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

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DECLARATION

I,Malesiba Naum Madiba,declare that thismini-dissertation “Experiences of families caring for the mentally handicapped atthe 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 duringmy periodstudy.
- My baby, Legoma Moses Madiba, for his love and understanding.
- My sisters, MakgaboFrangeline Madiba and Raesetja Rahab Madiba, for their love andperseverancewhilethey were guidingme, encouragement, and support they showed during thisstudy.
- All the families who participated in the study,sincethey sacrificed their time and duties to enableme with their participation during the data collection process.

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ABSTRACT

Background: The experiences of families living with the mentally handicapped childrenwho attended the Bana Ba Thari School in the Polokwane Municipality of the Limpopo Province were never evaluated and, therefore, the experiences of families werenot known.

Theaim: The aim of this study wasto describe the experiences of the families caring for the mentally handicapped children who attended theBana Ba Thari School in thePolokwane Municipality of theLimpopo 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 conductingsemi-structured face-to-face interviews. Data wasaudio recorded and field notes were written down. Data was analysed using Tech's open coding method forqualitative 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 observedand adhered to while conducting the study.

The results: The results showed that the parents lackedadequateknowledge about mentally handicapped children which ledto poor interaction.The study also revealed a gap of knowledge from various professions likedoctors andeducators which ledto poor intervention and delay of therapy for the mentally handicapped children. The study also revealed the psychological impact on the parents and siblings.Parents worriedabout the future of their mentally handicapped children, which led to their denial andanxiety 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 didnot 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 educatorsstill need to undergoin-service training with regard to mentally handicapped learners to enable them to make proper decisions or to execute accurate interventions.

Keywords: Experiences,mentallyhandicapped,caring,children,families,Bana Ba Thari.

DEFINITION OF CONCEPTS

Experiences

Experiences means to undergo or be affected by a situation.Knowledge and skillsare 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 areexperienced by families when caring for their mentally handicapped children.

Mentallyhandicapped

The term mental handicap refers toa subnormal intellectual functioning thatstartsduring the developmental period which results in asub-average intellectual ability equivalent to or less than an IQ of 70 and often inbehavioural or social problems(Cashin,2010).

In this study,handicapped child refers to a child whohas eithera permanent mental or physical condition thatmakes it impossible to use a particular part of the body or mind.

LIST OF ABBREVIATIONS

DSD	**Department of social development**
DWCCD	**Department of women, children & children with disabilities**
IQ	**Intelligence Quotient**
SNHL	**Sensor neural Hearing Loss**
UK	**United Kingdom**
UNICEF	**Unite For Children**

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OVERVIEW

1.1 INTRODUCTIONANDBACKGROUND

The WHO(2003)recognisesthat there is an estimated 450 million people worldwide living with either mental or behavioural disorders; 90 million aredrug or alcohol dependent, 25million suffer from schizophrenia, and 150 million enduredepression. InSouth Africa, 16.5% of the general population are diagnosed with some kindof 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 between35 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 personcouldlearn basic skills atschool and in daily living, while people with a moderate to severe mental handicapmighthave the ability to learn basic social, communication, and self-help skills,however, the acquisition of such skills might be more difficult with the result thatbehaviour problems are likely tooccur. While aprofound mentally handicapped person may have the ability to learn basic self-help skills,such a person wouldrequire constant supervision throughout life (Cashin, 2010).

Children who arementally 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 problemsolving, short-term

Memory, learning skills; as well as daily living, communication, and social skills(Cashin,2010).Individuals with a mental handicap aresignificantly less likely to complete high school, in comparison with their peers without a mental handicap(Kessler,Foster,Saunders&Stang,(1995). Thestudy by Homes (2005) showsthat 8% of disabled people are not working. A mental handicap could lead to reduced productivity at workand as a result,the unemployment rate of the mentally handicapped increases.

Mental health has profound effects on anindividual’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 asocial system that needs an improvedmental health care structuretodevelop 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 caredfor amentally ill family member.The study was conducted using in-depth interviews andmost families reported thattheirlack of financial and medical resourcesand the same lack on different community levels made it difficult andstressful 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 theSouth 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,sincecare giving duties prevented them from attending social events, such as funerals and church services;particularlyin rural areasthat lackedcommunity 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 improvespatient 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 familieswho carefor their mentally handicapped childrenwho attend school atBana 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 memberswho are living with their mentally handicapped children seemed to be having difficulties whilecaring for their mentally handicapped children. Itseemed not easy for them and it is stressfulbecause some family members complained that theydo not know how to care for their mentally handicappedchildren,sincethey do notreally understand the children’s disorganised behaviours. Therefore, it is important to understand the experiences of families who carefor the mentally handicapped children in order to assist and empower them in terms of the difficultiesthey 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 childrenwho attend theBana Ba Thari School of the Polokwane Municipality in the Limpopo Province, South Africa.

1.4 RESEARCH QUESTION

Thisresearch question guidedthestudy:

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 33handicapped children who attend Bana Ba Thari School of the Polokwane Municipality inthe Limpopo Province,South Africa.
- empower families to care for mentally handicapped children who attend theBana 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 describedlife experiences and gavemeaning tothose experiences. This method focuses on understanding the bigger picture and all its content.This approachis consistent with the holistic philosophy in nursing (Bedna, 2003). A descriptive and aphenomenological research design was used in this studyto explore and describe the experiences of families while they werecaring for their mentally handicapped children.A phenomenological design was used to understand the experiences of families who caredfor the mentally handicapped children(Gerrish &Lacey,2006).

The population for this study was all families caring for mentally handicapped childrenwho attended theBana Ba Thari Schoolof the PolokwaneMunicipality 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 inGa Dikgale were included in this study. It requiresjudgmental sampling that involves the conscious selection by the researcher of certain subjects to include in the study. The sample size ofthis study was limited to 23identified participants.However, the eventual sample size depended on the availability of members of thatpopulation on occurrence of data saturation.The details of the methodology are discussed in Chapter 3.

1.7 SIGNIFICANCE OF THE STUDY

This study mayassistthe 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 bythe families of mentally handicapped childrenwho attend theBana Ba Thari School of the Polokwane Municipality in theLimpopo Province.

1.8 CONCLUSION

This chapter presentsan 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 literaturethat is relevant to the research topic, namely experiences of families caring for mentally handicappedchildren at the Bana ba Thari School inthe PolokwaneMunicipality of theLimpopo 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 HANDICAPPEDCHILDREN

The prevalence of handicap appears unusually high for young children, 28 per cent of childrenin 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 retardationaffect 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 handicaphasnumerous potential causes.

2.3.1 Infections

Some infections that are either present at birth, or that happen soon after birth couldcause 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 usualplace,an error in the number of chromosomes couldcause mental handicap,andthe other childrengenetically inherit mental handicap fromtheirparents (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 conjunctionwith one another, since they are both heterogeneous conditions with acquired and genetic causes, however, causes are primarilygenetic. The human Xchromosome is estimated to containmore than a hundred mutated genes thatcause mental handicapwhileeight 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 ofneurological 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 agearestunted 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 couldalter neurochemistry and result in aggression.For example,when learning disabilities ofchildren are not identified or adequately measuredit might cause them to disconnect from school and the possibility of delinquent behaviourincreases.Parents who have warm relationships with their children, whoconsistently discipline them without being harsh, and who supervise their activities adequatelyare 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.Theeffect of such disabilities mediates the association between poverty and exposure to a range of environmental and psychological hazards.(Connor,2006). Secondly,families who supporta 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 childand also exclusion of people withmental handicap from the workforce increases poverty(Emerson,2007).

2.3.5 Lack of information

Many people do not have accurate information about mentaldisabilities, causes, prevention, and treatment (Jorm, 2012). This is the resultof a high illiteracy rate and poor knowledge about basic social, health, and educational services.Although the benefits of public knowledge aboutphysical diseases are widely accepted, evidenceshowsinadequatepublic 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 formilder problems,and first aid skills to help other members of the communitywho are affected by mental health problems(Rosekranz, 2004)

Knowledge about mental handicap has been somewhatneglected.Many members of the community are not able torecognise 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 membersofthe 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, negligencedue to limitedparental 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 relationshipallowsprofessionals to be prescriptive, therefore,the parents are disempoweredand their parental involvement is reduced which preventsparticipation in an equitable relationship with professional health workers(Case2000).

2.3.7 Unhealthy lifestyles

Mental handicap might also be causedby 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 psycho-social problems in a changing societysuch asmajor depression, generalised anxiety disorder, and phobia (Kenneth, Kendler, Carol, Prescott, Myerems, Michael, &Neale, 2003).

2.3.8 Environmental factors

Mental handicap might becausedby epidemics, accidents, natural disasters,pollution of the physical environment, as well aspoisoning 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 influencean individual’s perception of the social and physical world.These worlds contain anumber of circumstances; for instance sexualabuse, falling victim to crime, and the breakup of relationships which potentiallyproduces 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 assports injuries. Traumatic brain injury mightcause psychiatric disorders;this is evidentfrom an established set of causation criteria. Aftera head injury accident, one has the likelihood of developing the following disordersaccording tothe study thatwas conductedin a period of7.5 years with people who had head injury:Major depression, bipolar affective disorder, anxietydisorder, obsessive compulsive disorder, panicdisorder, 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). Sportcouldprovide an effective way ofstrengtheningsocialisationin conjunction with developmentally similar peers and supportive adults in order for thechildrentolearn about team work(Mcleod2014).

2.4 THE CHALLENGES THAT MENTALLYHANDICAPPED 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 andthese 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 disabilityin 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). Afamily's expensescouldincreasedue tomedical equipment, medical care, care-giving, private education, tutoring, adaptive learning equipment, or specialised transportation (Lucy,2011).

The review of literature examinedthe impact of poverty on the quality of life onfamilies who havechildren 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 waysimpacted on six social dimensions of family; including health (hunger), healthy living conditions, social impact,delayed cognitive development,emotional wellbeing, physicalendowment-overcrowded,increased stress due to the lack of emotional wellbeing,as well asmoney-related family interaction and marital conflictsin the family(Park, Turnbull,& Rutherford,2002).

People who receive social security grants for disabilityin South Africa are inclinedto be totally dependent on these benefitsfor 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 couldbe 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 asinadequate 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 createsbarriers that prevent mentally handicapped people from accessing equal opportunities (Poopedi, 2012).

This could be attributed topoor 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 differentlyfrom the issues ofother 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 livein rural areas often have a low life expectancy due to lack of care, support, and access to the most basic services. Families areseldom 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, Maphulaand Mashamba(2012), some participants reported that there was a lack of resources in hospitals to treat their children and owing to the shortage ofprofessionals,programmes that were supposed to be run on a weekly basis were happeningmonthly only.

Families of mentally handicapped children commonly experience emotional, physical,and school related problems,as well as social and financial challenges because these children havespecial needs in addition to the regular needs of all children(Mudhovozi,*et al*., 2012). Parents experiencefeelings of guilt, embarrassment, blame, and disappointment. The study by Govender (2002) revealsthat parents in rural areas of Zululandin the Kwazulu Natal Province love and accept their mentally handicapped children. However, the majorityof 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 challengesare syndromesthatarecaused by genetic factors, hereditary reasons, or many forms of irreversible brain damage. As hard as it is to accept, once parents realise that their childrenarementally handicapped and will always be their expectations of the child are adjustedaccordingly (Woolfson, 2004). Then, they are able tomove on bytaking the necessary steps to assisttheir childrenwith makingthe most of theirpotential by addressing theirspecial 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 recognisecontributing “poor sleepers” factors.The strongest predictor of poor sleep quality isparental stress.Parental stress isassociated with poor sleep quality when they care forchildren 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 whetherthey have donesomething wrong during the course of the pregnancy or after birth. They wonder whetherGod 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 peoplemight passcruel remarks about the child and as a result, parents feel isolated and without support (Pilusa, 2006). Using regression techniques, stigma isfound to have an impact on the social comparison process that ismediated by evaluative beliefs.These findings support a social-cognitive view of the importance thatthe social world have forpeople while they are coping withmental handicap and psychosocial damage that stigmatisation couldcause(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 mentallyhandicapped, more than 10% of children between the ages ofnine and 17 years are believed to suffer from mood disorders.A mentally handicapped child mightexperience learning disabilitiesthat interfere with reading, mathematics,and memory. Some of the mentally handicapped children develop depression,sincethey realise they are different from other children who are not mentally handicapped (Downs, 2010).

Many parents find it difficult to cope withbehavioural problems like screaming, crying, inability to concentrate, aggressiveness, and stubbornness that a child with mental challengesmight 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 carefora mentally handicappedchild – patience couldwear 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 peopleand 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 childrenaremaking 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. Whena child has the mental age of an eightyear old, he/she cannot be expected to embark upona vocation thatrequires complicated mental processes. When parents have unrealistic expectations of what their child can achieve, it leads to disappointment not only for them but also forthe child who does not understand what he/she is doing wrong (Chandrashekar, 2011).As a result, parents experience greater restrictions and epileptic childrendevelop a lower self-esteem anddo 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 worryhow their children will be taken care of. They feel that no one else couldtake care of their child with the same love and care that they doand 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 caregivingneedssuch a child has, parents feel overworked, stressed, and unhappy (Van der Want, 2014). The marital relationship couldbecome strained whenthe parents have different approaches todealing with the child or whenone 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 couldcomplicate matters in the way they react to the child (Lucy, 2011).

Parents have ahealthy self-esteem, although they report somewhat lower marital happiness and family cohesion(Higgins, Bailey, &Pearce, 2005). According to their study, marriagesfallapart because the wivesdo not have time for anything else than to take care oftheirmentally handicapped children.Friends and family are alsonot available forsupport while husbandsbecome distended, annoyed and cold due to having a mentally handicappedchild (Mudhovozi *et al.*,2012).Path’sanalysis revealsthat children’s being demandingand neediness for care are more related to maternal stress while child acceptability isrelated to paternal stress.A professional need exists to assistfathers with becomingemotionally close to their atypical children whilemothers have a pressing needfor respite services (Keller & Honing,2004).

2.4.13 Siblings

Siblings of mentally handicapped children mightadapt a plethora ofgood or bad qualities. They couldexperiencedepressive symptoms; such as resentfulness, being scared, frequent crying, hopelessness, appetite changes, loss of interest,as well astalking about self-mutilation andembarrassment. Siblings might assume extra pressure to take care of theirmentally handicapped sibling without parents having any such expectation. The siblingsmightalso feel lost or ignored, thinking that the mentally handicappedchild received all the attention(Taylor, 2008). Good qualities could be empathy for other peopleand insight into the challenges that mentally handicapped face, when growing up with a mentallyhandicapped sibling, children couldalso develop patience,be more accepting of differences,as well asbe supportive and compassionate towardsfellow 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 perceptioncouldlead to self-esteem issues, as well as emotional and behavioural problems. Younger children mightbecome withdrawn or anxious, or they mightexhibit angeror attention-seeking outbursts. Teenagers mightexhibit signs of depression. When these problems arenot treated,they couldimpede a child's progress. (Martinetz, 2011).

2.5 CONCLUSION

This chapter discusseddifferent kinds of problems that families experience while they are caring for mentally handicapped children.Evidence fromseveral research studiessupports this discussion. The experiences and main concerns arearranged 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 qualitativeand 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 toeighteenyears 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, andsenior.The school consists of 23educators,including the principal,and 201learners. 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 carefor mentally handicapped children (Creswell, 2009). Welman,Mitchel and Kruger(2006) describe a study design as aplan 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

Aqualitative research method emphasisesthe 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 provideviews of their own experiences with regard to caringfortheir mentally handicapped children at theBana Ba Thari Schoolof the Polokwane Municipality inthe 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 removalof barriers and fears surrounding the roles of researchers and participants with the purpose of encouragingcritical thinking. The researcher was concerned with the phenomenon on the grounds ofthe 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 requiresthe cooperation of participant and researcher(Leedy&Ormond,2005). The families who caredfor their mentally handicapped children described their experiences during semi-structured interviews. The approach also included bracketing,sincethe researcher endeavoured to exclude pre-conceived ideas while focusingon every perspective of the family member.The researcher appliedintuition by paying attention to the participants during the interview and by asking probing questions (De Vos, Fouche & Delport, 2005).This study solelyconcentrated on the perceived experiences of families who directly tookcare of their mentally handicapped children and the researcher paid careful attention to participants whilethey were describingtheir experiences aboutcaring for their mentally handicapped children and identified various meanings to develop acomprehensivedescription 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 whilecaring for their mentally handicapped children who attend theBana Ba Thari School in the Polokwane Municipality of theLimpopo Province,South Africa.

3.4 POPULATION

Brink*etal*. (2012) define population as the entire group of personsor 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 theBana Ba Thari School inthe Polokwane Municipality of theLimpopo Province.

3.5 SAMPLING

Sampling refers to the process of selecting a portionof the population whorepresents the entire population (Polit, Beck& Hungler, 2010).During purposive sampling, aresearcher searchesfor individuals, groups, and settings where the specific processes of interest to the studyaremost likely to occur.This method of samplingis an important part of non-probability sampling,sincearesearcher relieson participants' experiences, ingenuity, and previous research findings to deliberately obtain units foranalysis in such a way that the sample maybe regarded as representative of the entire population (Welman,et al 2006). In this study, purposive sampling was used to select twenty threefamilies caring for their mentally handicapped childrenwho attend theBana 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 availableand 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 andcaring for their mentally handicapped children who attend the Bana Ba Thari School in the Polokwane Municipality of the LimpopoProvince.

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 duringsemi-structured interviews by askingopen-ended questions andtaking field notes. One-on-one interviews were used thatyielded a great deal of useful information about facts,feelings,and motives, present and past behaviours, peoples’ beliefs and perspectives,standards ofbehaviour and conscience,as well as reasons forfeelings. The researcher confirmed the quality of data by using listening,reflecting,and probing.That process requiredthe researcher to have good listening skills in order toobtain quality information and togain a thorough understanding duringeachinterview (Karim& Karim, 2005).

The researcher secured appointment dates with the participants to ensurethe smooth executionof the study and also identified a suitable venue for the interviews. The researcher conducted semi-structured interviews that consisted of open-ended questions, including acentral 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 arrangementswith 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 formexplainedthe reasons for the study and questions they could expectto answer.The researcher started by obtainingdemographic informationfrom the participants.This approach put the participants at ease.The central question was"What are your experiences when caring for yourmentally handicapped child?"

Probing was done until saturation of data was reached. Bowling (2002) statesthat probing assistswith generatingmore dataaboutaphenomenon being studied and withobtaining clarity or a better picture of the participants in respect ofissuesthat 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 encouragingparticipants 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 persuadedparticipants to providemore information about the phenomenon under study.It also assistedthe researcher toobserve and notethe facial expressions and gestures whilethe participants were commenting.

The researcher interviewed twenty three participants caring for their mentally handicapped children who attend theBana Ba Thari School until data saturation was reached. Each interview session lasted between 30 and 45 minutes. The interviewswereconducted in Sepedi,sinceit was the medium of communication among the families. The information collected was audio recordedand 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 theirparticipation accounted forabout 90% of the dialogue because they toldtheir storieswhilethe researcher was listening attentively.
- The families were asked clear and brief questions that were easily understandable as indicated in AppendixD.
- The researcher asked one question at a time.
- Questions about experience were asked before eitheropinion or sentiment questions.
- Leading questions were avoided but questions were asked to clarify answers that were open to interpretation.
- Families were given the opportunityto think throughwhat they wanted to add or say before the next question was asked.
- The researcher followedup on the families' responses for confirmation purposes.
- The researcher monitored the effects of the interview on the families in order to establishwhetherto focus or whether to defocus.
- The audio recorderwas kept on at all times to avoid unnecessary distraction byturning iton 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 thisstudy, 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-mm*","*Yes, I see*", to demonstrate toparticipants that the researcher was listening and followed responses.This type of response encouraged the families to continuetalking and whilethe researcher confirmed that she was following what they were talking about.

3.8.2.2 Clarification

Clarificationembraces the method that seeks further explanationof 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 ontheir experiences about the phenomenon.

3.8.2.4 Listening

Aresearcher 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 repeatthe essence of what participants are sayingto confirm that the statements are correctly understood. The researcher tried to obtain accuratemeaning 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 aparticipant to provideinformation about the issue under discussion.This assistedthe researcher to get a detailedresponse 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 researcherlistened attentively to the families and confirmed it bysometimes repeating after them what they hadsaid.

- **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 toreduceraw 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 ofDeVos*et al*.(2005).

Step1: The researcher prepared and organised data for analysis thatinvolved 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 informationto obtain a general sense of the informationin order to reflect on the generalmeaning. Data was analysed in the samelanguage that the interview had beenconducted whilerandomly readingany transcript file and jotting down ideas as they came tomind. A careful line-by-line, paragraph-by-paragraph, and anentire text reading of the transcript wasconductedin order to become familiar with the data.

Step 3: The researcher conducted a detailed data analysisby following a coding process to organisethe material into ‘chunks’.That required the identification of text data, segments ofsentences, andimages with the purpose of grouping them intocategories.Each category was named after a term that a particularparticipant used. Audio recordeddata was transcribed verbatim into text.Thosetranscriptswere organised into files and clearly marked and labelled withnumbers 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 recordof information about people, places, and events in the setting. The phrases, lines, sentences,andparagraphs 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 stepto identify and interpret the data according to emerging themes and sub-themes. The themes grouped relatedpoints in relation to a research question.

3.10 MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness was ensured byapplying 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 30-45minutes confirmedthe responses given by the families,sincethe researcher had an opportunity to interrogate the phenomenon until the study reacheda saturation point. An audit trail was established that enabledthe supervisor and the co-supervisor to listen to the recorded interviews. The researcher submitted raw data to anindependent coder who wasregarded as an expert in the field of qualitative research to performan 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 whenthe enquiry wasreplicated 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.Inthis study, dependability was ensured by the use of an inquiry audit when the researcher was using field notes and audio recordings that were availableafter 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 whetherthe participants would providethe same responses(Babbie & Mouton, 2009).

3.10.3 Transferability

Transferability is the ability to transfer findings to other similar situations orproblems;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 apurposive sampling method,sincethe population only included familiescaring 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'sbias (Brink*et al*., 2012).It refers to the objectivity or neutrality of the data that two or more independent people wouldagree 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 thestudy

The Medunsa Research and Ethics Committee grantedethical clearance to conduct this study.Permission to conduct study was obtained from the principal atthe 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.

3.10.2Informed consent

According to Cohen and Morrison (2008), the principle of informed consent arises from the subjects' approvalto participateinastudy.Subjects'rightsneed to be observed. These rights includefreedom, self-determination, competence to make correct decisions voluntarily after full information was provided, andthe right to discontinue participation in the study at any time withoutprejudice.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 aboutthe advantages and disadvantagesof their participation, such as the improvement of the caring fortheir mentally handicapped children (De Vos *et al*.,2005).

3.11.3 Confidentiality and anonymity

Complete anonymity exists whenparticipants' identity cannot betraced, even by the researcher.Confidentiality is the way in which researcher managestheprivate information that participants share as stated by Burns and Grove(2003).All the data gathered were treated confidentiallyand anonymously during the period of study.All recordsand audio recordings were handled only by researcher and supervisor.Two years after the publication of these research results,thedata wouldbe completely destroyed.The participants were informed about the steps that would be taken to keep their answers and names anonymous.Thatincluded 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 theparticipants and the data (Gerrish& Lacey, 2006).

3.11.4 Right to protection from harm

The right to protection fromharm is based on the ethical principle of beneficence thatrequires a researcher not to cause any form of harm to the participants. Professional secrecy was maintained forall participants who explained their experiences whilecaring for their mentally handicapped children (Hill,2006).The participants were neither exposed to anyrisks,nor to discomfort.They were assured that they wouldnot be harmed physically or emotionally by giving the participants thorough information about the impact of studythat their personal information wouldbe kept confidential, and that it wouldnot 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 describesthe 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 theexperiences of families caring for theirmentally handicapped children who attended theBana 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.

4.2DEMOGRAPHIC DATA

Table 4.1: Demographic Dataof Participants

Demographic	Number
Characteristics	
1. Gender	
Female	21
Male	2
2. Age range	35-60
3. Family Types	
3.2.1 single mother	3
3.2.2single father	0
3.2.3 nuclear	20
3.2.4 Extended	nil
3.2.5Child headed	nil
4.Family size range	5-7
5. Location of families	
Nobody	6
Mentz	8
Mankweng unit A	3
Mankweng unit D	3
Ga Kama	3

Table 4.2: **Participants'Years of experience**

Age range of the mentally handicapped child	1-18 years
Years of caring for the mentally handicapped child	1 – 18 years

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 interviewsand also put into perspective with existing research conducted by different researchers on the same themes.

Table 4.3: Themes and sub-themes

Themes	Sub-themes
1. Physiological impact	1.1 Tiredness
2. Psychological impact on the family(parents &siblings)	2.1 Anxiety 2.2 Depression 2.3 Denial 2.4 Worriesabout the future 2.5 Rape 2.6 Acceptance 2.7 Effects on siblings
3. Poor knowledge ofparents and health professionals	3.1 Poor information of parents 3.2 Poorlyco-ordinated Intervention strategies by multi-disciplinary team members including school teachers
4. Socio-economic problems	4.1 Poverty 4.2 Occupational accessibility 4.3 Restricted social life

Themes	Sub-themes
	4.4 Stigma&discrimination
5. Lack of material resources	5.1 Lack of transport 5.2 Lack ofequipment forvocational training at school

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.Theyalso 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 life time (Lucy, 2011).

4.2.1.1 Sub-theme 1.1:Tiredness

Tiredness is a frequent and debilitatingsymptom that couldinterfere 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.Ieven teach her how to brush her teeth; I help her to wash whole body."*(Mother lookedemotional 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 Itake him to school in the morning and bring him back in the afternoon."*

Participant 15: Responsefrom 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 childrenand report poor physical health when both challenging behaviour and stress areperceived to be high (Logsdon, 2014).These parents encounter pain and fatigue the older they get owingto the daily heavy duties of bathing, feeding,and diapering of the mentally handicapped children (Gallagher& Whiteley, 2013).

4.3.2Theme 2: Psychological impact on the family

In the current study, it was found that having a child who wasmentally retarded placedgreater strain on a family than it otherwise would have. This corroborates with the study by Lucy (2011) who findsthat extra tasks need to be done to take care of the child.Parents feel overworked, stressed, unhappy, and they become frustrated with their children'sinability 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 andOutwater (2012) agree with the findings of thisstudy that familiesfeel sad and experience inner pain or bitterness due to the disturbingbehaviour 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 hadenormous emotional problems and suffered from mental worries and anxiety due tohaving amentally 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 wouldnot 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 expectationslead to the introduction of many uncertainties.The uncertainties generate fear forwhat the future mighthold 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 thatmight 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, Petteeand Hong (2001) agrees with the findings of this study that parents whose childrenhave a serious mental health problem experiencedepressionand have elevated levels of physical symptomsand 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 afamily,those family members at first denied that the child wassuffering from mental retardation.During pregnancy, no family wasprepared 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:Worriesabout the future

The findings in this study indicated that families were concerned about who wouldlook 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 thoseconcerns 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 andOutwater(2012)concurswith the findings of this study.They statethat families areconcerned about the future of their mentally handicapped children.One of the main concerns thatparents with mentally retarded children have is about the care oftheir children when they die and what life will be like for them when they die. They feel that no one else couldtake care of their child with the same love and care that they have and they are scared about how their child wouldmanage 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 beraped while at school and at home people tookadvantage of them.Sincethey werementally 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 schooland 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 studythat people with mental disabilitiesand mental health needs are particularly vulnerable to sexual exploitation and are more at risk than most other members in the society.Amentally disabled person is someone affected by any disorder or disability of the mind so that at the time of crime, he or she isunable to understand the implications of a sexual act, to make proper decisions about it, or to resist a sexual act. While thesepeople 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 educatorsand carers should be aware that they have a duty to report anyallegation of sexual abuse.

4.3.2.6 Sub-theme2.6:Acceptance

Findings of this study showed that parents had high levelsof frustrations and dissatisfaction.They onlyaccepted after a long time that their children are mentally handicapped.This finding concurswithKgole and Molepo (2014) who statethat parents undergo a series of reactions before they couldaccept that the child is mentally handicapped.Afamily'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 byfurther explainingthat as hard as it is to accept, once parents realise that their child is mentally retarded and wouldalways 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 andvocational 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 areinclinedto resist or even deny the diagnosis. Again, it isproved that the single most common predictor of parental stress isthe negative definition of the situation.Formothers, the negative definition isassociated with behavioural problems while for fathers it isconnected 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 challengesareincurable,it is very difficult to give up hope that someday something wouldtake their children'smental disability away. This hope is what might keep most parents going

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4.3.2.7 Sub-theme 2.7:Effectson the siblings

The findings of this study confirmedthat siblingsresponded emotionally in different ways towards their brother and/or sister with a mental handicap. Other siblingsshowed sympathy and empathy while somehad no patience when interacting with the handicapped child. These findings correspondwith those ofMarks andReeve (2007) that the presence of a child with autism appears to enhance the psychosocial and emotional development. The study by Rossiter andSharpe(2001) also agreeswith 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."*

Thefindings of the current study concur with the study by Alexis (2010) and Taylor (2008) that the presence of a mentally handicapped child in the familyhaseffects on the siblings.They mightexperiencedepressive symptoms; such as fear, frequent crying, loss of interest, andanger. On the other hand,they mighthave positive feelings;such asempathy for others and insight into challenges that disabled children face, additional responsibilities to take care of their sibling, and siblings couldalso 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, communitiesdonot haveconcrete information that explains the illness of their children. However, the study by Chandrashekar (2011)differs fromthe current study.That study emphasises that it might also arise from insensitive handling of acase 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 revealedthat 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 thedeficiency 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 aboutself-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 andSteenkamp (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 examplethe concept andconditions associated with being mentally handicapped; such as down syndrome, autism, hyperactivity, microcephalus, hydrocephalus, epilepsy, adjustment problems, and muscle weakness).They also do not know aboutexisting 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 whatmental disabilities were.They also did not teach parents how to care fora 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 start*[s] *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 correspondswith 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 forthe mentally handicapped child.Those circumstances createda financial burden forthe family and increasedpoverty.Kgole andMolepo (2014) explain that parents haveproblems with financial security funds thatprevent them from purchasing clothing, food, and other basic needs for their mentally handicapped children. Emerson's (2003) studyalso statesthat 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)findthatparents 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 wheremoney is less of an issue while South Africa is still a developing country.

4.2.4.1 Sub-theme 4.1:Poverty

Thecurrent study found that the families caring for their mentally handicapped children could notafford to havea permanent job due to the time it took to carefortheir mentally handicapped children.The situation is exacerbated by delaysin getting security funds,lack of access to rehabilitation services, fewer education and employment possibilities, and additional expenses that createda financial burden for the family and aggravatedpoverty.

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 16hours because I must take care of her after school. I used to let neighbours take care of her after school but Irealised 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) andDunlap (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 whilethrusting themdeeper 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 anincreased 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 varioushealthcare 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 stayedat 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 formfriendships 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, stigmathat results from mental disordersmakesit 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) andTree(2014) also agree with the findings of this study that occupational accessibilityis a problem among mentally handicapped people.There are extremely high levels of unemployment amongst people with a mental handicap.This couldbe 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 preventthe mentally handicapped to support themselves.Employmentassist onewithgaining self-esteem and formingvaluable 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 familiesof mentally handicapped children experienced social life restrictions.

Participant 21:*"The issue of my baby always having epileptic attacks affected me andinterfered 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 ofmentally 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 interactless frequently with theirpeers 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,Ieven told them that if they continue with their behaviour,Iwill 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 weara 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 they 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 andMolepo (2014) support this finding withtheir discoverythat rejection by the neighbours and community isalso one of the barriers to improve the mental healthof the mentally handicapped children,sinceotherparents instructtheir children not to play with the mentally handicapped children.Brohan, Slade, Clement,andThorncroft(2010) also agree that stigma is aformof 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 abilitiesto interact appropriately.Such stigma compels a group to exclude or ignore mentally handicapped children(Durban, Pabayos, Alontaga, Arreza, & Salazar, 2012).Thefindings 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, sincethis worsens someone's mental health problems and delays or impedes their getting help and treatment torecover.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 ofeconomics,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 weresometimes not going to school because they weretoo many for the available school transport. Therefore,they alternated their days of attending school.The vehiclesfrom school werenot enough to transport all of them.Thesefindings aresupported 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 collect*[s] *Mentz then,Nobody,Ga Kama, and other placesthen next time it comes to us to collect her."*

Participant 2:*"Transport is a problem to me because Ican'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 isa 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 withpeers, and for accessible facilities. Shields, Synnot, andBarr(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 thattakeplace at the day centre and identify a range of activitiesthatparticipants would liketo try in future.However, theinaccessible transport for the mentally handicapped makes any additional endeavours impossible.

4.2.5.2 Sub-theme 5.2:Lack ofequipment for vocational training at school

The findings of thisstudy identified a lack of material resources at schoolthat could enhance therehabilitation of the mentally handicapped children;such assewing 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 couldbeattributed toinadequate 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 butthey 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 schoolfor mentally handicapped children by saying that mentallyhandicapped 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 theobstacles 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 aboutthe experiences of care giving and the factors associated with the impact of caregiving provide a context forexaminingwhat type of interventions are appropriate in particularsituations. 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 discuss thesummary, recommendations, limitationsof,and aconclusion 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 teacherstoreduce problems experienced by families caring for their mentally handicappedchildren. The research report is summarised and appropriate recommendationsare 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 Schoolin the Polokwane Municipalityof the Limpopo Province,South Africa.

5.2.2 Research Question

Whatare the experiences of families caring for the mentally handicapped children who attend theBana Ba Thari School inthe Polokwane Municipality, Capricorn District, Limpopo Province?

5.2.3 Objectives of the study

To explore and describe the experiences of families caring for thementally handicapped childrenwho attended theBana Ba Thari School inthe Polokwane Municipality in Limpopo Province, South Africa.

To empower families for mentally handicapped children who attendBana Ba Thari School in the Polokwane Municipality of theLimpopo Province, South Africa.

5.3 FINDINGS OF THE STUDY IN RELATION TO THE OBJECTIVES

In Chapter 1, the researcher outlined the objectives of thisstudy 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 theBana Ba Thari School in the Polokwane Municipality of theLimpopo Province, South Africa. This objective was achieved,sincethe families expressed their experiencesabout caringfor theirmentally handicapped children according to five main themes.

Theme 1 Lack of parents'knowledge:Parents described that they didnot 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 theirworries about the present and future of their children.They described feelings of sadness, denial, depression,anxiety,and difficultieswiththe acceptance of the child.Parents also described theeffects of disabilityon the other siblings.Some siblings wereangry, cried,and foughtwith the mentally handicapped child.

Theme 3 Physiological impact: Parents described their experienceshow strenuous it was to bath,feed, put onclothes, move,and to watch their mentally handicapped childrento 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 haveenough money to support their families.

Theme 5 Lack of resources: Parents explainedhowthe lack of resources at school affects them and their children.As a result, their children didnot want to attend school because therewereno materials to assist them with acquiring skills to work,such ascarpentry and welding.So,they articulatedtheir feelingsabout the effects on them as parents,the worriesabout the future of their children, and about their concernsabout their childrenwhostayedat home withoutdoinganything.

The second objective was to empower families to carefor their mentally handicapped childrenwho attend theBana Ba Thari School in the Polokwane Municipality,Capricorn District of the Limpopo Province. The family members wereadvised 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 willgive 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 inChapter 4.

5.4.1 Addressing the lack of knowledge byparents, doctors, and educators

Early and effective management of problems during the antenatal period and intra-partum care isimportant,Providinghealth education to women about maternal substance use of drugs, alcohol, tobaccothat itcouldcause foetal alcohol syndrome,birth defects and the varying degrees of possible mental disability, andlearning disabilities of the child. Smoking has also been linked tolearning disabilitiesand emotional or behavioural problems later inlife. 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 disabilitiesbefore being dischargedfromhospital. Ophthalmologistsrecommend examining children at least at six months and at the age of five years to facilitate early intervention to prevent learning problemsat school .

Early interventions are available andinclude assistive technology devices serviceaudiology, familytraining, counselling and home visits, medical services for diagnoses or evaluation, health services, nursingservices, nutritionservices, occupationaltherapy, speech and hearing therapy, social work services,and transportation to school; some mightneed more than one of theseservices depending on the severity of the disability. Typically, family training or counselling andearly childhood educationshould beconducted by a multidisciplinary training team.

Awareness of and government funding for mental health initiatives are inadequatein comparison with HIV / AIDS, Malaria, and TB programmes.Therefore,an annual mental health awareness congress is recommended with the aim of educatingand increasingthe awareness about mental illness. Advocates for mental health and organisations across the country should synchronisetheir efforts bysponsoring a variety of events to promote community outreach and public education programmes aboutmental 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 advocatingfor 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 erasethe stigma of and discrimination againstmentally handicapped children.

It is recommended that the professionals should understand the needs of mental health care users byinvestigating or researching their plight in order to make fair and appropriate decisions.They need to receivein-service trainingto empower them withmore knowledge to advocate, assess, diagnose and take accurate decisionsfor or on behalf of the affected person. Health professionals should be familiar with Mental Capacity Act (2005) in order to protect people who do nothave the mental capacity to take decisions for themselves due to their learning disabilitiesor mental health conditions, such as brain injuries,astroke, or any other physical conditions or illness thataffects 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 thefulfilment of their sexuality. These people are vulnerable due to their lifelong relatively powerless position in society and due to thelack of education with regard tosexuality 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 thatprofessionals do not implementsuitable interventionsthat 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 assessmentabout the proper diagnosis.Instead, they sentthem back home afterthey were told that they werenot mentally handicapped on the assumption that they were merely interested in receiving a social grant. It is important to investigate among professionals whether thePatient’s RightsCharter and the Batho Pele Principlesareimplemented;their knowledge aboutmental illness should be assessed with the aim ofunderstandingwhethermental health care users are properly and accurately serviced.

5.4.2 Addressing the psychological impact on the family (parents andsiblings)

Having insight into psychological stressors is the first step that leads to self-actualisation and self-realisation.Therefore,thoroughknowledge and information are powerful coping tools. Families will benefit greatly from family education programmes. These programmes should bedesigned to equipfamilies with the most up-to-date information about intellectual disabilities. As parents become more informed, they become better preparedto cope with their stress. Likewise, skills training programmes, such as parent coached language intervention, teach families how to manage difficult behaviour.Communication inadequaciesare 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 programmesalso help families to use specialised learning techniques. Supportgroups offer opportunities for families to support oneanother .

Family therapy is useful for the entire family in order to ease tension and create the possibilitiesto properly manage a problematic situation, such as adjustment to the illness. It should be a continualprocess to resolvelong 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 totheir psychological distress.Hence,it is recommended that family therapycould be extremelyimportant 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 fromdepression, 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 oneanother. Support groups provide anideal platform whereparents express their difficulties, shareexperiences, solvetheir problems, and most importantly develop a mutual help system by sharingpractical advice and emotional support . They encourage one anotherto praise their children when they dowell, build the abilities oftheir children, assistthemwhen they need help, and collaboratively find opportunities in the community for social activities; such as scouts,recreation centre activities, and sports.This will help thechildren to acquiresocial skills while they arehavingfun.

When parents receive a diagnosis that one of theirchildren is disabled, many families may adjust to this in a healthy way and cope well.Other parents, however, do not.Social support systems arewell recognisedas a significant factor that enables familiesto copeand adjustbetter toachild’s disability.

The researcherrecommendsthat priests and other spiritual members of the community can help withthe therapy of mentally handicapped people by appealingto the community to love one another as human beings.This will decrease isolation and discrimination,decrease social destruction,sincethe parents and siblingsof amentally handicapped child get an opportunity to actively participatein church activities.Personswith disabilitiesshould be allowedto determine for themselves whetherthis is an area that is important to them;they should be allowed an opportunityto participate if they so desire.An individual'sparticipationin either spiritual or religious aspects of life potentiallycouldaffect 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 recommend that taking care of one'sphysical needs will reducesone'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 ofrecharging the batteries.Whenparents take care of their own relaxation needs first, then they wouldhave 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 wouldallow them to focus on solutions rather than on counter-productive guilt and self-criticism.Make time for laughter whilelimiting time for criticism(Logsdon, 2014).

5.4.4 Addressing socio-economic problems

The cultural community to which achild 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 inthe family. A person can feel isolated not only because of his or her difficulties but also because of the failureby a community to integrate that person. As a result, a person experiences loneliness, not onlybecause of personality or social skills, but because of failure of the systemsof thecommunity 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 wereunable to apply for work because theirmentally handicapped children needed special attention. Therefore, the easiest and cheapest way for them to make use ofthe health service is for health workersto reach them at their local clinics as often as possible. Social welfare should assist withproviding food parcels,hampers, and social grants. A study by (Kgole,2009)aboutempowerment report thatthe professional nurses believe families donot taketheir mentally handicapped children for the expected monthly visits at the clinic. On the other hand, nurses areunable to empower the families of the mentally handicapped,sincethey complain about the shortage of staff anddonot have transport to do the follow-up visits.They haveno opportunities outside thecommunities to educate the families about mental illness and refer those children withproblems to apsychiatrist at thehospital, for example childrenwho suffer from epilepsy.

Mental health communities should be monitored by including mental health indicators in heath 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 resultfrom 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 ofmental health services tocommunities 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 situationencourages 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 andwhile they are not taught skills like carpentry and welding, furthermore they do not attend school everyday due to limitedavailability of transport to and from school. The study definesthe impact of poverty to explain the inadequateprovision of resources for minoritiesin special education.The study indicatesthat learnersfrom special schools are more likely to be poor and povertyincreasestheir exposure to risk factors that compromise human development and the need for special services .The absenceof an understanding ofthe 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,sincethey provide training and other resources to equip mentally handicapped learnersto work.

Roles of professionals in assessingand planningfor learner ‘s skills to identify any problems with regard to the IQ arerecommended as a major ingredient forsuccessful school-to-work transition programme.Such a programme comprisesa comprehensive, interdisciplinary vocational assessment that integrates a variety of school personnel and community organisationsinto 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 collaborativelyto identify relevant transitional needs and plan appropriate services. Parents, state agencies, employers, business organisations, and learnersmust also be involved in the vocational assessment to some extent.

The goal of avocational assessment is to facilitate educational and vocational planning that will allow a learnerto adjust successfullyfrom schoolto 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 usingpublished tests and surveys, as well as direct interviewsand observation ofa learnerwith the aim ofidentifyingstrengths (advantages) and weaknesses (disadvantages) in differentareas. 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 simulatedwork environments,and career maturity (the extent to which a learnerhas anadequate understanding of themselves, the work world, and decision-making skills). Therefore,government should implement vocational training centres and allocate sustainablebudgets tothose 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 particularlyassist with the gathering of information that is relevant tolearners’ cognitive, academic, and interpersonal skills. Psychologists can also assistwithproviding career guidance. Therefore,the researcherrecommendsthat 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 learnerswill need when they leave high school.Representatives from these agencies can help facilitatecommunity living, arrange job training andeducation,assist with transportation and employment provision, and transition them from a school to a work setting.These representatives can help learnersand their families to complete and submitthe necessary paperwork and application material to ensure that all the necessary services are available to the learnerswhen they leave school. Learners should be present at transition planning meetings toincrease their self-determination and their ability to set goals and make choices.

5.5 RESEARCH SUGGESTIONS

More researchabout biological and psychosocial aspects of mental health is needed in order to enhancethe understanding of mental disorders and todevelop more effective interventions.Such research should be comprehensive and on an international basisto better understand variations betweencommunities 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 continuallyto either confirm or reject the findings of this study with the purpose ofaddressing 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 assistresearchers to check whetherthe experiences are similarin all categories and will enable them to provide recommendations that will assist them to address suchchallenges 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 inother provinces in South Africa to establish in what ways the copingoffamilies in caring for their mentally handicapped children is either similar or different.

5.6 LIMITATIONS OF THE STUDY

The study was conducted atone school of mentally handicapped learners inthe 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 enduretraumatic 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 thatleads to poor interaction with mentally handicapped children, and poor co-ordination of a multidisciplinary team thatdelays early interventionsin thedelivery 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 includethe families of children with developmental delays.This will ensure that parents and their children will receive the necessary assistance that they desperately need.

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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

UNIVERSITY OF LIMPOPO
Medunsa Campus
2013 -10- 03
MEDUNSA RESEARCH ETHICS COMMITTEE
MREC CHAIRPERSON

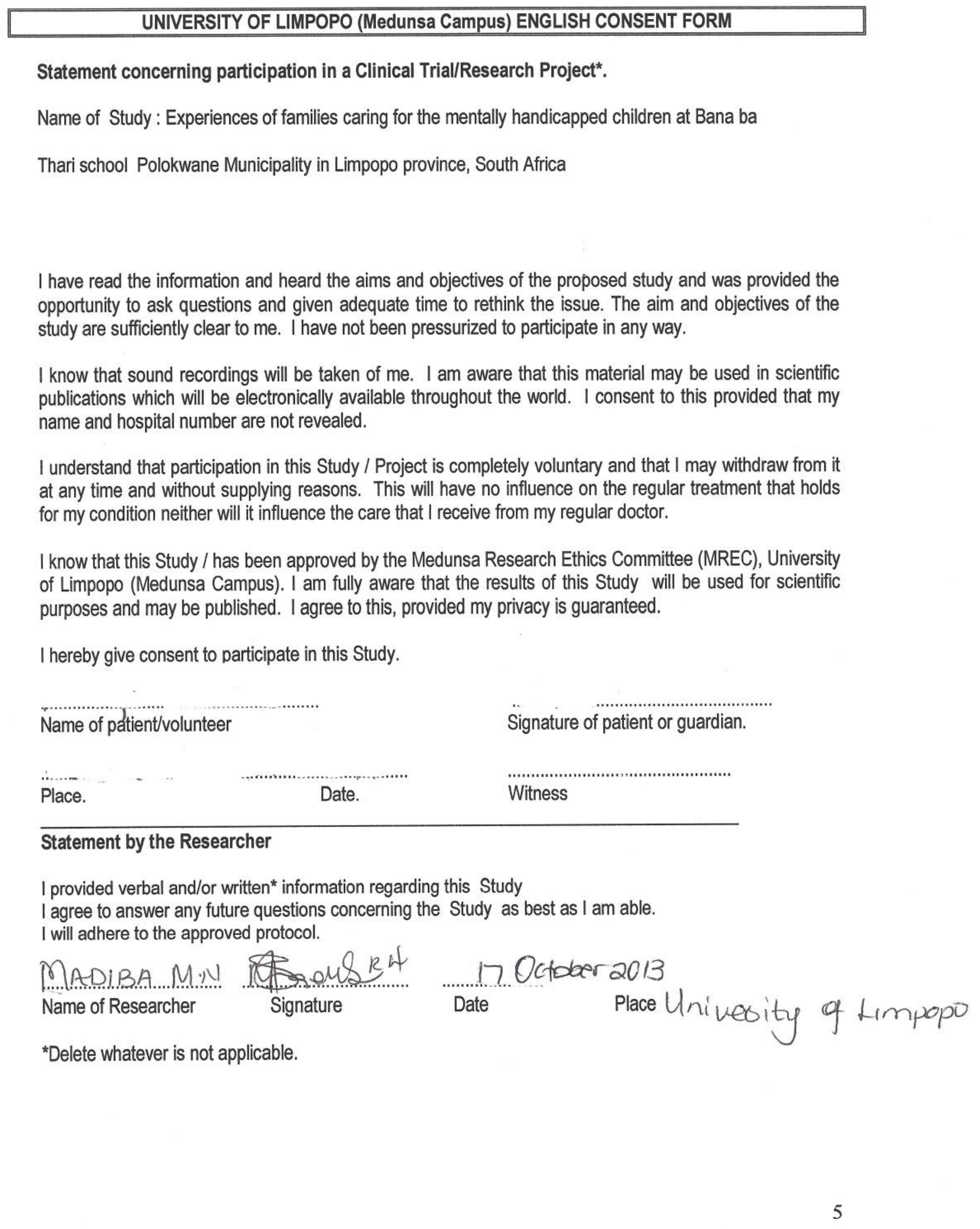
PROF N EBRAHIM
DEPUTY CHAIRPERSON MREC

The Medunsa Research Ethics Committee (MREC) for Health Research is registered with the US Department of Health and Human Services as an International Organisation **(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.

Finding Solutions for Africa

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.N   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 tšea karolo ka go ya Dinyakišišo

Leina la Dinyakišišo

Maitemogelo a ba lapa mabapi le go hlokomela bana ba bona bao ba sa itekanelago monaganong, Masepaleng wa Polokwane, districting ya Capricorn, Profenseng ya Limpopo.

Ke badile/ke kwele ka ga tshedimošo mabapi le *maikemišetšo le morero wa* dinyakišišo tšeo di šišintšwego gomme ke ile ka fiwa monyetla wa go botšiša dipotšišo gomme ka fiwa nako yeo e lekanego gore ke naganišiše ka ga taba ye. Ke tloga ke kwešiša maikemišetšo le morero wa dinyakišišo tše gabotse. Ga se ka gapeletšwa go kgatha tema ka tsela efe goba efe.

Ke a kwešiša gore go kgatha dinyakišišong ka ga boithaopo gomme nka tlogela go kgatha tema nakong efe goba efe ntle le gore ke fe mabaka. Se se ka se be le khuetšo efe goba efe go kalafo yaka ya ka mehla ya maemo a ka gape e ka se huetše le ge e ka ba tlhokomelo yeo ke e humanago go ngaka yaka ya ka mehla.

Ke a tseba gore dinyakišišo tše di dumeletšwe ke Medunsa Research Ethics Committee (MREC), Yunibesithi ya Limpopo (Khamphase ya Medunsa) .Ke tseba gabotse gore dipoelo tša Dinyakišišo/ di tla dirišetšwa merero ya saense gomme di ka phatlalatšwa. Ke dumelelana le se, ge fela bosephiri bja ka bo ka tiišetšwa.

Mo ke fa tumelelo ya go kgatha tema dinyakišišong.

....

Leina la molwetši/ moithaopi Mosaeno wa molwetši goba mohlokomedi.

....

Lefelo. Letšatšikgwedi.

Tlhatse

Setatamente ka Monyakišiši

Ke fana ka tshedimošo ka molomo le yeo e ngwadilwego mabapi le dinyakišišo.
Ke dumela go araba dipotšišo dife goba dife tša ka moso mabapi le dinyakišišo ka bokgoni ka moo nka kgonago ka gona.

Ke tla latela melao yeo e dumeletšwego.

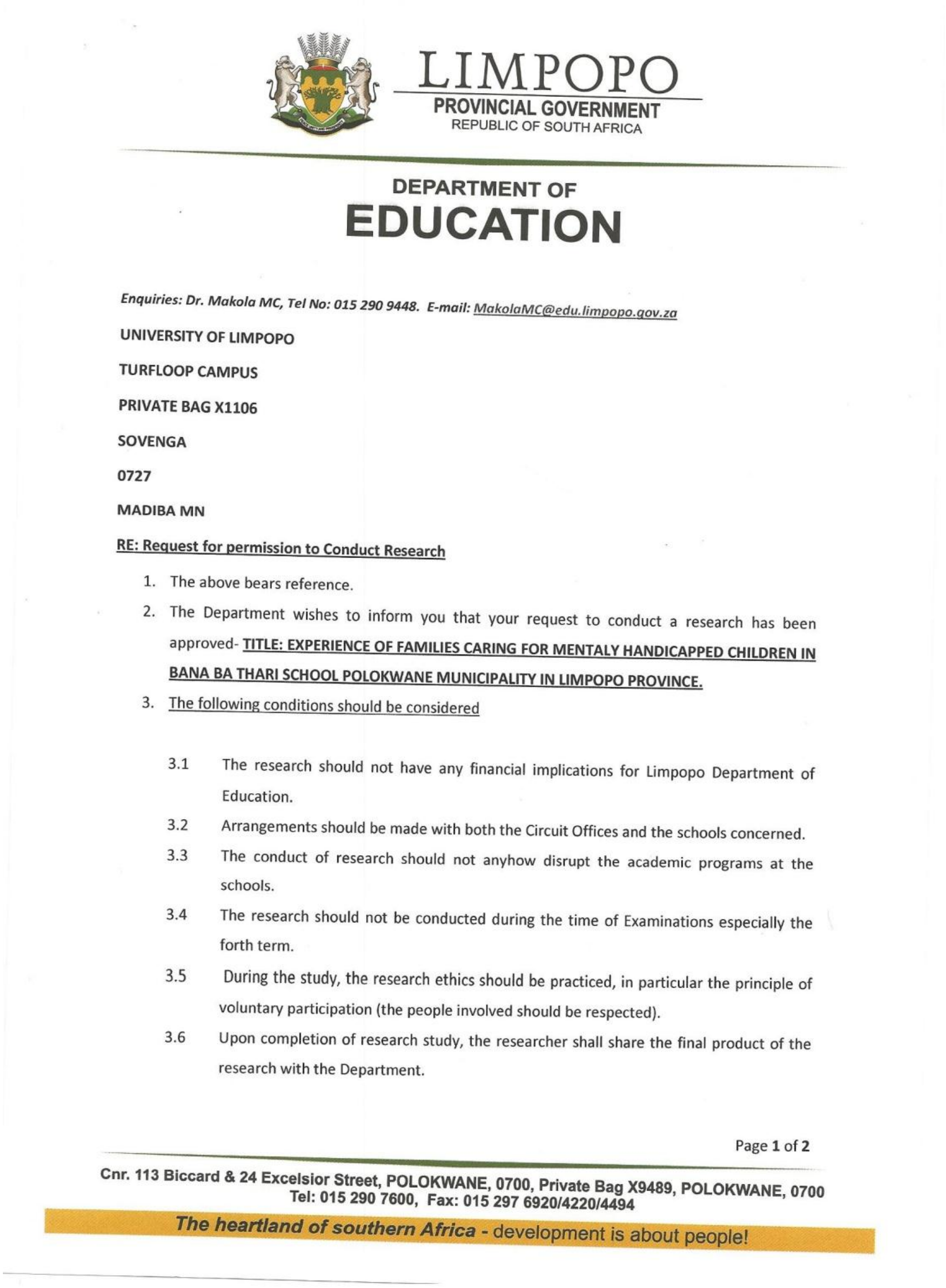
MADIBA M.N .... 17 October 2013 University of Limpopo

Leina la Monyakišiši Mosaeno Letšatšikgwedi Lefelo

*Phumola tšeo di sego maleba.

8

APPENDIXC: APPROVAL LETTER(DEPARTMENT OF EDUCATION)



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF
EDUCATION

Enquiries: Dr. Makola MC, Tel No: 015 290 9448. E-mail: *MakolaMC@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 MENTALY HANDICAPPED CHILDREN IN BANA 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 Biccard & 24 Excelsior Street, POLOKWANE, 0700, Private Bag X9489, POLOKWANE, 0700
Tel: 015 290 7600, Fax: 015 297 6920/4220/4494

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.

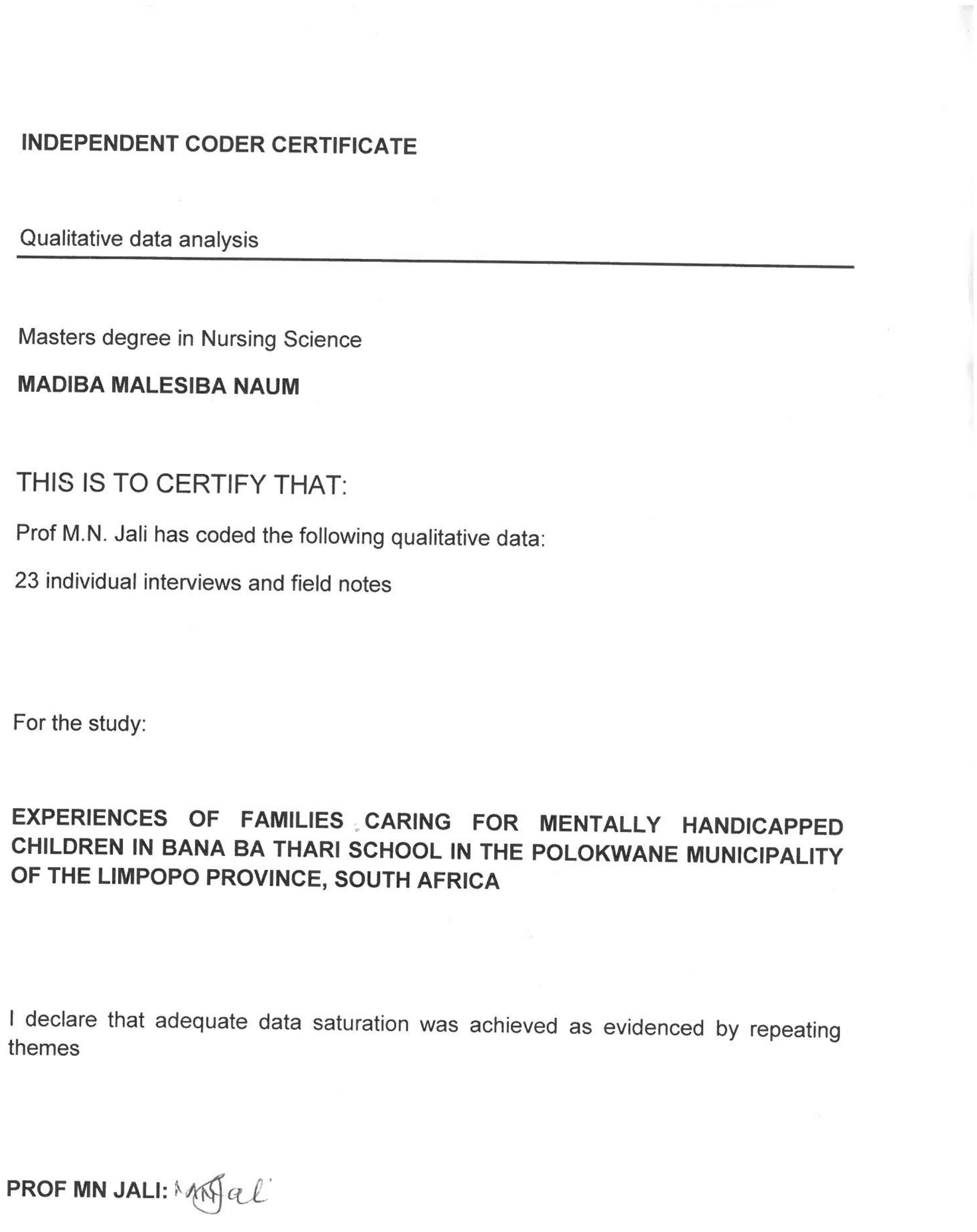
04/03/2014

Dederen K.O

Acting Head of Department

Date

APPENDIX D: INDEPENDENT CODER CERTIFICATE



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

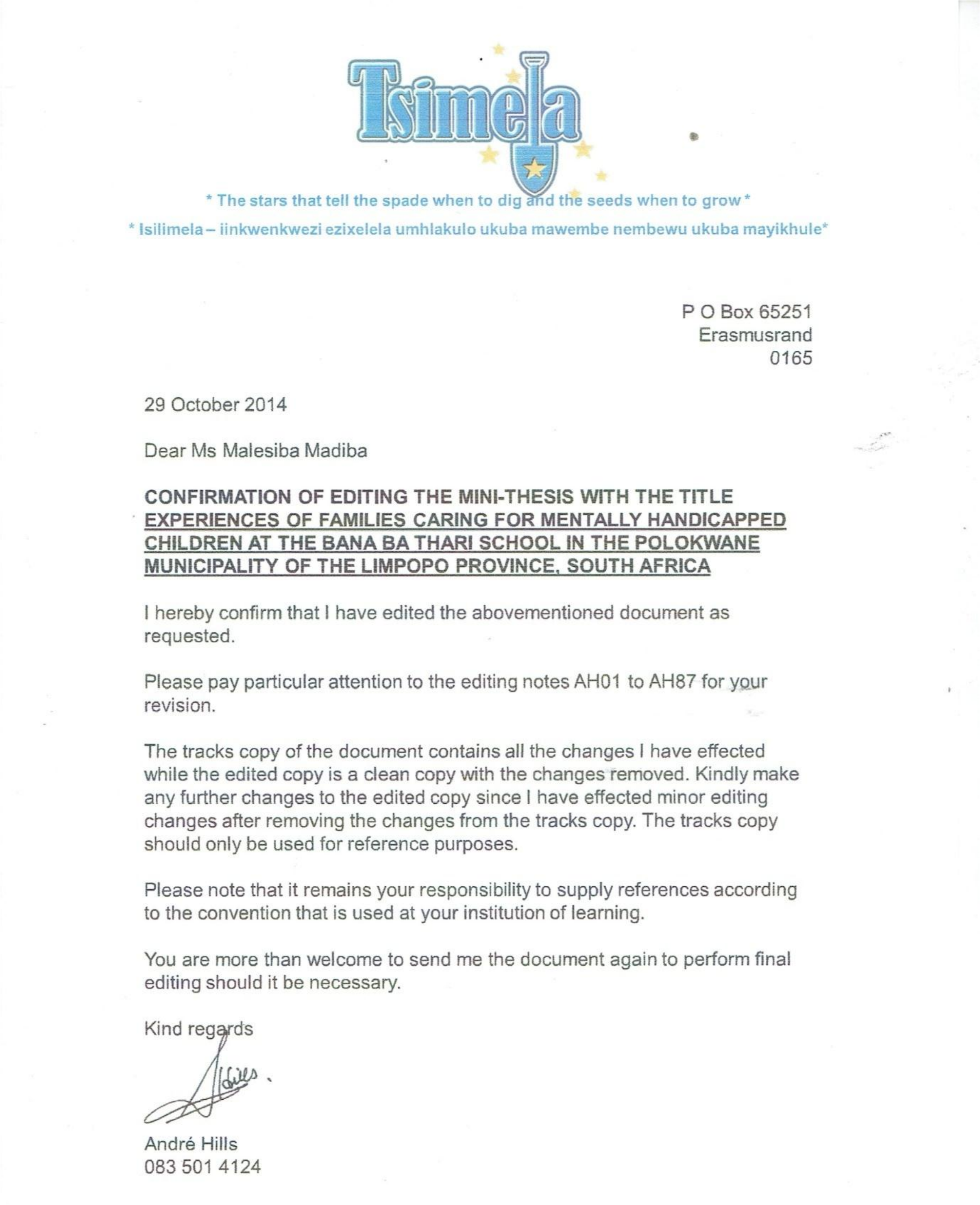
For the study:

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: MNJali

APPENDIX E: THE EDITOR LETTER



Tsimela

* The stars that tell the spade when to dig and the seeds when to grow *

* Isilimela – iinkwenkwezi ezixelela umhlakulo ukuba mawembe nembewu ukuba mayikhule*

P O Box 65251
Erasmusrand
0165

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

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 yousay to him do not touch, he touches. When youtake 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 hlalosa bjang boitemogelo bja gago mo tlhokomelong ya ngwana yo a sa itekanelago ka hlogong?**

P: Ngwanaka ke motho yoo a sa kgonego go bolela ga botse ga a kgone go hlalosa 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,Taba 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 bohloko ,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 mmuso 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 .