park and Folkman (1997) further introduced other coping strategies (meaning-focused) which included reinstating, creativity and meaning-construction from difficult life events, while Lai and Oei (2014) included spiritual

coping such as optimism, religion-focused and divine relief. In the context of this study, the findings showed that the participants used emotion-focused coping such as acceptance, and spiritual-focused coping strategies to deal with the challenges of caregiving. Consistent findings within the literature associated these different coping strategies with positive outcomes of caregiving (Edwardraj et al., 2010; Gona et al., 2010; Tsai & Wang, 2009). The current study did not identify incidences of active-avoidant coping. Perhaps this was the result of the religious beliefs that the caregivers possessed, which allowed them the space to accept and appreciate their children. Therefore, perhaps studies that explore all the coping mechanisms of caregivers caring for children with ID should be considered.

6.2 CONCLUSION

The current study concluded that the caregivers experienced confusions and frustrations as they had limited understanding of the condition that their children suffered from. This study also came to the conclusion that, as much as the caregivers reported negative experiences such as pain, lack of support and feeling burdened, there were instances wherein the experiences of caregiving were perceived as positive by these caregivers. Thus, the birth of a child with ID was not automatically an invitation to negative outcomes. The most common negative experience that this study revealed, as in other studies, was 'pain'. This experience of pain could be linked with previous studies that reported a variety of psychological processes. In line with social experiences, the study concluded that indeed there were some relatives who demonstrated a poor attitude towards the caregivers, leading into strained relationships. Most importantly, caregivers withdrew participation in social activities due to the community's attitude. The caregivers also went through experiences that were related to support organisations and health care services. Inadequate facilities and limited finances meant that the caregivers struggled to provide adequate care for

these children. However, despite the above-mentioned challenges, these caregivers demonstrated resilience by turning to prayer and faith to overcome their caregiving challenges.

6.3 RECOMMENDATIONS OF THE STUDY

In Kutama area, adverse psychological intervention and radio talks around caregivers raising children with special needs should be implemented by clinical psychologists to assist the caregivers with support groups to voice out possible frustrations especially around the prevalence of ID in this area. Therefore, other caregivers who hide their children might be encouraged to come out and seek professional help when they realise they are not alone. Based on the findings of this study, the following are recommended:

It is recommended that the results of this study be used to inform policy makers in health care sectors, especially Vhembe District which cater for all health-related issues around Kutama area to develop intervention strategies that will help health care professionals to support caregivers of children with ID. This study also recommends that the society should be educated about ID.

Awareness campaigns regarding ID in the community and schools can be created in Kutama. Importantly, this can be achieved through the collaboration of different stakeholders such as Department of Health and Social Development, Community Forum and Education Department on a provincial level.

The above-mentioned is also in line with the implementation of effective services and support structures to empower the caregivers with skills and knowledge on caregiving.

6.4 LIMITATIONS OF THE STUDY

The findings of this study were limited to female caregivers of Kutama area and therefore could not be generalised to the whole of Limpopo Province. There were no males who participated in this study and as such, the findings cannot be generalised to different gender groups of participants. The participants were black females, and the findings of the study were from a single racial background. Educational levels of the participants were poor, thus, their level of understanding of ID was questionable. The study took place in a rural environment, thus, lacking perspectives from an urban environment. The sample size might have also affected the results as only five participants were recruited. Therefore, the results could not be generalised to the whole of Limpopo province. The experiences of the caregivers were subjective, and as such cannot be generalised to the whole of Limpopo Province and South Africa. Lack of direct assessment of the children for the severity of ID might have affected the results. The study limited its focus to the psychological and social processes that the caregivers experienced.

6.5 IMPLICATION FOR FUTURE RESEARCH

The literature on caregiving within South Africa is scarce, this study recommends that researchers conduct future studies to contribute to the theoretical understanding of caregiving within the South African context.

It is recommended that contributory factors that may influence caregiving to be explored, i.e. caregivers' quality of life, burden, cultural factors, and financial factors. Additionally, the severity of the diagnosis should also be considered.

It may be necessary to consider exploring the positive experiences of caregivers in an African cultural context to have a deeper understanding of such experiences.

It is crucial for qualitative and quantitative studies that will explore whether caregivers experience challenges due to multiple diagnoses or the severity of the diagnosis.

It is emphasised that studies which could target a larger sample and possibly consider children between 3 – 15 years of age who are in special schools. Additionally, perhaps there is also a need for different population groups in both urban and rural areas to be part of future qualitative and quantitative studies.

Studies on siblings and extended family member's experiences of living with a child with ID should be considered within African context

Therefore, perhaps studies that completely explore the coping mechanisms of caregivers caring for children with ID should be considered.

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APPENDIX A: Certificate of Language Editing

1065 Hector Petersen Drive

Unit 5

Mmabetho

30/03/2017

This is to certify that the mini-dissertation entitled

**PSYCHOSOCIAL EXPERIENCES OF CAREGIVERS OF CHILDREN WITH
INTELLECTUAL DISABILITY IN LIMPOPO PROVINCE, SOUTH AFRICA**

Submitted by **MPFARISENI CHABALALA**

For the degree of

**MASTER OF SOCIAL SCIENCES
(CLINICAL PSYCHOLOGY)**

In the

**FACULTY OF HUMAN AND SOCIAL SCIENCES
MAFIKENG CAMPUS
NORTH WEST UNIVERSITY**

Has been edited for language by

Mary Helen Thomas (B.Sc. Hons. PGCE)

M. Helen Thomas

APPENDIX B: NWU Ethical Clearance Certificate



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ETHICS APPROVAL OF PROJECT

The North-West University Research Ethics Regulatory Committee (NWU-RERC) hereby approves your project as indicated below. This implies that the NWU-RERC grants its permission that provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title: The psycho social experiences of caregivers for mentally challenged children in Limpopo Province

Project Leader: Ms PS Kolobe
Student: M Chabelala

Ethics number:

N W U - 0 0 2 0 1 - 1 4 - A 9

Approval date: 2014-09-29

Expiry date: 2019-09-28

Special conditions of the approval (if any): None

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- The project leader (principle investigator) must report in the prescribed format to the NWU-RERC:
 - annually (or as otherwise requested) on the progress of the project,
 - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-RERC. Would there be deviation from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-RERC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-RERC retains the right to:
 - request access to any information or data at any time during the course or after completion of the project;
 - withdraw or postpone approval if:
 - any unethical principles or practices of the project are revealed or suspected,
 - it becomes apparent that any relevant information was withheld from the NWU-RERC or that information has been false or misrepresented,
 - the required annual report and reporting of adverse events was not done timely and accurately,
 - new institutional rules, national legislation or international conventions deem it necessary.

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance.

Yours sincerely

Prof Amanda Lourens
Chair NWU Research Ethics Regulatory Committee (RERC)

APPENDIX C: Approval Letter from the Department of Health

2014-11-19 09:05

dep of health 0 >>

P 3/7

P.O Box 184

KUTAMA

0940

18 November 2014

Email: mparisenimchabalala@gmail.com

To whom it may concern

I, Chabalala Mpariseni, write this letter in accordance to the research project titled 'The psychosocial experiences of caregivers for mentally challenged children in Limpopo Province. I am seeking permission to obtain contact information of eligible caregivers through the Psychology section in LTT Memorial Hospital. The aim of the study is to clarify the lived experiences of people who care for mentally challenged children and explore how they manage their lives. The study is being conducted to understand how caregivers cope with the demands of caring for a child with special needs and identify areas for improvement based on the results.

There are *medium risks* associated with participating in this research project as it utilizes focus groups and interviews. However, this study will not injure any participants as the researcher will look for slight dangers and guard against them. Participants will be informed about the nature of the study to allow them to make a decision if they want to participate or not. All aspects will be verbally explained to the participants.

The researcher will cover the distance expenses by reaching out to the participants through home visits if necessary. It will involve 8 participants from a remote/rural area, and another 8 from urban area. This application also serves as an ethical consideration. Should you have any questions regarding this application or the study itself, please contact:

M. Chabalala (Researcher): 071 105 0010

Ms P. Kolobe (Supervisor): 018 389 2129

2014-11-19 09:05

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LIMPOPO

 PROVINCIAL GOVERNMENT
 REPUBLIC OF SOUTH AFRICA

**DEPARTMENT OF HEALTH
 VHEMBE DISTRICT**
FAX COVER

TO: CEO	FROM: Acting SNR Manager: Hospital Services
INSTITUTION: LTT Memorial Hospital	DATE: 19 November 2014
FAX NUMBER: 015 518 3252	NUMBER OF PAGES: 07 Pages
ATTENTION:	ENQ: Ravele N.C
SUBJECT: Approval to conduct the study Chabalala Mpariseni	TELL: 015 962 1001 Ext 132

☒ X	Urgent	☐ For review	☐ Comment	☐ Reply
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Kindly receive as attached.

APPROVED: **DATE:**

Private Bag 9300 TROMPSBURG 0900
 Old Parliamentary Building Tel: (015) 962 1040, (015) 962 1042, (015) 962 1001/2/3/4/5/6
 Fax (015) 962 2575/ (015) 962 2274/ 4635.

APPENDIX D: INFORMED CONSENT FORM

I.....agreed to participate in the research entitled "The psychosocial experiences of caregivers raising children with Intellectual Disability" conducted by Mr M. Chabalala in the Department of Psychology at North-West University Mafikeng campus. I understood that this participation was entirely voluntary. I knew I could withdraw my consent at any time without penalty.

Signature of participant..... Researcher's signature.....

Research at NWU that involved defenceless communities' participation was overseen by the institution Review Board. Questions or problems regarding your rights as a participant should be addressed to, (telephone number), email address.....

Head of Department

Department of Psychology

NWU Mafikeng

Private Bag X2046

Mmabatho

2735

APPENDIX E: Biographical questionnaire

Caregiver's characteristics:

1. What is your age?.....years
2. What is your gender? ☐ Male ☐ Female
3. What is your marital status?
☐ Married and/or living with partner ☐ Divorced
☐ Separated ☐ Never married
☐ Widowed ☐ Other (specify).....
4. What is your education level?
☐ Did not complete junior high/middle school ☐ Bachelor's degree
☐ Did not complete high school ☐ Graduate degree
☐ Some college courses ☐ Other (specify).....
5. Can you tell me about your current work status?
☐ Working at a full-time job ☐ Working at a part-time job
☐ Unemployed ☐ other(specify).....
6. Can you please identify your relationship with the person you are providing care for?
☐ Daughter
☐ Son ☐ Sibling
☐ Grandchild ☐ Other (specify).....
7. What is the best way that you can describe your socio-economic status?
☐ Low
☐ Middle
☐ High

Care receivers' characteristics:

8. How old is the person that you are caring for?

9. What is the gender of the person you are caring for? ☐Male ☐-female
10. How long has this person been suffering from the condition (in months)?
11. How long have you been providing care for this person (in months)?
12. Approximately how many hours per week do you spend caring for the person?

APPENDIX F: Semi-structured interview

1. What is the situation of the child you are raising
2. How is the experience of raising this child? How is it for your other children? How is it for this specific child?
3. When you are with these children, do you love them because you feel pity for them or you love them equally?
4. When you did not have these children, and the time that these children came into your lives, do you still live the life you use to and do you still do the things you use to do?
5. When there are activities such as funeral and weddings, can you attend freely?
6. What can you explain deeply that is highly challenging while raising these children?
7. What support did you receive from friends, relatives, family and organisations?
8. What about people in the community?
9. How do you cope, people you live with, are they helping you to carry on?