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PRIMARY CARE GIVERS EXPERIENCE OF TAKING CARE OF CHILDREN WITH INTELLECTUAL DISABILITY IN MPUMALANGA PROVINCE, BUSHBUCKRIDGE REGION

BY

DIBAKOANE KGAHLISO ANTOINETH

STUDENT NO: 1527047

MASTER OF ARTS IN PSYCHOLOGY BY COURSEWORK AND RESEARCH REPORT

SUPERVISOR: PROFESSOR SUMAYA LAHER

DEPARTMENT OF PSYCHOLOGY

UNIVERSITY OF THE WITWATERSRAND (2016)

DECLARATION

I, Antoineth Kgahliso Dibakoane declare that this thesis is my own work. It is submitted in partial fulfilment of the requirements for the degree Master of Arts in Psychology by Coursework and Research Report in the Department of Psychology, University of the Witwatersrand, Johannesburg. It has not been submitted for any other degree or examination at any other university or institution.

Sign: 

Date. 02 June 2017

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CHAPTER 1: INTRODUCTION

Individuals with mental illnesses may be stigmatised or discriminated against and are regarded as vulnerable members of a community (Johnstone, 2001). Intellectual disability (ID) is a disorder which is characterised by the presence of detained mental development as indicated by the descent of concrete functions in the stages of development which contribute to the level of intelligence including language, cognition, motor as well as socialisation functions (Katz, & Lazcano-Ponce, 2008).

A previous study that focused on gender differences amongst individuals with Intellectual Disabilities (ID) (Christianson, Zwane, Manga, Rosen, Venter, Downs, & Kromberg, 2002) was conducted in Bushbuckridge which, at the time, was located in Limpopo Province. The results suggest that there is a connection between gender and ID in the region. Christianson et al. (2002) concluded that poor intellectual functioning can cause children to fail at school or limit their progress. They further stated that, by improving and integrating services such as primary health care maintenance, early diagnosis may take place. However, no studies have been done that look specifically at the experiences of caregivers of these children.

1.1. Research aims

This research study explored the lived experiences of caregivers of children with intellectual disabilities and focused on their experiences of caring for children with intellectual disabilities as well as their perceptions of intellectual disability and how these perceptions or experiences may be influenced by other factors.

1.2. Rationale for this study

Societies are governed by cultural and religious norms that have different perspectives regarding ID. A primary caregiver to a child with ID may have limited knowledge and the emotional state of the primary caregiver may also be of a burden not only to the caregiver but to the family as a whole hence not knowing how to manage a situation The reason for conducting this study is that, in South African communities, especially in rural societies, people know little or nothing about ID, its causes and how it affects individuals (Masasa**,** Irwin-Carruthers and Faure, 2005).

The study also focused on the experiences of the caregivers of individuals with ID and how they are treated in their communities. People have their own opinions about the world they live in which are based on personal and socially constructed beliefs and attitudes. Bond and McConkey (2001) and Lefton (2000) explain that "attitude" is a pattern of feelings or reactions which individuals hold with regards to particular people or objects and that such ideas are often based on the individuals' past experiences.

It has been noted that Caregivers of children with disabilities are mostly female and perceived to be approximately more than 90% mostly in their late 50s to early 60s. More or less of these caregivers have received high school education or higher education if not at all and live in urban areas (Burnette, 2000; Force, Botsford, Pisano, & Holbert, 2000; Janicki et al., 2000). Grandparents also assist as caregivers for their grandchildren with disabilities (Janicki, McCallion, Grant-Griffin, & Kolomer, 2000). One study indicated that these grandparents of children with disabilities provide primary caregiving daily typically until the child is seven years of age (Janicki et al., 2000).

A study which was conducted by Kromberg, Zwane, Manga, Venter, Rosen and Christianson, (2008) on intellectual disabilities in the framework of a South African population concluded that children were divided according to their disabilities4.3% of the children were diagnosed with one of five of the disabilities, 3.6% of the children appeared to be diagnosed with intellectual disabilities, 0.7% with epilepsy, 0.5% with visual disorders, 0.5% with movement disorders and 0.3% with audible range disorders. It indicated that mostly boys with hearing impairments were receipts of education that suits their needs or disabilities as opposed to girls and children with other disorders who were not receiving any relevant or suitable education.

Kromberg et al.'s (2008) study also indicated that parents and other caregivers did not only depend on western medicine or hospital services but also sought assistance from traditional healers for their affected children. In a report compiled from the study of epilepsy, it is also stated that traditional healers will therefore refer the children to the hospitals even though they had the effective medicine to treat epilepsy (Christianson et al., 2000 as cited by Kromberg et al., 2008).

In order to understand how intellectual disability affects a family, it is necessary to know the context by interacting with family members as well as other relevant people who deal with the individual who is intellectually impaired. They can provide relevant information such as how they understand the phenomenon and how their society responds to intellectual disability. This will identify the support structures which are already present and those which are lacking. Being able to understand the experiences within a family will be of great benefit to researchers and other stake holders such as non-government organizations and other relevant parties which will help in identifying strengths, support within a family structure which will be of benefit to the family and individuals with disabilities.

According to Macionis **(**2011), the family unit contributes towards the formation of an individual's personality. It is of significance that support is given to individuals with ID during their live span (Chou, Lin, Chang, & Schalock 2007; Hill, & Rose 2009; McConkey, 2005). The family structure provides roles for individuals with disabilities which influence their roles in the community **(**Rao, 2006).

Many research studies place their attention on the undesirable aspects of intellectual disabilities and portray caregiving as a burden for parents **(**Hassall, Rose, & McDonald 2005; Kenny, & McGilloway 2007; Salovita, Italinna, & Leinonen 2003). These studies also indicated that caring for individuals with intellectual disabilities results in the caregivers experiencing stress, burnout and more altitudes of despair than the average populace (Blacher, Neece, & Paczkowski 2005; Blacher & McIntyre 2006) however some parents seem to be well adapted and resistant in the face of encounters (Gerstein, Crnic, Blacher, & Baker, 2009). It has also been shown that there can be rewarding outcomes for caring for a child with an intellectual disability. Studies also indicated that many parents who find comfort in their spirituality refer to their children with intellectual disabilities as "blessings" and not burdens (Blacher et al., 2005).

Since this study aimed at exploring primary caregivers' experiences of caring for children with intellectual disabilities, it focused on the research questions below.

1.3 Research questions

- How do primary caregivers of children with intellectual disabilities understand intellectual disability?

- What do the caregivers believe about the causes of intellectual disability?
- What influences caregivers life choices of children they care for?
- What influences caregivers schooling choices for the child they care for?
- How does intellectual disability affect both the caregivers and the children with regards to the way people relate to both the child and the caregiver in the community?

1.4 Outline of chapters

Chapter 2 reviews literature from previous studies to gain more insight about intellectual disability by looking at its origin, how the Diagnostic statistical manual defines ID, the perceived causes of ID which range from medical/biological causes, cultural causes, which include witchcraft and ancestral punishment as well as how these illnesses may be treated. Experiences differ according to each person and the situation she/he is faced with which results in different reactions. Primary caregivers' experiences are explored as well as the experiences of their children with intellectual disabilities. Because of the debate whether children with intellectual disabilities should attend mainstream schools, a review is also conducted regarding the education system.

Methodology is discussed in Chapter 3. This chapter discusses how the study will unfold and which methods were followed for the research design, data collection and the analysis as well as the ethical considerations which need to be in place when working with human participants by making sure that they are not being violated in any way. It also includes self-reflection of the procedures which were in place to expose my own biases.

Chapter 4 consists of the results of the study. It includes the identification of themes and sub-themes following the analysis of the data and gives examples of the quotes which were obtained from the interviews.

Chapter 5 consists of the discussion of the results obtained, the limitations which affected the study as well as recommendations for further studies in the future.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter reviews literature from previous studies to gain more insight about intellectual disability by looking at its origin, how the Diagnostic statistical manual defines ID, the perceived causes of ID which range from medical/biological causes, cultural causes, which include witchcraft and ancestral punishment as well as how these illnesses may be treated and the theoretical framework is also explained. Primary caregivers' experiences are explored as well as the experiences of their children with intellectual disabilities. Because of the debate whether children with intellectual disabilities should attend mainstream schools, a review is also conducted regarding the education system.

According to Harris (2006), the acknowledgement of intellectual disabilities dates back to the Egyptian city of Thebes in 1552 B.C. The Romans and the Greeks believed that a child with ID was caused by the Gods' anger. Death from exposure would be considered for infants born with intellectual disabilities. However, children with ID born in wealthy families were given protection (Harris, 2006).

Before the 18th century, communities had different theories of intellectual disabilities. Individuals who were considered or categorised as having mild ID and were socially capable did not receive any identification nor treatment, however this was different to those who were considered to be having severe ID and thus were protected by their families as well as being placed in convents. People who were considered to be having severe ID were seen as the community as deserving to receive heavenly exposure (Beirne-Smith, Patton, & Kim, 2006; Harris, 2006).

In the year 1799 in France, a medical doctor known as Jean-Marc Itard was considered to be the first individual to have developed an intervention programme and Doctor Jean-Marc Itard further invented a skills-programme which he would use on a particular patient who was considered untamed and was named Victor. It is mentioned that the skills-programme was adopted by Eduoard Seguin and he developed his own methodological programme aid at educating people who were seen as being unintelligent at the Salpetrière Hospital in Paris. The methodological programme by Seguin's put emphasis on the education of the moral and physiological being as

well as other features such as how to manage behaviour and personalized teachings which are still being conducted. In 1866, Seguin published the persuasive book titled *Idiocy and its Treatments in Physiological* Methods after migrating to the United States of America (Beirne-Smith et al., 2006).

Alfred Binet (1857-1911) was a French psychologist who, in the early 20th century, invented the first intelligence test to identify children with learning disabilities for placement in special education classrooms (Garrison, 2009). Garrison (2009) further stated that Heber (1959) emphasised that efforts were made to define class using intellectual and social criteria. This was made possible by the American Association on Mental Deficiency manual written in 1959 which defined "mental deficiency", as it was then referred to, as the lack of mental functioning which is present in an individual's developmental stage and consists of impairments in learning, progress and social change.

The historical background of ID, as discussed above, provides an essential focus for the literature which will be reviewed in this section. It discusses how the view of ID has changed through time and includes the caregivers as an influential part of the intellectually disabled/impaired individuals.

Statistics South Africa (2014) estimated the populace of South Africa to be 51.8 million people and the number of individuals with disabilities to be 7.5%. Statistics South Africa (2011) showed that black Africans had the highest proportion of ID at 7.8% and the total of those living with mental disabilities accounted for 3.2% of the population. It also indicated that, in Mpumalanga, 6.7% of the people were living with different types of disabilities. According to the 2013 census, 2,255,982 people in South Africa had different forms of disabilities and that 12% of those were individuals with ID. The survey conducted in 2007 in 274,348 households showed that, when compared to 6.5% in 1996, there was a decline of 4% in the figures of people with ID in 2007 (Statistics SA, 2007). A study led by Kromberg et al. (2008) concluded that the prevalence rate of ID in South African rural areas is 3.6% and an estimated 2%-3% prevalence rate of ID in developed countries.

In South Africa, women are mostly caregivers or responsible for the wellbeing of individuals affected with ID (Adnams, 2010). Caregiver, in this context, refers to an individual who is

responsible for a child with disabilities in terms of supporting them in their daily lives, either socially, in decision making or with daily functioning. Scharlach, Li and Dalvi (2006) stated that families are a vital part of a person's life in terms of both social and emotional support and that care giving depends on the disability and how it affects family members directly or indirectly. Caregivers who care for individuals are most likely to experience strain either personal or interpersonal.

According to Baker-Ericzen, Brookman-Frazee and Stahmer (2005), families are viewed as a critical support structure for individuals including children with intellectual disabilities. Resources such as time, emotional and finance support are associated with having children with intellectual disabilities but spiritual growth has also been reported as being part of the outcome for caring for children with intellectual disabilities (Scorgie, & Sobsey, 2002)

Different cultures and demographics affect or influence the development of the child, either cognitively or otherwise, and can influence the way in which families perceive disabilities.

In most instances, biological parents are viewed as the sole caregivers of their children, whereas, in most cases of intellectual disabilities, grandparents play a significant role in raising their grandchildren. According to literature, there are a growing number of grandparents who are primary caregivers for children with intellectual disabilities and who provide custodial care.

According to the World Health Federation for Mental Health (2014), when associated to the overall populace, caregivers are at a greater risk of developing mental or physical illnesses such as stress or depression; they may become obsessive alcohol or substance users and some of them might exhibit harmful behaviours.

In South Africa, little or no consideration is given to caregivers and the focus is more on the individual with an intellectual disability rather than on the caregiver. Most individuals in rural areas have little or no education about mental health or mental illnesses and they may not realise that they are suffering from a mental illness when the symptoms present. The current study contributes to the mental health of caregivers as it focuses on the caregivers who will be provided with psychological education, the importance of counseling and where they can go for counseling when necessary.

This review therefore discusses the differences between DSM-IV-TR (2000) and DSM-5 (2013) and how these texts define intellectual disability, its symptoms/criteria while looking at the biological causes, cultural causes/beliefs of ID, the level of education in special schools and the biomedical and social models of disability.

2.2 Mental retardation and intellectual disability defined

Mental retardation (MR), as defined by DSM-IV-TR (2000), is an intellectual impairment of an IQ of 70 or less which is present before a child is 18 years old and is categorised by a lack of adaptive functioning. MR is characterised by criteria A, B and C. An individual who fits into criterion A has an intellectual impairment; criterion B has limited functioning in communication skills, academic skills, self-direction and physical wellbeing while criterion C is characterised by ID being present before the age of 18.

MR has four levels which are used to define certain persons with MR, namely, mild, moderate, severe and profound.

- An IQ level of approximately 70 or less (50 up to 55) is classified as mild MR.
- An IQ level of 50-55 or less (35-40) is categorised as moderate MR.
- An IQ level of 20-25 up to 35-40 is classified as severe MR.
- An IQ level of 20 up to 25 is classified as profound MR.

DSM-5 (2013) defines intellectual disability (ID) as a disorder which occurs mostly in the developmental stages and comprises impairments in the way individuals respond to social settings and how they conduct their daily lives. ID comprises criteria which help diagnose an individual with ID. These criteria are divided into A, B and C as follows:

A: An evaluation needs to be concluded to support the claims that there are inadequate operations in the educational areas such as knowledge, solving certain problems and critical reasoning;

B: Social accountability must be achieved particularly in the developmental stage; and

C: An individual requires continuing support from caregivers and family members as they are characterised by inadequacies in developmental stages.

There is a difference between DSM-IV-TR and DSM-5. In DSM 5, functioning of ID does not rely on scores obtained from IQ tests but rather on adaptive functioning which, in turn, determines the required support. DSM-IV-TR, on the other hand, relies on levels of functioning as well as IQ scores. Moreover, in DSM 5, IQ tests are perceived as less relevant/valid and "intellectual disability" replaces "mental retardation" (MR), according to the ICD-11. Therefore, the term "intellectual disability" will be used throughout the study. MR is no longer used by professionals such as medical, educational and the public (Diagnostic statistical manual, 2013).

2.3 Causes of intellectual disabilities

In this section, the focus of the discussion is on the different causes of ID which are biological causes, environmental causes and cultural causes. The discussion is supported by the models of disability mainly the biological model as well as the social model of disability.

2.3.1 Biological causes of intellectual disabilities

There is evidence that an important unrecognised cause for ID is that of chromosomal rearrangements which involve terminal bands of chromosomes (subtelomeric regions) and that young children with ID demonstrate behaviours which occur on more than one occasion as well as a lack of the ability to socialize, resulting in the inability to communicate (O'Brien, & Pearson, 2004).

Children with ID present with difficulties both suppressed and visible (Harley, Sikora, & McCoy, 2008). Zweier et al. (2007) stated that 30-40% of ID cases are mostly due to chromosomal/genetic disorders/mutations which explain an estimated 30% of causes of mild ID.

In South Africa, disabilities, more especially cognitive disabilities, are the result of substance abuse such as alcohol. Foetal Alcohol Syndrome (FAS) is one of the spectrum disorders with the highest prevalence rate that is caused by excessive alcohol drinking by the mother when she is pregnant (Adnams, 2010). Mostly, persons diagnosed with FAS in South Africa are considered to have mild ID and display difficulties with some parts of their daily functioning. It is also regarded as forming part of a burden carried by the government and its departments (Adnams,

2010). Prevalence of FAS in Mpumalanga Province is limited as most studies conducted on this subject focus on the Western Cape, Kwa Zulu Natal and the Northern Cape.

Substance use has negative consequences for pregnant mothers. Those living away from towns and/or hospitals are unlikely to seek or attend prenatal classes because of the distances they have to walk. As a result, they carry on abusing substances until birth. Maide (2012) demonstrated that substance abuse in pregnant mothers may result in premature birth and low birth weight, both symptoms of drug withdrawal and foetal damage to the growth of the brain. As a result, such children may portray complications in mood; have short attention spans (neurobehavioural) (Maide, 2012) and slow language development as part of their on-going problems (Fentiman, 2008). Jones (2011) highlighted that alcohol use by pregnant mothers can also result in Sudden Infant Death Syndrome.

Zwiere et al. (2007) indicated that 10 to 30% of causes of ID is the lack of nutrition which serves as one of the environmental factors. Children who are under-nourished are most likely to have difficulty with functioning skills related to motor, behaviour and reasoning (Grantham-McGregor, & Baker-Henningham, 2005). It has been proven by other studies that there is a relationship between poverty and intellectual disabilities. This is due to two discrete factors, firstly, the connection between being exposed to psychosocial factors and poverty (Leonard, Petterson, De Klerk, Zubrick, Glasson, Sanders, & Bower, 2005 as cited by Katz, & Lazcano-Ponce, 2008) and, secondly, the expenses incurred in families of people with intellectual disabilities which can make them vulnerable to poverty.

In South Africa, the highest prevalence of tuberculosis has been recorded in the Western Cape (Van Well, Paes, & Terwee, 2009). Tuberculosis meningitis (TBM) is linked to high rates of disease and death, particularly in children. An individual with HIV has a higher risk of having TBM, which is associated with complications such as Hydrocephalus, a commonly known complication of TBM that may be associated with a poor cognitive outcome if treatment is delayed. TBM is considered to be one of the major causes for severe ID in SA.

Traumatic brain injury (TBI) contributes significantly to ID in both children and adults. The World Health Organization (2012) shows that 33.2 people per 100 thousand of the population dies in an accident. There are other causes of ID such as congenital and degenerative diseases

which are conditions that occur before or after birth and are believed to be progressive in nature. Brain diseases such as those of that are hereditary neuromuscular like the spinal muscular atrophy which is the progressive brain disease also form part of the contributors to ID. Another is Batten disease which is an inherited metabolic disease that leads to the advanced weakening of brain functioning. Brain injury also may occur when infants are shaken or dropped. This unfortunate situation happens by accident or when caregivers are frustrated. The children of mothers who fall pregnant after the age of 35 run the risk of developing several kinds of disorders such as Down Syndrome which is caused by chromosomal imbalances.

2.3.2 Cultural causes of Intellectual Disability and treatment of intellectual disability

Culture can be understood as a "tradition", a method which can either be written or spoken words that pass cultural heritage from one generation to another. Culture can also be viewed as a "construction" of adjustable reactions. Cultural "creation" implies that the way in which people live their lives is structured by their feelings and/or thoughts that are a result of lived experiences (Eskay, Onu, Igbo, Obiyo, & Ugwuanyi, 2012). In South Africa, there are two factors which are used in terms of explaining the causes of illness, "western and African". The western view of illness is that it is due to heredity or lifestyle whereas, in the African context, including South Africa, illnesses are explained in terms of God, ancestors, pollution and witchcraft.

In SA, 3% of the population believe that disability is a result of being bewitched, according to the South African Department of Health's Disability Survey (2002). In Some African countries including SA, traditional beliefs regard ID as a form of punishment for the parents for not conducting proper rituals, untrustworthiness or misbehaviour. Because it is seen as a sign of disrespect for not following ancestral orders, parents of a child with an impairment are less likely to receive support or sympathy from family members or the society as they are blamed for their wrong doings (Odom et al., 2007).

In most African societies, the mother has to abstain from sex during pregnancy because they might give birth to a child with disabilities (Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005). According to Ogechi and Ruto (2002), it is considered bad luck for making fun of people with impairments, as it is believed that the people who are responsible may have

children with impairments, accidents may happen to them or the family might be cursed for generations. A study which was conducted in Kenya reported that it is believed that seizures present in children are a result of witchcraft or connection with restricted animals (El Sharkawy, Newton, & Hartley, 2006). In cases where a family member is believed to be very wicked, children in that family may be born without the ability to hear or speak, by doing so it will be preventing them from sharing their family mysterious (Omiegbe, 2001).

In most African societies, good health is associated with being in a good relationship with the ancestors. Health does not refer only to the physical being of the living but also refers to that of the ancestors in order to protect those who are still living. To be in good health, people are required to live according to their cultural norms or values to appease the ancestors (Iroegbu, 2005:81). In African countries, witchcraft is seen as a cause of ill health which is a result of evil spirits caused by enemies who make people sick in order to punish them (Olupona, 2004:113). Many illnesses, which may include infertility or persistent headaches, that defy scientific treatments, are believed to be transmitted through witchcraft and unseen forces (Obinna, 2012:137-139).

According to Westerlund (2006), spiritual protection is practiced across cultures depending on the perceived cause of illness. Some treatments in parts of Africa include the use of spiritual black powder known as "*talisman, charm, moto*", used for body marks and bathing in order to drive evil spirits away from a community.

In the Ewes tribe in northern Ghana, sacrifices such as the slaughter of an animal or burying an animal alive are viewed as an offering to the spirits (Olupona, 2004:104). The Ewes believe that a person's soul can be replaced by the life of a domestic animal such as a cat or a dog that is buried at midnight when a person is about to die. The Ewes also use herbs prepared for an individual seeking spiritual intervention and give instructions on how to use it to bathe in for a few days. Animals may be slaughtered and the blood of the animal will be poured on the head of the individual as an indication of being cleansed from evil spirits (Westerlund, 2006:127). A traditional health practitioner Bill of 2003 was drafted. Sections of the Bill, such as Act 35 of 2004, recognize the development of traditional medicines (Truter, 2007:60).

According to Sarpong (2002:95-97), even though faith healers may believe in God, their believes are rooted in ancestors and that we are connected to other living beings. Mbiti (2012) emphasized that the belief in God in the African context is influenced by the geographical location, culture and language. There is an acknowledgement of God's existence and that He works through the spirits of the ancestors as well as through traditional faith healers (Obinna, 2012:135).

Negative attitudes towards a certain person can lead a person to be judgmental which will then influence the way that person interacts with the other individual (Brehm, Kassin, & Fein, 2002). When undesirable arrogances are made around a certain collection of persons, it is to be expected that they will be treated poorly, rejected and diminished within society (Boyle, Williams, Brown, Molloy, McKenna, Molloy, & Lewis, 2010).

The arguments proposed for the etiology of ID correspond closely with the theoretical frameworks proposed to understand ID. The theoretical frameworks against which caregiver perceptions will be explored are presented below.

Currently Southern Africa's main focus on healing is that of a holistic approach to the wellness of patients as well as their health. Different types of healing play a significant role; those include the biomedical, traditional healing which may integrate mystical healing, psychological healing, physical and social healing. It is a normal reaction that to any disease or pain one has to seek healing and how to treat such diagnosis. In the African traditional culture, one of the most respected health mechanisms is the significance of believes as well as how traditional medicine can be of use in gaining health and wellness, by including spiritualists, midwives as well as herbalists. In African countries, specifically rural areas, the traditional healers are mostly visited in the search for the cause of illnesses as well as the rituals which can be performed to help the sick (Shizha & Charema, 2011).

The right messenger for millions of indigenous Southern African people remain the traditional health care practitioner, when looking at South African neighboring countries such as Lesotho, Swaziland, Zimbabwe as well as Malawi, most people associate traditional medicine with herbs or *Mishonga* as commonly known in the VhaVenda culture which are instructed by the inyanga or sangoma which include strong spirituality components. The traditional healers therefore

produce these medicine with the guidance of their ancestors which assists the sangomas to use metaphysical tools to diagnose or examine the dimensions of the person seeking help (Shizha & Charema, 2011).

According to study which was conducted in 2002 to 2005 by the World Health Organization in the rural areas of South Africa over 60% of the population depend on the traditional healers for health related advice as well as treatment as opposed to going to a professional medical doctor. Helwig 2009, as cited by (Shizha & Charema, 2011), amongst the Venda people of South Africa for every 700 to 1200 people there is only one traditional healer and for people in Swaziland has one traditional healer for. This indicates that most rural individuals consult traditional healers as they are considered to be respected members of their community.

According to the WHO (2002), as cited by (Shizha & Charema, 2011), traditional African medicine is defined as the sum of all the practices and the knowledge which is used to diagnose, prevent and the removal of either physical or mental imbalances; this is based on the practitioners experiences of observation and practical's which were being conducted from generations to generations.

Steinglass, (2002), as cited by Richter, (2003) , state that traditional medicine is perceived to be the most commonly used medication in the treatment of psychomatic diseases, these is based on the perception that traditional healers have knowledge that hold the ethnic backgrounds of their patients and they also have a contribution factor of conserving the African culture.

2.4 Theoretical framework

2.4.1 Biomedical model of disability

The biological model of disability, according Smart and Smart (2006), outlines disability according to medical terms, providing logical reliability to the idea that impairments are solely an individual understanding. The biological model's assumptions are based on the fact that disabilities are conditions which only exist in and of the individuals with the disability and therefore cannot be influenced by the environment. This model views diseases or illnesses as a

form of biological malfunction, with illness manifesting in chemical, structural, physical or bodily changes (Ross, & Deverell, 2010)

The biomedical model is used by specialists such as doctors and physicians who impose the idea that most people with incapacities do not have the capabilities, education, knowledge and experience of physicians, therefore those individuals may be regarded as individuals who cannot make decisions for themselves and rely on the physicians or doctors' advice (Smart, 2004). The biomedical model considers an impairment to be a difficulty which has been directly caused by an illness or any other condition and, as a result, needs medical assistance or rehabilitation (Mitra, 2006). Pfeiffer (2001:31) explained that a person using aids such as a wheelchair, as a result of their impairments, will never get well. This model therefore states that individuals with impairments do not present themselves as "normal" people would. Moreover, the priority of the biological model is to deliver healthcare services and rehabilitation to people in need of them (Amundson, 2000).

2.4.2 Social model of disability

The social model perceives disability as a social construct. It states that disability is not the characteristic of the individual; instead it is shaped by the social environment and requires social change. The social model of disability as per reviewed in this paper highlight that the population regraded as being marginalised, those with disabilities are the ones that come across ill-treatment or judgement based on factors such as cognitive, physical as well as economic barriers, thus referring to these different experiences as comparable to the smaller groups of individuals who experience oppression one way or the other (Mitra, 2006).

The social model of disability indicates that, for a person to be "cured" from their disability requires the restructuring of the society and the cure will thus benefit everyone. This model is different to the biomedical model which is based on medical cures where the focus is on the impairment. This approach suggests that the individual and collective disadvantage of people with a disability is due to a compound form of recognized judgment which is as important to society as sexism, racism or heterosexism (Intellectual Disability Rights Service, 2009).

The social model of disability, which established from the 1970s in the disability movement in the UK, offers a fundamental substitute to the customized medical concept of disability by

proclaiming that people with disabilities disadvantaged, not because of their deficiencies, but as a result of the restrictions imposed on them by social, cultural, economic and environmental barriers. Disability, according to this formula, is not about health or pathology but about judgement and social segregation. From a social model perspective, disability is a socio-political issue (Albert, 2004) that represents a protean challenge to traditional thinking about disability.

2.4.3 Biopsychosocial model

In contrast to the biological and social model of disability, the biopsychosocial approach or model of disability understands disability as an outcome of numerous aspects which may include physical, emotional and environmental. This model takes the emphasis which does not only include the individual but rather focuses on addressing issues which may affect an individual to have or maintain a healthy lifestyle and wellbeing in order to function well within a community. This model takes into account that disabilities are not due to one single cause but rather incorporates other contributing factors, they are often due to illness or injury and does not take for granted the impact of biological, emotional and environmental issues on health, well-being and functioning in society. There have been criticisms of this model suggesting that the condition which disables, rather than the person with the disability and their experiences is the defining construct of the biopsychosocial model (Smeltzer, 2007).

A human body may be regarded as a complex organic mechanism which can be “fixed”, bearing in mind that there are divisions between the mind and the body looking at an individual’s thoughts, attitudes, beliefs, feelings and the body such as bones, skin and organs and that the change which occurs is then as a result of bodily functions (McMahon, & Koltzenberg, 2003). The biopsychosocial model is perceived to play a vital role in studies which focus on the psychological stresses and how it might affect development such as somatic diseases considering that it mostly identifies the interactions between the nervous, endocrine, immune and other organic systems in stressful situations (Fink, 2000).

In the next section, experiences of ID are discussed from the child’s perspective and then from the caregiver’s perspective.

2.5 The experiences of intellectual disability

This section will focus on the experiences relating to ID which may arise for both the caregiver and the child. The discussion is based on stigma, abuse, socio-economic status and mental health, amongst other factors.

2.5.1 The child's experiences of intellectual disability

People with disabilities are more likely to experience physical and sexual violence than the general population, with disabled women experiencing gender-based violence and sexual abuse at extraordinarily high levels (Mall, & Swartz, 2012). Disabled children are equally vulnerable to violence and abuse for many reasons, which include lack of knowledge, understanding of disability and negative beliefs and cultural practices, to name a few (UNICEF, 2013). Negative beliefs that people hold about the of causes disability are often held and difficult to dismiss. Disability can be associated with punishment for past sins or bad luck, and may be considered "contagious" (Children and Young People with Disabilities Fact Sheet, 2013)

Gullibility is often a feature in individuals with ID, involving innocence which individuals take advantage of, resulting in them being controlled by others. Unwariness may be as a result of possible harassment or abuse. Such individuals may present with recurrent suicidal thoughts, and some may commit suicide (DSM-5, 2013).

According to Soussa and Yogtiba (2009 as cited by Bayat, 2014), children born with difficulties such as intellectual disabilities are most vulnerable to negativity in their communities as they may be rejected by the society. Other outcomes may be that the children are abandoned or live in very poor conditions with little or no formal education. These conditions are mostly experienced by children who are from countries which are economically underdeveloped. Despite the widespread abuse and killing of individuals with intellectual disabilities worldwide, there is little literature and few studies conducted in developing countries.

Discrimination means treating a person or group of people less favorably than others would be treated in the same circumstances because of their membership of a particular group, such as having a disability, or being a woman. The term "discrimination" refers to the mistreatment of an individual compared to another person in the same or similar situation; this may result in being viewed as belonging to a particular group such as that of sex, age or disability. Indirect

discrimination is based on the unfair exclusion of a particular group that appears to have an unequal impact (Intellectual disability rights services, 2009).

The United Nations (2006) views people with disabilities as those who have long-term physical, mental, intellectual or any other impairments which may hinder their participation in their society. The UN is built on the basis of principles which include that of equality and human rights (UN, 2004) therefore individuals who are deemed as disabled are also entitled to exercise their human rights (civil, political, cultural and religious, among others) equally when compared to a non-disabled person. In its preamble, the UN Convention on the Rights of Persons with Disabilities recognizes the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information (Tugli, Zungu, Klu, & Ramathuba, 2014).

2.5.2 The caregiver's experiences of intellectual disability

Childhood disabilities result in economic burdens not only for the caregiver but also for the entire family which implicates their wellbeing. The focus can be that of direct or indirect expenditure considering that the expenditure will depend on the severity of the disability.

According to Dunne (2015), individuals' understanding of the term "intellectual disability" has changed from one of fear and ignorance to one of recognition, knowledge and understanding. This, in turn, has led to changes in the way individuals with intellectual disabilities are being cared for.

Reichman, Corman and Noonan (2008 as cited by Dunne, 2015) explained that, as part of raising a child with intellectual disability, caregivers experience obstacles such as stress due to the financial burden and the demands of raising a child who is intellectually impaired. Foster, (2008) as cited by (Dunne, 2015) indicated that prejudice and discrimination may arise in the attempt to cure people against their will. This may affect the person's self-confidence and individuals subjected to it may be excluded. The results of a study conducted by Dunne (2015) indicated that caregiving was viewed as a two way experience being both demanding and also pleasant. Caregivers can regard their children as the souls of the family, however, at times they feel isolated and stressed by the amount of time required to care for the child with an intellectual disability.

Caregivers are at risk of developing mental or physical illnesses such as stress and depression; they may become obsessive alcohol or substance users or might exhibit harmful behaviors when compared to the general population. Illnesses or diseases which caregivers are likely to develop can be chronic, such as heart disease, diabetes and high blood pressure, because they tend to focus more on the wellbeing of the intellectually disabled child and less on their own mental and physical wellbeing (Döhner, Kofahl, Lüdecke, & Mnich, 2008).

The economic burden related to raising a child with ID has an impact on caregivers. Comparative studies conducted by Olsson and Hwang (2006) and Parish, Seltzer, Greenberg and Floyd (2004), concluded that mothers of children with disabilities work fewer hours and have lower earnings than mothers of typically developing children. In addition, mothers report spending more time caring for the child with the disability than fathers and that the caregiving demands associated with the child's disability leads to increased work absenteeism hence leaving the burden to the caregiver who has to provide for the child (Warfield, 2001).

There have also been studies which were conducted among large populations in relation to caregivers which reported little strains or negative health effects (Hirst, 2005). Brown (2007), indicate that in the early stages of caregiving it is unlikely that caregivers may experience any effects. Primary caregivers often view the positives of caring for people with intellectual disabilities rather than focusing on the demands which may lead to distress or even depression. They report that caregiving makes them feel good about themselves and if they are needed, this gives meaning to their lives, enables them to learn new skills and strengthens their relationships with others (Brown, 2007).

Statistics SA reported in 2001 (Donohue, Bornman, & Granlund, 2014) that about 5% of the South African population had a disability and, of those individuals, 12.4% had an intellectual disability.

A 2005 report handed out by the Nelson Mandela foundation established that low income South African families cannot afford to care for their children with ID by giving them the needs and nutrition necessary for their development. Financial constraints can also increase in cases where the child has multiple disabilities and thus requires additional care. Young caregivers with

relatively little education, moreover, may not have the knowledge or be empowered to provide optimal care and learning conditions for their children with disabilities.

The Constitutional Court in 1996 indicated that for individuals to be respected and valued, they have to be able to develop their humanness to its full potential. The dignity of individuals lies in their ability to realise their own potential and uniqueness however this cannot occur unless the individual is granted the opportunity to develop his/her talents optimally. The constitution highlights that individuals with disability are therefore not to be discriminated against because they too need to reach their full potential.

Caregiving is mostly regarded as a contributing factor the the feelings of stress or feeling of caring a burden, however it has also been noted that caregiving can contribute to positive feelings. For example, although Kenny and McGilloway (2007) found confirmation of caregiver strain in their study, other participants reported that they were satisfied with their lives in the study. These participants resorted in using positive copying strategies as well as having positive expectations of their children and the lives they will lead..

2.6 Education in South Africa for the disabled/intellectually impaired

The Constitution of South Africa states in Section 29(1) that "everyone has the right to a basic education, including adult basic education". Section 9(2) further develops the basic right to education and indicates that the government should ensure equality amongst the public and that discrimination is not to be practiced in SA (Sections 9(3), (4) and (5)). This refers to the public and includes learners in all formations, disabled or able-bodied. The Department of Education (2001) estimated that up to 70% children of school age are not in schools. Children with disabilities in developing countries mostly do not attend school as they are perceived as disruptive or unable to learn. The caregiver's attitude determines the way in which the caregiver responds to the child and ensures that the child receives education or not (Donohue, & Bornman, 2014). Cultural beliefs can also affect the parents' decision whether a child goes to school.

The Education White Paper 6 (Department of Education, 2001) which, according to Donohue and Bornman (2014), was designed to change the South African educational system by building

a combined system for all learners so that there will be no different special and ordinary schools, stated:

> We are persuaded that the inclusion of learners with disabilities that stem from impaired intellectual development will require curriculum adaptation rather than major structural adjustments or sophisticated equipment. Accordingly, their accommodation within an inclusive education and training framework would be more easily facilitated than the inclusion of those learners who require intensive support through medical interventions, structural adjustments to the built environment and/or assistive devices with minimal curriculum adaptation.

However, it has been more than ten years since the launch of Education White Paper 6 (Department of Education, 2001) and most learners with disabilities who attend school are still in separate, "special" schools for learners with disabilities due to the lack of agreement on what constitutes as ID in S.A (Heap, Lorenzo, & Thomas, 2009). As a result, many teachers in South Africa do not have the necessary skills to teach learners with disabilities (Donohue, & Bornman, 2014).

A disability grant refers to the money given to individuals with physical or mental disabilities as they are considered to be unfit for work. Every year on the 1st of April, grant money is increased. In 2015, individuals with disabilities received a sum of R1370.00 each month from the Department of Social Development.With the high level of poverty in South Africa, parents of children with disabilities therefore consider financial expenditure related to education because, in most schools in SA, parents are required to pay tuition fees. Parents may not send their child to a special school especially if the family depends on the monthly grant the individual is receiving (Donohue, & Bornman, 2014).

2.7 Conclusion

The literature reviewed in this section focused on the perceived causes of ID, the experiences of ID and the level of education which individuals with disabilities are receiving. Theoretical frameworks focusing on the biomedical and biopsychomedical models of disability were also discussed. With regards to the research topic, not much information was found on the experience of having an intellectually disabled child and the challenges which caregivers are facing. The

study will therefore be of significance, not only to the researcher, but also the South African community and the government because it will not be looking at the prevalence of ID but how individuals are affected by this phenomenon which is sometimes not considered as important.

CHAPTER 3: RESEARCH METHODS

3.1. Introduction

Babbie and Mouton (2001) emphasize that research methods are used or put in place when planning for the research design. A qualitative research approach helps the researcher to study the nature of a phenomenon by understanding the participants' points of view, thus it was used in this study (De Vos, Strydom, Fouche, & Delport, 2011). Dawson (2006) stated that qualitative research attempts to understand different opinions from participants including their attitudes, experiences and behavior. This kind of research therefore depends on a cautious explanation of words as well as how they interrelate (Walliman, 2011). In this study, the qualitative approach was used by the researcher as it allowed participants to be free to talk about their lived experiences as well as their beliefs.

3.2. Research design

The researcher used the phenomenological research design as an approach for this study, which, according to Holloway (2005:47), explains perceived experiences of participants and excludes the researcher's opinion.

Studying the experiences as perceived by the participants entails phenomenology. The notion behind phenomenology is that there is an essence to shared experience which is called "lived experiences". The aim of using the phenomenological approach is to explain individual experiences and the meanings they attach to them. Streubert and Carpenter (2002) stated that this research method is demanding, critical, and systematic.

3.3 Setting



Figure 3.1. **Location of the Bushbuckridge municipality in Mpumalanga Province**

Bushbuckridge or Bosbokrand (in Afrikaans) was established in 1884. In the 1880s, it is believed that there were large herds of bushbuck in this area resulting in the name of the town. The Bushbuckridge municipality has an approximate population of 541,248 of which 96.9% are black Africans, 0.2% are colored, 1.8% are Indians and 1% are other races (Statistics SA, 2011). Bushbuckridge falls within the Ehlanzeni district which is one of five districts in Mpumalanga province. The Kruger National Park is located east and Mbombela is south of Bushbuckridge which forms part of the Kruger canyon biosphere. The municipal area provides a connection to Limpopo Province and is referred to as the gateway to tourist attractions both in Mpumalanga and Limpopo. It is estimated that Bushbuckridge Municipality consists of 135 settlements and is divided into 34 wards (www.nra.co.za). This setting was chosen for the study because not many qualitative studies regarding ID have been conducted in the area. Those that were conducted were mainly quantitative. Christianson et al. (2002) conducted a study in Bushbuckridge focusing on gender differences amongst individuals with intellectual disabilities. The results of the study suggested that there is a difference with regards to gender and intellectual disabilities in

the region. It appears that studies of intellectual disabilities in Bushbuckridge have been inadequately conducted and thus it is difficult to compare these studies. With regards to the literature, there is also limited information about studies which were conducted in the area. The study was conducted in a special school in Acornhoek. The school has approximately 140 learners and is the only special school in the area.

3.4 Sample

Participants for the current study were purposively selected by the researcher. Grinnell and Unrea (2008) noted that this type of sampling does not depend on the views of the researcher but on the characteristics of the people that best suits the significance of the study. The study's specific target group was caregivers who have children diagnosed with ID in their families. The target was 10 participants, however nine interviews were conducted because one participant withdrew from the study. The participants were selected based on the inclusion criteria that they needed to be either a parent or guardian of a child who who was at a special school in Bushbuckridge region. A letter for recruitment permission was given to the principal of the special school since it holds meetings quarterly for parents of learners and those who are on the waiting list for their children to be accepted at the school. The caregivers ranged from biological parents, grandparents, both maternal and paternal and adoptive parents. Surprisingly, there were no male figures in this study even though it was not specified who should be interviewed in terms of age, race or gender. The age of the child was also not set since it relied on the primary caregivers who took part in the study. The ages of the children ranged from 6 to 15 years old, whilst the ages of the primary caregivers ranged from 31 to 77 years old. Primary caregivers included biological parents, aunts and grandmothers. Out of the nine participants, three primary caregivers are employed and six are unemployed thus they depend on their children's disability grants as well as their old age grants.

3.5 Data collection procedure

In this study, semi-structured interviews were used focusing mainly on three aspects, namely, background of the participant, psychological well-being and the awareness/knowledge of intellectual disability guided by the research aim and research questions. This ensured that the study covered the research questions, focused on the research topic and examined unexpected

situations and answers. Face-to-face semi-structured interviews were beneficial both to the researcher and the participants and also built a strong rapport. According to De Vos et al. (2011) an interview is intended to help the researcher and participant in exchanging information or knowledge which they both seek (Depoy, & Gilson, 2008). Wallison (2011) stated that semi-structured interviews are beneficial for the researcher as they have both unstructured and structured interviews with open-ended questions. The interviews scheduled by the researcher included specific or leading questions which are discussed below (Dawson, 2006).

The design of the interview schedule was guided by the literature reviewed. The interview schedule consisted of 15 main questions with six prompt questions covering the areas of caregivers' perceived lived experiences when caring for intellectually impaired children. Before the actual interviews were conducted, the interview schedule was pilot tested on two caregivers who are taking care of children with ID but who were not included in the sample for the study. This was done in order to assess whether the questions in the interview schedule were well constructed and easy to understand and in order to identify unsatisfactory questions so that they could be changed before the actual interviews were conducted.

The study was conducted in an area which is dominated by both Tsonga and Northern Sotho speaking people. Hence, there was a need to translate the interview schedule into both Tsonga and Sepedi. Assistance for this was sought from teachers in the area who are bilingual in English and the relevant African language. The researcher is also fluent in both Tsonga and Northern Sotho and was able to conduct the interviews in both languages.

Data was collected in Bushbuckridge region in Mpumalanga Province. The first meeting was scheduled to meet with the parents or primary caregivers but was later rescheduled. The researcher was unable to attend the next meeting but the principal kindly informed the caregivers from the presentation sent to her. The interviews were held at the participants' homes at a time convenient to them. Although the researcher's contact details were handed to the participants, no one called back. The researcher got contact details from the principal. Because of confidentiality issues, no parents' information was given, only the names of the caregiver and their cellphone numbers were given as well the names of the children they care for. The researcher contacted each potential participant to arrange a time for the interview. Before the interviews were conducted, the participants were asked to complete a consent form. Before completing the form,

they were required to read and understand it. Most of the participants had little or no basic education. For those who could not read, the researcher read the consent forms to them and helped them to sign the forms. A tape recorder was used to record the interviews. After the interview, participants were thanked for their participation.

3.6 Data analysis

Babbie and Mouton (2001) described qualitative analysis as the type of analysis which focuses on the meanings of relationships and their interpretations instead of on numeric data. Similarly, De Vos et al. (2011) explained that this type of analysis can structure the meaning of data collected. The Interpretative Phenomenological Analysis (IPA) method was used as it aims to understand lived experiences of individuals and how they attach meanings to them (Smith, 2004). The aim of the IPA is to interpret an individual's account of culture and/or social context (Smith, & Osborn, 2003).

Larkin, Watts and Clifton (2006) explained that IPA, in separating phenomenology and interpretation, is concerned with explaining participants' experiences taking into consideration their culture and social environment and hypothesising whether or not the world has an influence in the individuals' psychological framework. Phenomenology helps in explaining how a participant understands a certain phenomenon and how they orient themselves in the world.

Data was analysed using the steps outlined by Smith and Osborne (2003).

- ✓ Step1: Looking for themes in the first case

This involves working with transcripts, by reading and making notes or brainstorming. This helped the researcher to become familiar with the data to know the interpretations that were likely to be supported by the data.

- ✓ Step 2: Connecting themes

This involved looking for emerging themes in the transcripts and identifying connections between those themes. The researcher identified whether something important was missed or misunderstood in the transcripts.

- ✓ Step 3: Grouping themes together as clusters

The third step involved providing an overall structure for the analysis by relating the identified themes into “clusters” or concepts. The aim, at this stage, was to arrive at a group of themes and to identify super-ordinate categories that suggested a hierarchical relationship between them. Therefore, similar themes were grouped together with aim of identifying their relationships.

- ✓ Stage 4: Tabulating themes in a summary table

The researcher developed a summary of themes in an ordered system that identified the main features and concerns identified by the research participants. These were produced as a table with quotations from the interview that the researcher felt best captured the essence of the person’s thoughts and their emotions about the experience of the phenomenon being explored.

- ✓ Step 5: Identifying shared themes

The researcher learnt that there are numerous ways in which summaries can be grouped together under a single theme. These enhanced steps of importance were taken after the unique coding system for a thorough analysis. The researcher coded continuously and elaborated till there were no important perceptions emerging.

- ✓ Step 6: Writing up

The researcher then interpreted the findings while also considering the interpretations of the participants and translating themes into narrative accounts.

3.7 Ethical considerations

Ethical clearance was obtained from the Human Research Ethics Committee (HREC) at the University of the Witwatersrand (Protocol number: MPSYC/16/005 IH).

3.7.1. Informed consent

Participants volunteer to be part of a research study taking into consideration that they can withdraw from participation (Babbie, 2010). A Participant Information Sheet (PIS) was given to participants by the researcher which gave full details of the study, including its aims. The researcher explained the consent forms given to participants to avoid misunderstandings.

Participants were advised to ask questions for clarity before signing the consent form. Participants were told that they could withdraw from the participation at any time they see fit.

3.7.2 Anonymity

Anonymity is attained when people cannot recognize responses given in a research study (Babbie, 2010). Dawson states that anonymity can be attained if information cannot be traced to participants. Because the researcher knew the participants after the interviews, anonymity was not possible but confidentiality was ensured. Participants' names were replaced by pseudonyms to protect their identities. Information shared during interviews was kept anonymous.

3.7.3 Confidentiality

Babbie (2010) explained that the researcher ensures confidentiality by not disclosing information shared in an interview publicly by naming the participants. Thus both the researcher and participants must agree on confidentiality prior to findings of the study (Burns, 2000).

The researcher ensured confidentiality by not discussing information obtained from interviews with others except for the participants and the supervisor. However limits of confidentiality were also discussed if responses were to be used in the court of law or to protect participants from self-harm.

3.7.4 Avoidance of harm

The researcher has to guarantee harm, either psychological or physical, is avoided (Leedy, & Ormrod, 2001). Questions asked in the interviews avoided harming participants. Referrals will be made to the appropriate professionals if required. This was not included in the PIS but was determined as the interview progressed. If needed, the participant will be referred to the psychological services at the local hospital or the psychologist at the school in the area. The researcher notified the participants who appeared to be having psychosocial or psychological problems about the assistance which they could receive from different professionals and how or where to locate them.

3.7.5 Privacy

De Vos et al. (2011) stated that “privacy means to keep to oneself that which is normally not intended for others to observe or analyze”. As face-to-face semi-structured interviews were conducted, privacy was ensured because the interviews were conducted in closed rooms, so that the participants were free to express themselves during the interview.

3.7.6 Storage of data and access to results

Data which was collected during the research will be stored in a locked cupboard at the University of the Witwatersrand and will only be accessible to the researcher and the researcher’s supervisor. A two page summary of feedback on the study and its results will be given to the school and/or participants on request.

3.8 Self-reflexivity

According to Pillow (2003), reflexivity is an important tool in qualitative research. In the process of data collection, the researcher had to self-reflect whilst being critically and explicitly conscious of what she was doing in the research study. She tried to eliminate or avoid bias by not being guided by her own judgment. She had to constantly remind herself that her own norms or perceptions were not important only those of the participants.

The researcher had a diary and, after every interview, she reflected on the interview session with the participants to normalize situations where the participants became emotional. Honesty was maintained while insight and information were shared with the participants. Responses depended on how much knowledge the researcher gained about the question. The researcher made sure that the results were accurate and dependable whilst also clarifying that the data collected could not be generalized to the entire population but rather focused on the primary caregivers in the study as well as their experiences.

3.9 Conclusion

This chapter explored the different methods applied in a research project for collecting and analysing data. The methods which were employed in this chapter helped the researcher to gather information which was relevant to the study by allowing the participants to feel free and share

their own experiences. They also allowed the researcher to self-reflect and to avoid bias as much as possible. Interpretative Phenomenological Analysis (IPA) was employed to analyse the data and the results are presented in the next chapter.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter focuses on the presentation and discussion of findings from the data collected in the study on caregivers' perspectives of caring for individuals with intellectual disabilities. Using Interpretive Phenomenological Analysis (IPA) the researcher was able to gain insight about the phenomena under study and the experiences of the participants who are dealing with their current situations. This was done by coding themes and sub-themes which are presented in Table 4.1.

Table 4.1
Themes and subthemes for the interview with caregivers of children with intellectual disabilities

Themes	Sub-themes	Description
Social encounters	➢ Bullying ➢ Discrimination ➢ Social support	This theme focuses on how the primary caregivers as well as their children live their day-to-day lives also considering the positives and the negatives which they encounter.
Perceptions of intellectual disability	➢ Cultural beliefs ➢ Religious beliefs ➢ Medical beliefs ➢ Lack of knowledge	This theme aimed at gathering information on how primary care givers viewed intellectual disabilities and how their surroundings contribute to their judgment or knowledge of intellectual disabilities.
Experiences of caring for a child with an intellectual disability	➢ Financial strain ➢ Psychological strain ➢ Physical discomfort ➢ Acceptance	The core of this theme is to find out how primary care givers feel about their roles and how this affects their daily functioning.
Uncertainties about life	➢ Educational ➢ Uncertainties/anxiety about the future	This theme aimed at gathering information if whether or not the primary caregivers had uncertainties about their children's future

4.2 Social encounters

Most participants indicated that they were experiencing social problems because of discrimination or bullying of their children. These parents showed discomfort when talking about this subject because they did not have control over what was happening. Some thought that the community was laughing at them because of their situation and felt that they should hide that their children with intellectual disabilities.

Individuals' experiences differ according to their situation or environment. This section will explore the experiences of primary caregivers and how those experiences impact on their lives. This is done under three subthemes, namely, bullying, discrimination and social support.

4.2.1 Bullying

Bullying is defined as the actions of a person who intimidates or frightens weaker people or those who cannot defend themselves. Some children with ID were bullied by other children but were unable to express what was happening to them. This is evident by the following statements:

> ***Participant 4:*** *"I was emotionally hurt when he told me that there was a girl at her school that gave him condoms and forced him to blow and told her to eat and he did eat…".*
>
> ***Participant 5:****"… ""What hurts me is that there are children who know what time his transport drops him off and they will wait for him and take his clothes … sometimes he will come home bare feet without shoes …".*
>
> ***Participant 7:*** *"… It means she has to go with her sister and in a family where there are no kids in that way she will have peace because no one will laugh at her or be surprised. I notice that if they do that it will stress her since she is also able to think that why am I unable to do certain things …".*

4.2.2 Discrimination

The term discrimination refers to the mistreatment of an individual compared to the other person in the same or similar situation; this may result in being viewed as belonging to a particular group such as that of sex, age or disability, discrimination was evident by the following..

Participant 1: *"... if he did not go to school more especially here at home, he doesn't find children whom he can play with. But there, when he is with me during school holidays, the children that location loves him … he is able to… play with them the whole day...".*

Participant 2: *"… even me … at school they sell uniforms which are imprinted with the school name so I have thoughts of maybe removing the name … on the shirts so that they cannot know where she is attending, because to me it is more like these people are laughing at us behind my back you know…".*

Participant 2: *"... And when she was still studying at the school there I had a very big problem, you know kids separate. When she gets to school … immediately after arriving at school, she doesn't sit down, they say she would stand behind the door and she will eventually sit down whenever she feels like sitting down you see. … When we are at church, people know her from when she was still young, so people would ask me what was wrong/problem with my child …".*

Participant 6: *"… after coming back from the hospital, she wanted to go to school and she was still swollen on the head and the teachers would not allow her to play with other children in the fear that she will be injured … so she was isolated".*

Most of the primary caregivers indicated that their children experienced discrimination in one way or another. Parents seemed to be very concerned about this behavior as they expressed that they were not happy with what was happening to their children and they would become tearful when talking about such incidents.

4.2.3 Social support

The primary caregivers receive support in different ways, some found support in their families and some from the professionals who formed part of their lives. This is represented in the following excerpts:

Participant 2: *"… but I would explain this to my sister and she would say that's not the end of the world so if you have a problem tell me and I will help you wherever I can ... mmhm ... yes, like when it was the date for check-up she would give me money … and people I live with here at home they would always advise me to accept it but it is not easy…".*

Participant 4: *"… the only support I could say I receive is that of the social grant because he was very young when he received it, he started receiving it while they were still getting R400. At the hospital the doctors assisted me even today he is receiving social grant, the support that I received was from his father because he would say he is our gift from God and therefore we have to accept any challenge or situation …".*

Participant 4: *"… and also the fact that he takes ... he catches his transport to school very far my child, we wake up at 4am and bath him. Afterwards we walk to go down there like you're going to Thulamahashe, that's where he gets his transport like now since its winter it's still very dark outside but papa does that every day, but coming back people know him they give him lifts…".*

Participant 5: *"Those women (teachers from the primary school her grandson was attending) were of great help to me. I am still grateful to them even today...".*

Participant 6: *"… mhm, at first it was very difficult I remember the social worker once organised fundraising three years back or four years, there was even a newspaper article ... even at Jacaranda fm so I received clothes and blankets, the support that … I can say I receive was from my family members, who came to check on me but from her father's side they never came, they distanced themselves …".*

Participant 9: *"… no, I did not receive any support apart from the hospital, the people at the hospital are the ones that give me support and always give me advice. At home my sister is the one that gives me support, she is currently in Johannesburg, she is the one who supports me in most times. Like now that I am unemployed and survive with plans, she is the one who buys most of the things and she is also supporting my son financially, yes my sister…".*

With reference to the themes and sub-themes that emerged, it was evident that most parents indicated that their children were experiencing difficulties in their communities. Primary caregivers indicated that most of their children preferred to play with children younger than themselves and avoided playing with older children or children of the same age. This indicates that the children were treated unfairly by other children and but there was no evidence that older people treated the children unfairly. Despite the unfair treatment, the primary caregivers receive support from members of their families, professionals or the communities that show that they were able to rely on others for assistance.

4.3 Perceptions of intellectual disability

South Africa is a multicultural, multiracial country where there are cultural beliefs and values which give rise to different attitudes and practices towards people with disabilities.

4.3.1 Cultural beliefs

South Africa is a diverse country which was shown in the sub-themes that emerged. This indicated that the primary caregivers had different perceptions about intellectual disabilities as was evident by the following quotes:

> ***Participant 1:*** *"We don't know what the cause is. We think maybe it is 'leabela', because in my father, my uncle's brother was also like this, although I don't remember well because he is old. I am not sure if he can hear or not and my great grandparent was deaf, so she used sign language…".*

> ***Participant 9:*** *"I used my last money on my child, taking him everywhere, others saying maybe it is Lefika…".*

Most primary caregivers did not appear to have knowledge or understanding of the cause of intellectual disabilities with reference to their different cultures however they appeared to have more faith in their high God.

4.3.2 Religious beliefs

People may be guided by religious beliefs. The quotes below indicate that some primary care givers believe in God and that they consider their children's conditions to be as a result of God's will (Participant 4). Some sought answers from God as they blamed themselves (Participant 6):

> ***Participant 4:*** *"I don't know how or what happened for him to end up like this … according to me, as his father also usually told me, that this child is a gift I also believed it since he was a gift from God … and we also believe that his days on earth are still plenty you see…".*

> ***Participant 6:*** *"… and ask questions such as what have I done before God for him to punish me in that manner? … I blamed myself …".*

Primary caregivers found comfort in their religion which helped them deal with their circumstances as well as to accept their children's conditions.

4.3.3 Medical beliefs

As every illness has an origin or cause, participants identified the causes of intellectual disabilities medically or biologically:

> ***Participant 3:*** *"I think it is because she was in her mother's stomach after she was certified dead, if it was not for that I think she would be alright".*
>
> ***Participant 7:*** *"… what I know is that when I gave birth to her they said that's why she is like that because she was not ok in her brain. As for the culture, I don't know what causes it…".*
>
> ***Participant 9:*** *"… she held him and said your child has CP, I asked myself CP? What is that? She gave me pamphlets and asked if I could read and I said yes I read and I understood that there was something that disturbed my child's brain and then which means that my child will not be alright for the rest of his life. I was heartbroken that day, but I accepted it because I realised that it was the same until today knowing that my child has CP and that CP is not curable, yes not curable and no medication and that it doesn't kill, unless if there are other illnesses, like the ones of fits. If I don't give him medication, it might result to death".* **(Note: This child had Cerebral Palsy and ID)**

Most primary caregivers appeared to understand the biological causes of intellectual disabilities as opposed to how culture views such disabilities. However, it was clear that participants lacked knowledge of ID as is evident in the next subtheme.

4.3.4 Limited knowledge

Most primary caregivers indicated that they had little or no knowledge about intellectual disabilities. It was also evident that, for some, the diagnosis of their children was the first time that they had come across intellectual disabilities:

> ***Participant 2:*** *"… no, and I ask myself what it is? But I don't get an answer, would like to know …".*
>
> ***Participant 6:*** *"I don't know what caused it since they never told me at the hospital. They just asked me if at home there is someone with cancer. I told them about my sister-in-law's child, she/he was sick – you know, if you don't know things. They said half of his brain was*

'somehow' you see to the point that he was paralysed. Even the doctor told me that if I don't agree for my child to be operated she will be paralysed…".

Participant 8: *"I also want to know because it's like she is a slow learner, it's like she is carrying a heavy load …".*

Most participants indicated that they had no knowledge of or had ever heard of intellectual disabilities and some of the participants explained that they understood intellectual disability in terms of their cultures. Only one participant seemed to have insight on what may have caused her child to have an intellectual disability in terms of the "western perspective". Religion appeared in most of the interviews as well as culture.

4.3.5 Treatment of intellectual disabilities

The treatment of intellectual disability is perceived to be different across cultures. One participant indicated that that she searched for treatment through faith healers at church and through "*ditaelo*" but the child did not get better:

Participant1: *"… and also to do things religiously, and they would say he will be alright ... he will be alright…".*

Participant 9: *"I used my last money on my child taking him everywhere, even went to Joburg, Krugersdorp, this child ate a lot of things. I took him everywhere, [he] even ate donkey's faeces …".*

For the primary caregivers to seek treatment for their children, they first have to know about their children's health/mental health. Caregivers searched for treatment in different places based on the knowledge they had regarding their children's conditions.

4.4 Experiences of caring for a child with an intellectual disability

Participants' experiences included financial strain, psychological or emotional stress, denial or blaming themselves for what had happened to their children. Physical strain was also evident. However there are also parents who did not mention or portray any signs of psychological difficulties as some caregivers seemed more accepting than others of the child's ID. Their experiences are divided into three subthemes, financial strain, psychological strain and physical strain and acceptance. These are discussed below.

4.4.1 Financial strain

Most primary caregivers revealed that there is a financial strain as most of them are unemployed and dependent on the social grant of their children and this, in turn, puts a toll on the family finances. Some of the primary caregivers indicated that raising a child alone is very difficult (Participant 1) and that financial strain was due to unemployment (Participant 4) as indicated in the quotes below:

> ***Participant 2:*** *"… mmhm, yes it is, you know raising a child all alone is very difficult … very difficult and it was now worse because it was the two of them you see … even to get money to take the child to the doctor was a struggle because we have to pay for both me and the child and you find that I don't have money for transport…".*
>
> ***Participant 4:*** *"He (husband) is no longer employed where we will find money? We survive by my son's social grant money because when I get it we can combine it with the little 'papa' has and make something…".*
>
> ***Participant 6:*** *"… now is that I take her for checkup you find that I don't have money and you can't tell the doctor that I don't have or won't have money for the date they have set, so I will go around to borrow money, but, at times, when I explain that I won't have money, he understands and he would give me money from his. She still attends checkup after six months. He gave me R400 for transport".*
>
> ***Participant 7:*** *"I was with her most the time because I was unemployed so I would care for her so I started working last year when she started attending school and in the middle of the year knowing that I will bath her and feed her before she goes to school".*
>
> ***Participant 9:*** *"My life has changed a lot since I had my child because now I am unable to find employment away from home since I have to be the one taking care of him … I depend on his social grant … I don't know what else to do".*

Financial strain was experienced by most of the primary caregivers. That puts strain on their family as well as their well-being.

4.4.2 Psychological strain

Psychological strain was experienced by primary care givers and feelings such as sadness and

being heart-broken resulted in stress. Participant 4 further indicated that she does not stress only about her child with ID but rather all her children as indicated below:

> ***Participant 2:*** *"… it hurts me deeply; even now I haven't yet accepted … (sobbing) ... Because when I gave birth to her, she was a healthy child … so one day I had a thought of committing suicide because nothing was going well to me backwards and forwards was the same…".*
>
> ***Participant 4:*** *"I stress too much about him and my other children because when you have children ... your children become a problem at home. You find that some of the children are smokers and like the one who fetched you, they drink a lot, they are unemployed and all of that come here (pointing at the heart). I am experiencing all this because I am always stressing about the things that are happening".*
>
> ***Participant 6:*** *"… you would ask yourself what you were going to do in that situation. I would stress a lot".*
>
> ***Participant 9:*** *"… a lot, my life has changed, my life has changed a lot, my life has changed a lot and people who know me, now I am better say from January till now, my child, if you had seen me three years back, you would not want me or envy me. I changed and also lost weight due to stress, but now it shows that I am getting healed. A lot has changed, you see, I left my children to come stay here, this is my parents' home because I saw that there I have older children and this child's father might want to come see his son so they won't agree and also it's not ok because I was married in a big family".*

The above quotes identified different feelings which primary caregivers experience as they take caring for a child with an intellectual disability as a challenge

4.4.3 Physical strain

When individuals go through experiences in their lives, this may result in physical strain which changes their physical well-being. Primary caregivers indicated that they were diagnosed with hypertension (Participant 4) whilst others indicated that they had experienced weight loss (Participant 9):

> ***Participant 1:*** *"My mother is the primary caregiver of my son and now it stresses me because she is getting old and she is no longer able to do things since she is the one bathing*

him in the morning…".

Participant 4: *"…now I am going for check-up at the hospital I have arthritis. Ai, I don't know and it is not under control (blood pressure) since it is always high so I don't know…".*

Participant 9: *"I changed and also lost weight due to stress".*

Parents explained that, due to their experiences of caring for a child with an intellectual disability, drastic changes have been happening in their lives.

4.4.4 Acceptance

For some, it is difficult to accept situations they are faced with be seen and for others, it may be easy. Participant 2 mentioned that she has not accepted her child's condition simply because she never thought this might happen to her:

Participant 2: *"… it hurts me deeply; even now I haven't yet accepted … (sobbing) ... Because when I gave birth to her she was a healthy child".*

Participant 5: *"… I just thank God because he showed his mercy …".*

Participant 6: *"… at first it was very difficult but now… ahh ... I am used to it …".*

Participant 7: *"… what made me not to have a problem was the time I attended physio there are other children whom you would look at and they are not the same as her, they would tell you that the child is five years old but they can't walk or do anything and they are small".*

Participant 9: *"… that's why I am saying I have accepted and there is no one who would tell me to take my child somewhere because I am tired and I and I have accepted …".*

Even though primary caregivers have indicated that they accept the situations which they are as well as being the primary care gives for their children. They also expressed their concern or worries as well as how these experiences have affected them physically as they have mentioned above.

4.5 Uncertainties about the future

Parents expressed their worries in terms of their children's futures and how they will live their

lives either after school or if the caregivers are deceased. Particularly, parents were concerned with meeting their child's educational needs. Hence the two subthemes within this theme are educational as well as anxiety about the future.

4.5.1 Educational

Parents raised their concerns about their children's education. They were not sure of what was occurring at school and whether or not they were doing "hand work" as they believe that that is the only way they will make a living.

> ***Participant 1:*** *"I can say there is a difference because when he does not attend school, I don't think he will be ok here at home, you might find that he has mental strain".*
>
> *"… so what I want for him is to find a teacher of sign language so at least he can communicate because at times I feel pain since I can't understand what he wants even though I can see that he is trying to tell me something but I can't understanding him you see".*
>
> ***Participant 2:*** *"… mhm, yes I can say there is a difference because, for example, if she doesn't go to school, and she sees other children who will be telling her where they attend she will envy them and the little knowledge she is getting at school she will not be getting like when she is at here at home … at that school I think she is better because she is able to count. She did not know how to write her name but now she is trying".*
>
> ***Participant 4:*** *"… but it's the same as he is not doing anything because even when you say he should write something, he doesn't know how to. He is 15 years old but he is unable to write even today…".*
>
> ***Participant 6:*** *"Yes, there are because now when I look at her she is different than before even though she can't do several things but I say that God answered my prayers and helped me through and my child survived".*
>
> ***Participant 8:*** *"There is progress now that she is at that school and tell myself that maybe she is free and looks forward to going to school and she accepts what is going through there. But here I think she was under pressure but now she is ok even her body weight has increased".*

Parents raised concerns about their children's educational stability and whether what they learn at school will be beneficial for the children in future as independent individuals.

4.5.2 Uncertainties/anxiety about the future

Parents want what is best for their children throughout their lives and strive to help them. However, not knowing the future may bring anxiety and uncertainties with regards to their future. The same occurred during the interviews and primary caregivers expressed their anxiety. The quotes that follow evidence these concerns.

> ***Participant 1:*** *"…it's been long he doesn't want to use the toilet but when he is at my place sometimes he does go to the toilet … so now that he is growing up I ask myself as to where will he end up because he is not getting young … Yes, there will be a difference but they explained that this person will not be able to learn but only do hand work to make a living. He can make cupboards, he can do whatever. So I asked that, if that is the case since he won't be able to say how much he charges,… even though he knows to say 'money' but he still has to write it down …".*

> ***Participant 4:*** *"… can you not arrange that he attends a school for hand work because he is very good with photography…. There is death and mom and dad are old now. We, on the other hand, still want to live our lives. So he will be able to support himself, when we look – we assess him, he can be able to support himself".*

Most caregivers mentioned that they were anxious or had fears about their children's futures and how they were going to support themselves financially as adults because some were mute and others could not write, both basic necessities of life. Parents highlighted, with regards to the educational aspects of the children, that they had little knowledge of what their children were doing at school and some did not know which grade or level they were doing. Some noticed that they could see the difference in their children who were at school and some said that there were no identifiable differences.

4.6 Conclusion

The primary caregivers expressed similarities and differences in their experiences. Most caregivers indicated that they had experienced or are still experiencing psychological strain due to caring for a child with an intellectual disability while some found the experiences fulfilling

rather than a burden. Mostly, the overall study showed that the primary caregivers had no knowledge of appropriate professionals to consult as part of helping their children and themselves. They also did not have knowledge of ID and its meaning in their cultures since the intellectual disabilities were different and they noticed that their communities do not talk about intellectual disabilities. It appeared that religion was important for most participants as some took their children to church for healing and see their children as gifts from God. All participants mentioned their uncertainties about their children's education and their lives indicating that they want to be involved. Most primary caregivers were also concerned about financial strain. Overall, the study indicated that there is a lot that still needs to be accomplished in terms of intellectual disability awareness and education in the rural areas and that the needs of the primary caregivers themselves must be considered.

CHAPTER 5: DISCUSSION

5.1. Introduction

As presented in the previous chapter, primary caregivers presented various experiences taking into consideration the different intellectual disabilities of their children. The results were grouped as social encounters which discussed bullying, discrimination as well as social support, the perceptions of intellectual disability by cultural and religious beliefs, their limited knowledge about ID, their experiences of caring for a child with an intellectual disability and their uncertainties about the future.

5.2 Social encounters

Social encounters are defined as interactions which provide individuals with the assurance or feelings of attachment to a person or a group of individuals which is viewed as caring. It has been evident in numerous studies that having social support is crucial in maintaining both physical and psychological wellbeing and how poor social support can have consequences including that of the vulnerability to stress (Ozbay, Johnson, Dimoulas, Morgan, III, Charney, & Southwick, 2007). It has been evident in the results of this study that participants indicated that social support helped them to reduce their stress levels.

5.2.1 Bullying

Bullying is experienced by learners or people throughout the world and has a negative impact on the victim, either at school or in their daily lives, and interferes with the right to live without fear. Not only is it a harmful act but it may leave the victim with physical or emotional consequences. Bullies engage in hurtful, intimidating behavior against those who are not able to defend themselves because of size or strength, or because the victim is outnumbered or less psychologically resilient (U.S. Department of Justice, 2004; Brewster & Railsback 2001). Primary caregivers in this study indicated that their children were victims of bullying either at school or in the community as they cannot defend themselves. It appeared that the bullying affected the primary caregivers emotionally as they explained how their children were being abused and how they repeatedly mentioned “I was deeply hurt”. Even though the primary

caregivers themselves did not experience the bullying, they also felt the effects of such wrongful behavior**.**

5.2.2 Discrimination

Discrimination is handling a person, or group of people, less favorably than others would be treated in the same circumstances because of their membership of a particular group, such as having a disability, or being a woman. The term “discrimination” refers to the mistreatment of an individual compared to another person in the same or similar situation. This may result in being viewed as belonging to a particular group such as that of sex, age or disability. Indirect discrimination is based on the unfair exclusion of a particular group whilst it appears to be neutral to everyone else who has an equal impact (Intellectual Disability Rights Services, 2009). According to Soussa and Yogtiba (2009 as cited by Bayat, 2014), children born with difficulties, such as intellectual disabilities, are vulnerable to most of the negativity in their communities and may be rejected by the society.

This was evident from the interviews with primary caregivers who expressed that they were experiencing either bullying or even discrimination either directly or indirectly that affected them negatively. Disabled children are equally vulnerable to violence and abuse for many reasons, which include lack of knowledge, understanding of disability and negative beliefs and cultural practices, to name a few (UNICEF, 2013). People with disabilities are more likely to experience physical and sexual violence than the general population, with disabled women experiencing gender-based violence and sexual abuse at extraordinarily high levels (Mall, & Swartz, 2012).

5.2.3 Social support

Social support, on the other hand, may be available to individuals through their social ties with other groups of individuals in a community. The theoretical models of social support indicate that there are two identifiable dimensions, the structural and the functional dimension. The structural dimension includes the size of the social interactions and the functional dimension involves the emotional part such as love and empathy (Charney, 2004). Research studies indicate that relationships of better quality are better predictors of good health when compared to the structural dimension although they stress that both are important (Southwick, Vythilingam, & Charney, 2005).

Odom et al. (2007) found that parents of a child with an impairment are less likely to receive support or sympathy from family members or the society as the parents may be blamed for their wrongdoings. In the interviews conducted, the primary caregivers regarded teachers and other professionals as their support structure rather than people from the community or relatives close to them as some of them indicated that they did not receive any support from their family members. Most participants indicated that they received support from people outside their family and little support from their immediate family members.

5.3 Perceptions of intellectual disability

According to Uwagie-ero, Isege and Omiegbe (1998), culture refers to the values, beliefs and practices which is common to a group of people. Thus religion can be considered as part of culture. Superstition is defined as "a belief or practice resulting from ignorance, fear of the unknown" (Merriam-Webster, 2017, sv 'superstition'). According to Okafor (2003), it is believed that people with intellectual disabilities are social outcasts and that their disabilities are a result of offences committed by their forefathers.

In most African societies, pregnancy is viewed as a period during which the mother has to abstain from sex. If she does not, the mother might give birth to a child with disabilities (Hartley et al., 2005). According to Ogechi and Ruto (2002), it is considered bad luck to make fun of people with impairments, as it is believed that the person who is doing this may then have children with impairments, have accidents or bring a curse on the family for generations. In South Africa, the Department of Health's Disability Survey (2002) shows that some people believe that disability is a result of being bewitched and that traditional beliefs regard ID as a form of punishment for the parents not conducting proper rituals, being untrustworthy or misbehaving. Because it is seen as a sign of disrespect for not following ancestral rituals, parents of a child with impairment are less likely to receive a support or sympathy from family members or society (Odom et al., 2007).

A lack of inspiration which is concerned with ensuring a child's protection may be associated with deep-seated feelings a person has about being a parent, feelings of worry with his/her own needs, distorted perceptions or emotions about the child or a symptom of a disturbed parent-child relationship. There was confusion because most caregivers did not know the causes of

intellectual disabilities and how they are defined." (Odom et al., 2007). This was evident in the study because most participants gave their own different perceptions regarding ID, and its causes which consisted of factors such as culture as well as religion/faith.

5.3.1 Limited knowledge

Masasa**,** Irwin-Carruthers and Faure (2005) conducted a study which aimed to explore the knowledge, attitudes and beliefs related to disability focusing on three cultural groups in the Western Cape. The study found that caregivers who were white were familiar with intellectual disabilities from a young age whereas caregivers who were in black communities only knew about intellectual disabilities following the birth of their children. The three groups also showed negative experiences in relation to the education and transport available but this was mostly evident in the colored and black communities. A primary caregiver may have limited knowledge with regards to ID in numerous ways. A caregiver may not be able to provide care for a child with ID either by providing safety depending on the child's vulnerabilities. The emotional state of the caregiver may also be of hindrance in providing adequate care to the child and the family as a whole hence not knowing how to manage such situations.

5.4 Experiences of caring for a child with an intellectual disability

5.4.1 Financial strain

Greenberg and Floyd (2004) concluded that parents, particularly mothers of children with disabilities work don't have the opportunity to work long hours and as a result they lower than parents or mothers of children perceived as typically developed. these mothers have reported to be spending most of their time caring for the child with a disability than a father would and also the fact that the demand associated with caring for a child with ID lead to work absenteeism hence leaving the burden to the caregiver who has to provide for the child (Warfield, 2001). Resources such as time, emotional and finance support are associated with having children with intellectual disabilities but spiritual growth has also been reported as being part of the outcome for caring for children with intellectual disabilities (Scorgie, & Sobsey, 2002). The South African government amongst others is face with the challenge to eradicate poverty as well as the upliftment of the country's citizens. According to the World Development Report (2001), the great difference between the people considered being rich and those that are considered to be

poor is seen to be the greatest in the world. The Eastern Cape and Limpopo province have indicated to have the highest levels of poverty in SA (Bosh, 2008).

Poverty can be described as being absolute or and relative. Absolute poverty refers to when individuals are unable to afford basic provisions necessary for everyday survival. The value of food is the determining factor of poverty more especially to people who earn little or do not have any income and may be considered to be poor or living in the lower class (Mohr, 2010). Wold Bank, (2001a), confirmed that in South Africa, households that have a share of income are 46% and are considered to be the 10% that is considered to be rich, whilst 40% households that are considered to be poor have a share of 8.4%. The development of a child relies on the financial stability of the family in cases were poverty is rife, it also contributes to the child development in a negative manner and hinders the appropriate development required for the child.

Economic factors are considered to play a vital role in the development of feelings such as stress and depression and therefore it cannot be ignored. Economic factors may delay liberation and cause added stress therefore poor economic situations can lead to sadness, displeasure, suffering and depressive feelings (Kathree, & Peterson, 2012). This was evident in the interviews when the primary caregivers indicated that there is financial strain in their families. Some of them are unable to search for work since they have to care for their children and that the only income in the family is that of the ID child's social grant.

5.4.2 Psychological strain

According to the World Health Federation for Mental Health (2014), caregivers, when compared to the general population, are mostly at risk of developing mental illnesses or physical illnesses such as stress and depression, become obsessive alcohol or substance users and might exhibit harmful behaviors.

A study conducted by Dunne (2015) indicated that caregiving was viewed as both a demanding experience and also pleasant experience. Even though they regarded their ID children as the souls of the family, they also mentioned that at times they felt isolated by the time required to care for the child with an intellectual disability.

Seven of the primary caregivers in this study indicated that they experienced stress at some point in caring for the child with an intellectual disability but that other family problems also contributed to the formation of stress. Some participants indicated that they blamed themselves for their ID children. This was particularly evident in Participant 2 who indicated that she has not accepted the state of her child and that she wants her to be normal or the way she was before. Some participants indicated that they were happy and found comfort in caring for the child and seeing it as a blessing rather than a curse or burden and that they relied on their spirituality/religion. Even though they experienced stress, they also had a sense of gratitude for their children with intellectual disabilities.

In contrast to the literature review that showed that studies conducted with a large population of caregivers who reported not having any strains or negative health effects (Hirst, 2005), this study found that caregivers of children with ID had a propensity to develop mental illness or other negative effects particularly in the early stages of caregiving. Even when caregiving demands become more intense and result in high levels of distress and depression, caregivers often cited the positive aspects of the experience. They reported that caregiving makes them feel good about themselves and gives meaning to their lives, enables them to learn new skills and strengthens their relationships with others (Brown, 2007).

It has been shown that there can be rewarding outcomes for caring for a child with an intellectual disability. Many parents find comfort in their children and mostly refer to them as their blessings rather than burdens and they find comfort in their spirituality (Blacher et al., 2005). This was evident in the interviews as one primary caregiver saw her child as a gift and that she is constantly remained of this by her husband hence their child has a name that is a reminder that he was a gift.

5.4.3 Physical strain

Caregivers are mostly at risk of developing different kinds of mental or physical illnesses such as stress or depression or become obsessive alcohol or substance users and some of them might exhibit harmful behaviors as compared to the general population. Illnesses or diseases which caregivers are likely to develop can be chronic such as heart disease, diabetes or high blood pressure when compared to individuals who are not caregivers. They tend to focus more on the

wellbeing of the intellectually disabled child and less on their own mental and physical wellbeing (Döhner et al., 2008). Given this, caregivers need to take better care of themselves and reduce their levels of stress, depression, and anxiety. In the data collected, primary caregivers expressed that they have developed chronic illnesses. This was particularly evident in Participant 4 who indicated that she has several chronic illnesses including that of high blood pressure.

5.5 Uncertainties about the future

5.5.1 Education

A 2005 report by the Nelson Mandela Foundation established that young South African carers with relatively little education may not have the knowledge or be empowered to provide optimal care and learning conditions for their children with disabilities. Other socioeconomic factors that can affect development of a child include the caregiver's age. Most parents indicated that they were not aware of what their children were doing at school whilst others felt that it was a waste of time and money for their children to attend school because they did not show any progress although some indicated that there were changes which were identifiable. Similarly, most educators in special schools do not have the required training or appropriate qualifications to teach children with special needs.

Pre-vocational education which is based on professional training and education should be accessible to every child as well as to the primary caregiver of a child with an intellectual disability. Pre-vocational education therefore refers to a set of collected skills that improve a student's motor skills which then improves coordination and manual skills thus providing skills for the work place. Pre-vocational studies conducted on students helped to improve their attitudes, outlooks and social competence and provided interpersonal and psychosocial skills, developed coping and self-management skills and allowed them to effectively communicate with others. Pre-vocational learning should be achieved before child reaches adulthood as it prepares them for independence. Knowing that a child will be able to live independently gives the parent or caregiver a sense of security (Cabbeh, Villafuerte, Ruiz, & Adanza, 2015).

In contrast to the above, primary caregivers indicated their confusion or lack of understanding in terms of their children's education and how it would benefit them. The primary caregivers

indicated that the pro-vocational education was not offered at the school which appeared to raise concern and confusion as some of them were already adolescents.

5.5.2 Uncertainties

There are a lot of feelings involved when caring for a child with intellectual disability either by the caregiver or other family members since the responsibility takes a very big toll on them. However, according to Gupta and Singhal (2004), not only does taking care of the child daily raise stress levels, but caregivers also are concerned about the future of the child and may have questions such as “As I grow old, how will my child survive when I cannot do much?” or “Will my child be able to support himself when I die?”

Most primary caregivers raised the same questions in connection with the education their children were getting. Also, there were uncertainties about caring, as indicated by the biological mother (Participant 1) that since the primary caregiver of the child is in her late adulthood, how will they cope when her caring abilities deteriorate and the child needs constant care? Some participants indicated they were concerned about their children’s mental state and questioned whether they will improve.

5.6 Limitations of the study

The researcher acknowledges that the sample utilised was limited and only included primary caregivers in Bushbuckridge of children who are already in a special school. Therefore, the results should be interpreted with caution as they cannot be generalised to a larger population other than the one used in this study.

The use of translation was seen as a limitation in the study. The researcher had to translate interviews from Northern Sotho and Tsonga to English and acknowledged that some meaning of words may have been lost in the translation.

Another limitation to the study was that of using a tape recorder instead of a video recorder. The essence of the topic was sensitive to most of the primary caregivers therefore their facial expressions and how they carried themselves throughout the interviews while answering the questions would have been beneficial in the analysis as well as results of the study.

5.7 Recommendations

Future research should be conducted focusing on a larger population in South African communities and also including the primary caregivers at the schools, the teachers and the primary caregivers who are not at school. Since the study focused on a small population in a rural area, this should be conducted in the different communities, cultures and religions on caregivers and also those who take care of the children at home looking at how the school and primary caregivers can work together to the benefit of these children. Since intellectual disability differs according to its severity, a study could be done focusing on people with intellectual disabilities and how they live with their disabilities since. Focus groups can also be held with different community members sharing their views on intellectual disabilities.

5.8 Implications of this study

From the findings, it is evident that primary caregivers had little or no knowledge of ID and that psycho-education is very important, not only to caregivers of children with intellectual disabilities, but also the communities and educators. Most parents did not understand what their children were doing at school indicating that schools should engage with parents more often in their parents' meetings to reduce the uncertainties primary caregivers have. Community members as well as learners in schools should be engaged to promote anti-bullying campaigns both in special schools and main stream schools as this was highlighted in the study.

Another crucial aspect requiring intervention concerns the psychological well-being of caregivers. From the results of this study, it was evident that many caregivers presented with psychological problems as well as social problems. These caregivers also indicated that they did not have the relevant knowledge to help their children according to their intellectual disabilities hence there is a need for primary caregivers to be given training in terms of how to care for their children at home when they are not under the care of the schools or any other place. The socio-economic background of the caregivers should also be considered when helping them to develop activities which they can do using the resources which they have. Another intervention can include psychological practitioners at the school assisting primary caregivers. The government can work together with other stakeholders or professionals in this regard to train caregivers and providing information to reduce the stigmas and bullying.

5.9 Conclusion

The study explored the primary caregivers' experiences of caring for individuals with intellectual disabilities in the Bushbuckridge region, Mpumalanga Province. The study was qualitative in nature and consisted of interviews with nine primary caregivers from the area. From the results, it became evident that primary caregivers had little or no knowledge about intellectual disabilities and the treatment of children who suffered from them. Some participants rely on their faith for healing as children were taken to the church, sangomas or faith healers. Primary caregivers raised concerns about their children's futures which led to anxiety and other illnesses. Primary caregivers expressed their emotional difficulties as their children were victims of bullying in their societies. Recommendations were identified which can intervene and assist them in the future by further research.

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APPENDIXS

APPROACH LETTER

Psychology

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 086 553 4913

Dear Principal

My name is Kgahliso Antoineth Dibakoane and I am currently completing a Master's degree in Psychology by coursework and research at the University of the Witwatersrand.In South African Communities' Especially Rural Societies people tend to know little about Intellectual disability often making it very challenging to assist children and families where there are children with intellectual disabilities. Research that has been done has focused on the child and little consideration is given to the caregiver. Hence I am conducting a study on the caregivers' perceived experiences of caring for children who are intellectually impaired in Bushbuckridge also focusing on the cultural perspective of intellectual disability. I am writing to you in this regard to request permission from yourself and the School Governing Body to approach the caregivers of learners with intellectual disabilities at your school.

I would like to interview caregivers for approximately an hour at a place that is convenient for the caregiver. However I would like the school's assistance in making contact with the caregivers. There are no risks or benefits associated with participation in this study. The information acquired from participants will be confidential. The participants' identity will not be mentioned in my research report or any publication. An overall summary of the study will be submitted to the school if requested upon complexion of the research project. Should you have any further queries please feel free to contact my supervisor or myself. Our details appear in the signature below.

It would be appreciated if permission could be granted using the attached consent form.

Kind regards,

Ms kgahliso Antoineth dibakoane

Cell: 079 460 5086

E-mail: anto.kgahli@gmail

Prof. Sumaya Laher

Tel: 011 717 4532, Fax: 086 553 4913

E-mail: sumaya.laher@wits.ac.za

Psychology

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 086 553 4913

I, _____principal of _____ (name of school), grant consent for Dibakoane Kgahliso Antoineth to approach caregivers of the learners in this school to be part of her research study. I understand that participation in this study is voluntary and that all details will be kept confidential at all times. The school's name will also not be mentioned in the study further preserving the anonymity of responses. The school will/will not require a summary of the results of the study.

Name: _____

Signed: _____

Date: _____

INTERVIEW SCHEDULE

Introduction (Establish Rapport). Background information to be obtained from the caregiver either by observation (eg. Gender)

My name is Kgahliso Antoineth Dibakoane and what is your name? How are you today? We will be having an interview session and it will take us about 30 to 45 minutes.

1. Can you please tell me about your child?
    - When did you first find out about it? What did you do? Did you get any help/support? From whom did you get help or support?
    - Would you like to tell me about a brief history of your pregnancy? If you experienced any challenges during your pregnancy?
    - How is the child now? Are you getting any support for the child?
2. How does it make you feel to be the primary caregiver for your child?
3. How have you been coping in this situation?
4. What do you believe about the child's illness?
    - Prompt with: how do you understand it? What are the causes? How can it be treated?
    - If interviewee touches on cultural explanations, prompt with questions investigating cultural beliefs; if interviewee touches on biological/psychological explanations also prompt to understand further
5. Since you began to care for your baby would you say you have experienced significant changes in your life?
    - Prompt with work life, social life, home life
6. What challenges do you normally come across if any?

7. Do you receive support from other family members?
8. Since your child came to this school, do you think there are any differences from when he/she was not attending school? Why?
9. Can you please tell me how it makes you feel that your child is at this school?
10. Would you say there is a difference in children who attend in this school and those who don't? Why do you say so?
11. Do you usually have educational talks with health professionals in your community?
12. In your community have you heard people talk about disabilities?
13. Does the community have any specific beliefs about intellectual disabilities?
14. What do community members mention as treatment for intellectual disabilities
15. Is there anything else you would like add or discuss?

Thank you so much for your time and for sharing your experiences with me. I really appreciate it.

DEMOGRAPHICS

Age of caregiver	
Gender of child	
Age of child	
How long have you been taking care of (the child – try and refer to the child by name throughout the interview)	
Geographical area	
Level of education	
Socio-economic status/employment status	

INFORMED CONSENT

Psychology

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I, _____ consent to being interviewed by Ms Kgahliso Antoineth Dibakoane for her study on "caregivers' experience of caring for children with intellectual disabilities; Mpumalanga province Bushbuckridge region". I understand that:

- Participation in this study is voluntary.

- I may refrain from answering any questions.

- I may withdraw my participation and/or my responses from the study at any time.

- All information provided will remain confidential, although I may be quoted in the research report.

- If I am quoted, a pseudonym (Respondent X, Respondent Y etc.) will be used.

- None of my identifiable information will be included in the research report.

- I am aware that the results of the study will be reported in the form of a research report for the completion of a MA degree in psychology by coursework and research.

- The research may also be presented at a local/international conference and published in a journal and/or book chapter.

Signed: Date:

AUDIO RECORDING CONSENT

I, _____ give my consent for my interview with Ms Kgahliso Antoineth Dibakoane to be audio recorded for her study. I understand that:

- The tapes and transcripts will not be seen or heard by anyone other than the researcher and her supervisor.

- The tapes and transcripts will be kept in a locked cupboard at the university.

- No identifying information will be used in the transcripts or the research report.

- Although direct quotes from my interview may be used in the research report, I will be referred to by a pseudonym (Respondent X, Respondent Y etc.)

Signed: _____ Date: