EXPERIENCES OF FAMILIES CARING FOR MENTALLY HANDICAPPED CHILDREN AT THE BANA BA THARI SCHOOL IN THE POLOKWANE MUNICIPALITY OF THE LIMPOPO PROVINCE, SOUTH AFRICA

by

Malesiba Naum Madiba

A MINI-DISSEPTION SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF CURATIONIS(MCUR)

in the

Faculty of Health Sciences

at the

University of Limpopo, South Africa

Supervisor: Prof J.C. Kgole
Co-supervisor: Prof M. E. Lekhuleni

2015
DECLARATION

I, Malesiba Naum Madiba, declare that this mini-dissertation “Experiences of families caring for the mentally handicapped at the Bana Ba Thari school in the Polokwane Municipality of the Limpopo Province, South Africa” hereby submitted to the University of Limpopo for the degree Master of Curationis (MCur) has not previously been submitted by me for a degree at this or any other university; that it is my own work in design and in execution, and that all material contained herein has been duly acknowledged.

________________________________________  ______________________________
M.N. Madiba (Miss)                          Date
DEDICATION

This dissertation is dedicated to the following:

- The study is dedicated to my parents, Samuel Madimetja Madiba and Legoma Motion Madiba, for their love, care, encouragement, and support to achieve my goals during my period of study.
- My baby, Legoma Moses Madiba, for his love and understanding.
- My sisters, Makgabo Frangeline Madiba and Raesetja Rahab Madiba, for their love and perseverance while they were guiding me, encouragement, and support they showed during this study.
- All the families who participated in the study, since they sacrificed their time and duties to enable me with their participation during the data collection process.
ACKNOWLEDGEMENTS

I would like to extend my appreciation and gratitude to the Almighty God for granting me the opportunity, courage, wisdom, guidance, and strength to persevere despite the challenges during the period of study. The success of this study would have not been possible without the continued support from several people. I heartily acknowledge the significant contribution by the following:

- My supervisor, Professor J.C. Kgole, at University of Limpopo for her love, patience, support, assistance, encouragement, and reassurance during this study.
- My co-supervisor, Prof M.E. Lekhuleni, for giving me hope, courage, motivation to work harder, and for giving me every opportunity and for believing in my tenacity to complete this study.
- The University of Limpopo, Turfloop Campus, for the permission to conduct the study and for financial assistance.
- The Medunsa Research Ethics Committee for its approval of the study.
- The Limpopo Department of Education for the permission to conduct the study at school for the mentally handicapped, the Bana Ba Thari School.
- The Principal of the Bana Ba Thari School for his warm welcome and for the educators who allowed me an opportunity to interview the parents at the school, who assisted me with providing the parents’ addresses amidst all their other duties.
- All the families of the mentally handicapped children at the Bana Ba Thari School.
- Independent coder, Prof M. N. Jali, thank you for the advice and direction in respect of the data analysis process.
- The language editor, Mr A. Hills, for the meticulous editing of this dissertation.
ABSTRACT

Background: The experiences of families living with the mentally handicapped children who attended the Bana Ba Thari School in the Polokwane Municipality of the Limpopo Province were never evaluated and, therefore, the experiences of families were not known.

The aim: The aim of this study was to describe the experiences of the families caring for the mentally handicapped children who attended the Bana Ba Thari School in the Polokwane Municipality of the Limpopo Province, South Africa.

Study methodology: A qualitative phenomenological research approach was used. Data was collected from 23 families who cared for their mentally handicapped children by conducting semi-structured face-to-face interviews. Data was audio recorded and field notes were written down. Data was analysed using Tech’s open coding method for qualitative research. After the Medunsa Research and Ethics Committee had given ethic clearance for this study to be conducted, the Department of Education also gave permission for the study to be conducted. After the Medunsa Research and Ethics Committee had given ethic clearance for this study to be conducted, the Department of Education also gave permission for the study to be conducted. Ethical considerations and measures to ensure trustworthiness were observed and adhered to while conducting the study.

The results: The results showed that the parents lacked adequate knowledge about mentally handicapped children which led to poor interaction. The study also revealed a gap of knowledge from various professions like doctors and educators which led to poor intervention and delay of therapy for the mentally handicapped children. The study also revealed the psychological impact on the parents and siblings. Parents worried about the future of their mentally handicapped children, which led to their denial and anxiety while the siblings became depressed. Parents also experienced a physiological impact, socio-economic problems, lack of resources at school like material for rehabilitation, and lack of transport to take their children to school every day. In addition, it was found that most of the parents and siblings did not get continuing psychological support.
Conclusion and recommendations: It is recommended that government and agencies should provide assessment and therapy facilities for mentally handicapped children and their parents. It is also recommended that professionals like doctors and educators still need to undergo in-service training with regard to mentally handicapped learners to enable them to make proper decisions or to execute accurate interventions.

Keywords: Experiences, mentally handicapped, caring, children, families, Bana Ba Thari.
DEFINITION OF CONCEPTS

Experiences

Experiences means to undergo or be affected by a situation. Knowledge and skills are gained over time, observing, encountering or undergoing of things as they generally occurred (Soanes, Hawker & Elliott, 2010).

In this study, experiences refer to the challenges that are experienced by families when caring for their mentally handicapped children.

Mentally handicapped

The term mental handicap refers to a subnormal intellectual functioning that starts during the developmental period which results in a sub-average intellectual ability equivalent to or less than an IQ of 70 and often in behavioural or social problems (Cashin, 2010).

In this study, handicapped child refers to a child who has either a permanent mental or physical condition that makes it impossible to use a particular part of the body or mind.
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>DSD</td>
<td>Department of social development</td>
</tr>
<tr>
<td>DWCCD</td>
<td>Department of women, children &amp; children with disabilities</td>
</tr>
<tr>
<td>IQ</td>
<td>Intelligence Quotient</td>
</tr>
<tr>
<td>SNHL</td>
<td>Sensor neural Hearing Loss</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>UNICEF</td>
<td>Unite For Children</td>
</tr>
</tbody>
</table>
# TABLE OF CONTENTS

## TABLE OF CONTENTS

DECLARATION ................................................................................................. ii
DEDICATION .................................................................................................. iii
ACKNOWLEDGEMENTS ................................................................................ iv
ABSTRACT ....................................................................................................... v
DEFINITION OF CONCEPTS ........................................................................ vii
LIST OF ABBREVIATIONS ............................................................................. viii

1 CHAPTER 1 OVERVIEW ........................................................................... 1
  1.1 INTRODUCTION AND BACKGROUND ........................................... 1
  1.2 PROBLEM STATEMENT .................................................................. 3
  1.3 AIM OF THE STUDY ....................................................................... 3
  1.4 RESEARCH QUESTION .................................................................... 3
  1.5 OBJECTIVES OF THE STUDY .......................................................... 4
  1.6 METHODOLOGY ............................................................................. 4
  1.7 SIGNIFICANCE OF THE STUDY ....................................................... 5
  1.8 CONCLUSION .................................................................................. 5

2 CHAPTER 2 LITERATURE REVIEW ....................................................... 6
  2.1 INTRODUCTION ............................................................................. 6
  2.2 THE PREVALENCE OF MENTALLY HANDICAPPED CHILDREN ....... 6
  2.3 THE CAUSES OF BEING MENTALLY HANDICAPPED .................... 6
    2.3.1 Infections ............................................................................... 6
    2.3.2 Genes .................................................................................... 7
    2.3.3 Violence and war ..................................................................... 7
2.3.4 Poverty ..............................................................8
2.3.5 Lack of information ...........................................8
2.3.6 Failure of medical services ..................................9
2.3.7 Unhealthy lifestyles ..........................................9
2.3.8 Environmental factors .......................................9
2.3.9 Accidents .......................................................10
2.3.10 Social environment ........................................10

2.4 THE CHALLENGES THAT MENTALLY HANDICAPPED CHILDREN AND THEIR PARENTS FACE .........................................................10

2.4.1 Economic factors ..............................................10
2.4.2 Occupational accessibilities ...............................12
2.4.3 Access to health facilities ..................................12
2.4.4 Acceptance ....................................................13
2.4.5 Sleeping problems ...........................................13
2.4.6 Self-blame ......................................................14
2.4.7 Stigma ..........................................................14
2.4.8 Helplessness ....................................................14
2.4.9 Behaviour problems .........................................15
2.4.11 Worry about the future .....................................15
2.4.12 Marital / family problems .................................16
2.4.13 Siblings .......................................................16
2.4.14 Low self-esteem .............................................17

2.5 CONCLUSION ..................................................17

3 CHAPTER 3 RESEARCH METHODOLOGY .................................18

3.1 INTRODUCTION ..................................................18

3.2 STUDY SITE ......................................................18
3.3 RESEARCH METHOD AND DESIGN ................................................................. 18

3.3.1 Qualitative research method ........................................................................................................ 19

3.3.2 Phenomenological research design .................................................................................................. 19

3.3.3 Descriptive research design ......................................................................................................... 20

3.4 POPULATION ................................................................................................................................. 20

3.5 SAMPLING ......................................................................................................................................... 20

3.6 INCLUSION CRITERION .................................................................................................................... 21

3.7 EXCLUSION CRITERION .................................................................................................................... 21

3.8 DATA COLLECTION .......................................................................................................................... 21

3.8.1 Interview techniques ...................................................................................................................... 23

3.8.2 Communication techniques ........................................................................................................... 23

3.9 DATA ANALYSIS .............................................................................................................................. 25

3.10 MEASURES TO ENSURE TRUSTWORTHINESS ......................................................................... 27

3.10.1 Credibility .................................................................................................................................. 27

3.10.2 Dependability ............................................................................................................................... 27

3.10.3 Transferability .............................................................................................................................. 27

3.10.4 Confirmability .............................................................................................................................. 28

3.11 ETHICAL CONSIDERATIONS ......................................................................................................... 28

3.11.1 Permission to conduct the study ................................................................................................. 28

3.11.2 Informed consent .......................................................................................................................... 29

3.11.3 Confidentiality and anonymity ..................................................................................................... 29

3.11.4 Right to protection from harm .................................................................................................... 29

3.12 CONCLUSION ................................................................................................................................. 30

4 CHAPTER 4 DISCUSSION OF RESULTS AND LITERATURE CONTROL ........................................... 31

4.1 INTRODUCTION ............................................................................................................................ 31

4.2 DEMOGRAPHIC DATA ....................................................................................................................... 32
4.3 DISCUSSION OF FINDINGS .................................................................................................................. 33

4.3.1 Theme 1: Physiological impact

4.3.2 Psychological impact on the family ................................................................................................. 35

4.3.3 Theme 3: Poor knowledge of parents and health professionals ..................................................... 41

4.3.4 Theme 4: Socio-economic problems ............................................................................................... 43

4.3.5 Theme 5: Lack of material resources and facilities ......................................................................... 48

4.4 CONCLUSION ....................................................................................................................................... 50

5 CHAPTER 5 SUMMARY, RECOMMENDATIONS, LIMITATIONS, AND CONCLUSION .......................... 51

5.1 INTRODUCTION .................................................................................................................................. 51

5.2 SUMMARY OF THE FINDINGS OF THE STUDY ............................................................................. 51

5.2.1 Aim of the study ............................................................................................................................... 51

5.2.2 Research Question ........................................................................................................................... 51

5.2.3 Objectives of the study .................................................................................................................... 51

5.3 FINDINGS OF THE STUDY IN RELATION TO THE OBJECTIVES ................................................. 52

5.4 RECOMMENDATIONS ....................................................................................................................... 53

5.4.1 Addressing the lack of knowledge by parents, doctors, and educators ........................................... 53

5.4.2 Addressing the psychological impact on the family

  (parents and siblings) ............................................................................................................................. 55

5.4.3 Addressing the physiological impact ............................................................................................. 57

5.4.4 Addressing socio-economic problems ......................................................................................... 57

5.4.5 Addressing the lack of resources .................................................................................................... 58

5.5 RESEARCH SUGGESTIONS ............................................................................................................... 60

5.6 LIMITATIONS OF THE STUDY ......................................................................................................... 61

5.7 CONCLUSION ..................................................................................................................................... 61

5.8 REFERENCES ....................................................................................................................................... 62
APPENDIX B: CONSENT FORMS ............................................................... 75
APPENDIX C: APPROVAL LETTER (department of education) ............... 77
APPENDIX D: INDEPENDENT CODER CERTIFICATE ............................. 79
APPENDIX E: THE EDITOR LETTER ..................................................... 80
APPENDIX F: EXAMPLE OF A CONDUCTED INTERVIEW
(ENGLISH VERSION) ........................................................................... 81
APPENDIX G: EXAMPLE OF A CONDUCTED INTERVIEW
(SEPEDI VERSION) ............................................................................. 84

LIST OF TABLES
Table 4.1: Demographic data ................................................................. 32
Table 4.2: Participant's Years of experience ........................................... 33
Table 4.3: Themes and sub-themes ......................................................... 33
CHAPTER 1
OVERVIEW

1.1 INTRODUCTION AND BACKGROUND

The WHO (2003) recognises that there is an estimated 450 million people worldwide living with either mental or behavioural disorders; 90 million are drug or alcohol dependent, 25 million suffer from schizophrenia, and 150 million endure depression. In South Africa, 16.5% of the general population are diagnosed with some kind of mental illnesses. Since 2009, the StatsSouthAfrica Annual General Household Survey (GHS) has used the Washington Group Short Set Of Questions which asks survey respondents about difficulties experienced in seven domains of functioning, that is seeing, hearing, walking, remembering, concentrating, self-care, and communicating, therefore an individual is classified as disabled if having difficulty in two or more of the six categories. Following this approach the GHS 2009 classified nearly 2.1 million children (11, 2 per cent of the child population) as disabled (DSD, DWCPD and UNICEF, 2012).

An average intellectual quotient (IQ) for someone without a mental handicap is a 100. An IQ in the range of 50 – 70 is considered a mild mental handicap, an IQ between 35 and 49 is considered a moderate mental handicap, an IQ of 20 to 34 is considered a severe mental handicap, and an IQ of less than 20 is referred to as a profound handicap. A mildly mental handicapped person could learn basic skills at school and in daily living, while people with a moderate to severe mental handicap might have the ability to learn basic social, communication, and self-help skills, however, the acquisition of such skills might be more difficult with the result that behaviour problems are likely to occur. While a profound mentally handicapped person may have the ability to learn basic self-help skills, such a person would require constant supervision throughout life (Cashin, 2010).

Children who are mentally handicapped may continue with infantile behaviour longer than is considered normal; there may be developmental delays in the growing process and a failure to meet intellectual developmental milestones during their schooling age. Usually, they exhibit poor performance in problem-solving, short-term
Memory, learning skills; as well as daily living, communication, and social skills (Cashin, 2010). Individuals with a mental handicap are significantly less likely to complete high school, in comparison with their peers without a mental handicap (Kessler, Foster, Saunders & Stang, 1995). The study by Homes (2005) shows that 8% of disabled people are not working. A mental handicap could lead to reduced productivity at work and as a result, the unemployment rate of the mentally handicapped increases.

Mental health has profound effects on an individual's quality of life, physical and social well-being, and economic productivity. It is important to understand the effects of mental illness on individual patients in a social system that needs an improved mental health care structure to develop effective mental health care delivery programmes (WHO, 2003). According to Manyana (2012), people with mental illnesses are still abused and called names; such as “crazy”, “cuckoo”, or “weak”. Therefore, campaigns about mental illness are still needed in the community.

A 2006 study in Botswana investigated experiences of families who cared for a mentally ill family member. The study was conducted using in-depth interviews and most families reported that their lack of financial and medical resources and the same lack on different community levels made it difficult and stressful to provide adequate care (Seloiwe, 2006). There is some evidence of the establishment of consumer and family associations, often with the support of non-governmental organisations, such as the South African Federation for Mental Health with regard to mental health services, but the role of these associations in the formulation of policy and planning is limited (WHO, 2007).

In South Africa, in-depth interviews with eight family caregivers in the Limpopo Province revealed that many caregivers felt their own physical well-being was at risk, particularly when caring for a violent or destructive mentally handicapped family member (Mavundla, Toth, & Mphelane, 2009). Caregivers also reported social isolation due to their family members’ mental handicap, since care giving duties prevented them from attending social events, such as funerals and church services; particularly in rural areas that lacked community resources for the mentally ill. The degree of satisfaction with family functioning and the size of the caregiver’s support network may significantly influence patient functioning. Furthermore,
increased support improves patient outcomes even in cases with high reported family burden (Mavundla, Toth, & Mphelane, 2009). Therefore, this study aims at increasing the body of knowledge with regard to experiences of families who care for their mentally handicapped children who attend school at Bana Ba Thari of the Polokwane Municipality in the Limpopo Province, South Africa.

1.2 PROBLEM STATEMENT

During the researcher's community home visits I observed that some family members who are living with their mentally handicapped children seemed to be having difficulties while caring for their mentally handicapped children. It seemed not easy for them and it is stressful because some family members complained that they do not know how to care for their mentally handicapped children, since they do not really understand the children's disorganised behaviours. Therefore, it is important to understand the experiences of families who care for the mentally handicapped children in order to assist and empower them in terms of the difficulties they are experiencing.

1.3 AIM OF THE STUDY

The aim of the study was to investigate the experiences of families caring for the mentally handicapped children who attend the Bana Ba Thari School of the Polokwane Municipality in the Limpopo Province, South Africa.

1.4 RESEARCH QUESTION

This research question guided the study:

What are the experiences of families caring for mentally handicapped children who attend Bana Ba Thari School of the Polokwane Municipality in the Limpopo Province, South Africa?
1.5 OBJECTIVES OF THE STUDY

The objectives of this study were to:

- explore and describe the experiences of families caring for mentally handicapped children who attend Bana Ba Thari School of the Polokwane Municipality in the Limpopo Province, South Africa.
- empower families to care for mentally handicapped children who attend the Bana Ba Thari School of the Polokwane Municipality in the Limpopo Province, South Africa.

1.6 METHODOLOGY

A qualitative research approach was used in this study that described life experiences and gave meaning to those experiences. This method focuses on understanding the bigger picture and all its content. This approach is consistent with the holistic philosophy in nursing (Bedna, 2003). A descriptive and a phenomenological research design was used in this study to explore and describe the experiences of families while they were caring for their mentally handicapped children. A phenomenological design was used to understand the experiences of families who cared for the mentally handicapped children (Gerrish & Lacey, 2006).

The population for this study was all families caring for mentally handicapped children who attended the Bana Ba Thari School of the Polokwane Municipality in the Limpopo Province, South Africa. In this study, a non-probability purposive sampling method was used; only family members caring for their mentally handicapped children who attended the Bana ba Thari School for the disabled children in Ga Dikgale were included in this study. It requires judgmental sampling that involves the conscious selection by the researcher of certain subjects to include in the study. The sample size of this study was limited to 23 identified participants. However, the eventual sample size depended on the availability of members of that population on occurrence of data saturation. The details of the methodology are discussed in Chapter 3.
1.7 SIGNIFICANCE OF THE STUDY

This study may assist the Department of Health and Social Development to identify the challenges faced by family members of mentally challenged children. Through the study recommendations, empowerment may improve service delivery and the support needed by the families of mentally handicapped children who attend the Bana Ba Thari School of the Polokwane Municipality in the Limpopo Province.

1.8 CONCLUSION

This chapter presents an overview of the study, including its background, problem statement, purpose of the study, research question and objectives, research methodology, and significance of the study. Chapter deals with the literature review.
CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

This chapter discusses literature that is relevant to the research topic, namely experiences of families caring for mentally handicapped children at the Bana ba Thari School in the Polokwane Municipality of the Limpopo Province. The review of literature involved an in-depth evaluation of published scholarly literature in journals, books, and book chapters (an electronic literature search was conducted in the following databases: Science-Direct, EbscoHost, and Google).

2.2 THE PREVALENCE OF MENTALLY HANDICAPPED CHILDREN

The prevalence of handicap appears unusually high for young children, 28 per cent of children in the age group 0-4 years and 10 per cent in the age group 5-9 years were classified as disabled and disability was slightly higher among male and female (DSD, DWCPD and UNICEF, 2012). Research in the United States of America (USA) and the United Kingdom (UK) indicates that mental retardation affects between 1 and 3 per cent of the population. Specifically, these estimates contribute to service utilisation estimates, resource costing, and proposed service development targets for mental health (Fick, Flisher, Kleintjes, Lund, Molteno, Railoun, and Robertson, 2006).

2.3 THE CAUSES OF BEING MENTALLY HANDICAPPED

Many factors are responsible for the rising numbers of people with mental handicaps. Mental handicaphas numerous potential causes.

2.3.1 Infections

Some infections that are either present at birth, or that happen soon after birth could cause mental handicap; including congenital rubella, meningitis, encephalitis, HIV, or cytomegalovirus (Pilusa, 2006). Cytomegalovirus is the most common congenital infection in USA that is the leading cause of sensorineural hearing loss (SNHL), mental handicap, and cerebral palsy. It is a common opportunistic pathogen among immunocompromised patients associated with illness that requires expensive
treatment; it compromises vital organs, leads to disability, and diminished quality of life (Pass, 2002).

2.3.2 Genes

Chromosomal abnormalities before birth such as; deletions, a gene not located in the usual place, an error in the number of chromosomes could cause mental handicap, and the other children genetically inherit mental handicap from their parents (Cashin, 2010). A mutation in the human large gene causes a novel form of congenital muscular dystrophy with severe mental handicap and abnormal glycosylation of a dystroglycan. Mental handicap and epilepsy often occur in conjunction with one another, since they are both heterogeneous conditions with acquired and genetic causes, however, causes are primarily genetic. The human X chromosome is estimated to contain more than a hundred mutated genes that cause mental handicap while eight autosomal genes are linked to idiopathic epilepsy (Longman, Brockington, Torelli, Jimenez-Mallebrera, Kennedy, Khalil, Feng, Ravindra, Sara, Voit, Merlin, Sewry, Brown, & Muntoni, 2003).

2.3.3 Violence and war

Handicaps are caused by violence (especially against women and children), injuries as a result of landmines, and psychological trauma (Pooe-Monyemore, 2009). South Africa has high proportions of children who are exposed to risks of neurological damage in early life. The prevalence of foetal spectrum disorders is the highest in the world, 22.5 per cent of children between one and nine years of age are stunted or wasted. We also have high rates of domestic violence and child maltreatment (Ward, Artz, Berg, Boonzaier, Cawford-Brown, Dawes, Foster, Matzopoulos, Nicol, Seekings, Van As, & Van der Spy, 2012). Therefore, these causes could alter neurochemistry and result in aggression. For example, when learning disabilities of children are not identified or adequately measured, it might cause them to disconnect from school and the possibility of delinquent behaviour increases. Parents who have warm relationships with their children, who consistently discipline them without being harsh, and who supervise their activities adequately are less likely to have aggressive children (Ward et al., 2012).
2.3.4 Poverty

Handicaps are caused or exacerbated by overcrowded and unhealthy living conditions (Pilusa, 2006). Firstly, poverty might cause mental handicap. The effect of such disabilities mediates the association between poverty and exposure to a range of environmental and psychological hazards (Connor, 2006). Secondly, families who support a child with mental handicap and adults with mental handicaps are at increased risk of experiencing poverty due to the financial and social impact of caring for the mentally handicapped child and also exclusion of people with mental handicap from the workforce increases poverty (Emerson, 2007).

2.3.5 Lack of information

Many people do not have accurate information about mental disabilities, causes, prevention, and treatment (Jorm, 2012). This is the result of a high illiteracy rate and poor knowledge about basic social, health, and educational services. Although the benefits of public knowledge about physical diseases are widely accepted, evidence shows inadequate public knowledge about the prevention of mental disorders, recognition of when a disorder is developing, knowledge of help-seeking options and treatment available, knowledge of self-help strategies for milder problems, and first aid skills to help other members of the community who are affected by mental health problems (Rosekranz, 2004).

Knowledge about mental handicap has been somewhat neglected. Many members of the community are not able to recognise specific disorders or different types of psychological distress (Jorm, 2000). Therefore, if public mental health is not improved, this may delay public acceptance of evidence-based mental health care and may not receive appropriate support from other members of the community (Read, 2012).


2.3.6 Failure of medical services

The occurrence of disability is increased by the inadequacy of primary health care and genetic counselling services, weak organisational links between social and health care services, the faulty treatment of the injured when accidents occur, the incorrect use of medication, negligence due to limited parental knowledge, and lack of counselling and therapy (Logsdon, 2014; Ramey, Ramey & Lanzi, 2007). Results from other studies indicate that health professionals at the workplaces practices parent-professional relationship, assuming the role of expert rather than integrating and consulting parents in a negotiable decision making process. The lopsided relationship allows professionals to be prescriptive, therefore, the parents are disempowered and their parental involvement is reduced which prevents participation in an equitable relationship with professional health workers (Case, 2000).

2.3.7 Unhealthy lifestyles

Mental handicap might also be caused by the misuse and/or abuse of medication, the abuse of drugs and alcohol during pregnancy, low quality diets, smoking, and a lack of proper physical exercise. It is also caused by deficiencies in essential foods and vitamins (Cashin, 2010). Disability may also be caused by stress and other psychosocial problems in a changing society such as major depression, generalised anxiety disorder, and phobia (Kenneth, Kendler, Carol, Prescott, Myerems, Michael, & Neale, 2003).

2.3.8 Environmental factors

Mental handicap might be caused by epidemics, accidents, natural disasters, pollution of the physical environment, as well as poisoning by toxic waste and other hazardous substances (Downs, 2010). Historically, environmental health has viewed environmental threats in the context of infectious agents, pollutants, and exogenous factors that influence the individual’s physical surroundings. Environmental threats include pharmaceutical and illicit drugs. These threats create psychosocial conditions that influence an individual’s perception of the social and physical world. These worlds contain a number of circumstances; for instance sexual abuse, falling victim to crime, and the breakup of relationships which potentially produces psychosocial stress. But experts assume each of these circumstances triggers more primal reactions; such as
feelings of loss or anger that push the victim towards a particular frame of mind; these feelings of pure loss lead to depressive disorders (Schmidt, 2007).

### 2.3.9 Accidents

Mental handicap might be caused by industrial, agricultural and transport related accidents, as well as sports injuries. Traumatic brain injury might cause psychiatric disorders; this is evident from an established set of causation criteria. After a head injury accident, one has the likelihood of developing the following disorders according to the study that was conducted in a period of 7.5 years with people who had head injury: Major depression, bipolar affective disorder, anxiety disorder, obsessive compulsive disorder, panic disorder, and substance abuse (Van Reekum, Cohen, & Wong, 2000).

### 2.3.10 Social environment

The fact that people with mental handicap are marginalised and discriminated against creates an environment where prevention and treatment are difficult (Pooe-Monyemore, 2009). Sometimes, adults neither encourage their children to support other children in the community, nor do they prepare the disabled child for unpleasant encounters and cruelty from the peers (Stricker, 2001). Sport could provide an effective way of strengthening socialisation in conjunction with developmentally similar peers and supportive adults in order for the children to learn about team work (Mcleod, 2014).

### 2.4 THE CHALLENGES THAT MENTALLY HANDICAPPED CHILDREN AND THEIR PARENTS FACE

Other authors around the world in their studies such as (Chandrashekar, 2011) found that the following challenges from mentally handicapped and parents, when caring for their mentally handicapped children and these challenges made it hard for them to cope with daily living of caring for their children:

#### 2.4.1 Economic factors

Poor people face a greater risk of being mentally handicapped. In addition, the birth of a mentally handicapped child, or the occurrence of mental disability in a family,
often places heavy demands on family morale, thrusting it deeper into poverty. This means not only that there is a higher proportion of mentally handicapped people amongst the very poor but also that there is an increase in families living at the poverty level owing to the existence of mental handicap (Mcleod, 2014). A family’s expenses could increase due to medical equipment, medical care, care-giving, private education, tutoring, adaptive learning equipment, or specialised transportation (Lucy, 2011).

The review of literature examined the impact of poverty on the quality of life on families who have children with disabilities. According to Stats South African Survey 2007, children with disability are less likely to have access to adequate housing, water, sanitation and more likely to live in traditional dwellings and informal settlement than their non-handicapped peers (DSD, DWCPD and UNICEF, 2012). The study by UNICEF (2013) revealed that disability grant is provided to a total number of 113 1408 people in the whole South Africa and precisely a number of 91014 people in Limpopo province. Pressure on the Welfare System continues to grow most notably on disability grants which rose from about 600 000 in year 2000 to almost 1,3 million in 2004 (Nattrass, 2007). The review found that poverty in many ways impacted on six social dimensions of family; including health (hunger), healthy living conditions, social impact, delayed cognitive development, emotional wellbeing, physical endowment - overcrowded, increased stress due to the lack of emotional wellbeing, as well as money-related family interaction and marital conflicts in the family (Park, Turnbull, & Rutherford, 2002).

People who receive social security grants for disability in South Africa are inclined to be totally dependent on these benefits for their survival. Grants are either temporary (for six months) or permanent subject to periodic review and the grant of R1010 in year 2009 is received by approximately three percent of the South African population or 1,3 million people (Neves, Samson, Van Niekerk, Hlatswayo, Du Toit, 2009) The majority of people with mentally handicapped children, however, receive no grant at all. Parents had problems with applications for social financial security funds therefore this prevented them from purchasing clothing, food, and other basic needs for the mentally handicapped children (Kgole & Molepo, 2014).
2.4.2 Occupational accessibilities

The extremely high levels of unemployment amongst people with a mental handicap could be attributed to a number of factors; low skills levels due to inadequate education, lack of enabling mechanisms to promote employment opportunities, inaccessible public transport, as well as inadequate and inaccessible provision for vocational rehabilitation and training. Legislation has contributed to the social exclusion of people with disabilities. Firstly, legislation fails to protect the rights of people with a mental handicap. Secondly, legislation creates barriers that prevent mentally handicapped people from accessing equal opportunities (Poopedi, 2012).

This could be attributed to poor monitoring of the law. South African society still regards children with a mental handicap as incapable, ill, and a burden on society. In other words, they represent a 'problem' that needs to be dealt with differently from the issues of other children.

2.4.3 Access to health facilities

More than 80% of black children with a mental handicap live in extreme poverty in inhospitable environments. They have very poor access to appropriate health care facilities and early childhood development opportunities (Pilusa, 2006).

People with mental handicap who live in rural areas often have a low life expectancy due to lack of care, support, and access to the most basic services. Families are seldom able to meet the additional financial burden of regular visits to hospitals, additional expenses for equipment and assistive devices, and other necessities. The situation is exacerbated by considerable variation in service quality and availability, funding levels for care training, competence, inadequate physical access to community services, as well as non-existing or limited medical facilities for specialised and in-home care (Marks & Reeve, 2007). In a study by Mudhovozi, Maphula and Mashamba (2012), some participants reported that there was a lack of resources in hospitals to treat their children and owing to the shortage of professionals, programmes that were supposed to be run on a weekly basis were happening monthly only.
Families of mentally handicapped children commonly experience emotional, physical, and school related problems, as well as social and financial challenges because these children have special needs in addition to the regular needs of all children (Mudhovozi, et al., 2012). Parents experience feelings of guilt, embarrassment, blame, and disappointment. The study by Govender (2002) reveals that parents in rural areas of Zululand in the Kwazulu Natal Province love and accept their mentally handicapped children. However, the majority of parents are disappointed by having a mentally handicapped child and express feelings of embarrassment.

2.4.4 Acceptance

Many parents spend years in denial, trying to find some solution or cure to this problem. They might go from one hospital to another, try alternative forms of medicine, or look to religion for a miracle. Most mental challenges are syndromes that are caused by genetic factors, hereditary reasons, or many forms of irreversible brain damage. As hard as it is to accept, once parents realise that their children are mentally handicapped and will always be their expectations of the child are adjusted accordingly (Woolfson, 2004). Then, they are able to move on by taking the necessary steps to assist their children with making the most of their potential by addressing their special needs through special education, vocational training, etc. (Chandrashekar, 2011).

2.4.5 Sleeping problems

Parents of children with mental handicap report poorer sleeping quality. The majority of these parents recognise contributing “poor sleepers” factors. The strongest predictor of poor sleep quality is parental stress. Parental stress is associated with poor sleep quality when they care for children with mental handicap. Therefore, the monitoring and management of these parents’ sleep issues in their capacity of caregivers should be a priority for health professionals (Gallagher, Phillips & Carroll, 2010).
2.4.6 Self-blame

While taking care of a child, parents wonder whether they have done something wrong during the course of the pregnancy or after birth. They wonder whether God is punishing them for their sins (Chandrashekar, 2011). The guilt is caused by self-blame in terms of the aetiology of the disability of their child; it could be due to either the intake of substances (alcohol and drugs) during the prenatal period, genetics, or stress during pregnancy (Kaplan & Saddock, 2003).

2.4.7 Stigma

Many parents might feel that a mentally handicapped child is cause for being ashamed, therefore, the child could not be allowed out of the house. Neighbours, relatives, or other people might pass cruel remarks about the child and as a result, parents feel isolated and without support (Pilusa, 2006). Using regression techniques, stigma is found to have an impact on the social comparison process that is mediated by evaluative beliefs. These findings support a social-cognitive view of the importance that the social world have for people while they are coping with mental handicap and psychosocial damage that stigmatisation could cause (Dagnan & Warning, 2004).

2.4.8 Helplessness

Many parents don’t know how to get help for their child once he/she has been diagnosed mentally challenged. The interpretation of the parents experiences revealed themes of ‘joy & sorrow’, ‘joy & no hope’, ‘defiance & despair’ mediated by the lesions (Penelope & Graffin, 2001). The sense of helplessness comes both from a lack of understanding about mentally challenged and a lack of information about the resources available for mentally handicapped individuals. It might also arise from insensitive handling of the case by the mental health professional, who might not have enough time to talk to each family at length about their experience (Chandrashekar, 2011).
2.4.9 Behaviour problems

Among the mentally handicapped, more than 10% of children between the ages of nine and 17 years are believed to suffer from mood disorders. A mentally handicapped child might experience learning disabilities that interfere with reading, mathematics, and memory. Some of the mentally handicapped children develop depression, since they realise they are different from other children who are not mentally handicapped (Downs, 2010).

Many parents find it difficult to cope with behavioural problems like screaming, crying, inability to concentrate, aggressiveness, and stubbornness that a child with mental challenges might express (Smith, Romiski, Sevcik, Adamson, & Bakeman, 2011). For parents (especially mothers) – who have to take care of household tasks, work to earn a living, as well as care for a mentally handicapped child – patience could wear thin (Zupanick, 2014). Getting angry with the child or hitting him/her does not help in any way. Often, the child might not understand how disruptive his/her behaviour is to other people and why they get angry (Chandrashekar, 2011).

2.4.10 Unrealistic expectations

Many times, parents of mentally retarded children are dissatisfied with the slow progress their children are making in learning new things. They try and push harder to force the child to learn quicker in order to keep up with other children. However, these children can only learn to the best of their ability. When a child has the mental age of an eight-year-old, he/she cannot be expected to embark upon a vocation that requires complicated mental processes. When parents have unrealistic expectations of what their child can achieve, it leads to disappointment not only for them but also for the child who does not understand what he/she is doing wrong (Chandrashekar, 2011). As a result, parents experience greater restrictions and epileptic children develop a lower self-esteem and do not achieve academically (Long & Moore, 2006).

2.4.11 Worry about the future

One of the main concerns of parents with mentally handicapped children is their death, since they worry how their children will be taken care of. They feel that no one
else could take care of their child with the same love and care that they do and they are scared about their children’s ability to survive in the world (Chandrashekar, 2011).

2.4.12 Marital/family problems

Having a mentally handicapped child places greater strain on a family than otherwise. Due to the additional caregiving needs such a child has, parents feel overworked, stressed, and unhappy (Van der Want, 2014). The marital relationship could become strained when the parents have different approaches to dealing with the child or when one parent has to take care of the child all the time. Sometimes, mothers might feel they are not getting enough support from their husbands in relation to taking care of the child. Fathers might feel that the mothers are unnecessarily worried and overprotective of the child. Other family members could complicate matters in the way they react to the child (Lucy, 2011).

Parents have a healthy self-esteem, although they report somewhat lower marital happiness and family cohesion (Higgins, Bailey, & Pearce, 2005). According to their study, marriages fall apart because the wives do not have time for anything else than to take care of their mentally handicapped children. Friends and family are also not available for support while husbands become distended, annoyed and cold due to having a mentally handicapped child (Mudhovozi et al., 2012). Path’s analysis reveals that children’s being demanding and neediness for care are more related to maternal stress while child acceptability is related to paternal stress. A professional need exists to assist fathers with becoming emotionally close to their atypical children while mothers have a pressing need for respite services (Keller & Honing, 2004).

2.4.13 Siblings

Siblings of mentally handicapped children might adapt a plethora of good or bad qualities. They could experience depressive symptoms; such as resentment, being scared, frequent crying, hopelessness, appetite changes, loss of interest, as well as talking about self-mutilation and embarrassment. Siblings might assume extra pressure to take care of their mentally handicapped sibling without parents having any such expectation. The siblings might also feel lost or ignored, thinking that the mentally handicapped child received all the attention (Taylor, 2008). Good qualities
could be empathy for other people and insight into the challenges that mentally handicapped face, when growing up with a mentally handicapped sibling, children could also develop patience, be more accepting of differences, as well as be supportive and compassionate towards fellow human beings (Alexis, 2010).

2.4.14 Low self-esteem

Most mentally handicapped children intuitively sense that they are not as intellectually adept as their peers. This perception could lead to self-esteem issues, as well as emotional and behavioural problems. Younger children might become withdrawn or anxious, or they might exhibit anger or attention-seeking outbursts. Teenagers might exhibit signs of depression. When these problems are not treated, they could impede a child's progress. (Martinetz, 2011).

2.5 CONCLUSION

This chapter discussed different kinds of problems that families experience while they are caring for mentally handicapped children. Evidence from several research studies supports this discussion. The experiences and main concerns are arranged and discussed in a clearly defined manner. Chapter 3 describes the detailed methodology and design applied in this study.
CHAPTER 3
RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter focuses on the research methodology and design applied in the study and includes a description of the qualitative and phenomenological research design. Henceforth, the study site; population; sampling; exclusion criteria; inclusion criteria; data collection; data analysis; and trustworthiness measures of credibility, dependability, transferability, and confirmability; and ethical standards are discussed.

3.2 STUDY SITE

This study was carried out in one school for the mentally handicapped children of the Polokwane Municipality in the Limpopo Province, namely the Bana Ba Thari School. The school is situated in the rural area of Solomondale, 15km away from the Mankweng Tertiary Hospital and 45km away from the Polokwane city centre. The school serves children of Solomondale, Turfloop, Dikgale, Mentz, Nobody, Ga Kama, and GA Mailula. The study was undertaken at the school and the families were interviewed at the school during their bimonthly meetings as the families stay in far areas of Polokwane municipality. The school accommodates mentally handicapped children of different age groups. Admission starts between the ages of seven to eighteen years and the school also accommodates mentally handicapped from eighteen to fifty years because of limited centers for the mentally handicapped. The learners are accommodated in different groups; namely infant, junior, middle, and senior. The school consists of 23 educators, including the principal, and 201 learners. One hundred and thirty-six of them are girls and sixty-five boys.

3.3 RESEARCH METHOD AND DESIGN

A qualitative, descriptive, phenomenological research approach was used in this study to explore the experiences of families who care for mentally handicapped children (Creswell, 2009). Welman, Mitchel and Kruger (2006) describe a study design as a plan according to which participants are obtained and information is
collected from them. It also describes what processes the participants are going to take part in with a view to reach conclusions about problem statement.

### 3.3.1 Qualitative research method

A qualitative research method emphasises the importance of people’s interpretations of events and circumstances rather than the researcher’s point of view (Brink, Van der Walt, & Van Rensburg, 2012). In this study, the qualitative research method attempted to assist the participants to provide views of their own experiences with regard to caring for their mentally handicapped children at the Bana Ba Thari School of the Polokwane Municipality in the Limpopo Province, South Africa.

### 3.3.2 Phenomenological research design

A phenomenological research design aims at examining the meaning of human experiences by describing and understanding the events in the concrete or natural context where they happen (Babbie & Mouton, 2009). Phenomenology is applied by exploring and preparing information and requires the removal of barriers and fears surrounding the roles of researchers and participants with the purpose of encouraging critical thinking. The researcher was concerned with the phenomenon on the grounds of the participants’ description of their experiences related to caring for their mentally handicapped children in the Polokwane Municipality, Limpopo Province.

Phenomenological research almost depends exclusively on lengthy interviews with carefully selected samples of participants and requires the cooperation of participant and researcher (Leedy & Ormond, 2005). The families who cared for their mentally handicapped children described their experiences during semi-structured interviews. The approach also included bracketing, since the researcher endeavoured to exclude pre-conceived ideas while focusing on every perspective of the family member. The researcher applied intuition by paying attention to the participants during the interview and by asking probing questions (De Vos, Fouche & Delport, 2005). This study solely concentrated on the perceived experiences of families who directly took care of their mentally handicapped children and the researcher paid careful attention to participants while they were describing their experiences about caring for their
mentally handicapped children and identified various meanings to develop a comprehensive description of the phenomenon.

3.3.3 Descriptive research design

A descriptive design aims at gaining new facts about the situations, people’s activities, or frequency with which certain events occur. The purpose is to provide a picture of situations as they naturally happen without the researcher making any attempts to influence the responses of participants (Gerrish & Lacey, 2006). Brink et al. (2012) add that a descriptive design seeks to obtain complete and accurate information about the phenomenon through observation and description. Participants were given an opportunity to describe their experiences while caring for their mentally handicapped children who attend the Bana Ba Thari School in the Polokwane Municipality of the Limpopo Province, South Africa.

3.4 POPULATION

Brink et al. (2012) define population as the entire group of persons or objects that meet the investigation criteria which the researcher is interested in studying. In this study, the population comprised one hundred and fifty families caring for their mentally handicapped children who attend the Bana Ba Thari School in the Polokwane Municipality of the Limpopo Province.

3.5 SAMPLING

Sampling refers to the process of selecting a portion of the population who represents the entire population (Polit, Beck & Hungler, 2010). During purposive sampling, a researcher searches for individuals, groups, and settings where the specific processes of interest to the study are most likely to occur. This method of sampling is an important part of non-probability sampling, since a researcher relies on participants’ experiences, ingenuity, and previous research findings to deliberately obtain units for analysis in such a way that the sample may be regarded as representative of the entire population (Welman et al, 2006). In this study, purposive sampling was used to select twenty-three families caring for their mentally handicapped children who attend the Bana Ba Thari School as participants. The families consisted of five to seven members in size. Sample size of the study was twenty-three, The were two types of
families found which were nuclear families whereby both parents were available and were twenty in number, and single mother family were three. Data was collected from one representative of the family which was the head of the family and they were the ones who gave consent. Under nuclear families, eight fathers came to school as participants to the study as heads of the families representing the families and gave consent while twelve mothers came to school as participants for the study and were the ones who gave consent as heads of the family because fathers in those families were not available but at work. These parents were interviewed individually.

3.6 INCLUSION CRITERION

The participants were selected according to the following inclusion criterion:

- Only families living with and caring for their mentally handicapped children who attend the Bana Ba Thari School in the Polokwane Municipality of the Limpopo Province.

3.7 EXCLUSION CRITERION

The participants were excluded according to the following exclusion criterion:

- Families who were not living with and caring for mentally handicapped children.

3.8 DATA COLLECTION

Data was collected during semi-structured interviews by asking open-ended questions and taking field notes. One-on-one interviews were used that yielded a great deal of useful information about facts, feelings, and motives, present and past behaviours, peoples’ beliefs and perspectives, standards of behaviour and conscience, as well as reasons for feelings. The researcher confirmed the quality of data by using listening, reflecting, and probing. That process required the researcher to have good listening skills in order to obtain quality information and to gain a thorough understanding during each interview (Karim & Karim, 2005).
The researcher secured appointment dates with the participants to ensure the smooth execution of the study and also identified a suitable venue for the interviews. The researcher conducted semi-structured interviews that consisted of open-ended questions, including a central question followed by probing questions that aimed at obtaining the factual significance of the selected participants' experiences of the study phenomenon (De Vos et al., 2005).

In preparation for the interviews, the researcher made proper arrangements with the principal of the school after school meetings which are held by monthly in order to interview the parents. A private room for the interview was prepared at the school to ensure privacy. At the beginning of each interview, the researcher greeted each participant, asked for their consent to write down fields notes in order to document important facts that assisted in structuring of probing questions and the preparation of written reports, use of audiotape and also to participate in the study by signing consent form. The researcher explained the reasons for the study and questions they could expect to answer. The researcher started by obtaining demographic information from the participants. This approach put the participants at ease. The central question was “What are your experiences when caring for your mentally handicapped child?”

Probing was done until saturation of data was reached. Bowling (2002) states that probing assists with generating more data about a phenomenon being studied and with obtaining clarity or a better picture of the participants in respect of issues that were noted as vague during an interview. The researcher showed interest in the participants' responses by affirming responses with responses, such as “mmm” and “okay” in order to maintain interaction. For the purpose of gathering more information, the researcher repeated some of the keywords with the aim of encouraging participants to reflect on what they had said already (Brink et al., 2012). For example, “You said the community do not like this [sic] children with mental handicapped [sic]. could you kindly elaborate?” Probing persuaded participants to provide more information about the phenomenon under study. It also assisted the researcher to observe and note the facial expressions and gestures while the participants were commenting.

The researcher interviewed twenty-three participants caring for their mentally handicapped children who attend the Bana Ba Thari School until data saturation was
reached. Each interview session lasted between 30 and 45 minutes. The interviews were conducted in Sepedi, since it was the medium of communication among the families. The information collected was audio recorded and field notes were written down.

3.8.1 Interview techniques

The researcher collected the data guided by the following interview techniques as indicated by De Vos et al., (2005):

- The families dominated the interview sessions as their participation accounted for about 90% of the dialogue because they told their stories while the researcher was listening attentively.
- The families were asked clear and brief questions that were easily understandable as indicated in Appendix D.
- The researcher asked one question at a time.
- Questions about experience were asked before either opinion or sentiment questions.
- Leading questions were avoided but questions were asked to clarify answers that were open to interpretation.
- Families were given the opportunity to think through what they wanted to add or say before the next question was asked.
- The researcher followed up on the families’ responses for confirmation purposes.
- The researcher monitored the effects of the interview on the families in order to establish whether to focus or whether to defocus.
- The audio recorder was kept on at all times to avoid unnecessary distraction by turning it on and off during the interview.

Interviews were concluded with a general question, “Is there anything further that you feel is important?”

3.8.2 Communication techniques

In this study, the following communication techniques, according to De Vos, et al (2005) were utilised during the semi-structured interviews:
3.8.2.1 Minimal verbal responses

Verbal responses were accompanied by occasional nodding, for example “Mm-mmm”, “Yes, I see”, to demonstrate to participants that the researcher was listening and followed responses. This type of response encouraged the families to continue talking and while the researcher confirmed that she was following what they were talking about.

3.8.2.2 Clarification

Clarification embraces the method that seeks further explanation of unclear statements. The researcher asked follow-up questions, “Could you tell me more about…?” to gain more insight and a better understanding of the responses provided.

3.8.2.3 Encouragement

The participants were encouraged to pursue a line of thought. In this study, the researcher encouraged the families to elaborate on their experiences about the phenomenon.

3.8.2.4 Listening

A researcher is expected to have good listening skills. The families were given the opportunity to talk and describe their experiences without interference. The researcher also observed non-verbal and facial expressions.

3.8.2.5 Paraphrasing

Paraphrasing involves a verbal response when a researcher would repeat the essence of what participants are saying to confirm that the statements are correctly understood. The researcher tried to obtain accurate meaning by asking the families the same questions in a different manner, using the same words that the participants used.
3.8.2.6 Probing

This is the technique used to persuade a participant to provide information about the issue under discussion. This assisted the researcher to get a detailed response to a question, to increase the richness of the data being obtained, and to give cues to the families about the level of response that is desired.

- Linking

The researcher linked the responses to the information desired to obtain what is already known about the phenomenon.

- Challenging

The researcher explored more information from the families as a way to prove validity of the information given.

- Acknowledging

The researcher listened attentively to the families and confirmed it by sometimes repeating after them what they had said.

- Direct Questioning

The researcher obtained more information by asking the families questions that were directly linked to the problem under discussion.

3.9 DATA ANALYSIS

The researcher analysed the data through the subsequent use of words to describe and discuss data (Cormack, 2000). Therefore Tech’s opening coding of qualitative data was used to reduce raw data to the central story line of the information obtained from the participants. Categorising is generally initiated as soon as data collection begins. The researcher followed the steps for data analysis by following the steps of DeVos et al. (2005).

Step 1: The researcher prepared and organised data for analysis that involved transcribing interviews, optically scanning material, typing field notes, as well as
sorting and arranging the data into different types depending on the sources of information.

**Step 2:** The researcher read through all the information to obtain a general sense of the information in order to reflect on the general meaning. Data was analysed in the same language that the interview had been conducted while randomly reading any transcript file and jotting down ideas as they came to mind. A careful line-by-line, paragraph-by-paragraph, and entire text reading of the transcript was conducted in order to become familiar with the data.

**Step 3:** The researcher conducted a detailed data analysis by following a coding process to organise the material into ‘chunks’. That required the identification of text data, segments of sentences, and images with the purpose of grouping them into categories. Each category was named after a term that a particular participant used. Audio recorded data was transcribed verbatim into text. Those transcriptswere organised into files and clearly marked and labelled with numbers and distinct identifiers.

**Step 4:** The researcher used a coding process to generate a description of the people, as well as categories or themes for analysis. The ensuing description involved a detailed record of information about people, places, and events in the setting. The phrases, lines, sentences, and paragraphs were coded with different colours and numbers in order to identify similarities, differences, categories, themes, concepts, and ideas.

**Step 5:** The researcher discussed the information in a qualitative narrative and tables. The discussion conveyed descriptive information about each participant in a table. General themes or sub-themes were identified with the aim of reducing data into small and manageable sets of themes that facilitated interpretations and the writing of the final report.

**Step 6:** The researcher used this final step to identify and interpret the data according to emerging themes and sub-themes. The themes grouped related points in relation to a research question.
3.10 MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness was ensured by applying Guba’s model as illustrated by DeVos et al. (2005); that is credibility, dependability, transferability, and confirmability.

3.10.1 Credibility

Credibility refers to the establishment of confidence in the truth of the findings from the participants and the context of the study (De Vos et al., 2005). In this study, the researcher ensured credibility by having several contacts with the families. The prolonged engagement of 30-45 minutes confirmed the responses given by the families, since the researcher had an opportunity to interrogate the phenomenon until the study reached a saturation point. An audit trail was established that enabled the supervisor and the co-supervisor to listen to the recorded interviews. The researcher submitted raw data to an independent coder who was regarded as an expert in the field of qualitative research to perform an independent examination of the data. A literature control was conducted using previous studies to support the results.

3.10.2 Dependability

Dependability is determined by the extent to which a study would be consistent when the enquiry was replicated with the same participants in a similar context (Babbie & Mouton, 2009). Dependability of qualitative data refers to the stability of conditions and data over a period of time. In this study, dependability was ensured by the use of an inquiry audit when the researcher was using field notes and audio recordings that were available after data collection for the purpose of conducting an audit. The researcher coded and recorded collected data according to the stepwise replication of Tech’s approach to ensure dependability. The researcher also asked the same questions during follow-up sessions to check whether the participants would provide the same responses (Babbie & Mouton, 2009).

3.10.3 Transferability

Transferability is the ability to transfer findings to other similar situations or problems; it refers to the generalisability of the data (Polit & Hungler, 2001). In this study, transferability was ensured by providing a detailed description of methodology.
in Chapter 3 of the research method, the research design, and the results of the study for future reference by other researchers. The research design and methodology were described to the families and the researcher adhered to a purposive sampling method, since the population only included families caring for their mentally handicapped children (De Vos et al., 2005).

3.10.4 Confirmability

Confirmability occurs when the findings of the research are a product of inquiry and not of the researcher's bias (Brink et al., 2012). It refers to the objectivity or neutrality of the data that two or more independent people would agree on the meaning of the data. In this study, the researcher obtained valuable information through prolonged contact with the participants observing them during data collection, and without allowing bias or her own perspectives to influence the conversations. Both the supervisor and co-supervisor had an opportunity to listen to the recorded interviews and also had hard copies of the transcripts to confirm the process (Polit, Beck, & Hungler, 2010).

3.11 ETHICAL CONSIDERATIONS

The following ethical standards were followed while conducting the study as outlined by Creswell (2011):

3.11.1 Permission to conduct the study

The Medunsa Research and Ethics Committee granted ethical clearance to conduct this study. Permission to conduct study was obtained from the principal at the Bana Ba Thari School for mentally handicapped children and The Limpopo Department of Education as the researcher was going to use the premises of school as the study site for data collection, and the register book of the school in order to identify the children together with their parents. Individual interviews took place during bimonthly meetings at the school, which falls under the Department of Education.
3.10.2 Informed consent

According to Cohen and Morrison (2008), the principle of informed consent arises from the subjects’ approval to participate in a study. Subjects’ rights need to be observed. These rights include freedom, self-determination, competence to make correct decisions voluntarily after full information was provided, and the right to discontinue participation in the study at any time without prejudice. Informed consent was obtained from all the participants after the purpose and the aims of the study had been explained to them and all relevant information clarified. The families signed consent forms as evidence that they were not forced to participate in the study and they were also shown the instrument used to collect data in order for them to provide information with no fear that the captured data could be tampered with. The participants were also told about the advantages and disadvantages of their participation, such as the improvement of the caring for their mentally handicapped children (De Vos et al., 2005).

3.11.3 Confidentiality and anonymity

Complete anonymity exists when participants’ identity cannot be traced, even by the researcher. Confidentiality is the way in which researcher manages the private information that participants share as stated by Burns and Grove (2003). All the data gathered were treated confidentially and anonymously during the period of study. All records and audio recordings were handled only by researcher and supervisor. Two years after the publication of these research results, the data would be completely destroyed. The participants were informed about the steps that would be taken to keep their answers and names anonymous. That included codes used during the study and a control sheet that would be destroyed on completion of the study. The participants’ privacy and dignity were protected by ensuring that no connection could be made between the participants and the data (Gerrish & Lacey, 2006).

3.11.4 Right to protection from harm

The right to protection from harm is based on the ethical principle of beneficence that requires a researcher not to cause any form of harm to the participants. Professional secrecy was maintained for all participants who explained their experiences while caring for their mentally handicapped children (Hill, 2006). The
participants were neither exposed to any risks, nor to discomfort. They were assured that they would not be harmed physically or emotionally by giving the participants thorough information about the impact of study that their personal information would be kept confidential, and that it would not be disclosed to any unauthorised people. Mutual trust was built between the researcher and participants (Breakwell, Hommond, Fife-Schan, & Smith, 2006).

3.12 CONCLUSION

Chapter 3 describes the detailed methodology of this study; including the research method, research design, population, sampling, inclusion criteria, study sites, data collection, data analysis, ethical considerations, and measures to ensure trustworthiness. Field notes were written down during the interviews and interviews were audio recorded, data was analysed according to Tech’s method of data analysis. The discussions of the research findings and the literature control are discussed in Chapter 4.
CHAPTER 4
DISCUSSION OF RESULTS AND LITERATURE CONTROL

4.1 INTRODUCTION

This chapter describes the findings of data collected about the experiences of families caring for mentally handicapped children who attended the Bana Ba Thari School. Table 4.1 described the demographic variables of participants and table 4.2 described participant’s years of experience caring for mentally handicapped, while table 4.3 described themes and sub-theme.
### 4.2 DEMOGRAPHIC DATA

**Table 4.1: Demographic Data of Participants**

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>1. Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>21</td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
</tr>
<tr>
<td>2. Age range</td>
<td>35-60</td>
</tr>
<tr>
<td>3. Family Types</td>
<td></td>
</tr>
<tr>
<td>3.2.1 single mother</td>
<td>3</td>
</tr>
<tr>
<td>3.2.2 single father</td>
<td>0</td>
</tr>
<tr>
<td>3.2.3 nuclear</td>
<td>20</td>
</tr>
<tr>
<td>3.2.4 Extended</td>
<td>nil</td>
</tr>
<tr>
<td>3.2.5 Child headed</td>
<td>nil</td>
</tr>
<tr>
<td>4. Family size range</td>
<td>5-7</td>
</tr>
</tbody>
</table>

5. Location of families

<table>
<thead>
<tr>
<th>Location</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nobody</td>
<td>6</td>
</tr>
<tr>
<td>Mentz</td>
<td>8</td>
</tr>
<tr>
<td>Mankweng unit A</td>
<td>3</td>
</tr>
<tr>
<td>Mankweng unit D</td>
<td>3</td>
</tr>
<tr>
<td>Ga Kama</td>
<td>3</td>
</tr>
</tbody>
</table>
Table 4.2: Participants’ Years of experience

<table>
<thead>
<tr>
<th>Age range of the mentally handicapped child</th>
<th>1-18 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years of caring for the mentally handicapped child</td>
<td>1 – 18 years</td>
</tr>
</tbody>
</table>

### 4.2 DISCUSSION OF FINDINGS

Tech's open coding method was used during data analysis and five themes and 15 sub-themes emerged (Table 4.2). The results are discussed based on experiences expressed by the families during the data collection interviews and also put into perspective with existing research conducted by different researchers on the same themes.

#### Table 4.3: Themes and sub-themes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physiological impact</td>
<td>1.1 Tiredness</td>
</tr>
<tr>
<td>2. Psychological impact on the family</td>
<td>2.1 Anxiety</td>
</tr>
<tr>
<td>(parents &amp; siblings)</td>
<td>2.2 Depression</td>
</tr>
<tr>
<td></td>
<td>2.3 Denial</td>
</tr>
<tr>
<td></td>
<td>2.4 Worries about the future</td>
</tr>
<tr>
<td></td>
<td>2.5 Rape</td>
</tr>
<tr>
<td></td>
<td>2.6 Acceptance</td>
</tr>
<tr>
<td></td>
<td>2.7 Effects on siblings</td>
</tr>
<tr>
<td>3. Poor knowledge of parents and health</td>
<td>3.1 Poor information of parents</td>
</tr>
<tr>
<td>professionals</td>
<td>3.2 Poorly co-ordinated Intervention strategies by multi-disciplinary team</td>
</tr>
<tr>
<td></td>
<td>members including school teachers</td>
</tr>
<tr>
<td>4. Socio-economic problems</td>
<td>4.1 Poverty</td>
</tr>
<tr>
<td></td>
<td>4.2 Occupational accessibility</td>
</tr>
<tr>
<td></td>
<td>4.3 Restricted social life</td>
</tr>
</tbody>
</table>
### Themes and Sub-themes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4.4 Stigma&amp;discrimination</td>
</tr>
<tr>
<td>5. Lack of material resources</td>
<td>5.1 Lack of transport</td>
</tr>
<tr>
<td></td>
<td>5.2 Lack of equipment for vocational training at school</td>
</tr>
</tbody>
</table>

4.2.1 **Theme 1: Physiological impact**

Families of mentally handicapped children also experience physical challenges. Mentally handicapped children often need physical effort of bathing, feeding, moving, clothing, diapering. They also need to be watched to avoid self-harm, such as falling down the stairs and walking in the street. Often, these physical constraints of caregivers last a lifetime (Lucy, 2011).

4.2.1.1 **Sub-theme 1.1: Tiredness**

Tiredness is a frequent and debilitating symptom that could interfere with daily functioning. Findings indicate that fatigue is common and episodically experienced by families caring for their mentally handicapped children. Quite a few participants supported this claim.

**Participant 1:** "It is tiring to wash her as she is older she does know how to apply skin lotion on her body, does not know how to handle water when she bathes. Even teach her how to brush her teeth; I help her to wash whole body." (Mother looked emotional and even wanted to cry).

**Participant 7:** "He does not know how to go to the toilet. I try by all means to teach him but no chance. This is tiring because he is eighteen years now, while on the other hand I take him to school in the morning and bring him back in the afternoon."

**Participant 15:** Response from a grandmother: "The face she tries to bath, so I just help her to wash the rest of the body to remove dirt as she can't do it herself correctly, what can we do? I don't have a plan."
Participant 8: “If he gets out of the house, he is out we will search for him everywhere until at times you find him at the police station because the police realised that he roams around, while we cannot lock him in the house, so is tiring.”

Maytum, Himan & Corwick (2004) in their study also agree that parents of children with intellectual disabilities report more physical health problems compared to those parents with non-intellectual disabled children and report poor physical health when both challenging behaviour and stress are perceived to be high (Logsdon, 2014). These parents encounter pain and fatigue the older they get owing to the daily heavy duties of bathing, feeding, and diapering of the mentally handicapped children (Gallagher & Whiteley, 2013).

4.3.2 Theme 2: Psychological impact on the family

In the current study, it was found that having a child who was mentally retarded placed greater strain on a family than it otherwise would have. This corroborates with the study by Lucy (2011) who finds that extra tasks need to be done to take care of the child. Parents feel overworked, stressed, unhappy, and they become frustrated with their children’s inability to perform certain tasks or to complete certain actions. Psychological and emotional challenges include caring tasks that cause stress and worries about the present and future life of their children. In their study, Ambikile and Outwater (2012) agree with the findings of this study that families feel sad and experience inner pain or bitterness due to the disturbing behaviour of the children. They also experience some communication problems with their children due to their inability to talk.

4.3.2.1 Sub-theme 2.1: Anxiety

In this study, the researcher found that parents had enormous emotional problems and suffered from mental worries and anxiety due to having a mentally handicapped child.

Participant 1: “We taught her not to close the door while in the toilet because she might have attack while in the toilet due to epilepsy and we don’t see her.”

“We check her time and again while in toilet if she is not having attack.”
Participant 5 & 8: “Sometimes, when she is angry she just goes out of the house and goes far. Those who know her bring her back home. So, we are always anxious that she would not come home one day and strangers might kidnap her.”

The findings of this study concur with those of Reichman, Corman, and Woonan (2008) that families develop anxiety and that sudden destruction of expectations lead to the introduction of many uncertainties. The uncertainties generate fear for what the future might hold for their children.

4.3.2.2 Sub-theme 2.2: Depression

The findings of this study indicated that family members with mentally handicapped children experienced many challenges, such as repeated emotional crises and interactive family issues. The initial response could be in the form of emotional disintegration that might evolve into a period of adjustment and later into reorganisation of the family’s depression during the care of a mentally handicapped child.

Participant 9: “If she does not go to school at all, and stay at home, [it] is a problem because she goes to the neighbours steal and damage their properties, therefore, neighbours come and claim their things and we pay for the damage.”

Participant 14 & 20: “Every time when the sunset[s], I must check if he is around, because sometimes he just sleeps at his friends without telling us. So, we pay for a car to help searching for him.”

The study by Seltzer, Greenberg, Floyd, Pettee and Hong (2001) agrees with the findings of this study that parents whose children have a serious mental health problem experienced depression and have elevated levels of physical symptoms and alcohol-related symptoms.

4.3.2.3 Sub-theme 2.3: Denial

In this study, the findings revealed that when mentally handicapped child was detected in a family, those family members at first denied that the child was suffering from mental retardation. During pregnancy, no family was prepared for the presence of a mentally handicapped child.
Participant 18: “Teachers [sic] were calling me to come to school to discuss about my child (16 years) because they said he qualifies to attend special school because he used to climb trees instead of attending class also beating other children, I refused for three months because I wanted him to attend normal school so I accepted when they told me he has beaten the teacher [sic] and ran away.”

The study by Chandrashekar (2011) and Pilusa (2006) also agrees with the findings of this study that families experience denial, parents spend years in denial, trying to find some solution and cure to this problem. They might go from one hospital to another, try alternative forms of medicine or look to religion for a miracle.

4.3.2.4 Sub-theme 2.4: Worries about the future

The findings in this study indicated that families were concerned about who would look after the children in future. Worrying about the future life of the child was another form of disturbing thought that some parents experienced due to the inability of the child to accomplish personal and social needs, such as self-care and education. They showed those concerns when the child could not do certain developmental tasks expected at specific ages; such as feeding, toileting, bathing, and dressing.

Participant 10: “Aretse!!! Taking a deep breath as long as she is living but worried I don’t know who is going to take care of her in the future, since I’m old and I’m the one who takes care of her since she was a baby until now [that she] is an adult.”

Participant 9: “We are worried about her future so that at least when we die she [sic] will be able to make a living out of her hands, that is why we decide to take her out of that school to a private school of mental [sic] handicapped because they are not teaching them handcraft work.”

The study by Ambikile and Outwater (2012) concurs with the findings of this study. They state that families are concerned about the future of their mentally handicapped children. One of the main concerns that parents with mentally retarded children have is about the care of their children when they die and what life will be like for them when they die. They feel that no one else could take care of their child with the same
love and care that they have and they are scared about how their child would manage to survive in the world.

4.3.2.5 Sub-Theme 2.5: Rape

The study found that parents with mentally handicapped children are concerned that their children would be raped while at school and at home people took advantage of them. Since they were mentally handicapped, they were unable to understand the implication of a sexual act, to make proper decisions about it, or to resist a sexual act (Balogh, Berney, Bretherton, Firth, Graham, Richold, Whibley & Worsley, 2011).

Participant22: “My boy-child was accused at school by teachers [sic] saying he raped one of the student boy[s] at school and they did not even take the accused to the clinic. So, my child was arrested for two weeks until he went to court and was not guilty. So, I decided my child should no more go to school because they take advantage of him as he is not talkative; now he is staying at home.”

Participant13: “My girl-child was raped and did not talk [about] it and she was quite. So, I could see something is wrong with her. I decided to take her to the doctor. It was proven is true; she was raped then the boy was arrested as he was bigger than her.”

Sexual Offences and related Matters Amendment Act (No. 32 of 2007) concurs with the findings of this study that people with mental disabilities and mental health needs are particularly vulnerable to sexual exploitation and are more at risk than most other members in the society. A mentally disabled person is someone affected by any disorder or disability of the mind so that at the time of crime, he or she is unable to understand the implications of a sexual act, to make proper decisions about it, or to resist a sexual act. While these people with a mental handicap have a right to express their sexuality, they have a complementary right to be protected from sexual abuse and exploitation. This right is reinforced by criminal law on rape, assault, and consent. All educators and carers should be aware that they have a duty to report any allegation of sexual abuse.
4.3.2.6 Sub-theme 2.6: Acceptance

Findings of this study showed that parents had high levels of frustrations and dissatisfaction. They only accepted after a long time that their children are mentally handicapped. This finding concurs with Kgole and Molepo (2014) who state that parents undergo a series of reactions before they could accept that the child is mentally handicapped. A family’s reactions include denial, feelings of guilt, and grieving. This process takes time and dependson the strengths and weaknesses of an individual. Chandrashekar (2011) supports the findings of this study by further explaining that as hard as it is to accept, once parents realise that their child is mentally retarded and would always remain so, their expectations of the child readjust accordingly. They can move on to taking the necessary steps to help the child make the most of his or her potential by addressing his or her special needs through special education and vocational training.

**Participant 16:** “I used to feel ashamed but now I have accepted [it].”

**Participant 18:** “I started to accept my child is having a problem when at school they told me he has beaten one of the teachers [sic] and run-away [sic].”

**Participant 10:** “It was painful and I took a long time to accept but at last I accepted and took my child to special school, Bana Ba Thari.”

In the study ‘Explaining the parental stress of fathers and mothers caring for a child with intellectual disability’, Saloviite, Italina, and Leinonen, (2003) also concur with the findings of this study that families find it hard to accept. Some families adapt flexibly and mobilise themselves into effective action while other families are inclined to resist or even deny the diagnosis. Again, it is proved that the single most common predictor of parental stress is the negative definition of the situation. For mothers, the negative definition is associated with behavioural problems while for fathers it is connected with the social acceptance of the child. It takes time, support, and accurate information to understand and accept their children as they are. Even after coming to terms with the fact that mental challenges are incurable, it is
very difficult to give up hope that someday something would take their children's mental disability away. This hope is what might keep most parents going.

4.3.2.7 Sub-theme 2.7: Effects on the siblings

The findings of this study confirmed that siblings responded emotionally in different ways towards their brother and/or sister with a mental handicap. Other siblings showed sympathy and empathy while some had no patience when interacting with the handicapped child. These findings correspond with those of Marks and Reeve (2007) that the presence of a child with autism appears to enhance the psychosocial and emotional development. The study by Rossiter and Sharpe (2001) also agrees with the findings of this study that siblings of children with mental retardation score higher on measures of depression and anxiety and scored lower on measures of acceptance and conduct.

Participant 18: “The other children are afraid of him because he is bully and beats them.”

Participant 14: “The other siblings are not patient when they talk to her. So, I tell them to be patient because she is a slow learner and she didn’t love to be the way he [sic] is.”

Participant 1: “Her siblings know her better and also feel pity for her and wish was like them.”

The findings of the current study concur with the study by Alexis (2010) and Taylor (2008) that the presence of a mentally handicapped child in the family has effects on the siblings. They might experience depressive symptoms, such as fear, frequent crying, loss of interest, and anger. On the other hand, they might have positive feelings such as empathy for others and insight into challenges that disabled children face, additional responsibilities to take care of their sibling, and siblings could also become more supportive and compassionate to others (Alexis, 2010).
4.2.3 Theme 3: Poor knowledge of parents and health professionals

The findings of the current study concur with the study by Pooe-Monyemore (2009) that as a result of the inadequacy of primary health care and genetic counselling services, weak organisational links between social services, the faulty treatment of the injured when accidents occur, and the incorrect use of medication, communities do not have concrete information that explains the illness of their children. However, the study by Chandrashekar (2011) differs from the current study. That study emphasises that it might also arise from insensitive handling of a case by the mental health professionals who might not have enough time to talk at length to each family about their experience (Allan, 2014).

4.2.3.1 Sub-theme 3.1: Poor information of parents

The findings in this study revealed that parents seemed to have no information about mental illnesses, causes of mental disabilities, and conditions associated with mental retardation. The study by Jorm (2012) describes the deficiency in public knowledge about the prevention of mental disorders, recognition of when a disorder is developing, knowledge of help-seeking options, treatment available, and knowledge about self-help strategies of milder problems.

Participant 4, 17 & 12: “I do not have knowledge about this disease.”

Participant 8: “At hospital, they did not explain to us what the cause of illness was but he is on medication.”

Participant 6: “I just know that is fall sick but I don’t have enough information but when season enters we see changes on her she also changes.”

Participant 11: “When my baby starts to have epileptic attack, at times I get confused don’t know what to do and people think you’re negligent. So, I think I still want to understand her illness better.”

Participant 6: “Traditional healers said she was bewitched, was given something to eat when they went to school trip.”
Busman, (1993) and Steenkamp and Steenkamp (1994), in study “A model of empowerment of families with mentally handicapped children” by Kgole (2009), support the findings in this study that families do not have knowledge and information on mental disabilities, for example, the concept and conditions associated with being mentally handicapped; such as down syndrome, autism, hyperactivity, microcephalus, hydrocephalus, epilepsy, adjustment problems, and muscle weakness). They also do not know about existing health services.

4.2.3.2 Sub-theme 3.2: Poorly co-ordinated intervention strategies by multi-disciplinary team members including school educators

This study found that there was poor co-ordination of the interventions strategies among the members of the multi-disciplinary team including educators. Participants stated that health professionals did not explain what mental disabilities were. They also did not teach parents how to care for a mentally handicapped child.

Participant 23& 13: "I took time to get [a] grant because there was poor communication between teachers[sic], psychologist, and doctors. The doctors did not want to approve for grant saying the child is not mentally handicapped and do not see anything wrong with the child while the teachers[sic] at school have confirmed that the child is mentally handicapped and qualify for special school. So, there was a delay of early intervention."

Participant 20: "My child, while he was 18 years, he started to be aggressive and rough. Teachers [sic] called me at school and said he punched car tyres of the teacher’s [sic] car. So, I asked them a referral letter to [the] psychologist. At [the] psychologist they asked me if he was getting any medication. I said no. So, they said they can’t give me medication while he is old so I got confused and I was in a dilemma because we don’t know how to handle him when he starts to be aggressive."

Participant 23: "One of the teachers [sic] recognised that the child was mentally handicapped, but the other teacher [sic] denied to write a letter to psychologist until grade 3 where it was worse, and no improvement. It was then that the teacher [sic] in grade 3 decided to write the letter."
Participant 15: “My child was always being beaten as [sic] school by the teachers [sic] for not knowing how to write until I talked to [the] teachers [sic] to stop beating her.”

The findings in this study concur with the findings by Liptak, Yingling, Orlando, Theurer-Kaufman, Malay, Tompkins, and Flynn (2006) who conducted a test on parents of children with a mental handicap with regard to the health service of health providers. In their study, parents rate primary care physicians lower on several aspects of care, including physicians’ knowledge about complementary and alternative medicine and their qualifications to manage developmental disabilities rank worse than neutral. Parents’ ratings are the lowest for the primary care physicians’ ability to put them in touch with other parents. This corresponds with the current study that interventions of professionals are poorly co-ordinated due to a lack of knowledge.

4.2.4 Theme 4: Socio-economic problems

According to the findings of this study, it was found that the families with mentally handicapped children were economically disadvantaged due to lack of employment and additional expenses for the mentally handicapped child. Those circumstances created a financial burden for the family and increased poverty. Kgole and Molepo (2014) explain that parents have problems with financial security funds that prevent them from purchasing clothing, food, and other basic needs for their mentally handicapped children. Emerson’s (2003) study also states that families caring for their mentally handicapped children are economically poor and experience more than one potentially stressful event, such as poverty and an unhealthy lifestyle.

However, the study by Olsson and Hwang (2003) does not corroborate these findings. Olsson and Hwang (2003) find that parents in Sweden describe most of the stressors proposed in the international literature with the exception of financial strain. Restricted social life and time restrictions seem to be the two most evident and bothersome stressors for Swedish families. This is because Sweden is a developed country where money is less of an issue while South Africa is still a developing country.
4.2.4.1 Sub-theme 4.1: Poverty

The current study found that the families caring for their mentally handicapped children could not afford to have a permanent job due to the time it took to care for their mentally handicapped children. The situation is exacerbated by delays in getting security funds, lack of access to rehabilitation services, fewer education and employment possibilities, and additional expenses that created a financial burden for the family and aggravated poverty.

Participant 13: “My child’s security funds is [sic] being stopped time and again and we spent months without money still waiting for it to be sorted out.”

Participant 1: “I can’t afford to work a permanent job which knocks off around 16 hours because I must take care of her after school. I used to let neighbours take care of her after school but I realised this kind of child really needs a parent. Then I found [a] job which knocks off at around 13 hours. This illness really affected my work because if the teacher [sic] could phone telling me the child was not well, I could not focus anymore. I will leave everything, just run immediately back home while the manager sometimes could not understand and if I was supposed to buy bread when I knock off I just fail.”

Participant 23: “After taking my baby to [a] psychologist, they told me she needs special school at the time I was not working while some special schools are expensive she spends a year not going to school, is then that I found Bana ba Thari which was reasonable.”

Participant 7: “He channelled me because I cannot seek for a job or work as I have to take care of him the whole day.”

The study by Pilusa (2006) and Dunlap (2014) discovered that families of mentally handicapped children experience socio-economic problems. The birth of a mentally handicapped child often places heavy demands on family morale while thrusting them deeper into poverty. This means not only that there is a higher proportion of mentally handicapped people amongst the very poor, but also that there is an increase in families who are living at the poverty level as a result of mentally handicapped children. Disabled children are more likely to live in poverty than non-
disabled children. Furthermore, poverty increases the risk of a child having impairment and an increased risk of low-birth weight babies among low-income families. Parents may find it more difficult to maintain full-time employment. Housing can be inadequate for the child’s needs. Expenditure on the child’s basic needs increases. This is often coupled with increased spending on transport and car park fees when attending various healthcare clinics.

4.2.4.2 Sub-theme 4.2: Occupational accessibility

This study found that parents of mentally handicapped children were stressed and concerned when their children stayed at home as a result of not working due to inaccessible vocational training. For people with serious mental disorders, employment is an important stepping stone to recovery. It is a normalising factor that provides daily structure and routine, meaningful goals, improves self-esteem and self-image, increases financial means, and alleviates poverty. It also provides opportunities to form friendships and obtain social support, enriches quality of life and decreases disability. People with mental disorders who are not working or unemployed and who lack meaningful social roles are in position of double jeopardy. On the other hand, stigma that results from mental disorders makes it harder to either gain competitive employment, or to cope with the lack of an occupation (Stuart, 2006).

Participant 18: “This year my child is saying he is not going back to school anymore because he is older but there is no progress as they should be teaching them skills like carpentry and welding to go and work. So, he is tired of going to school with small children; they are doing nothing for them.”

Participant 19: “My older daughter attended at Bana ba Thari School for a long time participating in mental handicapped athletics [sic]; running always taking position one. She decided to quit because she said she felt being used by school just to be on top position as while she was no longer attending the teachers [sic] still requested her to be part of [the] sport team and accompany them and she not being rewarded, so she needs money.”

Poopedi (2012) and Tree (2014) also agree with the findings of this study that occupational accessibility is a problem among mentally handicapped people. There
are extremely high levels of unemployment amongst people with a mental handicap. This could be attributed to a number of factors, namely low skills levels due to inadequate education, lack of enabling mechanisms to promote employment opportunities, inaccessible public transport, and inadequate and inaccessible provision for vocational rehabilitation and training (Levinson & Palmer, 2005). These factors prevent the mentally handicapped to support themselves. Employment assists one in gaining self-esteem and forming valuable relationships with co-workers; employment is a way of developing mentally.

4.2.4.3 Sub-theme 4.3: Restricted social life

The study found that families of mentally handicapped children experienced social life restrictions.

Participant 21: “The issue of my baby always having epileptic attacks affected me and interfered with my school work. I dropped school and did not manage to do grade 12 because I had to take care of her as she was being admitted time and again and there was nobody to take care of her if I go to school.”

Participant 7: “He likes running and does not recognise home. That is why you find us in the house like this. I am always locked with him inside the house, am not going anywhere to avoid searching around looking for him. He needs my care.”

The findings concur with Willacy (2012) who states that parents of mentally handicapped children have lower rates of social participation than parents without a disabled child. They are unable to attend churches, parties, trips, and have fun. They are also less likely to have large families.

4.2.4.4 Sub-theme 4.4: Stigma and discrimination

This study found that families of the mentally handicapped experienced high levels of stigma and discrimination from the neighbours and community. The parents of the mentally handicapped children tried to arrange public transport in the community because the school transport was not enough to carry them all but their efforts failed because the children who were not handicapped refused to mix with the mentally handicapped. Therefore, drivers stopped to transport them; they said they could not
afford to lose customers. They tease them, they do not want them in their house, they do not want to integrate with them due to widely held misconceptions about the causes and nature of mental health conditions. The findings in this study are supported by Green’s (2003) who explains that children of mothers who perceive high levels of stigma interact less frequently with their peers of the same age in the informal settings of homes and neighbourhoods.

Participant 7: "We tried to get transport for them. So, drivers are no longer taking them because children from normal schools are saying they are afraid, some urinate, some having too much uncontrollable saliva coming out of their mouth of the mental [sic] handicapped children. So, they cannot manage to lose customers."

"Neighbours don’t need them… will hear them saying ‘Get out!!!’ ‘Get out!!!’"

Participant 13: "She does not want to wear uniform of school because they will laugh at her saying she is attending Bana ba Thari. She is crazy again; we could not live [sic] her to stay at home because we are afraid of strangers might do nasty things to her."

Participant 14: "They laugh and tease him. Children and their parents saying he is crazy. So, I even told them that if they continue with their behaviour, I will report them to the police."

Participant 16& 3: “People were laughing. Reg!!! When he gets inside the school bus our family is called Bana Ba Thari. He was crying… didn’t want to go to school, even denying to wear a school uniform shirt."

Participant 18: “I don’t talk to one of the neighbours because she was saying I must go away calling all my children with the name of the school Bana ba Thari. So, this made me to always feel think and become feel depressed."

Participant 2: “If you’re with him inside the taxi, some people don`t want him to touch them. People say they don’t take care of these things of theirs". (Responded with a very sad facial expression.)

Kgole and Molepo (2014) support this finding with their discovery that rejection by the neighbours and community is also one of the barriers to improve the mental health of...
the mentally handicapped children, since other parents instruct their children not to play with the mentally handicapped children. Brohan, Slade, Clement, and Thorncroft (2010) also agree that stigma is a form of deviance that leads others to judge an individual as suitable to interact socially. This happens, since a perception exists that they lack either skills or abilities to interact appropriately. Such stigma compels a group to exclude or ignore mentally handicapped children (Durban, Pabayos, Alontaga, Arreza, & Salazar, 2012). The findings in this study agree with Pooe-Monyemore (2009) who says the fact that people with disabilities are marginalised and discriminated against creates an environment in which prevention and treatment are difficult, since this worsens someone’s mental health problems and delays or impedes their getting help and treatment to recover. Discrimination can trap people in a cycle of illness (Mauro, Meyer, Vandasy, 2008).

4.2.5 Theme 5: Lack of material resources and facilities

The findings of this study supported by Belfer (2008) who found that there is still a gap based on policy and resources of care for the mentally handicapped children and the gaps in resources might be a matter of economics, manpower, training services, and policy. In this study it was found that there is lack of transport to take the mentally handicapped children to school on daily basis and there is also lack of equipment for vocational training at school.

4.2.5.1 Sub-theme 5.1: Lack of transport

This current study identified a lack of transport as a material resource, since the children were sometimes not going to school because they were too many for the available school transport. Therefore, they alternated their days of attending school. The vehicles from school were not enough to transport all of them. These findings are supported by Poopedi (2012) who identifies inaccessible public transport for the mentally handicapped children.

Participant 23: “If transport to school does not come because they say vehicles get broken sometimes, she even thinks of walking to school. So, the problem is she gets confused as she have [sic] to take two taxis before she reaches school, therefore, she might get lost.”
**Participant 19:** “They don’t go to school every day because transport is not sufficient to collect them all at the same time. So, they alternate days of going to school. Today, it collects Mentz then, Nobody, Ga Kama, and other places then next time it comes to us to collect her.”

**Participant 2:** “Transport is a problem to me because I can’t manage to take him to school and return again to bring him back is tiring as I also having a small baby at home and we tried to organise the public transport but we fail because the drivers said they cannot manage to lose customers as the non-disabled children refuse to be with them in the same car.”

Beart, Hawkins, Kroese, Smithson, and Tolosa (2001) support the findings that the lack of transport is a barrier for mentally handicapped children to learn and interact with peers at school. According to their study, barriers, including lack of transport, interfere with the child’s desire to be active, practising skills, interacting with peers, and for accessible facilities. Shields, Synnot, and Barr (2012) also support the findings of this study, since their study focuses on determining which leisure opportunities young people and adults with mild or moderate handicap can access. They mention a variety of activities that take place at the day centre and identify a range of activities that participants would like to try in future. However, the inaccessible transport for the mentally handicapped makes any additional endeavours impossible.

### 4.2.5.2 Sub-theme 5.2: Lack of equipment for vocational training at school

The findings of this study identified a lack of material resources at school that could enhance the rehabilitation of the mentally handicapped children: such as sewing machines, carpentry, welding, and plumbing. The absence of those facilities decreased chances of employment for the mentally handicapped children. Poopedi (2012) agrees that extremely high levels of unemployment amongst people with a mental handicap could be attributed to inadequate education, as well as inaccessible provision for vocational rehabilitation and training (Connor, 2006).

**Participant 23:** “The teacher [sic] said [it] is difficult to teach her. So, [it] is better to buy her sewing machine at least to make some aprons. So, up to now I did not manage to buy it because of money.”
Participant 18: “This year, my child is saying he is not going to school because there is no way forward. At least if they taught them carpentry or welding and they are also older students but they attend classes with small students. So, they are enough and want work, there are big men attending school but still not working.”

Thompson (2004) concurs with the lack of material resources at school for mentally handicapped children by saying that mentally handicapped children face challenges in exercising their fundamental right to education and employment. Moreover, denial to education leads to lifelong dependency, poverty, and social exclusion. Therefore, there should be vocational rehabilitation to bridge the obstacles to employment and provide enabling resources that lead to employment (Van Pelt, 2008).

4.3 CONCLUSION

An impact of caring experiences on the mental health of caregivers is summarised in the findings of this study. Information about the experiences of caregiving and the factors associated with the impact of caregiving provide a context for examining what type of interventions are appropriate in particular situations. Given the numerous factors that affect the impact of caring on caregivers, it is not surprising that the evaluation of interventions aimed at supporting caregivers has produced inconsistent results in terms of their effectiveness. Chapter 5 discusses the summary, recommendations, limitations, and a conclusion to the study.
CHAPTER 5
SUMMARY, RECOMMENDATIONS, LIMITATIONS, AND CONCLUSION

5.1 INTRODUCTION

In this chapter, the results of the data analysis is summarised in order to draw conclusions with the purpose of implementing in-service education guidelines for health professionals and school teachers to reduce problems experienced by families caring for their mentally handicapped children. The research report is summarised and appropriate recommendations are suggested. The chapter concludes with a description of the limitations of this study.

5.2 SUMMARY OF THE FINDINGS OF THE STUDY

5.2.1 Aim of the study

The aim of the study was to investigate the experiences of families caring for mentally handicapped children who attend Bana Ba Thari School in the Polokwane Municipality of the Limpopo Province, South Africa.

5.2.2 Research Question

What are the experiences of families caring for the mentally handicapped children who attend the Bana Ba Thari School in the Polokwane Municipality, Capricorn District, Limpopo Province?

5.2.3 Objectives of the study

To explore and describe the experiences of families caring for the mentally handicapped children who attended the Bana Ba Thari School in the Polokwane Municipality in Limpopo Province, South Africa.

To empower families for mentally handicapped children who attend Bana Ba Thari School in the Polokwane Municipality of the Limpopo Province, South Africa.
5.3 FINDINGS OF THE STUDY IN RELATION TO THE OBJECTIVES

In Chapter 1, the researcher outlined the objectives of this study and the researcher managed to achieve the set goals.

The first objective was to explore and describe the experiences of families caring for their mentally handicapped children who attend the Bana Ba Thari School in the Polokwane Municipality of the Limpopo Province, South Africa. This objective was achieved, since the families expressed their experiences about caring for their mentally handicapped children according to five main themes.

**Theme 1** Lack of parents’ knowledge: Parents described that they did not have enough knowledge or skills to care for their mentally handicapped children.

**Theme 2** The psychological impact on parents and siblings: Parents described their stress while performing caring tasks and their worries about the present and future of their children. They described feelings of sadness, denial, depression, anxiety, and difficulties with the acceptance of the child. Parents also described the effects of disability on the other siblings. Some siblings were angry, cried, and fought with the mentally handicapped child.

**Theme 3** Physiological impact: Parents described their experiences of how strenuous it was to bathe, feed, put on clothes, move, and to watch their mentally handicapped children to avoid self-harm on a daily basis.

**Theme 4** Socio-economic problems: Due to their children’s disability, parents expressed their frustration about being unable to go and work for their families. As a result, they remained poor and did not have enough money to support their families.

**Theme 5** Lack of resources: Parents explained how the lack of resources at school affects them and their children. As a result, their children did not want to attend school because there were no materials to assist them with acquiring skills to work, such as carpentry and welding. So, they articulated their feelings about the effects on them as parents, the worries about the future of their children, and about their concerns about those who stayed at home without doing anything.
The second objective was to empower families to care for their mentally handicapped children who attend the Bana Ba Thari School in the Polokwane Municipality, Capricorn District of the Limpopo Province. The family members were advised to share information about their children’s condition with those who are involved in the care of that handicapped child. Sharing information about the handicapped child’s condition will help in improving the child’s condition and also how to manage the child. They were advised to join support groups so that they can get a chance to share information and connect with people affected by similar experience. In a way, they will relief themselves from negative emotional distress. Again, it will give them opportunities to access other essential services which were not known to them. They were encouraged to continue to seek professional help and were also taught about channels of lodging complains, should those services not be satisfactory.

**5.4 RECOMMENDATIONS**

The recommendations comprise a few standards that could be utilised in order to achieve the best results in the provision of health care to the families caring for their mentally handicapped children. If these recommendations are carefully and correctly followed, better results would be achieved in the provision of vocational skills and care for the mentally handicapped children, their families, and the community they live in. The recommendations follow the themes in Chapter 4.

**5.4.1 Addressing the lack of knowledge by parents, doctors, and educators**

Early and effective management of problems during the antenatal period and intrapartum care is important. Providing health education to women about maternal substance use of drugs, alcohol, tobacco that it could cause foetal alcohol syndrome, birth defects and the varying degrees of possible mental disability, and learning disabilities of the child. Smoking has also been linked to learning disabilities and emotional or behavioural problems later in life. Such education is necessary, since most parents are not familiar with the causes of a mental handicap. It is also important to emphasise the importance of screening all babies for disabilities before being discharged from hospital. Ophthalmologists recommend...
examining children at least at six months and at the age of five years to facilitate early intervention to prevent learning problems at school.

Early interventions are available and include assistive technology devices such as audiology, family training, counselling and home visits, medical services for diagnoses or evaluation, health services, nursing services, nutrition services, occupational therapy, speech and hearing therapy, social work services, and transportation to school; some might need more than one of these services depending on the severity of the disability. Typically, family training or counselling and early childhood education should be conducted by a multidisciplinary training team.

Awareness of and government funding for mental health initiatives are inadequate in comparison with HIV/AIDS, Malaria, and TB programmes. Therefore, an annual mental health awareness congress is recommended with the aim of educating and increasing the awareness about mental illness. Advocates for mental health and organisations across the country should synchronise their efforts by sponsoring a variety of events to promote community outreach and public education programmes about mental illnesses and to educate the community about the human rights policy of mentally handicapped people. An awareness week creates community awareness and enables discussion in an effort to reduce stigma while advocating for treatment and recovery. Such programmes would honour the challenges encountered by mentally handicapped people, as well as their loved ones who embrace their recovery. These programmes would also erase the stigma of and discrimination against mentally handicapped children.

It is recommended that the professionals should understand the needs of mental health care users by investigating or researching their plight in order to make fair and appropriate decisions. They need to receive in-service training to empower them with more knowledge to advocate, assess, diagnose and take accurate decisions for or on behalf of the affected person. Health professionals should be familiar with Mental Capacity Act (2005) in order to protect people who do not have the mental capacity to take decisions for themselves due to their learning disabilities or mental health conditions, such as brain injuries, stroke, or any other physical conditions or illness that affects a person’s judgment.
The Sexual Offences Act (2007) focuses on the right for special protection from sexual assault and rape. The challenge for mental health professionals and educators is to protect persons who are mentally retarded from sexual abuse and exploitation, to provide appropriate psychotherapeutic interventions when abuse occurs, to respect their rights to developmentally appropriate knowledge about sexuality and sexual abuse, and to allow them the fulfillment of their sexuality. These people are vulnerable due to their lifelong relatively powerless position in society and due to the lack of education with regard to sexuality and sexual abuse. Parents and educators should have thorough knowledge of this act in order to take appropriate action when sexual assault occurs. This study clearly indicates that professionals do not implement suitable intervention that are congruent to the law.

This study found from the participants that most doctors delayed the treatment of patients by not referring them immediately to the psychologists who could help with fair and appropriate assessment about the proper diagnosis. Instead, they sent them back home after they were told that they were not mentally handicapped on the assumption that they were merely interested in receiving a social grant. It is important to investigate among professionals whether the Patient’s Rights Charter and the Batho Pele Principles are implemented; their knowledge about mental illness should be assessed with the aim of understanding whether mental health care users are properly and accurately serviced.

5.4.2 Addressing the psychological impact on the family (parents and siblings)

Having insight into psychological stressors is the first step that leads to self-actualisation and self-realisation. Therefore, thorough knowledge and information are powerful coping tools. Families will benefit greatly from family education programmes. These programmes should be designed to equip families with the most up-to-date information about intellectual disabilities. As parents become more informed, they become better prepared to cope with their stress. Likewise, skills training programmes, such as parent-coached language intervention, teach families how to manage difficult behaviour. Communication inadequacies are quite common and may magnify the stress experienced by parents of mentally handicapped children. It is relatively rare that parents actively participate in the language
intervention process for their children with disabilities. These programmes also help families to use specialised learning techniques. Support groups offer opportunities for families to support one another.

Family therapy is useful for the entire family in order to ease tension and create the possibility to properly manage a problematic situation, such as adjustment to the illness. It should be a continual process to resolve long term and continually entrenched issues about the mental illness of a family member. In the current study, most families reported that they were never referred for psychological intervention in relation to their psychological distress. Hence, it is recommended that family therapy could be extremely important to them. The researcher found that siblings shared many of the concerns that parents of children with special needs experienced. Other studies show that families of mentally handicapped children suffer from depression, feelings of guilty, anger, loss of interest in their daily activities, fatigue, and isolation. These symptoms mostly affect importance areas of functioning; such as work, academic performance, and interpersonal interaction. This recommendation emphasises the importance of psychological intervention.

Service providers should develop support groups in communities for parents with children with a mental handicap; the parents should be encouraged to interact with and support one another. Support groups provide an ideal platform where parents express their difficulties, share experiences, solve their problems, and most importantly develop a mutual help system by sharing practical advice and emotional support. They encourage one another to praise their children when they do well, build the abilities of their children, assist them when they need help, and collaboratively find opportunities in the community for social activities; such as scouts, recreation centre activities, and sports. This will help the children to acquire social skills while they are having fun.

When parents receive a diagnosis that one of their children is disabled, many families may adjust to this in a healthy way and cope well. Other parents, however, do not. Social support systems are well recognised as a significant factor that enables families to cope and adjust better to a child’s disability.
The researcher recommends that priests and other spiritual members of the community can help with the therapy of mentally handicapped people by appealing to the community to love one another as human beings. This will decrease isolation and discrimination, decrease social destruction, since the parents and siblings of a mentally handicapped child get an opportunity to actively participate in church activities. Persons with disabilities should be allowed to determine for themselves whether this is an area that is important to them; they should be allowed an opportunity to participate if they so desire. An individual’s participation in either spiritual or religious aspects of life potentially could affect his or her quality of life in terms of emotional wellbeing, physical wellbeing, interpersonal interaction, personal development, self-determination, and social inclusion (Ault, 2010).

5.4.3 Addressing the physiological impact

The researcher recommends that taking care of one’s physical needs will reduce one’s stress as it was realized in this study that often parents stay on the go and leave little time to take care of their own physical needs, such as following a healthy nutrition plan, getting healthy sleep, and exercising. Making time for relaxation is one way of recharging the batteries. When parents take care of their own relaxation needs first, then they would have more energy to cope with the demands of a mentally handicapped child. Parents can reduce stress by simply acknowledging their failures, correcting any wrongs they have done, fixing their mistakes, accepting their mistakes, and making an honest effort to correct them. Such a frame of mind would allow them to focus on solutions rather than on counter-productive guilt and self-criticism. Make time for laughter while limiting time for criticism (Logsdon, 2014).

5.4.4 Addressing socio-economic problems

The cultural community to which a child belongs may have different responses to disability. The parents may have to cope with additional negative and stigmatising beliefs about causes of disability while managing the situation in the family. A person can feel isolated not only because of his or her difficulties but also because of the failure by a community to integrate that person. As a result, a person experiences loneliness, not only because of personality or social skills, but because of failure of the system of the community to integrate that individual.
One of the important factors that could prevent the community from using health services is financial problems. Most parents reported in this study that they were unable to apply for work because their mentally handicapped children needed special attention. Therefore, the easiest and cheapest way for them to make use of the health service is for health workers to reach them at their local clinics as often as possible. Social welfare should assist with providing food parcels, hampers, and social grants. A study by (Kgole, 2009) about empowerment report that the professional nurses believe families do not take their mentally handicapped children for the expected monthly visits at the clinic. On the other hand, nurses are unable to empower the families of the mentally handicapped, since they complain about the shortage of staff and do not have transport to do the follow-up visits. They have no opportunities outside the communities to educate the families about mental illness and refer those children with problems to a psychiatrist at the hospital, for example children who suffer from epilepsy.

Mental health communities should be monitored by including mental health indicators in health information and reporting systems. The indices should include both the numbers of individuals with mental disorders and the quality of their care, as well as some more general measures of the mental health of communities. Such monitoring helps to determine trends and to detect mental health changes that result from external events, such as disasters. Monitoring is important to assess the effectiveness of mental health prevention and treatment programmes and also strengthens arguments for the provision of more resources. New indicators for the provision of more resources and new indicators for the provision of mental health services to communities are necessary.

5.4.5 Addressing the lack of resources

Public schools for learners with disabilities do not have enough resources for vocational skills, unlike private special schools. Therefore, the situation encourages learners not to attend school at all. They prefer to stay at home because they say they are older (over eighteen years of age) to wear school uniform and while they are not taught skills like carpentry and welding, furthermore they do not attend school everyday due to limited availability of transport to and from school. The study defines the impact of poverty to explain the inadequate provision of resources for
minorities in special education. The study indicates that learners from special schools are more likely to be poor and poverty increases their exposure to risk factors that compromise human development and the need for special services. The absence of an understanding of the effective and accessible vocational rehabilitations or counselling services are barriers to regular employment for many adults with autism (Connor, 2006). Vocational rehabilitation centres are also recommended, since they provide training and other resources to equip mentally handicapped learners to work.

Roles of professionals in assessing and planning for learner’s skills to identify any problems with regard to the IQ are recommended as a major ingredient for successful school-to-work transition programme. Such a programme comprises a comprehensive, interdisciplinary vocational assessment that integrates a variety of school personnel and community organisations into the assessment process. The assessment process should include educators, counsellors, psychologists, as well as representatives from community mental health/mental retardation representatives, vocational rehabilitation centres, and social services agencies with the aim of working collaboratively to identify relevant transitional needs and plan appropriate services. Parents, state agencies, employers, business organisations, and learners must also be involved in the vocational assessment to some extent.

The goal of a vocational assessment is to facilitate educational and vocational planning that will allow a learner to adjust successfully from school to work, postsecondary education, and community living. Without a comprehensive assessment of a learner’s skills, it is difficult to identify the needs that should be addressed in the learner’s transition plan.

Assessment data can be gathered by using published tests and surveys, as well as direct interviews and observation of a learner with the aim of identifying strengths (advantages) and weaknesses (disadvantages) in different areas. The assessment should address areas such as academic skills, daily living skills, personal and social skills, occupational and vocational skills (including performance tests that assess a learner’s ability to perform specific work-related activities, work samples that expose a student to natural job responsibilities, as well as situational assessments that measure a learner’s interests, abilities, and work habits in actual and simulated work environments, and career maturity (the extent to which a learner has an adequate
understanding of themselves, the work world, and decision-making skills). Therefore, government should implement vocational training centres and allocate sustainable budgets to those centres. This could greatly assist with the reduction of poverty and unemployment among the mentally handicapped in South Africa.

School psychologist should be involved in conducting psycho-educational assessments, explaining assessment results, and making recommendations to the multidisciplinary team. School psychologist can particularly assist with the gathering of information that is relevant to learners' cognitive, academic, and interpersonal skills. Psychologists can also assist with providing career guidance. Therefore, the researcher recommends that every public school should have its own school psychologist to assist with psychological assessments. Social services should be involved in the process too. Such agencies provide case management services and funding services that learners will need when they leave high school. Representatives from these agencies can help facilitate community living, arrange job training and education, assist with transportation and employment provision, and transition them from a school to a work setting. These representatives can help learners and their families to complete and submit the necessary paperwork and application material to ensure that all the necessary services are available to the learners when they leave school. Learners should be present at transition planning meetings to increase their self-determination and their ability to set goals and make choices.

5.5 RESEARCH SUGGESTIONS

More research about biological and psychosocial aspects of mental health is needed in order to enhance the understanding of mental disorders and to develop more effective interventions. Such research should be comprehensive and on an international basis to better understand variations between communities and to learn more about factors that influence the cause, course, and outcomes of mental disorders.

There is a need for further research in this field. Similar studies can be conducted continually to either confirm or reject the findings of this study with the purpose of addressing the changing nature of the problem. This study should be repeated at all multi-disciplinary team members in order to consolidate views of their experiences.
and to determine their challenges. This will assist researchers to check whether the experiences are similar in all categories and will enable them to provide recommendations that will assist them to address such challenges and obstacles that stand in the way of providing services.

Similar studies can be conducted at other schools to either support these results, or to reach more definite conclusions. The study was conducted at only one school for the mentally handicapped in the Limpopo Province and can further be conducted at schools in other provinces in South Africa to establish in what ways the coping of families in caring for their mentally handicapped children is either similar or different.

5.6 LIMITATIONS OF THE STUDY

The study was conducted at one school of mentally handicapped learners in the Polokwane Municipality of the Limpopo Province, South Africa. Therefore, the findings of this study cannot be generalised to other schools for the mentally handicapped in the rest of the Limpopo Province and other provinces in the country.

5.7 CONCLUSION

This study finds that parents endure traumatic experiences and face serious challenges in the caring of their mentally handicapped children. There is a gap of knowledge about mental handicap causes, its prevention that leads to poor interaction with mentally handicapped children, and poor co-ordination of a multidisciplinary team that delays early interventions in the delivery of appropriate health care services. Therefore, a partnership between government institutions, the Department of Health, private hospitals, and other related agencies is imperative to provide assessment and therapy facilities for children with developmental delays. Support programmes should be expanded to include the families of children with developmental delays. This will ensure that parents and their children will receive the necessary assistance that they desperately need.
5.8 REFERENCES


Emerson, E. 2003. Mothers of children and adolescence with intellectual disability: social and economic situation, mental heath status and self-assessed social and psychological impact of the child’s difficulties. Journal of Intellectual Disability Research. Published AISSD. 47(4-5) 385-399


Manyana, O. 2012. The Star (1 August 2012 at 03:52pm) [Date accessed: 24 Feb 2013].


Poopedi, M. H. 2012. Characteristics of persons with mental retardation presenting at Polokwane / Mankweng Hospital complex. University of Limpopo (Turfloop Campus), School of Social Science. 1-75.


Tree,A.,2014. What are the Different Types of intervention for me. Conjecture corporationwww.wisegeek.com/what-are-the-different-types-of-interventions-for-me [Date accessed 22 April 2014].


APPENDIX A: APPROVAL LETTER (MEDUNSA RESEARCH ETHICS COMMITTEE)

UNIVERSITY OF LIMPOPO
Medunsa Campus

MEDUNSA RESEARCH & ETHICS COMMITTEE
CLEARANCE CERTIFICATE

MEETING: 08/2013
PROJECT NUMBER: MREC/HS/282/2013: PG
PROJECT:
Title: Experiences of families caring for mentally handicapped children in Bana ba Thari School Polokwane Municipality in Limpopo, Province South Africa
Researcher: Miss NM Madiba
Supervisor: Dr JC Kgole
Co-supervisor: Prof ME Lekhuleni
Department: Nursing & Human Nutrition
School: Health Sciences
Degree: M Cur

DECISION OF THE COMMITTEE:
MREC approved the project.

DATE: 03 October 2013

PROF N EBRAHIM
DEPUTY CHAIRPERSON MREC

The Medunsa Research Ethics Committee (MREC) for Health Research is registered with the US Department of Health and Human Services as an International Organization (IORG0004319), as an Institutional Review Board (IRB00005122), and functions under a Federal Wide Assurance (FWA00009419).
Expiry date: 11 October 2016

Note:

i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.

ii) The budget for the research will be considered separately from the protocol. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.
APPENDIX B: CONSENT FORMS

UNIVERSITY OF LIMPOPO (Medunsa Campus) ENGLISH CONSENT FORM

Statement concerning participation in a Clinical Trial/Research Project.*

Name of Study: Experiences of families caring for the mentally handicapped children at Bana ba

Thari school, Polokwane Municipality in Limpopo province, South Africa

I have read the information and heard the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I know that sound recordings will be taken of me. I am aware that this material may be used in scientific publications which will be electronically available throughout the world. I consent to this provided that my name and hospital number are not revealed.

I understand that participation in this Study / Project is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this Study / has been approved by the Medunsa Research Ethics Committee (MREC), University of Limpopo (Medunsa Campus). I am fully aware that the results of this Study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this Study.

Name of patient/volunteer ______________________________ Signature of patient or guardian.

Place. ______________________________ Date. ______________________________ Witness ______________________________

Statement by the Researcher

I provided verbal and/or written* information regarding this Study.

I agree to answer any future questions concerning the Study as best as I am able.

I will adhere to the approved protocol.

Madiba M. H. ______________________________ 17 October 2013

Name of Researcher Signature Date Place University of Limpopo

*Delete whatever is not applicable.
UNIVERSITY OF LIMPOPO (Medunsa Campus) SEPEDI CONSENT FORM

Setatamente mabapi le go tša tša karolo ka go ya Dinyakšíšo

Leina la Dinyakšíšo

Maitemogelo a ba lapa mabapi le go hlokomele bana ba bona bao ba sa lekanelago monaganong, Masepateng wa Polokwane, districting ye Capricorn, Profenseng ya Limpopo.

Ke badíle ka la lekgwe ka ga tshedimošo mabapi le "malakmášišo le morero wa" dinyakšíšo tšo le ašánítšwe gomme ke le ka fwa monyeta ka go botšiša dipotšišo gomme ka fwa nako yeo e lekanego gore ka negamášišo le ka taba ye. Ke tioga ka kwešíša malakmášišo le morero wa dinyakšíšo tše gabotše. Ga se ka gapelešiša go kgatha tema ka testa efe goba efe.

Ke a kwešíša gore go kgatha dinyakšíšišong ka ga bošhopo gomme nga tiogela go kgatha tema nekong efe goba efe le kgobe ka fe le le kgabe ka sa le le kgabe ka fe le kgabe. Sa se ka se be le kgquéšíša efe goba efe go kaliko yaka ya ka mehišya ya maemo a ka gape e ka kgutešíša le ge a ka ba tshokomele yego ke e humanego go ngaka yaka ya ka meliša.

Ke a lešíla gore dinyakšíšo tše di dumelešiša ke Medunsa Research Ethics Committee (MREC), Yunibséthi ya Limpopo (Xhamphase ya Medunsa). Ke lešíla gabotše gore dipeloší tše dinyakšíšišo di di dumelešiša merero ye saense gomme di ka phatlašiša. Ke dumelešiša le se, ge lešíla bochrome bja ka bo ka tšišiša;

Mo ke fa tumelelo ya go kgatha tema dinyakšíšišong.

Leina la motšiši molthaši Mosaeno wa motšiši goba mohlokomedi.

.................................................................

Letšo. Thats@

.................................................................

Setatamente ka Monyakšíši

Ke tana ka tshedimošo ka molomo le yeo e ngwadišwe mabapi le dinyakšíšo. Ke dumela go araba dipotšišo dife goba dife tše ka moso mabapi le dinyakšíšo ka bokgoni ka moo nka kgono ka gona.

Ke tše letša meliso yeo e dumelešišwe go.

.................................................................

MAGOLO MUN MOKGOKOTSIKOE 17 October 2013 University of LIMPOPO

Leina la Monyakšíši Mosaeno Lešišišišiša Letšo

*Phumola tšo le di sego maleba.
APPENDIX C:  APPROVAL LETTER (DEPARTMENT OF EDUCATION)

DEPARTMENT OF EDUCATION

Enquiries: Dr. Makole MC, Tel No: 015 290 9448. E-mail: MakoleMC@edu.limpopo.gov.za
UNIVERSITY OF LIMPOPO
TURFLOOP CAMPUS
PRIVATE BAG X1106
SOVENGA
0727
MADIBA MN

RE: Request for permission to Conduct Research

1. The above bears reference.

2. The Department wishes to inform you that your request to conduct a research has been approved. 
   TITLE: EXPERIENCE OF FAMILIES CARING FOR MENTALLY HANDICAPPED CHILDREN IN 
   RANA BA THARI SCHOOL, POLOKWANE MUNICIPALITY IN LIMPOPO PROVINCE.

3. The following conditions should be considered:

   3.1 The research should not have any financial implications for Limpopo Department of Education.

   3.2 Arrangements should be made with both the Circuit Offices and the schools concerned.

   3.3 The conduct of research should not anyhow disrupt the academic programs at the schools.

   3.4 The research should not be conducted during the time of Examinations especially the forth term.

   3.5 During the study, the research ethics should be practiced, in particular the principle of voluntary participation (the people involved should be respected).

   3.6 Upon completion of research study, the researcher shall share the final product of the research with the Department.

Page 1 of 2

Cnr. 113 Biscoad & 24 Excelsior Street, POLOKWANE, 0700, Private Bag X9489, POLOKWANE, 0700 
Tel: 015 290 7600, Fax: 015 297 6920/4422/4494

The heartland of southern Africa - development is about people!
4. Furthermore, you are expected to produce this letter at Schools/ Offices where you intend conducting your research as an evidence that you are permitted to conduct the research.

5. The department appreciates the contribution that you wish to make and wishes you success in your investigation.

Best wishes.

Dederen K.O
Acting Head of Department

04/03/2014
Date
INDEPENDENT CODER CERTIFICATE

Qualitative data analysis

Masters degree in Nursing Science

MADIBA MALESIBA NAUM

THIS IS TO CERTIFY THAT:

Prof M.N. Jali has coded the following qualitative data:

23 individual interviews and field notes

For the study:

EXPERIENCES OF FAMILIES CARING FOR MENTALLY HANDICAPPED CHILDREN IN BANA BA THARI SCHOOL IN THE POLOKWANE MUNICIPALITY OF THE LIMPOPO PROVINCE, SOUTH AFRICA

I declare that adequate data saturation was achieved as evidenced by repeating themes

PROF MN JALI: [Signature]
29 October 2014

Dear Ms Malesiba Madiba

CONFIRMATION OF EDITING THE MINI-THESIS WITH THE TITLE
EXPERIENCES OF FAMILIES CARING FOR MENTALLY HANDICAPPED
CHILDREN AT THE BANA BA THARI SCHOOL IN THE POLOKWANE
MUNICIPALITY OF THE LIMPOPO PROVINCE, SOUTH AFRICA

I hereby confirm that I have edited the abovementioned document as
requested.

Please pay particular attention to the editing notes AH01 to AH87 for your
revision.

The tracks copy of the document contains all the changes I have effected
while the edited copy is a clean copy with the changes removed. Kindly make
any further changes to the edited copy since I have effected minor editing
changes after removing the changes from the tracks copy. The tracks copy
should only be used for reference purposes.

Please note that it remains your responsibility to supply references according
to the convention that is used at your institution of learning.

You are more than welcome to send me the document again to perform final
editing should it be necessary.

Kind regards

[Signature]

André Hills
083 501 4124
APPENDIX F: EXAMPLE OF A CONDUCTED INTERVIEW (ENGLISH VERSION)

PARTICIPANT 8

Date: 2014-02-28

R: How are you?

P: I’m fine thanks, and you?

R: I’m fine.

R: How long have u been caring for [your mentally handicapped] child?

P: Since he was born.

R: How can you explain your experiences when caring for [your] mentally handicapped child?

P: My child is someone who does not know how to talk clearly. His speech is not clear. He took time to walk when he was a child and now he is 8years…[He] does not know how to go to the toilet he urinate[s] [in] his clothes. Then if he gets out of the house he does not come back. He gets lost and sometimes we are called by the neighbours and police to come and pick him up. Now our problem is that now that he is growing older, he is not controllable. He goes out to the shopping complex too often and when you take him he becomes aggressive.

R: What could be the cause of mental handicap [sic]?

P: I do not know and the is no family history of this mental handicap.

R: How do you feel about your [son] as he is mentally handicapped?

P: This is bothering me a lot because I wish he could also attend school for children who are not mentally handicapped.
R: What does the society say or feel about your child's mental handicap.

P: People are not the same. Some they tell us if they sees [sic] him walking alone or at the shopping complex alone, while others they do not care... do not want to see him next to them.

R: How do you feel when you are in public with your mentally handicapped child?

P: (In a slow tone.) Now I have accepted... I don’t have a problem.

R: How do you deal with your child regarding school related issues?

P: I'm teaching him how to write because at the Bana Ba Thari School is like they do not teach the[m] how to write.

R: Do you have some knowledge about this type of illness? If yes, how did you get that knowledge?
If no, how did you know about your child's condition?

P: No, I donot have knowledge about this condition. I just observed him and released [sic] he does not behave like other children. If you say to him do not touch, he touches. When you take him from the shopping complex to home and tell him not to go there, he just return again.

R: Do you have enough social support in managing the needs of your child with mental handicapped [sic] from relatives and other organizations?

P: He is getting [a] social grant, but the[re] is no support from the relatives.

R: How do other siblings relate or cope with you mentally handicapped child?

P: They are sometimes not patient and with anger when they talk to him. I therefore stop doing that because he is also my baby. I love him.
R: Are there any government departments or non-governmental organisation[s] that assist you and your child with psychological counselling?

P: The[pre] are no other non-governmental organisations that assist. Our child only attended the psychology once during the first assessment with the referral letter from [the] doctor and we as parents, we never attended the psychology.
APPENDIX G: EXAMPLE OF A CONDUCTED INTERVIEW (SEPEDI VERSION)

PARTICIPANT 8

Date: 2014-02-28

**R:** Na o ka hlasosa bjang boitemogelo bja gago mo thokomelong yaa ngwana yo a sa itekanelago ka hlogong?

**P:** Ngwanaka ke motho yoo a sa kgonego go bolela ga botse ga a kgone go hlasosa ga botse, o tseere sebaka go sepela ge a sale yoo monnyane, ga bjale o nale o nale mengwaga e seswai ga akgone go ya ntlwaneng, o rotela diaparo tsa gagwe, Ge a ka tswa ka mo gae o tswele ga a sa bua,wa timela. Ka nako ye ngwe re botsa ke baagisane le maphodisa go tlo motsea moo a beng gona, Tabta ya go swenya ke gore ge a gola o ba worse ga a laolege, o ya mabekeleng ga ntsi ge ore wa motsea wa gwaba.

**R:** Na bolwetši bjo bja monagano bo hlotšwe ke eng?

**P:** Ga ke tsebe ebile ga o na wa leloko woo a nago le bona.

**R:** Na o kwa bjang ka ngwana wa gago ge a lwala ka hlogong?

**P:** Ke kwa boholoko, kea swenyega kage ke be ke rata ge ngwanaka a ka tsena sekolo sa banaba go itekanela monagano.

**R:** Na setšhaba se reng ka bolwetši bja ngwana wa gago bja hlogo?

**P:** Batho ga ba swane ba bangwe ga bana taba le yena ga ba mo nyake kgauswi le bona mola ba bangwe bare thusa ge ba mmona a sepela a le tee goba a ile mabenkeleng ale tee, bare botsa gore re yo mo tsea.

**R:** Na o ikwa bjang ge o na le ngwana wo wa gago mo bathong?

**P:** O bolelela fase, "ga bjale ke amogetse ga kena bothata".
R: Na o šoma bjang le ngwana wa gago ka mošomo wa go ama sekolo?

P: Ke mo ruta go ngwala ka gore kua sekolong sa Bana Ba Thari ga ba ba rute go ngwala.

R: Na o na le tsebo ye itšego ka bolwetši bja mohuta wo? Ge go le bjalo o e humane bjang? Ge go se bjalo o tsebile bjang ka bolwetši bja ngwana wa gago?

P: Ke no mmona e sale ngwana gore ga aphele go swana le banaba bangwe, ge ore o seke wa swara moo yena wa swara, ge o motsea mabenkeleng o mmusa ka gae o mmotsa gore a se boelele yena wa boelela.

R: Na o na le thego ye e lekanego mo dinyakweng tša ngwana wa gago go tšwa go meloko le mekgatlo ye mengwe?

P: Ga re humane thekgo go ba meloko, Social grant yona wa e humana.

R: Na bana ba gago ba bangwe bja phela bjang le yo wa go lwala ka mo gae?

P: Ba fela bamo felela pelo, ba bolela le yenaka go befelwa efela kea ba kgalemela kaba botsa gore le yena ke ngwanaka ke a morata.

R: Na go na ke kgoro ya mmušo goba makgotla a go se be a mmušo ao a thušago wena goba ngwana wa gago ka thušo ya Saekholotši?

P: Ga o na makgotla ao se bego a mmušo are thusago, ngwanaka o bonwe ke psychologist ga tee la mathomo geke mo isa for assessment ka referral letter ya ngaka, rena batswadi ga seke ra humana thuso ya psychology.