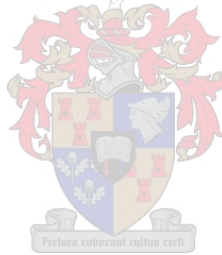**Exploration of the Coping Strategies of Parents/Care-givers in the Management of Health and Rehabilitation Problems of their disabled Children**

V. V. Duma

Research assignment presentation in partial fulfilment of the requirements of the degree of M Phil Majoring in Rehabilitation at the University of Stellenbosch

Supervisors: **Gubela Mji**

Alana de Kock

March 2012

DECLARATION

By submitting this thesis, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification. I have used the Vancouver style for citation and referencing. Each contribution to, and quotation in, this assignment from the work of others has been attributed, and has been cited and referenced.

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Date: march 2012

ABSTRACT

This is a descriptive, phenomenological, qualitative study which explores the experiences of and coping strategies employed by the parents/caregivers of disabled children in the management of their care, including rehabilitation and schooling.

The study was conducted in the rural communities of the Eastern Cape outside Mthatha, where parents/caregivers of disabled children have historically had challenges finding suitable schooling for their intellectually impaired children. In 1999, Happy Home community rehabilitation centre for disabled children was established by Mrs. V.V. Duma, a parent of a disabled child. Study participants comprised of parents or care-givers of the disabled children residing at Happy Home. A total of 37 participants took part in the study, comprising of six focus group discussions of six parents/caregivers per group, and one individual interview.

Study findings revealed that parents/caregivers used a variety of coping strategies to manage the care of their disabled children. Both positive and negative coping strategies were used. Negative coping strategies included abandoning the child, which was justified by, for instance, belief that the child had been bewitched by in-laws, or on the pretext that the mother's HIV positive status had been caused by the father, leading to the mother abandoning the child. In cases where both parents had abandoned the baby, or the death of a parent occurred, a caregiver, often a relative, would take responsibility for the child.

Positive strategies can be characterized as willingness by parents/caregivers to do whatever it takes to help the children to survive and access better opportunities. The caregivers/parents who adopted positive coping strategies were mainly from Christian backgrounds and consequently believed that a disabled child is God's gift. These parents/caregivers seek assistance from a number of different sources to help the disabled child, including from faith healers, traditional healers, and western medical treatments.

Cultural influences on the reactions of parents, extended family and the wider community as revealed in the study show that disability is seen in negative terms and that the abuse of women, including while pregnant, is supported as a cultural norm. It was found that

stress, abuse, and poverty during pregnancy were perceived by parents to be some of the causes of disability in new born babies. Parents/caregivers experienced barriers to health and rehabilitation including; long distances to health and rehabilitation centres with prohibitive transport costs. It appeared that health care providers did not communicate about children's conditions or would not treat sick disabled children. There were also data that indicated that there were some health care providers who were helpful and that parents/caregivers used other resources such as radio programmes to educate them about disability.

The study sought to understand the challenges that disabled children and their parents/caregivers experienced. The results of the study indicate that workshops with the health professionals to change their attitudes, and enhance their understanding of disability should be conducted. In addition, community awareness and education campaigns about causes, and signs and symptoms of disabilities; and the issue of cultural norms that impact on the abuse of women and negative attitudes towards disabled children need to be conducted among the communities from which the study participants originate. Furthermore, the study recommends that the Health Science curriculum include a generic module on disability studies to be completed by all health science students, to ensure that as health practitioners such as therapists and nurses, they can be more effective in responding to the needs of disabled children.

ABSTRAK

Die studie is 'n beskrywende fenomenologiese navorsing, wat die ervaring van ouers/versorgers van gestremde kinders ondersoek; asook die strategiee wat deur hulle aangewent word om te help met die versorging, rehabilitasie en onderrig van gestremde kinders. Die studie het gebruik gemaak van kwalitatiewe data kolleksie metodes. Ouers/versorgers van gestremde kinders wat in Happy Home woon het aan die studie deelgeneem. Ses groepsbesprekings, met ses ouers in elke groep, sowel as individuele onderhoude met elke deelnemer was uitgevoer. In totaal was daar 37 deelnemers in die studie.

Die studie was uitgevoer in die plattelandse gemeenskappe buite Mthatha, in die Oos Kaap. Ouers/versorgers van intelektueel gestremde kinders het probleme ondervind om geskikte onderwys te vind vir hulle kinders in hierdie area. Happy Home, `n gemeenskapsrehabilitasie sentrum vir gestremde kinders, is in 1999 deur Mev J.J.Duma, `n ouer van `n gestremde kind, gestig.

Daar was bevind dat ouers/versorgers `n veskeidenheid hanterings meganismes, positief en negatief,gebruik om hulle gestremde kinders te versorg. Negatiewe stratigee soos om die kind te verlaat is ingesluit en is geregverdig deur, bevoorbeeld, die geloof dat die kind deur skoonouers betower was, of op die voorwendsel dat die moeder se HIV postief status, veroorsaak deur die vader, die oorsaak was dat die moeder gevolglik die kind verlaat het. In Ingevalle waar beide ouers die baba verlaat hetof waar `n ouer gesterf het, het `n versorger wat gewoonlik `n familielid was, verantwoordelikheid geneem vir die kind. Postiewe strategiee is kenmerkend van ouers/versorgers se gewilligheid om alles moontlik te doen, om die kinders te help om te oorleef en toegang te he tot beter geleenthede. Ouers/versorgers wie positiewe strategiee aangewent het was waarskynlik van Christelike agtergronde en het gevolglik geglo dat 'n gestremde kind 'n gesekenk van God is. Sulke ouers/versorgers soek bystand van 'n verskydenheid hulpbronne, om die gestremde kind te help; insluitend die dienste van 'n geloofsgeneser, tradisionele genesers, en westerse mediese behandelings.

Die studie het gewys dat kulturele invloede op die reaksies van ouers, die familie en die wyer gemeenskap veroorsaak het dat gestremdheid in `n negatiewe lig gesien word en dat die mishandeling van vroue, insluitende swanger vroue, ondersteun word as `n kulturele norm. Daar was bevind dat spanning, mishandeling en armoede gesien word as oorsake van gestremdheid in pas gebore babas. Ouers/versorgers het struikelblokke teegekom met betrekking tot toegang tot gesondheids dienste en rehabilitasie. Dit het lang afstande na gesondheids- en rehabilitasie sentrums asook onbekostigbare vervoer uitgawes   ingesluit. Dit het voorgekom asof gesondheidsorg voorsieners nie oor die kinders se toestande gekommunikeer het nie en nie siek gestremde kinders behandel het nie. Daar was data wat daarop gewys het dat sommige gesondheidsorg voorsieners behulpsaam was en dat ouers/versorgers ander hulpbronne soos radio programme gebruik het om hulself in te lig.

Die studie het gepoog om die plattelandse konteks en die uitdagings wat gestremde kinders en hulle ouers/versorgers ondervind het te verstaan. Die studie resultate dui daarop dat werkswinkels met gesondheidsorg verskaffers gehou moet word om hulle begrip van gestremdheid te verbeter om sodoende hulle houding teenoor gestremdhied te verander. Daarbenewens moet opleidings en inligtings veldtogte oor die oorsake, tekens en simptome van gestremdheid, oor die impak wat kulturele norme het op die mishandeling van vroue, en oor die negatiewe houdings teenoor gestremde kinders, in die gemeenskappe waarvandaan die studie deelnemers kom gehou word 'n Verdere aanbeveling is dat die kurrikulum vir Gesondheids Wetenskappe 'n algemene module oor gestremdheid studies insluit; om voltooi te word deur all studente wie Gesondheids Wetenskappe studeer; sodat terapeute en verpleegsters grooter kennis sal dra van die behoeftes van gestremde kinders.

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Finally, words of gratitude go to my family for their support during my study, My daughters Busiswa and Ayanda and my grandsons Siyamthemba and Lilo who was four years old; for understanding when I told him I cannot read story books for him because I am busy with my school work. My lovely son Zola; I now understand why I gave birth to you; you gave me insight into my life's purpose, and ability to think globally about disability. This achievement is for both of us.

Definition of terms

Disability

"A person with disability is limited in one or more functional activity. This may be in seeing, hearing, communicating, moving, learning or other intellectual and emotional activities. The impairment may be permanent, recurring or transitory. It may be sensory, physical, cognitive or psychological. However, people who have severe impairments experience barriers and discrimination in society".[1]

Coping

Coping refers to the thoughts and actions we use to deal with stress. In large part, feeling stressed or not depends on whether we believe we have the coping resources to deal with the challenges facing us[2.]

Culture

The term culture generally comprises languages, religions, customs, and manners, material goods, aesthetics and education. Language is considered as a particularly important key for understanding foreign cultures as information is transferred this way. Speaking the same language allows for direct access to diverse cultures[3.]

Rural

The Rural Doctors Association of South Africa (RuDASA) defines rural as characterized by inadequate access to health services and relatively high levels of deprivation. Rural areas are outside of cities and towns, farming and other communities with very low population density, and areas that are poorly served with basic services such as water, sanitation, electricity, schools, supermarkets etc[4.]

Stress

Stress is a state of mental, emotional or other strain; physical, emotional, or mental pressure. Stress comprises a pressure of adverse influences, circumstances and so forth that disturbs the natural physiological balance of the body[5]

Ubuntu

Archbishop Desmond Tutu defines Ubuntu as an African Philosophy of personal attributes whereby a person with Ubuntu is open and available to others, has a proper sense of self assurance that comes from knowing that he or she belongs to the whole and is diminished when others are diminished or humiliated, tortured, or oppressed[6.]

List of Acronyms

ADL	Activities of Daily Living
CP	Cerebral Palsy
CBR	Community Based Rehabilitation
COBES	Community Based Education and Service
DICAG	Disabled Children Action Group
DPO	Disabled Peoples Organisations
FAAR	Family Systems theory and Family Adaptation and Adjustment Response
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ILO	International Labour Organization
ISO:	International Standards Organization
RuDASA	Rural Doctors Association of South Africa
SAFOD:	Southern African Organisation for the Disabled.
SINTEF	Norwegian Independent Research Organisation
UNESCO	United Nations Educational and /Scientific and Cultural Organizations
WHO	World Health Organisation

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CHAPTER 1

1. 1.   Introduction

An introduction of the study is provided in this first chapter, the definition of disability is also outlined. This is followed by the description of the problem. Under the motivation of the study, the researcher as a parent of a cerebral palsied child narrates the story on how she coped with the management of health related challenges of her child.   The significance of the study to the community is discussed and the chapter closes with a summary.

1. 2.   Background of the study and the evolution of the problem

The aim of the study is to explore the coping strategies; that is; the thoughts and actions, of parents and care-givers of disabled children that live in the rural areas around Mthatha, in the Eastern Cape Province of South Africa, in the management of health and rehabilitation related problems.

The parents that are the focus of this research are mostly illiterate and live in rural areas. Some parents were stuck with their children, not knowing how to deal with their conditions, feeding was the major problem, they were dying before reaching the age of five years and some died due to home accidents. For example, there are cases where parents lock their children up at home and go to fetch firewood from afar or sometimes go to the river to fetch drinking water. In 2009 there was a case of a disabled child who was ordered by other children to fetch honey from a bee hive with bare hands, in an area of Mthatha called Tabase, when the bees attacked him, his peers laughed and ran away leaving him to be killed by the bees. Other children die from accidents at home when they have epileptic attacks when left alone, this has resulted in some of them falling over fires and burning to death.

I am a parent of a disabled child who is impaired with cerebral palsy. I too have experienced similar challenges to what the parents of disabled children in this study have experienced. For example, I had problems with care-givers who left me due to the belief that they would be infected with the epilepsy of my child. I used to explain to each new care-giver as this was disturbing to me since I was working in the communities as a health educator but that did not help me. I started by forming an organisation of parents

of disabled children called the Disabled Children Action Group (DICAG) where parents voiced their challenges. Most parents told us they were single due to partners who deserted them because they gave birth to a child who brought embarrassment to their families. The organisation provided consolation and relief for the parents as they were able to confess that they were happy to discover that disability is not for illiterate and poor people only, since even I, an educated person, who is respected by the community, also have a disabled child. The experience with DICAG made me appeal to the former State President Nelson Mandela to help us access the land to build a centre for our children. Former President Mandela was happy to assist us through the Sanlam Insurance Company who bought a small farm for the parents, where Happy Home, a centre for rehabilitation was built. The facility was opened on 25 October 1999. The centre accommodates children who attend the special school for children with Intellectual Impairment; young children from 3 years attend pre-school and physiotherapy treatments at Happy Home. Youth with intellectual disabilities do voluntary services such as gardening, egg production, cattle farming and vegetable gardening. They earn a monthly stipend for this work. They socialise and make friends, enjoy recreational facilities, water therapy with swimming and a jet bath, and hippo-therapy with two horses. That is how Happy Home started and became what it is today - a Happy Home for disabled children from rural villages of the Eastern Cape.

The Disability Discrimination Act defines a disabled person as someone who has a physical or mental impairment that has a substantial and long term adverse effect on his or her ability to carry out normal day to day activities.[7] Haywood.[8] in describing the United Kingdom's disability status, used a definition of disability in the report for improving the life chances of disabled people that recognised some of the wider social issues. She defined disability as the disadvantage of inequality experienced by an individual as a result of barriers that impact on people with impairments and/or ill health[8]. The report makes a clear distinction between health and rehabilitation. The research proposes that the distinction between disability and impairment or ill health can be stated as follows; disability is the result of social barriers that result from ill health or impairment, therefore, disability is not the ill health or impairment itself. In the researcher 's experience, the challenge is not about the disability of the children, but the social challenges which the parents are confronted with, such as; lack of support systems in the management of health and rehabilitation related problems of their children. At Happy Home parents could

not afford to take their children to schools with better facilities for their children due to financial constraints. Huang[9] states that learning a child's diagnosis of disability is a crisis for parents. Their reactions include shock, refusal to accept the diagnosis, anger, fear and uncertainty about the extent of disability and associated impairment. [9]   Dura-Vila[10] argues that raising a child with intellectual disability has significant consequences for parents and family. The impact of the disability has been found to be influenced by the socio-cultural context. Children born with intellectual disabilities are not always perceived negatively, but can be viewed as benefit if the parents attribution a sacred meaning to the birth of that child. It is suggested that these beliefs influence parental care and are related to a high level of parental concern and closeness. This has implications for family relationships and the life-cycle, as well as the propensity for help-seeking and service uptake.[10] Murray[11] argues that until policy, legislation, and some medical practitioners move from its present perspective of viewing disability as the failure of the individual, to a perspective that focuses on bringing equality of value for all, the relationship between health professionals and parents of children with disabilities, will be fraught with difficulties. It is further argued that, until disabled children are centrally and positively placed within the relationship between parents and professionals, the existing prejudice and oppression experienced by disabled children will dominate the relationship.[11]

The problem is not only the disability of their children but the lack of facilities and health care centres to assist them in the management of the health related challenges of their children. The Developmental Approach to Disability in South Africa stipulates that disability policies affirm the rights of disabled people. It is expected that institutional structures such as health and rehabilitation services support and respond to policy implementation and service delivery. However, these objectives are difficult to achieve in a society where the majority of the people experience gross poverty, inequality and under development.[12]

The Case Study of People with Activity Limitations by the Foundation for Scientific & Industrial Research at the Norwegian Institute of Technology (SINTEF) illustrates this situation more clearly in their study which was conducted at Madwaleni Hospital in the Eastern Cape on accessibility to the health care centres in 2008.

A mother who had a 7 year old child with severe cerebral palsy often needed to take her child to the local clinic because of recurring upper respiratory tract infections. The child was too big to carry and it cost up to 12% of the annual household income to pay for transport and fees for every visit to the clinic. The mother thus only took the child when the illness was really severe. This resulted in the child having pneumonia, loss of energy and not progressing in her development. Persons with disabilities are a heterogeneous group with a wide range of different abilities and needs. In a study conducted by Grut on access to Health Services for People with Disabilities in the Rural South Africa in the Eastern Cape, at Madwaleni Hospital, even where the disability might be of a similar type, contextual factors varied. Further, the impact and consequence of disability reaches far beyond the disabled individual to issues such as role changes, care needs, and lack of income. Disabled people have health and rehabilitation needs that require specialised management.[12] these needs are further exacerbated by lack of coordination and communication between programmes, departments, government and civil society; this is a critical factor that undermines the prioritisation of disability issues. Other sectors tasked with service delivery to promote the economic development of disabled people, include the Department of Social Development which provides Social Grants. The grants have been successful in alleviating the poverty in marginalised regions, which is an exception compared to the situation in most developing countries.[13]

There was still the need for a place where parents could bring their children for education. There were no specialised schools for their children in rural areas and they were not accepted in the mainstream schools. Parents were unemployed and used the disability grants of their disabled children to feed the whole family and pay the school fees for their non-disabled children. Looking after their children and transport fees to take their children to the hospital for physiotherapy treatments was not possible. I realised how difficult it was for me to take care of a disabled child with better health services since I was living in an urban area, how much more difficult for those who did not even understand the needs of their children. When the disabled child died he would not be taken to the mortuary since it is believed the child was not a human being, and would be buried without proper funeral arrangements. I started to inform parents and the community that a disabled child has human rights in our constitution and should be treated like any human being.

The question that still remained was whether the democratic changes that were followed by both constitutional and policy developments had any impact on disabled children and their parents/caregivers?

1. 3. The problem: policy to practice

In 1994 the first democratically elected government of South Africa developed policies that were meant to assist the plight of parents with disabled children. They can be summarised as follows:

- The National Rehabilitation policy states that people with disabilities are entitled to an assistive device that promotes a normal lifestyle, improves their quality of life, and enhances the prospects of employment, education and participation. Simultaneously, it reduces the cost of care and dependency. An assistive device reduces the extent of hospitalisation, as well as the demand for hospitalisation, and therefore liberates scarce resources for other use[14]

- The Health Policy Framework for Non-communicable Chronic Conditions in Children states that; chronic conditions, defined as physical conditions lasting for longer than one year, require comprehensive and co-ordinated long term health care.[14]

- The Free Health Care Policy for people with disabilities states that there will be free health care for disabled people. This would cover out-patient visits to hospital and admissions as well as disability aids such as wheelchairs and hearing aids.[14]

- The Children's Act states that Disabled children, like all other children, have important rights under the UN Convention on the Rights of the Child.[15]

It is evident that health and rehabilitation policies are available but the question is; have they improved access to health for all? And more pertinent to this study, has access to health and rehabilitation services for the parent/caregiver of a disabled child improved? There are many reasons that influence parents' delay in taking their children to health facilities. Some of these might be financial constraints to pay for transport or lack of transport itself and the long distance from their homes to the health care facility. In some cases, by the time the child gets to hospital, the condition has complicated to secondary impairment or death. If the child survives, he/she will need rehabilitation intervention from experienced health and rehabilitation professionals. In the Eastern Cape Province, the communities are mostly rural, and there is a scarcity of health and rehabilitation

professionals, such as doctors, physiotherapist and occupational therapists at district levels, and even worse at the community level.

The researcher found that due to a shortage of these professional services areas, there is a perception that parents of disabled children develop coping strategies to manage these health and rehabilitation related problems. Kaplan[16] stated that planning for the future of the disabled children and navigating limited resources, overcoming barriers in the environment, and creating positive social support were the four most important areas of mothers' abilities to cope with the demands of care giving for their disabled children.[16]

The goal of researcher has been to find out whether there are personality traits, beliefs, or ways of viewing the world that are more or less adaptive in various situations for the mothers and carers of disabled children. This study aims to explore the coping strategies of parents/care-givers of disabled children in the management of problems they experience. In other words, what are the personality traits, beliefs, or ways of viewing the world that enhance the lives of disabled children and their parents/caregivers?

1. 4. Motivation for the study

Many researchers have defined coping in different ways; Fuad.[17] citing Lazarus and Folkman, defines coping strategies in different ways and three themes seem to emerge:

- That it is relational, in that it reflects the relationship between the individual and the environment
- That it is a process, in contract to more traditional trait-content orientated approaches.
- That it is interactive in nature, linking other components of the stress process.

These imply that coping involves a certain amount of effort and planning. This concept of coping does not include automatic or reflex responses to a challenge this definition does not imply a positive outcome. Some of our coping responses may work well for us while others may not. The definition emphasises coping as a process taking place over time. The above features are important in a definition of coping because they allow us to study different styles and strategies of coping and to evaluate which ones work best in different situations. After looking at what has been learnt about coping strategies, one will be able

to distinguish between effective coping strategies and those that could be ineffective or dangerous. [17]

On the positive side, Cody[18] suggests that rising to the challenge of coping may raise some parents' morale. To their surprise, they discover in themselves unsuspected organizational strengths and parenting skills. They will inevitably meet a number of well-educated professionals and therapists and may share with them their otherwise unknown community resources. They may enlarge their circle of friends by bonding with parents of children with similar or other disabilities. Mothers may even return to school to start a new career related to their child's impairments.[18]

Providing care for the children with impairments comes with challenges linked to the nature of the child's diagnosis and to the resources to the caregiver. The author as a mother of a disabled child has experienced this. She will present her own personal experience of the coping strategies she used for her own 23 year old son with cerebral palsy who was born prematurely at seventh months weighing 3.8 kg as a case study.

My son started to have seizures at the age of three months. This is when I was informed that the child was disabled and that the condition was permanent. It was the first time there was a disabled child in my family, and this caused stress for our family. My first born who was 12 at that time, helped to care for her brother when the care giver left me due to the belief amongst rural Xhosa speaking South Africans, that epilepsy is infectious. The concept of Ubuntu in our culture has been defined in many ways. Desmond Tutu stated that a person with Ubuntu is open and available to others, does not feel threatened, believes that others are able and good, has a proper self assurance that comes from knowing that he/she belongs in a greater whole and is diminished when others are diminished or humiliated, tortured or oppressed.[6] My relative offered to take me to the faith healer. In order to show my appreciation to her for passionate concern, we went to the faith healer   My child came back with knitted wool tied around his waist, wrists and ankles, and two electric wires red and white were given to put in water to wash his eyes. I was surprised and told my cousin that it was a recipe for disaster besides the intellectual impairment my child was already suffering washing him with the electric wires in the water could have harmful consequences and would exacerbate his suffering. This prescription from the faith healer had no connection with epilepsy that I could understand.

The researcher's case study is an example of what parents of disabled children go through as a result of frustration from having a sickly and disabled child. My family's support helped me to acclimatise to the challenges of raising a disabled child. My coping strategies included establishing Happy Home, a centre for disabled children where I would share my experiences with other parents and use my counselling skills to console mothers who were deserted by their husbands and empowered them to be strong for their children. .

Some coping strategies may be harmful and these will be identified so that health education and prevention of secondary impairment through empowerment programmes can be provided, and promotion of safe coping strategies encouraged. Ingstad[19] says in her study conducted in Botswana with parents of disabled children that the role of women in the daily care of children and other dependant household members makes them the undisputable main actors of the popular sector of health care. Only in cases when the housewife is very ill, and there are no other suitable woman around, will a man feel obliged to take over the functions of care. Part of the health care done by women is performed through fulfilling the ordinary obligations attached to roles of mother, grandmothers, sisters, and daughters. Another part is more ritualised and acted out through institutionalised practices concerned with birth, pregnancy, and perhaps most important of all, the period of confinement after birth.[19]

The researcher in this study will show the supporting evidence of the assertion that personality traits and personal beliefs play a big role in one's choice of coping strategies. The researcher feels that parents in rural areas are influenced by their traditional beliefs, norms and values of their communities in choosing their coping strategies. Azar[20] stated that when a child has a disability; the role of caring takes an entirely different meaning for the parents. One of the main challenges of parents is to effectively cope with the child's chronic condition while juggling the requirements of everyday living. The coping strategies adopted by parents are often based on the culture they live in. Culture is regarded as the shared ideals, values, rituals, norms of behaviour, and beliefs within a society, which are passed down from one generation to the next. Although extensive research over the past two decades has identified the coping behaviours of Western mothers in caring for their child with chronic illness or intellectual disability, a limited

amount of research has been conducted regarding the coping behaviour of Middle Eastern and African parents. [20]

1. 5. Study Aim

To explore the coping strategies used by the parents/care-givers of disabled children in the management of health problems they experienced.

1. 6. Study Objectives

- Describe demographic details of the mother/care-giver, of the disabled child and family.
- Describe health and rehabilitation related problems identified by parents/care-givers of disabled children
- Investigate from parents/care-givers how and where these problems should be dealt with.
- Explore critical health related incidents experienced by parents.
- Describe the perception and experiences of parents/care-givers regarding accessibility of health and rehabilitation services.
- Describe facilitators and barriers to assessing health and rehabilitation services
- Explore coping strategies of the parents/care-givers of disabled children in the management of health related problems and critical health related incidents

1. 7. How the study will be used to benefit the community

- Initially results from perceptions of parents and carers of disabled children's will establish if there is any basis to the belief that health and rehabilitation services are often inaccessible to those in most need of care?
- Parents and carers of disabled children will share how they have developed coping strategies for the various health and rehabilitation problems they have experienced in caring for their children.
- The relationship between parents/caregivers of disabled children and professionals can develop, resulting in parents/care givers of disabled children sharing information on useful coping strategies and therapists sharing their bio-medical rehabilitation approach to the health related needs of the disabled child.

- The researcher is envisaging that once appropriate coping strategies discovered; these could be transferred to therapists in rural areas who struggle to deal with disabled children who require a special rehabilitation approach.

- The researcher perceived that amongst coping strategies of parents there could also be dangerous coping strategies and the mothers/caregivers of the disabled child will be discouraged from using those dangerous coping strategies and those will be replaced with more appropriate skills for that situation

- The therapists can use the knowledge of parents and help them to establish the practices that are dangerous and differentiate them from those that can be merged with professional knowledge.

- The results and recommendations of this study will contribute towards further development of the Happy Home Centre. Once the practices are fully documented, they can enhance collaboration between parents and professional service providers and planners. The Centre for Rehabilitation Studies, at the Stellenbosch University, as an academic resource centre, will use the research findings in journal publications.

1. 8. Study Outline

Chapter one provides the background and the motivation for the study, while chapter two discuss the literature that is available on coping and life skills of parents of disabled children in respect to the management of health and rehabilitation related problems of their children. The research design and methodology of the study is explained in chapter three. Study results are presented and discussed in chapter four. In chapter five the findings of the study are discussed and conclusions are drawn. In addition, chapter five will include recommendations for health and rehabilitation professionals, and parents/caregivers of disabled children.

1. 9. Summary of the chapter

The chapter started by defining disability, and the background of the study. The emerging problem was supported by giving health and disability policies in South Africa and the challenge of lack of implementation of these policies. Motivation as to why the study is being conducted was given through a narrative of the researcher as the parent of a disabled child. The aim and the objectives of the study were clearly stated. This was

followed by the significance of the study, and how the study will be used by the community. The study process was also outlined.

Chapter 2

Literature Review

2. 1. Introduction

This chapter will cover the definition of disability and disability models, parents' perceptions about disabilities of their children and health belief models with examples, the facilitators and barriers to healthcare facilities and the coping strategies of parents/caregivers. A description of the health conditions of children at Happy Home is provided. This chapter ends with a summary.

2. 2.   Disability Approaches

This section will cover the International Classification of Functioning, Disability and Health, the social model, traditional model, and the medical model and the definitions of disability by the World Health Organisation (WHO) will be discussed including the views of researchers about these definitions.

The WHO distinguishes between 'impairment' which is a loss of psychological, anatomical or physiological function or structure, and 'disability' involving the loss of functional skill resulting from an impairment and handicap, characterised by an inability to fulfil a normal role in society as a result of a disability. In the case of intellectual disability, the impairment in cognitive skills results in disability, which invariably affects the fulfilling of social roles.[21]

2. 2. 1. The International Classification of Functioning, Disability and Health (ICF)

The World Health Organisation in their definition of the International Classification of Functioning, Disability and Health defined an individual's functioning and disability as a dynamic interaction between health conditions and contextual factors. These contextual factors include both personal and environmental factors. Environmental factors can have a facilitating or hindering impact on all the components of functioning and disability.

The interactions between the components influencing a person's functioning and disability, as described by the ICF, are summarised in the model below in figure 1:

Figure 1: Diagrammatic representation of International Classification of Functioning, Disability and Health [21]
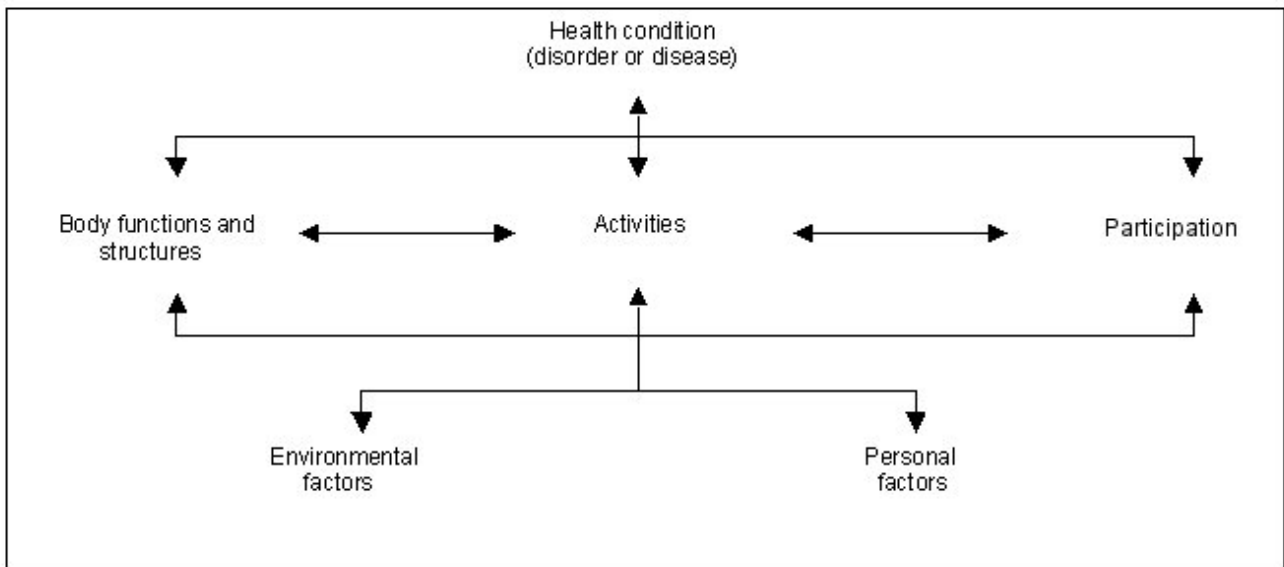
Source: WHO, 2004

In this diagram, an individual's functioning in a specific domain is an interaction or complex relationship, between the health condition and contextual factors (i.e. environmental and personal factors). There is a dynamic interaction among these entities: interventions in one entity have the potential to modify one or more of the other entities. These interactions are specific and not always in a predictable one-to-one relationship. The interactions work in two directions, the presence of disability may even modify the health condition itself. To infer a limitation in capacity from one or more impairments, or restriction of performance from one or more limitations may often seem reasonable. It is important, however, to collect data on these constructs independently and there after explore associations and casual links between them. If the full health experience is to be described, all components are useful. For example one may:

- Have impairments without having capacity limitations (e.g. a disfigurement in leprosy may have no effect on a person's capacity)
- Have performance problems and capacity limitations without evident impairments for e.g. reduced performance in Activities of Daily Living (ADL), associated with many insidious chronic conditions;

- Have performance problems without impairments or capacity limitations for e.g. an HIV positive individual, or a patient recovered from mental illness, facing stigma or discrimination in interpersonal relationships and at work;
- Have capacity limitations without assistance and no performance problems in the current environment for e.g. individual with mobility limitations may be provided by society with assistive technology to move around;
- Experience a degree of influence in a reverse direction for e.g. lack of use of limbs can cause muscular atrophy; institutionalization may result in a loss of social skills.[21]

The ICF defines disability as the outcome of the interaction between a person's health condition and the context in which the person finds him/herself. The context includes both factors external to the person (environmental factors) and those internal to the person (age, sex, education and skills level, coping style and personality). In order to fully describe the interaction and understand the relationships between all the different elements that lead to the experience of disability, we need information on the elements listed below. These apply both to negative and positive outcomes:

- The person and their personal characteristics;
- The external environment described both by the person and by an objective outsider;
- The process of interaction between these different elements, that is whether environmental factors are facilitators or barriers and how the environmental factors interact with each other;

If any one of the three aspects changes, the outcome will also change. An example is the wheelchair user who experiences severe disability when confronted with an inaccessible environment. The same person will experience very little disability, if any, when confronted with an entirely accessible and supportive environment.[21]

The researcher acknowledges the ICF Model for its contribution to understanding that disability is not a problem where the environment is user friendly to the disabled person, within this context, the incorporation of social model is also important in disability definition discussion. The social model is popular among the parents of disabled children

because it promotes the inclusion of the family in all stages of rehabilitation processes and recognises the family as role players in the health management of their family members.

2. 2. 2. The Social Model

This is not only consistent with what the international disability movement has been arguing for decades, but also with the stated policies of an increasing number of multi-and bi-lateral development agencies.

The social model of disability says that it is globally accepted that disability is a social construct and most of its effects are inflicted on people by the social environment. A person is disabled if the world at large will not take into account their physical, sensory or mental differences. Most of the day to day problems facing people with disabilities are caused by living in a hostile, disabling world which is largely designed to suit able-bodied people.[22] Disagreements over the answer to the definition of disability will continue. However, all the work done under disability knowledge and research has adopted, in one form or another, a social model based on an understanding of disability as a starting point.[23]

It is also important to include the traditional model since the children at the centre come from rural areas where the model is entrenched and plays a pivotal role in the decision making of parents and families of the disabled child.

2. 2. 3. Traditional Model

According to Seelman[24] the traditional model is based on culturally and religiously-determined knowledge, views, and practices. Depending on cosmology, social organization and other factors, cultures show a broad range of perspectives which place people with disabilities on a continuum from human to non-human. For example, some cultures practice infanticide, rejecting the humanity of disabled infants. The roles people with disabilities may assume within a given culture range from participant to pariah. When persons with disabilities are devalued, they may be perceived as demonic or unfortunate, and often take on the role of an outcast. The bias of the traditional model is cultural relativity. Objective, scientifically-based knowledge is not associated with this model. Across cultures, people with disabilities have been valued differently. In his presidential address before the American Association of Physical Medicine and Rehabilitation, Strax in 2003, made the following observation:

"From the beginning of time, humankind has wrestled with the paradox of what to do with people with disabilities. In ancient times, they were simply put to death. They were a burden on the tribe. In ancient Greece, there were 2 cities. Sparta removed the weak and the elderly for the good of the rest. In Athens, the warrior class protected the weak".[24]

The researcher is of the opinion that the traditional model and dehumanisation of people with disability need to be linked with the ICF model which considers the environmental factors as hindering the mobility of people, and personal factors; like the attitude towards them as limiting people from identifying their abilities.

2. 2 .4. Medical Model

Seelman continues to discuss the medical model and stated that it is based on scientific views and practice, based in the medical and health knowledge. The "problem" is located within the body of the individual with a disability. The context of the medical model is the clinic or institution. Authority lies with the professionals. The bias of the model is that the bio-medical and health-related explanation of disability is reduced to the impairment level. The perspective of the person with a disability and social factors are not routinely within the knowledge base of the medical model. The knowledge base used to educate health professionals is rigorously and routinely limited to medicine and the health sciences. As a consequence, health professionals may develop a view of disability that differs substantially from the reality of many disabled people. The following is a quotation from a medical doctor, cited in Seelman[24], before he became disabled, and afterward:

"I began to examine his nervous system…felt a sense of horror come over me. You can't feel anything here on your shoulder? You can't move your legs? I next met this man in spinal cord unit in 1985 as I was pushed to the computer next to him in occupational therapy. A few months earlier, I had severed my cervical spinal cord playing rugby and I was a quadriplegic- slightly more impaired than my former patient. Now, 15 years after becoming disabled, I find myself completely at home with the concept of ...being me. Now I know that my assessment of the potential quality of life of severely disabled was clearly flawed [24]

2. 2. 5. Critique of the medical model of disability

Lang[25] stated that in the medical model disability is defined primarily as a disease state and perceived as a deviation or abstraction from normality. The model asserts that the most significant problem that disabled people face is the loss of physical and/or cognitive impairments as well as occupational ability. Hence the medical model is deficit model, which views disability essentially as a problem, focusing upon the individual physical and /or mental impairments. Lang continues to say that the medical model has been criticised, especially by the disability movement, and found to be deficient on a number of counts. The principal criticism is that the medical model fails to give consideration to the socio-cultural contexts in which impairments are placed, and that disability is essentially a social, not a biological construct. The emphasis placed upon impairments and physiological conditions perpetuate the notion that disabled people are weak and dependent, and that physical incapacity essentially defines the quality of life that a disabled person is able to live. In criticising the model, one does not question the necessity and validity of receiving high quality medical support, but rather one challenge the nature of social conditions and relationship that are encountered when disabled people and the medical profession relate with each other [25].

2. 3. Stress associated with the diagnoses of a child's impairment/s

This section will give an overview of the experiences of the parents of disabled children, the stress associated with diagnosis of their children, the perceptions according to different cultural backgrounds, the impact of their cultural backgrounds on their coping and the beliefs of parents regarding disability and health as it impacts their health seeking behaviour.

2. 3. 1. Perceptions that cause the parent/caregiver of the child stress according to different cultural backgrounds

Bourke[26] argues that children with disabilities, are dependent on a capable, healthy and well-resourced environment for full community integration to occur. The results of the study revealed that the child's mother most often provides the care that ensures that child's health, service access and community integration are attended to successfully. Participants identified a multitude of challenges related the context within which the child is raised, such as maternal and family characteristics - especially emotional distress and mental health issues affecting the mother and family, services and the community. [26]

McKenzie[27] stated that the paradox is that while medical and welfare professionals undermine parents' confidence in their ability to do what is right for their children, they depend almost entirely on parents/caregivers to implement what those same professionals perceive to be the correct approach. It is always assumed that parents know better than anyone that raising a disabled child involves extra challenges, and that parents consequently need support. Mc Kenzie raised a concern that there is a general perception that parents are not deciding what form this support should take, but rather only the professionals are. It is as though the responsibility for the disabled child belongs less to parents, and more to professional helpers. This is often seen in rural communities where, as a result of years of a medical and welfare approach to disability, a disabled child is seen to be a "government's child. [27] The preliminary study by Manor[28] compares family functioning, caregiver burden, and coping abilities between mothers of children with developmental disorders and mothers of children with no such disorders in the Bedouin community in Israel. The study highlights the need to provide professional support for mothers of children with developmental disorders and to develop awareness and culturally appropriate intervention programs to enhance these mothers' coping abilities[28.]

"Parents of children with cerebral palsy (CP) perceive themselves as more stressed than parents of able-bodied children. This is supported by studies that looked at stress in parents of children with disabilities; largely reflecting the increased care demands placed on these parents. Parents of children with CP were, as a group, less satisfied than parents of able-bodied children with their inpatient experience at the Royal Children's Hospital in Melbourne. Because these children have complex needs and often require more care than able-bodied children, it is imperative that their needs are met and that parents are satisfied with all aspects of the care they receive in hospital. Phua suggested that further studies sampling other populations in different settings were needed to confirm her findings." [29]

In a study conducted in Turkey it was determined that a 61.2% depression ratio was found in mothers of children with CP compared with mothers of healthy children in Turkey. It was determined that, contrary to what would normally be expected, mothers' depression was not correlated with the severity of CP. It was reported that mothers of children with speech disorder had significantly higher levels of depression than the mothers of healthy children. In contrast, children of mothers suffering from depression

were reported to be at risk of speech impairment because their mothers tended to communicate less. Therefore, speech impairment of a child may either be the reason or the consequence of a maternal emotional disorder[30]

This is the case study of a parent of a child with disability showing that parents sometimes have unrealistic expectations for their child and these expectations may manifest as some form of psychosis where a person loses the ability to distinguish reality from fantasy.[30] As one such mother said: "I speak for a moment, as one such woman who had a daughter with cerebral palsy. Like any mothers of children with disabilities, she said I played a mind game. What if someone – a magician, a god, a doctor were to say to me "I will remove your daughter's disabilities"? In spite of my enormous respect for the disability rights perspective which values life regardless of (dis)ability and which eschews the search for cures, I know that without a moment's hesitation I would say, "Yes, please, oh please, give my daughter clear speech so that others can understand her." If that wish were to be granted, I would unabashedly beg that she be given the ability to make her hands do whatever she bid them to do- to pick up a crayon and draw, to feed her, to write with a pencil or type on a computer with ease. And if there were gifts still to be given, yes, I would ask that she get out of her wheelchair and walk. And yet, paradoxically, I now suspect that such a joyous day would also be one of profound loss for me. For I can no longer imagine who my daughter would be without her disabilities."[30] It appears that parents of disabled children are at risk of poor mental health. This poor parental mental health could be attributed to perceived parental distress.

In the study conducted in the Eastern Cape Province, Gara[31] in her Master's thesis, published in 2007, states that even with mothering a normal child, problems may arise, but with a disabled child these problems are profound because they have emotional, physical and financial implications. Strategies for the development of parents/caregivers could be to support them in their struggles through programmes that would be devised to eliminate the extent of their struggles, which could be achieved with assistance from advocacy organisations.[31] The difficulties (e.g. care, psychological, social and economic) experienced by family members during the process of adaptation toward living with the disabled child can lead to conflict within the family and there may be changes in individual roles and functions within the family.[32] Ingstad[19] made clear that "the presence of a disabled family member may clearly affect the use of time in a household. Extra time

taken up in caring for the disabled person takes the care person's time away from other tasks and the need for attention puts constraints on the activities that non-disabled members may allocate their time for."[18]

Van Rooyen states that a disabled child can pose a serious threat to, or even damage, the parental ego because a child represents the extension of the parent's self. Thus the reaction of parents when they recognise impairment in their child is highly unpredictable. In most instances these children cause their parents extreme disappointment because of their inability to meet the parents' expectations.[33] Many parents when they are informed that they have a disabled child, will start with self-search which, often leads to self-blame and guilt, especially with children who are autistic where the cause is still unknown. stated that Guilt is difficult to dispel and professionals can help the parents to channel their energy into more constructive emotionally healing activities.   As defence mechanism, withdrawal, might shield the parents against outside pain if not against the hurt inside. However, withdrawal is damaging because parents isolate themselves from friends, family, and professionals who can help with the healing process.[34]   The researcher anticipates that parents of disabled children are subjected to stress, and sometimes have unrealistic expectations.

2. 4. The impact of the parents' cultural backgrounds on their coping strategies

American mothers of children with disabilities find themselves at the crossroads of four, sometimes mutually supportive, sometimes competing, discourses:

Landsman[35] provides a useful discussion of the discourses surrounding parenting:

- The discourse of popular culture, in which childhood disability is a tragedy which either a mother caused through her improper behaviour during pregnancy, such as` drug or alcohol use, or for which she was specially chosen by God as being strong enough to bear;

- The discourse of paediatric medical practice that presents disability, especially mental impairment whereby the central nervous system has permanent, pathological and located within the individual, i.e., in which children with brain damage or other disabilities are often "written off" as hopeless burdens;

- The heroic discourse of progress and rehabilitation, in which disability can and should be cured or its effects overcome- a discourse supported by the concept of

developmental delay, in which a combination of therapy, parents' hard work, and a disabled child's determination and force will minimize or eliminate disability; and

- The discourse of disability rights activism, the independent living movement, and the associated social model of disability according to which it is primarily society's response to impairment, rather than impairment itself, that presents obstacles to a high quality of life, a position that presents disability, a high quality of life, and personhood as indeed fully compatible. Landsman stated that "While it is increasingly possible to envision "perfect" babies, it is not always the case that reproduction actually precedes according to individual will; for example, there has been no recent reduction in rates of childhood disability."[35]

Cody,[18] in her study with children with cerebral palsy, stated that a planned pregnancy is usually a time of joyous anticipation; parents expect the birth of a healthy, cute, vigorous infant who will give little anxiety while growing up to become an independent, capable adult who will provide grandchildren to cherish and spoil. The premature delivery of their child, or an infant born with an obvious medical problem or an illness that becomes evident later in infancy, provides a brutal awakening from these rosy dreams. Most parents react with anger at this injustice, become depressed, and often overwhelmed by this unanticipated and unwelcome blow. How they learn to cope with the challenge will have life-long consequences for them, their affected offspring and other children and even more distant family members.[18]

Some Cambodians hold a religious belief that a disability is a punishment. To them it means a disabled child is shameful for a family , quite often disabled children are kept at home doing nothing or sometimes abandoned on the streets to make their own way, however they can manage. Without education it becomes impossible for these children to get good jobs, earn money for themselves, be independent of their families or leave a happy life.[35]

Ryan and Runswick[36] cited the criticisms of the mothers by the Disabled People's Direct Action Network in 2006, which stated that mothers are sometimes regarded as allies or oppressors by their disabled children. The quotation of a young disabled man provides an example "It's Saturday night and my friends are going to the disco. I want to go but I can't. My mom won't let me". While the academic community offers interpretations of the lives of parents of disabled children as delusional, grief stricken and/or self-interested.[37]

In a study conducted by Miles[37] it was confirmed that although mothers have been extremely effective in organising themselves into support groups, they have not achieved the same levels of recognition or success as the disability rights movement, and what they have achieved is poorly documented. A major reason for the disparity between the two groups in Southern Africa is undoubtedly gender-related, as the Disabled Peoples Organisations (D.P.O's) tend to be led by men, and parents' groups by women who are primarily the sole breadwinners for their families. Southern African Federation for the Disabled (SAFOD) has a progressive gender policy which will in time redress these imbalances, but the fundamental inequalities between men and women in relation to child care are likely to continue. [37]

According to Borgunn, Wendelborg and Lundeby[38] parents of children with learning difficulties seem to experience a very tough period when their child reaches the age of approximately 8 years. The mother of Tom (11 years 5 months, multiple impairments) explained that physical care had become a great challenge in the last few years and they had had to reorganise their care work at home. "Now Tom's father is more involved because it demands a man's physical strength in the evenings. First I think of the fact that he has become larger and heavier. We are in need of a man. But it is not easy to find any manpower. Tom is not clean. He still uses nappies, and he still does B three times a day. To handle these unhygienic things; becomes a challenge to the parent"[38]. This example not only illustrates the increased workload in handling a disabled child but shows at some stage you need an assistant, if you are a single parent it becomes worse when the child is growing bigger. The Community Based Rehabilitation Centre, Happy Home was a necessity to relieve parents who are single.

Cornill H [39] suggested that early intervention by means of specific motor training programs and general developmental programs in which parent learn how to promote infant development may be the most promising ways to promote infant motor and cognitive development of infants with or at high risk for developmental motor disorders.[39]

The cultural background of the parents at Happy Home is a mixture of both Christian and African traditional backgrounds. The researcher realised that the causes of disability are understood differently by parents and it depends on the religious beliefs of the parents. Some believe that it is God's will that they have disabled children and some suspect

witchcraft.   When children have health problems the parents'/caregivers' response is determined by their cultural beliefs. The Canadian Model of Occupational Performance[40] states that in occupational therapy, both spirituality and religion have important consequences for clients' choices and for outcomes of care. There is evidence that occupational therapists are somewhat reluctant to address spiritual or religious factors because they feel unprepared or unqualified to do so. At the same time, there is growing awareness of the importance and centrality of these concerns in the occupational lives of individuals.   Ultimately, it seems likely that in working in the community, religious and spiritual beliefs and motivations must be considered.   Without attention to these considerations, it is possible, perhaps even probable, that interventions will not address central concerns of the group.   Culture including religion and spirituality, are vital motivating factors for both individuals and groups.   In order to move toward cultural competency, they must be understood and valued. The range of therapists working with persons with disability should understand the Canadian Model of Occupational Performance.

Figure 2.   Canadian Model of Occupational Performance
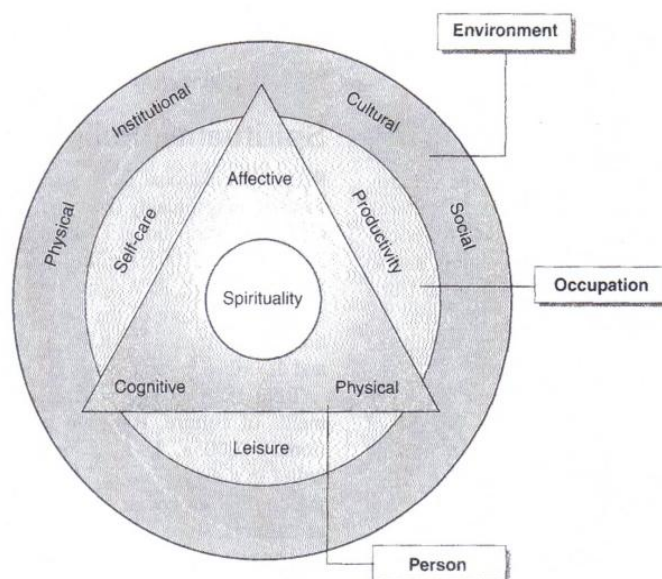
Source: WHO, 2004

The professional culture of occupational therapy holds that individuals should identify goals that are meaningful to them and that the therapist's interventions should be client-centred, assisting the individual to accomplish those goals including, cultural influences, individual or group values, beliefs, and behaviours. It is inevitable that understanding the culture of an individual is central to intervention.   The hope is that understanding and

incorporating these beliefs will improve outcomes of care. Although this remains to be validated through careful outcomes research, there is certainly a growing body of literature to suggest that this is true.[40]

The research will bring to the attention of the physiotherapist, and other therapists who have no experience in the field, and other professionals, the importance of taking into consideration the cultural backgrounds of the parents/caregivers during the rehabilitation processes and to respect their religious and cultural backgrounds. Failure to do so will retard the growth of the programme and can result in poor relationships with the parents/caregivers of disabled children. A positive societal and family attitude can yield good results for the therapy of disabled children, and be positive and less stressful for the professional.

2. 5. Health belief models and their impact on parents of disabled children

The researcher considers that when parents are faced with the health related problems of their children their response to the challenge is determined by their beliefs hence, it is important to discuss Kleinmans' Health Belief model.[41] there are three categories explaining the model. In every society, people suffering from some physical or other discomfort have a number of ways in which they help themselves and seek the help of other people to alleviate their suffering. All such ways constitute the health –care system of that society. Societies differ in organisation of their health-care systems. Kleinman suggests that in any complex society, three overlapping sectors of heath care can be identified namely:-

- **Popular Sector**

  This sector consists of the lay, non professional and non-specialised domain of the society where the health condition of an individual (whether health or ill-health) is first recognised and defined. In every society, health-care activities are always started first in the popular sector. Health-care activities of this sector include all those therapeutic options which people utilize without any payments and without consultation with any traditional/folk healer or professional medical practitioner. The options available in this sector generally are self-medication, advice and treatment given by family members, relatives, neighbours, and workmates or consultation with another lay person who has special experience of the particular health disorder. The family is the main arena of healthcare in the popular sector

where ill-health is first recognised, diagnosed and treated. In every society, family is the real site of primary health-care.

- **Traditional/Folk Sector**

  The traditional or folk sector consists of a mixture of sacred and secular traditional/folk healers in the society. There is a wide variation in types of healers found in any society from purely secular and technical experts like acupuncturists, vaids, hakims, bone setters, and herbalists to spiritual healers like Shamans, Sadhus, and Siddhs. The most important characteristics of the folk healers are that most of the folk healers in a society share the cultural values, perspective and world-view (including beliefs about the origin, significance and treatment of ill health condition) of the community in which they live and work. In a small society, such a healer also has first-hand knowledge of the family conditions, cultures, and beliefs of the family along with the psychological profile and history of the patient. This knowledge is usually very useful in diagnosis and treatment. The most important advantages of the traditional/folk sector are that it has extremely well developed skills of understanding and creating rapport with the socio-cultural concepts and beliefs of the patient as well as the skill of involving the family in diagnosis and treatment.

- **The professional sector**

  This sector comprises of the organised, legally sanctioned healing professional including recognised medical practitioners of various types, specialists and para-medical professionals in a society. In the last century, modern scientific medicine (i.e. allopathic medicine) has become the basis of the professional sector in most countries. A most interesting observation about the modern scientific medical professional sector is that persons who practice modern scientific medicine in any society have come to form a group apart with their own sets of beliefs about body image, food, diet, nutrition, health, ill-health, diagnosis, treatment, and health-care. The modern scientific medical profession can be seen as a healing sub-culture with its own particular world-view. In the process of medical education, the students of modern medicine undergo a form of enculturation thereby acquiring the particular perspective which may be termed: the scientific medical perspective.

This perspective that lasts throughout their professional life is quite hard to change. Therefore, in understanding various aspects of health, ill-health, disease, diagnosis, treatment, and health-care the predominant approach of the modern scientific sector is the search for physical, measurable, empirical evidence of the disease condition and the use of physical administrations, such as, drugs or surgery to treat the underlying abnormality thought to be the cause of a disease condition.**[41]**

In recognition of the obvious advantages of traditional/folk systems, the WHO, in 1978, recommended that traditional or folk healing be integrated wherever possible with modern scientific medicine and stressed the necessity to ensure rapport, recognition and collaboration among practitioners of various systems. In the last two decades, there has been much fruitful effort in generating meaningful interaction between modern scientific and alternative, traditional/folk medicine. Presently modern scientific and alternatives, such as traditional/folk systems are being mixed on a hit and miss basis and not much serious effort has been made to synthesise the concepts of modern and alternative systems into a meaningful whole.[21]

According to Parker[42], parents with spiritual beliefs and practices, and who raise children without disabilities, generally experience higher levels of private and public acceptance and marital satisfaction than parents raising a child with disability. Mothers scored higher on religious variables than fathers, and mothers' ratings of spirituality and family type predicted their ratings of marital conflict. Higher spirituality and raising typically developing children were associated with higher ratings of marital satisfaction for both mothers and fathers. These factors are clearly strong influences on the coping ability of parents raising children with disabilities, and therefore knowledge of these issues may help improve interventions for families raising children with disabilities and add to the literature on the interplay of religious, spiritual and marital relationships.[42]

Mji stated that Culture is what gives meaning to people's lives, so to challenge it, is to challenge their belief systems, which underpin their existence. On the other hand, where some parts of cultural activities are repressive, they need to be challenged. This needs to be done with a cautious and caring approach as sometimes an inquisitive questioning attitude is often seen as deeply subversive in communities with a strong cultural identity.

The challenge to developing a meaningful reciprocal relationship is how to stimulate change without undermining people's sense of identity and dignity. That is one of the major thrusts of developing community partnerships as this task (raising awareness with regard to unacceptable cultural practices) can best be attempted by people within the culture itself who have questioned themselves at first and have made that shift.[3]

Kleinman's health belief model helps us to understand the parents'/caregivers' decision to choose where to take their children when they are sick; and that is influenced by beliefs, sometimes it is traditional healers that comes first in their mind when they experience health related problems and during critical incidents. For other parents what comes first, is to take their children to faith healers; or to use what they have heard from their parents, that is, indigenous knowledge.

The conditions of the children in the study need to be explained so as to understand the rehabilitation needs of the children at Happy Home (see Appendix 1 for a detailed table). The most prevalent impairment is cerebral palsy which can differ in intensity. Some are profoundly disabled and are not educable; they need constant supervision and regular physiotherapy treatment, while others are able to attend local special schools for children with intellectual impairments. According to Fuad children who lag behind their peers in development are classified as clumsy children. All these children during their development might require regular health and rehabilitation during their development which is rarely available for those that live in rural areas such as the parents/caregivers of the disabled children from Happy Home.

The parents/caregivers of the disabled children at Happy Home are dealing with the conditions mentioned in Appendix 1 and are also faced with the responsibility to provide for their non-disabled children, including, the provision of a home, daily necessities and education. Above all they have the life time responsibility to take care of the needs of their disabled children. Let us look at the health and rehabilitation needs of disabled children and how various authors explain this burden.

2. 6.   The health and rehabilitation needs of the disabled children

Harries[43] stated that it is important to recognise that the needs of disabled children vary in severity and can sometimes be met by informal support without service intervention. Understanding the needs of children and families can better enable practitioners to provide appropriate support and the additional pressures faced by the families of disabled children can be alleviated by breaks from caring in the form of respite or domestic help. In addition, to palliative care, hospices provide respite care for severely impaired children. Many families report that they regard hospice care as a lifeline, because of the specialist care that it provides for the child and the relief it provides for families through short-term breaks.[43]

Gara[31] also stated that thousands of poor people across the world were given an opportunity to share their experiences and needs within their poverty stricken circumstances. The study provides a heightened insight into the lives of poor people. The focus in the study on women who currently have disabled children, and live in poverty, suggested that mothers of disabled children are especially affected by poverty. Gara cited Tumusani who argues that poverty, disability and unemployment exist throughout the world and have a detrimental impact on the level of inclusion of those affected in society. Using a materialist analysis to explore this notion, he shows that capitalist development, although not exclusively the only factor responsible for the creation of the triangle of poverty, disability and unemployment, still has a particular impact on mothers of disabled children as well as on the lives of societies. The mothers as well as all family members are faced with poverty.[31]

According to the research it would appear that the primary needs of disabled community and disabled children are rehabilitation programmes to minimise secondary impairment and to promote health through good diet, management of their condition to prevent pressure sores and stress associated with disability. This is a challenge to parents of disabled children in rural areas to achieve all of these basic needs due to high unemployment rates, most parents of the children at Happy Home are not working and depend on social grant for their living. The poverty, and distance to the health care facilities renders the service inaccessible to the parents. Thus, as it is discussed in the literature, addressing disability needs to also take into account poverty and unemployment alleviation.

2. 7. Barriers in Health Care Services in South Africa

From 1994 the focus of the former State President Nelson Rolihlahla Mandela was the improvement of the health conditions in rural South Africa, especially in the Eastern Cape where there were no clinics. He brought many funders to the Eastern Cape. The building of schools and clinics by companies like BMW, Sanlam and Mercedes Benz, made a drastic change. Despite all these changes there are still barriers to health care services in South Africa and in the rural areas of the Eastern Cape. These challenges will be discussed briefly from various researchers' points of view.

2. 7. 1. Lack of sufficient health and rehabilitation personnel in rural South Africa

The Rural Doctors Association of South Africa (RuDASA)[4] stated that while South Africa has a general shortage of most categories of health providers, in particular; doctors, nurses, dentists and pharmacists, a major challenge is that the majority of professionals in most categories, with the possible exception of nurses, work in the private health sector. So while the public health sector experiences general shortages, it is the rural areas of the country where the shortages are most acute.

The issues are however not new. The problems and a range of recommendations are contained in the South African government document called National Human Resource Strategy of 2000. Given their importance to rural development they are quoted in detail below:

"It is difficult to retain staff in rural areas; there is lack of an attractive career structure to entice doctors away from urban areas. This leads to a lack of doctors in remote rural areas. It has been difficult to retain doctors, and in some areas, the small size of the population does not warrant assigning one. What is required is a new way of thinking about how the necessary services may be provided to those areas, while ensuring that residents receive quality care. It will require a new and creative vision of staffing for these under-populated areas. One possibility is to use nurse practitioners to fill some or all of the gaps in services to these communities. Another possibility is to expand the skills of existing technical workers with enhanced competencies (e.g., nurses, pharmacy technicians etc; combining driver, cleaner, grounds care work in rural areas (though it may raise the issue of exploitation from the unions". Rudasa further stated that the role and practice of the generalist doctor in rural community hospitals in South Africa is extremely wide and poorly documented. In the absence of specialist support, the rural

generalist is called upon to perform clinical duties ranging from primary care to emergency surgery within the health team. The definition of general practitioner is someone who is able to "deal with any patient, with any problem, at any time". Often these doctors have had little or no formal training in the procedures that they have been asked to perform. It has been recommended that doctors be formally trained in community-based medicine so that they can better cope with the tasks that they are asked to perform in those settings.[4]

Haywood[8] defined disability as the disadvantage or inequality experienced by an individual as a result of barriers that arise from impairments and/or ill-health. The definition makes a clear distinction between the disability and the impairment or ill-health, suggesting that disability is a consequence of the societal barriers that result from ill health or impairment – the disability is not the ill health or impairment itself. This implies that if people in rural communities were to have better access to health care facilities and other services, i.e if existing barriers are reduced or eliminated, they could enjoy a higher quality life and additionally, parents of disabled children can develop better coping skills.[9]

Koshti R.[30] asked parents/caregivers of disabled children about the greatest challenges and gaps in services and what needs to change to ensure that their children can be cared for at home. One parent said sleep deprivation was a major concern, in particular coping with the struggle to manage a child's medical needs with little or no sleep. One mother stated that "For convenience, I have opted to deal with my child's intravenous antibiotics myself, but I have found this increasingly difficult when faced with continual nights of broken sleep with perhaps fewer than four hours' sleep in total" She said that an adequate night's sleep would allow her to cope with her child's medical needs the following day, allowing her to be patient, caring and able to tolerate her child's demands.[30]

2. 7. 2. Poverty and disability as a barrier to access community resources including health services

Little empirical knowledge exists about the relationship between disability, poverty, and health seeking behaviour and less information exists about the consequences regarding various types of disabilities. Studies indicate that socio-cultural factors do play a vital role on how disability is perceived by society and that woman and children within the disability

context are more vulnerable and the consequences of deficiencies and disablement are particularly serious for women and children who are subjected to social, cultural and economic disadvantages that impede their access to health care, education, vocational training and employment. Not only are women with disabilities discriminated against as disabled people, but they also experience oppression and marginalization as women in a patriarchal society.[12] According to Ingstad, in the study conducted in Botswana, she stated that women who were parents/care-givers of disabled children were more often unemployed and were single parents who depended on the extended family for coping with a disability in a poor resource setting. In some cases teenage girls sometimes drop out of school to help their parents. Poverty is closely connected to both disability and poor health, both as an important cause and as a consequence.[19]   As outlined in the Global Health Programme, one of the critical roles of global research is to ensure that the measures proposed to help break the vicious cycle of poor health, including disability, and poverty are based on solid evidence, so that the resources available to fund these measures are used in the most efficient and effective possible way.

Poverty in Cambodia means many families have to make choices about which of their children they afford to send to school. Parents of children with disabilities have even more difficult choices, as they struggle to pay for medical treatment, special equipment and transport. Some parents of disabled children believe that their children will never earn living, and contribute to the upkeep of the family, so sending them to school is seen as waste of time and money. [40]

The draft WHO/ILO/UNESCO/CBR guidelines stipulate that, not all disabled people are poor. At the same time, in any community, the poorest of the poor are likely to be people with disabilities. In fact, the majority of people with disabilities are living with chronic poverty in the most of the world. Poverty is a root cause of many disabilities and disability increases poverty. About 400 million people with disabilities live in low income countries, often in poverty and isolation and despair. Poverty also limits access to basic services, including health care, rehabilitation and education. This forms a cyclical link between disability and poverty [21]

According to the reports by the Disability and Research Programme; disabled people struggle to find employment in all three countries studied; Rwanda, Cambodia and India.

Having a physical impairment makes it difficult to work in the agricultural sector which dominates in all the economies. Vocational training opportunities are limited, tend to be in urban areas and are not generally linked to gainful employment. Because they are seen as presenting a high risk, disabled people are also usually denied access to micro-credit schemes. It was also found that in Cambodia, poor people tend to live near areas that had been mined, are forced to use more risky means of transport, have more dangerous jobs and cannot access health care so that minor illness or injury can become more permanent impairments. Malnutrition, which makes having a whole range of impairments more likely, is also closely associated with being poor.[44]

According to Hilton[45], other key problems that continue to exclude people with disabilities from mainstream society are prejudice, social stigma, isolation, lack of access to support networks and resources for an independent daily existence, lack of access to infrastructure, services, communication, transport, opportunities, resources, education, technical aids that allow them independence and promote their dignity, self- sufficiency and responsibility.   Selected categories of people with disabilities such as children, women and older persons are particularly vulnerable to discrimination, abuse, and encounter barriers to participation in society.[45]

Due to South Africa's history of injustices, no special schools could be found for black disabled children, only places where black children were institutionalized. Disabled children that lived in rural communities, where the parents struggled for survival with no information about available resources, or special schools for their children. Thus disability, in addition to being a health issue is also a human rights issue.   This statement is confirmed by South African Government White Paper 6, (1997), on an Integrated National Disability Strategy, which explains the ways in which people with disabilities have been marginalised and disempowered. If policy-makers and legislators understand how the needs and rights of people with disabilities are systematically excluded from governance structures and processes, sustainable transformation can begin.[46]

2. 8. Facilitators of Health care services in rural areas of the Eastern Cape

 Iputo E.[47] of the Walter .Sisulu .University. Of Technology, stated in his article that from 1985 to 1991, medical training at the Faculty of Health Sciences followed a traditional curriculum. The faculty was aware, however, that it was admitting students with a

precarious academic background whose success in the program required reinforcement. Another critical issue in curriculum development was the need to provide students with the knowledge and skills to understand, research, and solve the health problems of rural South Africa. It is generally accepted that clinical competence is largely problem specific and does not generalize well across different clinical problems. Therefore, training a competent doctor with the technical and social skills needed to function in the healthcare delivery system in rural South Africa must include exposure to the common health problems in this community.[47]

The medical educators developing a curriculum in the former Transkei, now the Eastern Cape Province also hoped that early and prolonged exposure to rural community settings would increase students' commitment to serving those communities upon graduation. These concerns led to the adoption, in 1992, of a student-centred, problem-based, community oriented and community-based curriculum that fostered active, life-long learning. Iputo further stated that full implementation of the community based education and service concept, to include service learning in the communities has yet to be fully realized. The faculty plans to strengthen the Community Based Education and Service (COBES) component of the program by building learning centres in at least 10 district hospitals and by developing the concept of a wellness village as a vehicle for service learning in the communities. However, dwindling funding and rising transportation costs continue to be major challenges for the completion of this projects.[47]

As important as the initiatives described are, it is also important to take into account the experiences of parents/caregivers regarding health care services. Lindbald states that it has been demonstrated that various kinds of support, such as emotional, social, economic, and practical, are very important for parental well-being. Howe-ever, research into parents experiences of various areas and aspects of professional support, regardless of the child's diagnosis, discloses parental dissatisfaction with information about available support that answer the families' own estimate of their needs and emotional support in relation to the gravity of the child's health. Parents are also dissatisfied because they do not feel that they are respected as partners who have parental expertise and competence.[34]

2. 9. Coping strategies of parents with disability of their children

Ingstad describes coping as an analytical concept that is seen to be broader than the concept of viability. "Viability has to do with organisation of material resources in order to fulfil people's physical needs. Coping includes this, but has also to do with how people actually feel about their situation, how their emotional needs are fulfilled and how this is reflected in their ability to perform special tasks; in this case, caring for a disabled family member. Coping used in this way analytically has two dimensions; coping with life in general and coping with the care of a disabled family member. In real life, however, these two are so intertwined that it is futile to try to distinguish them empirically from each other."[19]

Coping with stressful situations that are beyond one's control is one of the greatest challenges of life. With no scope for reducing or eliminating the sources of stress, such situations require strategies where one changes the self to fit the situation. Understanding the ways families cope is very important, as these are central to cognitive models of stress and coping often applied to families of children with disabilities. The following coping strategies were identified as useful and that influence the stress felt by the families: expectations, attributions, parent's views of the causation of the disability, nature and quality of daily interactions with the child, parent's notions about their child's efficacy as "changing agents' in facilitating the child's development, attitudes and social support. Other mediating factors that have been identified include; family beliefs and perceptions, religious and moral beliefs, overall philosophies and ideologies held by the families, family lifestyles and the extent of harmony in the family.[18]

Cheshire[49] stated that positive re-interpretation was positively correlated with self-efficacy and negatively correlated with depression and stress. Interviews identified two types of positive reinterpretation: focusing on the positive aspects of the situation and finding meaning in caring for a child with a disability. Positive reinterpretation appeared to be an adaptive coping strategy used to deal with emotional stress experienced by parents.[49]

Norizan and Shamsuddin[50] stated that parenting stress among mothers of children with disabilities varied greatly, depending on the behavioural characteristics displayed by their children. Parenting stresses also significantly correlated with frequent use of acceptance, religious and optimist coping styles, and presence of maternal depressive, anxiety and

stress characteristics.   Hierarchical regression analysis identified maternal depression and lack of acceptance of having a child with disability as the most significant predictors of parenting stress in these mothers. [50]

In a study conducted in America at the University of Wisconsin, Hong stated that parents who have an adult child with a lifelong or chronic disability face atypical care-giving challenges that may cause stress and threaten their physical and mental health.   There was heterogeneity in parents' responses to the demands of the long-term care-giving role. Coping and social support are protective factors that can maintain the resiliency of individuals exposed to adversity, where as the stresses for the care-giving situation are risk factors that may increase the likelihood of physical and mental consequences.[51]

Wang[52], in a study conducted in the Republic of China to understand the stress and coping strategies amongst families with autistic children and other developmental disabilities, found high levels of stress related to the degree of the parent's pessimism towards the child's condition, the child's characteristics, and parent or family problems. Coping strategies employed included acceptance, active coping, positive reinterpretation and growth. Parents of children with autism experienced more stress and used planning as a coping strategy to a greater degree than parents of children with other developmental disabilities[52.]

The study conducted by Churchill et al[53], stated that analysis found that the level of coping strategies differed between parents of children with disabilities with varying degrees of severity of the child's condition and   family demographic characteristics.[53] Gillian[54] stated that Children with severe cerebral palsy (CP) experience dysphagia (i.e. problems with swallowing and eating). Making it difficult for them to achieve an adequate nutritional; intake orally.   Children with CP are typically small and underweight and characterised by poor growth compared with their non-disabled peers. They are often described as malnourished by clinicians.[54] In the study conducted by Larson[55]nine mothers with diverse backgrounds whose sons had autism spectrum disorders participated. Data gathered through intensive interviewing and analyzed using deductive interpretive approach. Mothers characterised their Care giving as vigilance rather than burden. Yet, this vigilance was highly fatiguing. Mothers intensely attended to their children's activities. This intense focus promoted participation in self-care, leisure, and

social activities, and prevented frustration and behavioural melt down. This intense vigilance may be a key factor in maternal health issues, such as anxiety and depression. While these problems fall within the scope of occupational therapy's expertise, it appears that many of these issues were not addressed by the current service-delivery models, leaving families to continue to struggle and children to lack the skills for independent living as adults.[55]

Hartley[56] stated that inhibitors to coping are reported to include financial hardship, stigma, and demands on time, and difficulties in care-giving tasks such as feeding, reduced time for sleep, social isolation, less time for recreational pursuits and difficulties in managing behaviour problems. He cited Porter and McKenzie who suggested that the way families respond to and cope with disability depends on four issues, internal and external resources, support, their own goals for their children and the local culture.   Internal resources include personality characteristics, energy and self determination.   External resources include support from the extended family and community and government programmes.[56]

Murray C.[57] et all cited other writers who stated that; the Family Systems theory and Family Adaptation and Adjustment Response (FAAR model) used by families of children with limb difference and chronic conditions cope with an array of challenges and stressors with varying degrees of ease. The scope and ubiquitous nature of these stressors can become overwhelming. Areas of family life that may be affected include daily routines, developmental transitions, financial decisions, careers, friendships, school performance, parenting strategies, and sibling relationships (Stein, 1983). Some of the specific challenges these families face include tension in family relationships, disrupted family activities, time management struggles, high medical costs, disconnection from social networks, and difficulties interacting with the children's schools (Patterson & McCubbin, 1983). These challenges put family members at increased risk for psychosocial stress (Wallander & Noojin, 1995). However, these stressors provide opportunities for families to develop problem-solving and coping skills (Patterson & McCubbin, 1993; Sallfors & Hallberg, 2003). Families who face a child's chronic health condition frequently use and develop numerous strengths and resources to manage the child's condition and its related stressors. Previous research has highlighted a number of resources that families may use to cope with a child's chronic health condition, including developing positive

meaning systems (Garwick, Kohrman, Titus, Wolman, & Blum, 1999; Patterson & McCubbin, 1983); expressing positive feelings for the child (Heiman, 2002); seeking services and social support (Patterson & McCubbin, 1983); searching for information (Sallfors & Hallberg, 2003; Taanila, Jarvelin, & Kokkonen, 1998; Taanila, Syrjala, Kokkonen, & Jarvelin, 2002); and holding positive expectations for the child's development (Woolfson, 2004). Once established, these resources. She emphasizes the important role resources play in determining the manner in which a family adapts to a child's chronic health condition. The model asserts that the primary determinant of a family's response to a stressor is its coping capabilities. Coping capabilities refer to the strategies the family uses to manage demands placed on it by stressors. To cope, a family may draw on existing or new resources. When the family is able to cope effectively with the challenges of the chronic health condition the demands become more manageable. The family is then able to develop a coherent, adaptable meaning system related to a health condition and its related challenges. [57]

Some of the most commonly used coping strategies in times of distress are religious beliefs, destiny, karma theory, and theory of reincarnation. An investigation was conducted about cultural beliefs and attitudes of a rural Indian community towards physical disability and the results revealed fatalistic attitudes and external dependence in families with disabled children. It was found that irrespective of the economic status of families with a child with disability, intervening factors like mother's personality, optimism, and religious support were found to alleviate the degree of stress. Positive attitude, social support and faith in God, helped mothers generate psychic energy to cope with the physical, emotional, and financial aspects of care giving. [44]

Indian communities empower parents with life skills in problem solving and coping strategies. Interventions focused on parents' coping skills have reported positive results. These interventions use ideas from stress and coping theories to inform parent training in problem solving and decision-making, communication skills, skills in accessing and utilising social networks, and coping strategies such as positive self-statements, self-praise and relaxation. Some successful strategies include gaining perspective, finding meaning in an event, acceptance, positive reinterpretation, and humour. Training carried out in groups rather than with individual mothers showed a great deal of improvements in

communication skills and coping strategies due to the satisfaction derived from the family support.[58]

In their article, Gupta and Singhal[59] report studies recognising families that have been successful in developing positive perceptions regarding raising a child with disability. According to Gupta and Singhal parents of disabled children in India are particularly vulnerable to stress. High levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children. In addition, both the general psychological literature and specific studies of disabled children show that parental distress and family functioning impacts children in numerous ways affecting their cognitive, behavioural and social development. Although there are many other developmental disorders, which also present parents with ongoing grief, autism is unique in several ways since the disorder has no clear biological marker, unlike many other developmental disabilities such as mental retardation, deafness, or blindness.[59]

According to the literature is has been established that Indians in rural communities share the same religious belief and attitudes towards physical disability as South Africans. The researcher has strong belief that South African mothers play a big role in changing the attitude of the whole family and acceptance of disability as it is in India.

2. 10.   Coping strategies of Parents of disabled children in South Africa

The researcher would like to present a South African case study of some parents who established an organisation for parents of children with disabilities in 1993 called Disabled Children Action Group (DICAG). The organisation started with two programmes that targeted training in advocacy skills as key integrals that required to be promoted in mothers of disabled children. Advocacy training in the nine provinces of South Africa was conducted by eight (8) parents who were the founders of the organisation. This programme was implemented in all the 9 provinces of South Africa. Training of parents about care of their disabled children and knowledge about disability issues and the responsibilities of parents were the main objectives of the organization. This group of parents were also trained in leadership skills in all provinces of South Africa. This organisation played a large role in the establishment of Community Based Rehabilitation Centres in rural areas where parents used their huts and took turns in taking care of their children as voluntary workers. That improved socialisation of children and the support

groups helped the parents in coping with the disability of their children.[60] Gara[33] stated that in the study conducted in 2007 the community participation forums were used as a means of raising disability awareness and identifying possible participants from the community. These forums enabled the researcher to make contact with parents and caregivers of disabled children and to invite their active engagement in this study. This was how the parents of disabled children from DICAG developed coping strategies for the management of their disabled children.[33]

2. 11. Need for a rehabilitation strategy that integrates the biomedical approach of therapy and basic skills of parents of disabled children

The conditions of the children who live at Happy Home showed that there is a need for Community Based Rehabilitation Centres to assist parents with early detection, referral and intervention before a child develops secondary impairment and the prevention of the estimated high mortality rate among disabled children. The Canadian model defines culture as influencing decisions made by individuals, group values, beliefs and behaviour patterns. It is inevitable that understanding and incorporating those beliefs will improve outcomes of care. There is a need for a rehabilitation strategy that integrates the biomedical approach of therapists and basic Skills of parents of disabled children.

Historically, approaches to the promotion of population health have been based on deficit models. That is, they tended to focus on identifying the problems and needs of populations that required professional resources and high levels of dependence on hospital and welfare services. These deficit models are important and necessary to identify levels of needs and priorities. But they need to be complemented by other perspectives as they have some drawbacks. Deficit models tend to define communities and individuals in negative terms, disregarding what is positive and works well in a particular population. In contrast asset models tend to accentuate positive capability, to identify problems and activate solutions. They focus on promoting salutogenic resources that promote the self-esteem and coping abilities of the individuals and communities, eventually leading to less dependency on professional services.[25]

Levin[61] states that despite evidence to suggest that single mothers are more likely to be parenting children with disabilities; their experiences have received minimal attention

within social science research. Furthermore, when single mothers do become the focus of study, much of the attention is directed toward identifying the deficits within their family system. It is stated that the family's ability to adapt or emerge strengthened from their experiences will vary as a function of family-based relational processes. These include: (a) family functioning variables of flexibility and cohesion, (b) family belief systems, or meaning-making processes, (c) the importance of the socio economic, and environmental contributions to the family well-being, and (d) the family's relationship with external systems. Each emphasizes the necessity to understand family adaptation and resilience as a process that occurs over time.[61]

It would appear that parents in their struggle with developmental stages of their children use different coping strategies. Parminder Raina[62] et al say that, although care giving is a normal part of being the parent of a young child, this role takes on an entirely different significance when a child experiences functional limitations and possible long term dependence. One of the main challenges for parents is to manage their children's chronic health problems effectively and juggle this role with the requirements of everyday living. Consequently, the task of caring for a child with complex disabilities at home might be somewhat daunting for caregivers. The provision of such care may prove detrimental to both the physical health and the psychological well-being of parents of children with chronic disabilities. [62] Woodgate, and Roberta argues that parents of children with special healthcare needs who have better coping skills have fewer depressive symptoms.[63]

The notion of developmental strategies as discussed in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities as prescribed by the United Nations General Assembly on the 20 December 1993 is of great importance. The term equalisation of opportunities, means the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all particularly to persons with disabilities. The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within

the ordinary structures of education, health employment and social services. As persons with disabilities achieve equal rights, they should also have equal obligations. As those rights are being achieved, societies should raise their expectations of persons with disabilities. As part of the process of equal opportunities, provision should be made to assist persons with disabilities to assume their full responsibility as members of the society.[64]

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities has further been supported by the United Nations Convention on the Rights of Persons with disabilities (UNCRPD) that was adopted on the 13 December 2006 at the United Nations Headquarters in New York, and was opened for signature on the 30 March 2007 for ratification. There were 82 signatories to the Convention, 44 signatories to the Optional Protocol, and No.1 ratification of the Convention. This is the highest number of signatories in the history of a UN Convention on its opening day. South Africa has rectified the UNCRPD. It is the first comprehensive human rights treaty of the 21st century and is the first human rights convention to be open for signature by regional integration organisations. The Convention entered into force on 3 May 2008. The Convention marks a paradigm shift in attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as objects of charity, to medical treatment and social protection towards viewing persons with disabilities as subjects with rights, who are capable of claiming those rights and making decisions for their lives based on their free, and informed consent as well as being active members of society.[65]

The researcher believes that the integration of the UN standard rules and the UNCRPD that are the main instruments that address issues of equal opportunities for disabled people into the South African Health Department primary health care policy implementation will have a far reaching and encompassing impact for health and rehabilitation rendering for the disabled children in South Africa. Advocacy in health promotion can be used as a process of defending and promoting their rights to equitable health services. It may mean representing the interests of disadvantaged groups and it may mean speaking on their behalf or lobbying to influence policy. It may also mean action to gain political commitment, policy support, social acceptance and systems support for a particular goal or cause. Health promotion networks in Australia, New

Zealand, the U.S.A. and Canada have long advocated for a focus on the health of indigenous peoples.[65]

The research observes that there is a need to form community advocacy forums that will help to influence the policy makers, and it should be constituted by multi disciplinary teams. There is also a need for all Health Professional Organizations to join the newly formed African Network for Evidence to Action on Disability (AFRINEAD) which was initiated in 2007 by Stellenbosch University. The researcher sees this organisation as a tool that will unite disability and researchers and influence the policy makers on the African continent to move from evidence to action on disability issues. At the helm of all this, the experiences of mothers and care givers of disabled children must not be forgotten to be included as a pillar of this process – as it has already been mentioned under disability definition in the ICF that contextual factors are usually the determinants of how disability will be experienced.

2. 12. Summary of the chapter

This chapter has offered a discussion of the literature reviewed and the narrative stories of parents from developed and developing countries and various definitions of disability. The health belief models have been unpacked and the influence of these models in relation to the decision making of parents/care-givers discussed. The discussions about challenges and frustrations facing the parents of disabled children and coping strategies which they use were critically analysed and critiques about the management of disabled children by their parents were addressed. Facilitators and barriers to health and rehabilitation services in rural South Africa were discussed. The chapter ended with a discussion of the developmental strategies in health care for the disabled children.

CHAPTER 3

Methodology

3. 1. Introduction

The chapter will describe the methodology used in the study, the study population, and the study sampling including the pilot study. It will also address how the data was collected, reliability, limitations of the study, as well as data analysis, and will end with the summary of the chapter.

3. 2. Description of the study design

This is a descriptive study that utilized qualitative methods of data collection. In qualitative studies the type and size of the sample is usually based on existing knowledge of the research topic and knowledge of the place where one wishes to collect information. The size of the sample is often difficult to assess at the onset of the study, varying from very few to maybe about fifty or more. Though the number of informants is important in qualitative studies the type and the character of informants is more critical in the selection of the sample for informants as the research question depend mostly on the experiences of informants, thus there is a need to purposefully select informants. In qualitative studies the sampling is strategic. For this study the sample that has been chosen are parents, guardians and care-givers of disabled children, it is believed that this cohort has lived experiences of coping with disabled children.

3. 3. Study setting

The study setting was Happy Home, a Community Based Rehabilitation Centre (CBRC) for disabled children from the rural area of the O.R. Tambo Municipality, in the Eastern Cape, South Africa. The researcher is the founder of Happy Home. The centre came about as a result of problems experienced by parents with their disabled children such as the lack of rehabilitation programmes in rural areas. Even though the hospital provided services parents/caregivers could not take their children for their monthly appointments even though the treatment was free, due to financial constraints which made the cost of transport prohibitive. The money which parents/caregivers get from the Department of Social Development for their disabled children is used to feed the whole family and pay school fees for siblings. These parents belong to a parents' organisation which is the

umbrella body of parents of disabled children in South Africa, namely; the Disabled Children Action Group (DICAG) where they are empowered to take informed decisions and to know the rights of their children and their responsibility as parents.   The organisation also empowers the children with disabilities about sexually transmitted diseases and HIV/AIDS. Happy Home is used as a training centre during holidays and the hostel is used to accommodate parents.   They learn agricultural skills, sewing skills, health education, personal hygiene and Occupational Health and Safety (OSHASS ISO 180001: 2007).   The cerebral palsied children who are profoundly disabled are accommodated at the centre for stimulation, physiotherapy, and hippo-therapy treatments.   The students with mild intellectual impairment are also accommodated at Happy Home but attend Tembisa Special School which is a distance of about 2 kilometres from Happy Home.   Parents are relieved of the burden of daily care and their children receive appropriate therapy and schooling, and during holidays their children go home.   This is in line with the policy of the South African Government, that the parents/caregivers and their families should be involved in the rehabilitation of their children.   During the school holidays all children go to parents/caregivers except for the abandon disabled child and one orphan. Since the inception of the centre these 2 children stay all the year round. The two siblings of the one who is orphaned are both mentally ill and therefore cannot stay with their brother. When the researcher investigated the cause of their mental illness it transpired that they were using drugs. The question is; who is taking care of these two siblings. This means that there is a need to do research on child headed families in Mthatha.

3. 4. Study population

The study population was from parents and care givers from Happy Home; the Community Based Rehabilitation Centre for disabled children from the rural area of O.R. Tambo Municipality, in the Eastern Cape. About 90% of parents/caregivers are illiterate, and unemployed. There are 67 children residing at the centre. Some of the children at Happy Home have biological parents, while others have legal guardians.

Parents/caregivers of disabled children residing at Happy Home participated in the study. The admission criterion was first come first serve since Happy Home is the only CBRC in the region that caters for children.

Of the total of 67 parents/caregivers of children at Happy Home 37 participated in the study. An initial meeting was called at Happy Home with the aim of providing context to, and sharing the objectives of the study with the parents. At this meeting, an appeal was made to parents to avail themselves, as participants in the study was not compulsory. In order to avoid bias in study participation, it was made clear that non-participation in the study would not affect parents or their children in any way. However, parents' attendance of this meeting could be viewed in itself as an indication of their willingness to participate. All parents/care givers present at the initial meeting expressed their willingness to participate by a showing of hands. Following their expression of willingness to participate, participants introduced themselves and gave the names of their children, and were grouped into six groups by the research assistant. The date for each group discussion was discussed by the researcher and participants, who were free to choose the dates that were suitable from the suggested dates.

A phenomenological approach was taken by the researcher since, according to Hilton[45], before parents can open up and express what is important to them, they need to know that they can trust the helper not judge them harshly or laugh at them. They have to learn that they will be respected, shown care and helped. Most people have these concerns, but they differ dramatically in how long it takes for them to establish basic trust and engage in the relationship. For some it will be a matter of minutes, for others several hours. One mother interacted for about ten hours with a very skilled counsellor, before she was able to talk about the real problems she was having with her husband. She later explained that she had difficulties trusting men because of being raped in her teens and treated badly by the police and a social worker. She felt that everyone thought she was bad, including professionals. The process of establishing the relationship is mutual, and the basic tasks are for the helper and parents to get to know and trust each other as quickly as possible.[6] The researcher felt that she was the right person to collect this data from the parents since she is a parent of a disabled child and decided not to have a research assistant to ensure the comfort of the participants.

3. 5. Pilot Study

The pilot study was conducted at Sinovuyo Disabled Children centre outside Mthatha with parents of disabled children. The parents were first called to a meeting to explain the study and request permission for the use of the centre. Permission to use the centre was

granted and the parents were called to a meeting where the study and the reason for the study were explained. In addition, their rights to participate in or to withdraw from the study, that study participation was voluntary, and the tape recording of the study was explained. Participants gave their consent by signing the informed consent form. The participants were self-sampled.   There were two fathers and four mothers who volunteered to participate to the study. The centre was chosen because the participants were not going to be part of the main study. The discussion group comprised of six participants and one key informant. After the discussion the one key informant was then interviewed. There was no ambiguity about the questions asked and the main study was conducted at Happy Home

3. 6. Data Collection

Jervis[66] stated that Terre Blanche and Kelly have reservations about the term data collection. They state that the term can imply discrete information that is not necessarily context specific, whereas interpretive research works with material that is thick, rich and interconnected in its meaning. In this study the word data collection is used to refer to any information obtained via interviews, observation, reports, observations and narrative stories given by parents/care-givers of disabled children.

3. 7. 1. Methods used in data collection

In this qualitative study, an interview schedule was used as an instrument to gather information by the researcher. The method of focus group discussion was used to collect study information. The method was chosen because it was convenient for people who wanted to elaborate on their experiences without interruption. There was no language barrier; the researcher speaks the Xhosa language as did the participants.

The dates were set for each group which comprised of six parents per group. The parents were given open dates and they had to fit themselves into groups of six participants. One group discussion was conducted per day to allow for the privacy of the participants in each group discussion. Participants who took part in the group discussions were reimbursed for their transport expenses.

Each group discussion took place in the Happy Home board room where participants were seated at a round table. This allowed the participants to all see each other and for

the researcher to observe non-verbal cues. Refreshments were placed on the table and were available to the participants throughout the discussion.

 Although the demographic details were available on the files from the Happy Home administrative office the researcher felt it would be necessary to take demographic details from the parents/caregivers, and the names of the children. The questions discussed were guided by the research schedule and based on the study objectives. Six discussion groups were successful. Some groups were disrupted by social problems such as strikes in the taxi industry and some had different problems. One individual interview was conducted for which an interview schedule was used. The interview guides are attached as Appendices II and III.

During the data collection, two themes emerged from parents and were added to the objectives since they impacted on coping strategies used by parents.
These themes were;
- Possible causes of disability as understood by parents/caregivers.
- Reactions from parents, family and community members towards disabled children.

These themes were interpreted by the researcher as important for the aim of this study as they were seen to have a direct impact on the coping strategies of parents and care givers of disabled children. The researcher determined that the addition of these two themes does not change the study aim – instead, it adds further insight into the coping strategies of parents and caregivers of disabled children. For clarity the researcher will include the above two themes as objectives of this study and re-state the aim and objectives of this study.

3.7.2 Aim and objectives of the study
Aim:
To explore the coping strategies used by the parents/care-givers of disabled children in the management of health problems they experienced.

Study Objectives

- Describe demographic details of the mother/care-giver, of the disabled child and family.
- Possible causes of disability as understood by parents/caregivers.
- Reactions from parents, family and community members towards disabled children.
- Describe health and rehabilitation related problems identified by parents/care-givers of disabled children
- Investigate from parents/care-givers how and where these problems should be dealt with.
- Explore critical health related incidents experienced by parents.
- Describe the perception and experiences of parents/care-givers regarding accessibility of health and rehabilitation services.
- Describe facilitators and barriers to assessing health and rehabilitation services
- Explore coping strategies of the parents/care-givers of disabled children in the management of health related problems and critical health related incidents

3. 7. 3.   How biases were avoided in the study

The researcher was aware that in a study where participation was voluntary it would be difficult to completely clean the study of bias as the perception from the researcher was that those that had voluntarily agreed to participate were biased towards the study. To avoid biases in the study the research assistant was appointed to do transcription and translation to both languages Xhosa and English.   To address ethical issues of confidentiality a priest was appointed as research assistant.

3. 7. 4.   Ethical considerations:

The Human Research Ethics Committee of the Stellenbosch University granted approval to conduct the study (Ref. No9/06/167). The study protocol was followed and permission to conduct the study was granted by the members of the Happy Home Board. Parents were fully informed about the study, and consent was given in the form of signed consent forms before they participated in the research.   Confidentiality was stressed since sensitive issues were to be discussed. Participants were informed that, should it be required, they would be referred to the psychologist. Permission to record interviews was

requested and provided by parents. No participant was paid for participation in the study except expenses incurred for the transport to the venue where the study was conducted. All participants in the study were invited to participate voluntarily.

3. 8.   Reliability of the Study

A note pad was used during interview and group discussions, to note down the non-verbal cues, to support the oral text. All participants were audio-taped. The tapes were later transcribed to assure accuracy and validity. Reflections and observations made by the interviewer during the interviewing process were noted in brackets and italics. Jervis emphasised that during an interview non-verbal cues and facial expressions are as important as the actual words used and suggested that not only a full transcription of all interviews be kept, but also that a record of observations and reflections be noted by the interviewer during the interview sessions.[66] A second round of meetings was called with the participants to establish whether the data and stories were transcribed correctly. Where there were mistakes those were rectified. Each interview lasted for two hours and there was only one group discussion per day to ensure the privacy of the group members. The recordings and transcripts of group discussions and individual interviews were kept confidential and only seen by the researcher and research assistant.

3. 9. 1.   Limitations of the Study

Although the original study design called for one key informant interview per discussion group, only one interview occurred. Two key informants did not keep their appointments due to various commitments. The problem of the lack of technology in rural areas was a challenge to parents who could not phone when they were not able to come and the group discussion had to be cancelled and new date had to be set. This had negative financial implications for the researcher as participants who came for the appointment had to be reimbursed for a second trip to the research location. The key informant was interviewed because he had two disabled persons in his house. He was a male participant who had to deal with management of health and rehabilitation needs of his wife and of his child.

3. 9. 2. Impact of the researcher being part of Happy Home as Manager

As the mother of a child with disabilities, I was acquainted with some of the problems caring for a child with disabilities. Furthermore, my involvement with experienced

researchers on the field assisted me to develop the approach I needed for research purposes. Professor Ingstad taught me how to 'switch off' or detach one-self from previous experiences as a parent and to become a researcher. I observed her when I was her interpreter collecting data on the Study about Health Services for People with disabilities in Rural South Africa which was conducted in Madwaleni Hospital in the Eastern Cape; 2009. She did not utter a word about her own experiences with disabled children. I was surprised when she told me after completion of the study that she is a mother of a disabled child, but that her child has since passed away. I had thought that she was insensitive not showing empathy with her participants, and appearing during the interviews to be someone who has no connection whatsoever with disability.

This experience allowed me the opportunity to divorce my passion for the topic and the participants from my research and to wear a different cap. There were no questions about Happy Home itself. If parents happened to talk about how they had secured a place for their children at Happy Home, there was no response from me. In each group only one person spoke about this and when the other members of the group noticed that such a comment was out of place they did not follow suit. In all six of the groups parents broke down when narrating stories about experiences unforgettable to them and which were among critical moments in their lives. When the male participants barely managed to hold back their tears- you could tell by the redness of their eyes - I pretended I was not even touched. I provided them with tissues. However all their stresses and frustrations came back to me at night making it difficult for me to sleep. I had to re-schedule the group discussion meetings to have a break of at least two days in between the meetings. The reason for this was that some of their experiences were my own experiences and which resulted in the establishment of the rehabilitation centre. The parents/caregivers experienced similar responses from the community to me; neighbours expected me to hide my disabled child and did not understand why I did not do so. When I took my child out for shopping, the people gathered around us expressing their surprise that a disabled child should be exposed in public. While part of me understood that they were trying to show their support and admiration for me, as a mother it was disturbing to realise that my child was a walking circus.

3. 10.   Data Analysis

The researcher used phenomenological qualitative research. According to Hancock[67] such a study explores the meaning of several people's lived experiences around a specific issue or phenomenon. The assumption is that an essence or central meaning of experience shared by individuals exists that can be investigated and explained through research. In phenomenological studies, the experiences of different people are analyzed to describe the essence of a phenomenon.[67]

According to Brett[68] phenomenological reflection includes the two major steps of thematic analysis and the determination of essential themes. Significant statements from the parents and care-givers were highlighted, the themes and categories were selected and were also highlighted in the transcripts, until the themes illuminated the essence of the phenomenon under study. The researcher used two methods namely:

- **Interpretive technique**

The researcher used interpretive technique as an analysis of qualitative data is observer impression. "That is, expert or layman observers examine the data, interpret it via forming an impression and report their impression in a structured and sometimes quantitative form.[69]

- **Coding**

The researcher also used coding since it is an interpretive technique that both organizes the data and provides a means to introduce the interpretations of it into certain quantitative methods. Coding was done by the researcher by reading the data thoroughly and demarcating segments within it. Each segment is labelled with a code usually a word or short phrase that suggests how the associated data segments inform the research objectives. "A frequent criticism of the coding method is that it seeks to transform qualitative data into quantitative data, thereby draining the data of its variety, richness, and individual character. Analysts respond to this criticism by thoroughly exposing their definitions of codes and linking those codes soundly to the underlying data, therein bringing back some of the richness that might be absent from a mere list of codes[69]

3. 11.   Trustworthiness

The researcher strove to achieve trustworthiness by conducting the following measures:
Improving credibility of information through prolonged engagement with the participants. Each focus group discussion continued to validate the previous focus group discussion with regard to findings. In this way the researcher continued to gather data until ssaturation was reached. Validation of interpretation of information was done at every stage of analysis. The analysed data was given to a researcher skilled in qualitative data analysis to check whether there was agreement with themes. During a process of member checks occurred after analysis of data the participants were given the opportunity to engage with the interpretation of the findings. In the process of transferability, or thick description, extensive field notes were taken on the environment in which the study took place. This was done in order to indicate whether there were any observations noted that could contradict the researcher's original perceptions about the main aims of the study. A thorough description of processes and data has been given to allow judgements about transferability to be made by the reader.

3. 12.   Summary of the chapter

This chapter gave an overview of the methodology used in the study, a description of the study, the ethical considerations and a phenomenological reflection. The chapter included a description of how the pilot study and main study were conducted. The chapter closed with describing how ethical issues will be addressed and analysis of the study data. Chapter 4 will present data collected.

Chapter 4

4.1.   Introduction

This chapter will present the findings of the study. The demographic details of the parent/caregivers and the disabled children will be described. The responses of mothers and fathers to the birth of a disabled baby will be presented and the perceptions of mothers/caregivers of what caused the children to be born with disabilities will be presented. The reactions to disabled children by the study participants' families and community will be presented. The difficult experiences of having a disabled child and coping strategies of the parents/care-givers of disabled children will be described. The health and rehabilitation of disabled children, including problems, and how they should be dealt with according to the study participants, will be described. The chapter will end with a summary.

The overall aim of this study was to explore the coping strategies; that is thoughts and actions of parents and caregivers of disabled children. The analysis of the data collected has shown that there are a broad range of issues with which the study participants had to cope. This chapter will address these problems and challenges experienced by the parents/caregivers of the children and explore the ways in which they tried to manage their situations. This management included both functional management of the problem and the rationalisation of the parents/caregivers for the predicaments in which they found themselves. Because each study objective presents a challenge that may have been experienced by the study participants, how the parents coped with each challenge cuts across each objective.

4. 2.   Presentation of demographic details

Data was collected from 6 focus group discussions with a total number of 6 participants per group, and one key informant. The majority of the participants were women with only 3 men among the 37 parents/caregivers who participated in the study. The average age was 37 years for both female and male participants. The majority of participants were biological parents (29), and the balance were guardians (8) who are referred to as care givers in the study. Below in Table 1 the demographic details of parents/caregivers from this study are given:

Table 1. Demographic details of parents/caregivers

Parent/Caregiver: Gender N=37	Parent/ Caregiver: Age Range	Parent/Caregiver: Average Age
Female: 34	23-60 years	37 years
Male:3	35-48 years	37 years

- **Demographic description of the disabled children**

The total number of children represented by the participants was 37, of whom 18 were girls and 19 were boys. The average age of the children was 12 both for females and males. The youngest was 4 years, and the oldest 18 years. The majority of the children came from the rural areas of the Eastern Cape and only 2 lived in the urban area of Mthatha. The disabilities of the children were divided into general intellectual disability and Cerebral Palsy. The majority of the children residing at Happy Home and represented in the study had an intellectual disability (78%), while the rest of the children were Cerebral Palsied.

- **Employment and social status of parents/caregivers of disabled children**

Out of 37 participants only 5 were employed and one was a pensioner. The educational qualifications of parents were as follows:

- One had a bachelor's degree
- One professional nurse
- One teacher
- One student at the Walter Sisulu University of Technology, Eastern Cape
- Three passed Grade 12 of which, one was unemployed and two were employed.
- One care-giver was a pensioner, who was taking care of her grandson.

The participants who were unemployed survived on the Care Dependency Grant, which is the monthly amount of R1080 given to disabled children for their needs by the Department of Social Development. Table 3 below describes the economic status of the study participants:

Figure 3: Employment and social status of parents/caregivers of disabled children

Total Participants	Employed	Pension R1080	Care Dependency Grant R1080
37	5 (12%)	1 (2%)	36 (88%)

Although the primary focused of the study was on the parents'/caregivers' experiences of their children's respective disabilities, it was important to understand the different disabilities of the children. This provides an insight into what the parents/caregivers faced when raising their disabled children. There was a range of different disabilities amongst the children of parents, all of which are comprehensively described and explained in Appendix I.

Although two questions: the possible causes of disability as understood by parents/caregivers and the reactions of parents/care givers, family and community members towards disabled children, were not part of the objectives of the study they have been added as these factors impacted directly on the coping strategies of the participants.

4. 3.   Possible causes of disability as understood by parents/caregivers

Parents/caregivers perceived abuse as the cause of giving birth to disabled children because mothers experienced abuse during the pregnancies of disabled children. In all six focus group discussions the theme of stress during pregnancy due to abusive partners emerged. Married mothers were abused by partners while young mothers who were unmarried were abused by their families in various forms. The following cases describe this abuse of pregnant women.

"During my pregnancy things were not okay with me, I was always in tears, there was no money from her father, who worked in Johannesburg. As she grew up I used to give her mielie-meal porridge without sugar, which she later refused to eat as it was tasteless" "At one stage we ate a dead cow which had a poison we all felt sick including the disabled child. I decided to take the child to the father in Johannesburg but he sent us back asking me if there no doctors in Mthatha? I was crying the whole journey back. He said we must come to the Eastern Cape because he has no place for us to sleep."

'I think it is because I did not have it easy way with the father during my pregnancy. He had a tendency of not coming back home after work and when he does would quarrel with me; I then developed high blood pressure".

Both participants blame the disabilities of their children on abuse by either the partner or relatives during pregnancy.

Other participants blame it on their cultural practices of their communities. These findings reflect the perception of participants;

This participant was a mother who became pregnant while she was in Grade 10. Her boyfriend who was in the same class as her, could not pay the damages as expected according to Xhosa traditional culture, she said that;

"*I fell pregnant, being a girl not married; I got abused both verbally and emotionally. Mam I was insulted by my family saying my boyfriend is a dog because he cannot even pay lobola, I was not given food to eat, yes I was ill-treated and beaten up. My mother was there but I don't have a father, my paternal uncles were doing all this to me.'*

This young woman's trauma continued after the birth of the child and her marriage to her child's father. Her child could not stay with her because she was born out of wedlock and the husband was expected to pay damages and money to reimburse the mother's family for the expenses incurred to raise the child. The fathers' of children who were not married were expected to pay damages for the first born babies. This was done to cleanse the girl who had been disgraced in the community by falling pregnant before marriage. The mother expressed pain at not staying with her child and yet she was expected to do everything for her such as buying clothes and taking her to the doctor when she was sick, while the disability grant was used by her family for their own needs. This was a very painful experience for this mother. Cultural norms and values were also used as a defence for abusive partners when they abuse their pregnant wives. One parent believed that her husband was beating her because she was pregnant. There is a belief among Xhosa speaking traditional people; that if a woman carries a baby boy who resembles the features of the father, he will beat her up or even send her to her maiden home and allow her to return after the birth and they will stay peacefully again. There is a Xhosa name for

that called "Ukwaliswa" meaning to "*avoid somebody*" They believe that the quarrel starts from the third month. According to them even if one carries a baby girl if she resembles the features of the father he will also beat the mother up. That is why this participant said;

"*We used to quarrel with his father and he used to beat me up, but we would come to terms again. I don't know whether that has something to do with the scar my child has on the head at birth. He used to punch me and kick me, but his father also had a disabled sister*"

Malnutrition and poverty among mothers of disabled children occurred during pregnancy and after the children were born. All affected parents perceived that this may have contributed to the disabilities of their children. They associated lack of food during pregnancy; after the child was born and stress related problems with the disability.

This caregiver suspected that since her daughter was hiding the pregnancy from her, she may have done things she was not supposed to do like belt tightening, which could have caused the disability

"*One day she complained of stomach ache, I thought it was a tummy problem needing just stomach cramps treatment. My sister told me that she was in labour pains, and I was very shocked because she is still a student.*"

4. 4. Reactions from parents, family and community members towards disabled Children

Reactions to the birth of a disabled child and to disabled children in general varied could be grouped in terms of positive and negative responses.

4. 4. 1. Parents and Family

The responses of mothers and fathers, to the birth of a disabled child, were often negative and resulted in one or both of the parents abandoning the child.

One young mother who said she was not even aware that she was pregnant until the next door neighbour brought that to the attention of her parents. She was also surprised to notice that she was pregnant and she gave birth to the disabled child and dropped out of school. The child is cerebral palsied. The boyfriend who was still a student at the time rejected her after the birth of the child, she said about him:

"Whoo! That one did not buy even the vest for the child he said in his family there has never been a disabled person."

Other parents and caregivers, however, gave accounts of family support and care for disabled children, even when the mother was young and unmarried. One study participant, a grandmother; said that she was not aware that her daughter was pregnant. When she woke up during school holidays, her daughter who was in Grade 12 complained of stomach cramps and she thought it was normal stomach cramps. The neighbour informed her that her daughter was in labour. She was so shocked and took her to the hospital where she gave birth to a disabled child. She said she was so worried because she had a sister who was disabled who had since passed on; and she thought her grandson has taken after her late sister, had this to say;

"I was very worried to discover that my grandson was disabled; but what I thank God for is that my grandson who I said took after my sister in everything except fits, my sister used to have fits that lasted the whole day but this one does not have fits,"

They do everything to make life easy for the child. The mother is a tertiary institution and the whole family is supportive. The mother's parents take good care of their disabled grandson.

Male study participants shed light on the difficulty that men have with the birth of a disabled child, especially if it is a boy. In African Xhosa traditional culture a baby boy is the father's pride. A male participant expressed how hurtful it was to see his child being born on the tar road and became disabled. He said these words;

"Yes indeed I was very worried to the extent that I took ill" [he was holding back tears as he showed me his right arm, which was affected by stroke *Yes I think one of the reasons is that he is a boy"*

The care-giver was forced to stay with the child since she was the only aunt to the child and the only sister to the father of the child. She went back to fetch her brother's son from Cape Town very much against her will because she was not prepared to stay with

the child. She then called the family to discuss about who shall stay with the child since his brother could not do it as a man and was also working in Cape Town. No one was prepared to take the child everyone say they cannot cope with the child. The negative attitude from the family surprised this participant since she considered them as perfect Christians and even refers to them as Good Samaritan;

"*My close relatives whom I thought were kind hearted, I mean Good Samaritans declined to stay with the child and brought the child back to me because of his condition. I then decided to take him back, what else could I do? My brother being a man could not manage the disabled child.*"

When children were born with HIV/AIDS of parents who had not been tested for HIV both parents would accuse each other. This kind of scenario occurs less frequently now that it is compulsory for pregnant mothers to be tested for HIV/AIDS when they attend ante natal clinics. One participant who was the grandmother of the child with possible AIDS described how she came to be the caregiver of her grandson:

"*My grandson came with my son in 2003 from Gauteng; he was one year and one month old. He told me that he was in love with a lady who accused him of infecting her with the disease. She dropped the child on the bed and off she went, leaving my sick son with the child*". She said she was very shocked to see her son looking very sickly, arriving with the child who also looked very sick. Describing the condition of the child she said;
"*You could actually count his ribs.*"

She took the child to hospital the day he arrived. At the hospital she also consulted the doctor since she felt sick. Both the grandmother and the child were admitted the grandmother due to her high blood pressure. She cited her son who said "*Aunty you see how I look like crying*" [as his son referred to her as aunty] she believed that looking at her son who was skin and bones had raised her blood pressure and believed it was due to severe depression that she had.

There is the problem of teenagers who continue to have unwanted pregnancies in spite of the fact that the clinics provide contraceptives at no cost. In the case of this particular teenager, the community campaigns in schools about the use of condoms to prevent

HIV/AIDS fell on deaf ears. Her reason for not wanting the child was because she was doing her final year at a tertiary institution and wanted to get a job after she qualified. The care-giver who was the aunt of the child had this to say:

"*Her mother was not expecting him; she was at the last year of her tertiary education and was looking for a job*"

The stress experienced by pregnant mothers also related to their responses to being pregnant, which were often informed by cultural norms. One woman did not want her child because the boyfriend was a married man and had grown up children, and due to her fear of the community she was scared to tell the boyfriend about the pregnancy. When asked about his reaction after the delivery of the disabled child she said;

No Mam; there was not any bad reaction from him; he was so supportive we go to the doctor together with him and the child, even at this moment" the support of the father love for his disabled son, and love of the disabled child's support the mother. That helped her cope better with the condition of her child.

In some cases both a parent and significant family members rejected the disabled child as is shown by this woman's story: She carried the burden of her child because she was deserted by her boyfriend, she said;

"*My boyfriend did not give me the money for the baby he said I gave birth to a disabled child I should bear the consequences, I decided to take my child to Cape Town where I had relatives.*"

This mother searched for information and discovered that there was children's hospital in Cape Town, the Red Cross Hospital. She had a cousin who invited her to come to Red Cross Hospital since it was not far from where they lived. Her cousin's wife and children did not accept her disabled child in their house. They did not give the disabled child food to eat; she would crush potatoes and spinach from her plate to share with her child from the food that was given to her. When she was given the occupational equipment for the child the cousin's wife threw the equipment in the dust bin saying that they made the room untidy. As she narrated the story she was crying. She mentioned that the

empowerment programmes they got as parents from the Red Cross Hospital gave her the power to cope with the condition of her child. She thought the reason why she gave birth to a disabled child was due to her social status; she had this to say;

"*At Red Cross hospital were given health education combined with black and white parents of children with disabilities; I discovered that the problem of disability is for all races; it has nothing to do with me and since then I started coping with her condition.*"

This shows that despite active hostility from family members, this mother was able with the help of her cousin to access resources for her child's rehabilitation and her ability to cope with her situation as a mother of a disabled child. This mother gave birth to a second child with the same man after she had had a disabled child with him. However, he said that he would never give her any support because she must suffer the consequences of having a disabled child. She said that she did that in desperation to get a sibling for her son who is disabled so that he/she would love the disabled sibling and take good care of him even if she is not there for her son. There was concern from parents about the future for their children once they died and were no longer there for their children. This concern showed that parents were not worried because they do not want their disabled children, but thought about the future of their children.

Religion played a big role in the lives of some of the participants, enabling them to accept their situations and to actively seek assistance for their children. This mother is an example of extreme distress that was alleviated by her faith:

"*The day I will never forget is the day when I was taking my child to the clinic, which was too far and at that particular moment she was having attack of fits. No one wanted to give me company since my mother got married to another man and left me when I was too young. I was so scared and I wished if I could give him poison so that he can die and be relieved from this great pain and even the clinic is too far. I thought the tank tablet [she* was referring to the pesticide people locally use it to commit suicide, it is quick, people die within thirty minutes*] was a quick solution; but I did not do it. I thought she is my own blood; God does not allow anyone to kill, to take away human being's soul no matter what type of a person; is not the right thing to do, I did not do it*"

This is another example of religion providing support for a parent of a disabled child, the mother said;

"*The day I was told that my child is disabled; Whoo! I was so disturbed; I did not know whether there was a missing limb because the doctor and nurse did not explain what they mean when they say the child is not right; but again I consoled myself all creations come from God, if I do not accept that this is my child who then will*"

A cultural norm which dictates who may become pregnant was revealed in this case: A mother rejected her child before he was born; this woman was 45 years of age when she gave birth to the unwanted child. The community considers women who are single and post menopausal to be celibate and not sexually active. The mother was ashamed of herself for being pregnant thinking about her children, and neighbours who would be surprised that she was still sexually active. The parent was feeling guilty because she did not want the pregnancy and was worried day and night she thought the disability was caused by her, she said:

"*I think all this came from me, (disability), discovering that I was pregnant, I was surprised, worried, and disturbed, because I thought I had passed a child bearing age, but it happened. I had grown up children, what are my children going to say? What about the neighbours in the community, what are they going to think of me, I could not sleep well at night, what kind of a woman am I? I think all these things had negative effect to the child*"

The cultural beliefs, norms and values of Xhosa speakers in the rural Eastern Cape are entrenched in the society and directly affect the negative behaviour towards pregnant women and disabled children. These beliefs, norms, and values increased the stress experienced by parents/care givers. The parents shared their different stories that can tell that these beliefs still oppress the females in rural South Africa.

The mother who gave her child porridge without sugar, who subsequently ate the dead cow that was sick and was sent back by the husband the same day she arrived in Johannesburg because the husband was living with the mistress and told her he has no place for them to sleep. She was embarrassed and could not go back to her house since

the neighbours were going to laugh at her because she told them that she was visiting her husband the previous day, she decided to go to her mother at her birth place. She said her mother gave her money to buy food for her child with her old age pension but because of the cultural values that you cannot leave your in-laws no matter what. She said after few days she returned back to her house because of the other children she left: "*My mother used to help me with her old age grant but suggested that I should go back and stay with my in-laws* "[meaning she must not leave her husband]

A caregiver was the uncle of the child; who took over since his sister passed away. He was the only one who looked after the disabled child. He said all the, other family members never gave her sister any support; instead they made a mockery of her. He said;

"I will not tell lies the whole family *including the uncles*[meaning his brothers*] of the child felt bad about the whole thing, with us the whole family was disturbed when the mother of the child came back from hospital, the disability was visible the child had squinty eyes"*

Another participant said the mother in law was negative towards her disabled child. She used to ridicule her, even when everyone she was laughing because there was something amusing them; she would utter discouraging words to the child saying;

"*Whoo! This one is laughing louder because of her disability; and would ask her to close her mouth. When there are visitors my mother in law will show off and ask if we have managed to find a suitable school for this imbecile stupid girl of Mzukisi, referring to the father who is her son:"*

4. 4. 2. The community

There are negative attitudes and lack of understanding about disability within rural South African communities. Parents/caregivers narrated their different stories. The negative attitude of the community impacted on coping strategies of the parents; this caregiver used positive strategies and was supported by her family and did everything to improve the condition of the child. The mother used negative coping skills hence she abandoned the child.

The caregiver said it was not easy with the community but the family was coping. The child could not walk and his eyes were squinty. They took the child to various health care centres for this condition until he managed to walk and eyes looked normal after the operation. She said;

 "Yes it was difficult because of his condition, but we had accepted him as family as we still love him." "He was not able to walk instead crawled with his buttocks, people called him snake". "Mhh! even neighbours did not want him to visit their children; because he used to go out to play with other children; parents said he must not play with others because he is something else."

One care-giver was the guardian of her sister; their mother had passed away. She said her sister was not happy in the mainstream schools due to the humiliation she suffered from her peers. The disabled child had a hearing impairment.

"There was no problem in the family, only at school where she was a mockery, statements like she is stupid, senseless is even seen as she walks that she is an imbecile."

The children, whose condition labels them as 'clumsy children' in the literature, are the hardest hit in the mainstream schools because their disability is not visible and they lag behind their peers. Even the teachers do not easily identify the problem and label them as stupid. These children are mocked by other children because they often repeat the same class three times until the teachers decide to promote them to the next class. Some of these the stories were shared by participants.

One mother described how her son was made a mockery of by the other students who used to say that:
 "He was not progressing at school and they were pointing fingers at him saying he is just coming for nothing."

This care-giver was the guardian to his brother's daughter who died after the birth of the child and the mother married another man. The child had a physical and intellectual impairment.

"*The challenge was at school where they made mockery of him saying he is limping***"**

Parents/caregivers also related problems they experienced due to a community cultural practice; that the neighbour has a right to send the neighbours' child to the shop or to do any home chores; he/she can do it without asking permission from the parent of the child. These neighbours do that to the disabled children and do not consider the fact that they might not understand what she/he is being asked to do; the parent said;

"Sometimes when a neighbour sends her to do something and she does not understand the instruction the neighbour's utterances like this child is ill-disciplined, as a parent you intervene and say this child is disabled"

4. 5. Health and rehabilitation related problems identified by parents and where these problems should be dealt with

All the participants described how having a disabled person in the family is coupled with health and rehabilitation problems that affect them negatively financially and have brought unhappiness to the whole family and parents do everything to establish whether their child's disability is real. The participants cited problems ranging from difficulty in feeding, epilepsy, and stiff muscles and said disabled children are very sickly by nature. From the parents descriptions of the health and rehabilitation problems it appeared that all the problems started at birth due to prolonged labour, home deliveries and poor nutrition both during pregnancy and after birth. They also blamed their partners and families for the physical and emotional abuse they suffered throughout their pregnancies. All participants in all six groups agreed that having a disabled child in a family is very stressful both financially and emotionally. The challenge for parents of disabled children was that they had to discover and recognise the disabilities of their children without any aid for health practitioners. Parents would notice "strange" behaviour on the part of the child or observe visible signs of a disability. Children who were unable to make any progress at school, at times would alert parents to a possible intellectual disability. At other times, parents carry out their own assessment about the child's type of disability. Some parents listened to the radio health education programmes about disability and health. One such parent suspected that her child had an intellectual impairment. Her child was promoted to the next class but could not write or read. She said the child was 8 years old.

"One day I was listening to the radio, parents were advised to make the child to draw his/her hand on a paper to see if the child's intellectual capacity is sound, I did that with her although she was 8 years old she could not do it, I suspected that she was disabled"

One participant was not informed that she had given birth to a disabled child. Her mother was illiterate, and was unsure if the child had a disability but the shape of the head made her suspicious and she spoke to her daughter about it;

"I noticed the shape of his head and said my daughter jokingly; it seems you are going to get a social grant; the mother was upset and annoyed."

Her daughter then left the child with her and married another man who is not the father of the child.

This participant said her mother did not to tell her about the suspicion she had about disability of her child, instead she suggested that she should take the child to the doctor because there was something wrong with the child:

"My mother advised me to take the child to the doctor because there was something wrong with the child; the doctor told me that the child is disabled due to lack of oxygen at birth".   "But I do not hate her child because of his disability."

4. 6. 1. Perceptions and experiences of parents/caregivers regarding accessibility of health and rehabilitation services

These two objectives facilitators and barriers will be discussed under the same topic since parent's perceptions regarding services were both positive and negative about the service delivery at the health care facilities. Despite the challenges facing the parents with regards to health care facilities, parents felt there is a need for more of these health care facilities.

Some parents/care givers said although the health care facilities are situated far from their homes, these facilities do offer them help and treatment. Others parents said that they had tried other methods and treatments such as traditional and spiritual healing but

in vain; their children continued to have epileptic seizures until they used medical treatment.

Participants in all groups said the traditional treatments did not stop the seizures of their disabled children but that when they started medical treatment the seizures were reduced. Where before medical treatment the child's seizure used to continue without stopping for three hours, he/she would have seizures once a month and the seizures would last for fewer hours once they were having medical treatment.

During a group discussion, a participant who was a father of a child with disabilities said he had been to faith healers and traditional healers. Traditional healers suggested to him that before they could treat his child, some rituals had to be carried out. Accordingly some sheep and goats were slaughtered but the child became worse until the he decided to consult some medical practitioners who referred his child to the hospital for monitoring. The neighbours also came with different suggestions about the best traditional healers they knew. He described his state of mind at the time;

"I ended up confused and did not know who the real best is,"
and how it had changed as a result of seeking medical treatment for his child
 "He is now using the treatment ever since there is improvement, before I used to take the traditional medicine to hospital, hid it from nurses and told them it was tea but my child; continued to have seizures, I don't want to hear anything about traditional medicine"

Another set of parents said;

"In our community we have realised that there is need to have a nearby clinic for emergency services when these attacks do happen at night it becomes a big problem"
"the clinic is far but we and get help and fetch pills" Another positive statement from parent was; *"They help [*referring to health care facilities*] us because it is much better to fetch pills and medication from the clinic that from the hospital"*

4. 6. 2. Barriers to accessing health care facilities

According to the study findings there were no physiotherapists, occupational therapists, speech and hearing therapists or clinical psychologists at the health care centres in the study area. The health care centres provided treatments for chronic illness like, diabetes

and hypertension. There was one vehicle to take the emergency referrals like difficult labour or accidents to the Nelson Mandela Academic hospital in Mthatha which is approximately one to two hours drive from each health care centres.

The first barrier mentioned by parents was the distance and transport costs for reaching the health care facilities. The second was the attitude of the health professionals; Poverty was mentioned as a cause of not attending antenatal care. According to Government Policy, health services are free to the disadvantaged: antenatal, post natal, and immunisations are free, but they are still inaccessible due to transport services and the distance to those health care facilities. They cited the following challenges;

"*I delivered at home; I was using traditional medicine because I had no money to go to the clinic.*"

Parents of disabled children in rural areas, struggled to get to a health care facility. In this context, it is not unusual for a mother to carry a disabled child on her back to a bus stop, sometimes for as long as two hours. Upon arrival at the clinic, the parent is tired and hungry; instead of receiving quality service they are met with disdain from health practitioners and are often insulted. The participants shared their challenges with the group. The disrespect they receive from health care professionals constitutes a barrier and discourages parents/caregivers of disabled children from using the health care facilities, while traditional healers welcomed the parents and gave them hope when they visited them. The participants shared similar stories about their experiences of the attitudes of the health care professionals;

 "*My child was at the door steps of the clinic when he got epileptic attack nothing could be done to him, not even medication to stop the fit, not even the word of consolation; it shows that they do not care for us*"

This parent believes that if the hospital staff were diligent in rendering their service her child could have been saved from being disabled. This mother was informed the cause of disability of her child is the fact that child was tired by the time she gave birth to him. She said;

"They kept on telling me that the child was still far, even when I told them that some drops of water were coming out, the nurses scolded me asking if I once had a baby, didn't I say this is my first child/ they made mockery of me"; "I delivered on my own, but it was very difficult they were struggling to pull him out using the instruments to pull out the baby since he was tired."

When this mother went to seek the grant for her child from the Department of Social Development the was confronted with another challenge of professionals who was not sensitive to the needs of the disabled people; Social Worker said;

"Whoo! You are so fond of money; I responded by saying, it's not the love of money but I want to take my child to school"

The participants shared their concerns regarding the mobile health care facilities and mobile clinics. They said the staff at the clinics were not supervised, they did as they pleased and knew that no one would report them; the mobile clinics were also not effective because the staff members visited the venues for the mobile clinics only when they wanted to go to their rural homes. They would stop there for a short time and leave saying there were no people even if they saw the people coming they did not wait.

4. 7. Critical health related incidents and coping strategies of the parents/care-givers in the management of health related problems of their children

The research objective, dealing with critical health related incidents, will be combined with the coping strategies objective since these two are intertwined. It was noticed in the course of the group discussions that parents used coping strategies when dealing with critical health related incidents of their disabled children. The coping strategies used by parents were drawn from or occurred in those families who were supportive. The extended family situation, where there are grandmothers, sisters, and brothers staying in one house, constituted the most effective support system. Many parents reported that even during poverty the grandmothers supported their daughters with their pensions. The few participants who were not lucky enough to have parents had poor coping strategies; but, managed to draw strength from the Bible during difficult times. Other parents and

caregivers gave accounts of family support and care for disabled children even when the mother was young and unmarried.

Some parents did not believe that their children were disabled. This denial defence mechanism resulted in parents using various health practitioners for medical opinions. One parent sought a second opinion when the first doctor she consulted said the child had a disability, hoping that another doctor would say something different. The health problem of the child manifested as the child stopping breathing for a second, becoming quiet and then beginning to breathe normally after a few seconds. The coping strategies that used by parents are described below under the following headings: running from pillar to post, hope for change, the role played by religion in coping strategies of parents, prior knowledge about giving birth to a disabled child and the use of family as support and the need for quick solution to the problem and avoidance

- **Running from pillar to post**

One parent said she did not want to go back to the first doctor who diagnosed her child as epileptic and gave her a treatment for the child which would reveal epilepsy symptoms instead of the child's breathing stopping. The night he was given the treatment the child had an epileptic seizure which lasted the whole night. The mother did not want to go back to the doctor and instead went to another doctor, believing that it was the treatment that had caused the child to have the epileptic seizure lasting all night;

"He was given treatment and the doctor said if he has fits he will show clearly after taking the treatment he had fits for the whole night and we could not sleep. I was scared to go back to the same doctor, I went to the hospital the following day; he was admitted and my mother in-law remained with him as I was pregnant."

It appears that their lack of knowledge and understanding of impairment and disability was the reason some parents/caregivers of disabled children were running from pillar to post.

Parents/caregivers indicated that at health care facilities they often received poor reception from health professionals. The poor reception discouraged them from returning to health care facilities. The negative experience leaded them to consult with traditional

healers. One mother shared her experience of her inhumane and disrespectful treatment at the hands of health care professionals;

"The day I will never forget is the day the hospital could not help me. Instead I was sent back... As he was having fits outside the hospital the people at Out Patients' Department (O.P.D.) advised me to go inside again and I told them I have been sent away... "They insulted me, asking why I bring him when he is just like disfigured old tin; they said they cannot do anything for me. When they weighed him he just sat there helplessly as ever looking like a sick lamb. As I was going out with my child one nurse said maybe you can bring him for drip. After a while we were given treatment. From the hospital we went to the traditional healer. We waited as he was preparing traditional mixtures and things to burn so as to chase the evil spirits. He confirmed that the child was critical and was also teething."

This parent ended her story by saying it was the first time she had consulted two different kinds of medical practitioners but she did it because she saw herself as having no choice.

- **Hope for change**

Parents in all the focus groups took their children to a range of health practitioners including medical doctors, clinics, specialised children's hospitals and traditional and faith healers. The parents took the initiative to look for special schools for their children. This shows that even the parents who were illiterate had adapted to dealing with the health and rehabilitation of their disabled children.

It appeared that caregivers derived positive coping strategies by remaining hopeful and believing in positive change. Despite a child being born disabled and not being able to walk for five years, the doctor's reassurance that the child would be able to walk despite developmental 'milestones' being delayed;

"*But the report from the doctor that the girl will be able to walk brought relief and joy to the family*"

The doctor's comments gave them the strength to be positive and to do their best to achieve the best results.

Despite the many difficulties that parents/caregivers of children with disabilities face, there is also much resilience and determination among them to ensure that their children receive what they need as far as is possible.

- **Role played by religion as a coping strategy for parents**

One mother related her experience of religion providing support for a parent of a disabled child:

"*The day I was told that my child is disabled; Whoo! I was so disturbed. I did not know whether there was a missing limb because the doctor and nurse did not explain what they meant when they say the child is not right, but again I consoled myself all creations come from God. If I do not accept that this is my child who then will?*"

- **Prior knowledge about giving birth to a disabled child and using family as support**

The courage of one mother was evident in her story of how she called all the other siblings of her two disabled children and explained to them the condition of their two disabled brothers. The participant had gained coping strategies from the previous experience of giving birth to the first disabled son who was her first child born child. She described how she used her experience to cope with her disabled sons and to gain the acceptance of them by her other children and enlist their support:

"*I have 8 children, I sat down with them and made them understand and accept their special siblings, one in Tsolo special school* [meaning she had two disabled children who had intellectual impairments]. *The other one is very destructive. When I was annoyed when he broke the radio, the siblings reminded me: 'But mama you said he is disabled. How can you punish him?' I felt sorry, and apologise to them; I think to call them was a good idea*"

The mother used her family as a support system by educating her children about disability and in they turn helped her acquire better coping skills.

- **Access to health facilities needs urgent attention from Government**

One mother described her extreme distress: the distance to the health care centre, facing her problem alone when other family members did not want to accompany her. Such was her fear and intense pain and desperation to solve her child's health problem that the thought of killing the child to relieve her (baby girl) from the suffering entered her mind. The only thing that alleviated her distress was her faith:

"The day I will never forget is the day when I was taking my child to the clinic, which was too far and at that particular moment she was having attack of fits. No one wanted to give me company since my mother got married to another man and left me when I was too young. I was so scared and I wished if I could give him poison so that she can die and be relieved from this great pain and even the clinic is too far. I thought the tank tablet [she was referring to the pesticide people locally use to commit suicide: it is quick and people die within thirty minutes] *was a quick solution, but I did not do it. I thought she is my own blood; God does not allow anyone to kill, to take away human being's soul no matter what type of a person. Is not the right thing to do, I did not do it"*

Even though she was tempted to take the quickest and easiest way out of her predicament, this woman's faith helped her to start regarding her child as a human being and saw that poisoning her child was not a human thing to do.

- **Avoidance**

Sometimes those professionals who do not understand disability as a human rights issue are a problem in the delivery of government programmes. Parents depend entirely on the teachers tasked with the early childhood development phase of children to mould the future of their children. It is a matter of grave concern that in rural communities the people who are entrusted with the responsibility of taking care of children show poor communication skills, and callous behaviour towards mothers of children. A teacher expressed that she was "happy" that the child was involved in car accident; communicating that to a parent of a disabled child who came to report at the school that her child was admitted in hospital after the child was involved in a serious accident. The utterances of this teacher devastated this mother;

"*His teacher told me that she was very happy my son got the accident; she was relieved since my son was the youngest in the class in Grade R".* This mother went on to say, *"I*

am happy because I have moved from that community. I will never see her again"[referring to the teacher.]

The health professionals did not respond differently although they are generally expected to give hope and to provide counselling to the parents, and yet they show the parents little kindness or respect. The family of the child involved in the car accident, relayed that the doctor's utterances further dashed the parents' hopes for the recovery or development of the disabled child. Thus the parents do not wish to see that medical practitioner again.

"What I will never forget is what the doctor told me. He said my child will never be anything; will never do anything. He crushed all hopes..... I cried a lot until my husband said the doctor is not God. The child was born normal; she may change and be something else. I don't want to see that doctor in my life"

Both parents said they did not want to see those health professionals who had hurt them. This would not bring them closure. What this story indicates is that there is a need to provide counselling to these parents although they said they did not need counselling.

Another parent said that when her child had seizures lasting 3 hours, the distance to the health care centre made both parents resort to the faith healer.

"I remember the day the child had epileptic attack for 3 hours non- stop. I had to accompany my mother in law to a place of prayer where we stayed for a week. By the time we came back he was much better"

4.8   Summary of the chapter

This chapter presented the findings of the study. It included the demographic details of the study and outlined the possible causes of disabilities as perceived by parents/caregivers. The reactions from parents, family and community towards disability as experienced by the participants in the study were presented. The critical health related incidents and coping strategies of the parents/care-givers of disabled children were described, as were the perceptions and experiences of parents regarding health and rehabilitation services according to the study participants. Chapter 5 will discuss the in-depth the findings of the study.

Chapter 5

5. 1.   Introduction

This Chapter will discuss the findings of the study, initially providing the context of the study participants.   The parents/caregivers perceptions of disability and its possible causes will be explored. Reactions to a disabled child will be discussed within the context of the parents/caregivers; the extended family and community, and health care providers will be discussed in depth. Critical incidents and coping strategies used by parents/care givers will be discussed in depth. These responses will be further explored in terms of cultural influences. The perceptions of parents about accessibility and barriers of health and rehabilitation resources will be discussed. The chapter will end with a summary.
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5. 2. The context of the study participants

Most parents/caregivers of disabled children in the study lived in the rural areas. The parents/caregivers of disabled children are also mainly women. The high levels of poverty can be seen from the high rate of unemployment among the study participants. State disability grants and even pensions are crucial for the survival of whole families; this leaves little or no finances available for accessing health and rehabilitation care for the disabled children themselves. Distances to health and rehabilitation services are long and transport is expensive.

5. 3. Possible causes of disability as perceived by parents/caregivers

Regarding epilepsy, all parents believed that it is caused by evil spirits but they agreed that traditional medicine or faith healers cannot heal it. Some participants said they had tried these traditional remedies for long periods of time.   They concluded that using conventional medical treatment was the only solution.   There is a general lack of understanding on the part of these parents of the biomedical cause of epilepsy. This affects their management strategies, causes a delay in treating the child and as a result complications can develop such as brain damage and physical problems. As the child grows it becomes difficult to carry her or him to a health care facility which may be situated far from the parents' home. This causes the parents to default on their child's medical treatment and this becomes a vicious cycle. Poverty and malnutrition were also experienced by women whose partners were in urban areas and the absent partners

indicated that either they had no means to support the women, or that they were no longer interested in the women and had other partners.

Psychologically this is not good for the self esteem of these women. They move from pillar to post looking for a partner who can appreciate and support them. Generally it is very difficult to find partners who accept the disabled children of these women. They then decide to leave their children with their mothers or extended families and marry other men who are not the fathers of their disabled children. Due to radio health education programmes parents/caregivers are coming to associate the disability of their children with lack of food during and after birth. In all the focus group discussions stress during pregnancy was mentioned as possible cause of disability. Parents/caregivers consulted traditional healers first before they resorted to medical sectors. Traditional healers associated epilepsy with witchcraft or ancestors are not happy about something.

5. 4.   Reactions of the parents/family and community towards disabled children

- **Reactions of parents/caregivers and family towards disabled children**

Extended family members were a source of support for some parents/caregivers, while in other cases the attitudes of the extended family members were either hurtful or damaging. Participants reported being abandoned by the extended family including female relatives, which was the how one of the male participants came to be a caregiver, he was the uncle of a disabled child and took responsibility after the death of the child's mother, and the only member of the family prepared to care for the child. Parents/caregivers reported that loosing the support of the extended family was a shock because the extended family was considered the support base for all family members. The abandonment of a parent by extended family and/or a partner, as already mentioned in the previous paragraph, causes the parent to weigh up the extent of her/his loyalty between the family, partner and disabled child. Usually the disabled child becomes the loser.

In other cases, the extended family members mocked and taunted the disabled children in the family causing much hurt to the parents. The disabled children were referred to as imbeciles in their hearing. In some cases, certain extended family members would refuse contact with the disabled child, even in the same home. Parents reported that even close

relatives still think that a disabled child should not be seen by visitors since she/he is an embarrassment to the family As a result the disabled child becomes isolated and her/his development of cognitive and life skills is delayed. Van Rooyen[33] in the literature states that a disabled child can pose a serious threat to, or even damage, the parental ego because a child represents the extension of the parent. Thus the reaction of parents when they recognise impairment in their child is highly unpredictable.   This unpredictability in parents' reactions tends to impede the development of positive coping strategies on the part of parents, resulting in poor planning for the child and the shifting of blame because they do want to take full responsibility for doing proper planning for their children. Ryan[36] states that many parents, when informed that they have a disabled child, will start a process of self-searching which, often leads to self-blame and guilt. This self-blame and guilt drain the energies of parents of disabled children and hinder them from the proper planning and development of positive coping strategies.

Parents reacted differently to the birth of a disabled child. All parents/ caregivers in the study agreed that having a disabled child was painful. Some parents, however, either the mother or the father or both abandoned the disabled baby. Various justifications were used by parents who abandoned their children. The parents used the reasons to rationalise their actions thus, enabling them to cope with the decision. Parents abandoned children due to a cultural belief that disabled children are bewitched. Fathers would refuse to support or have anything to do with a disabled child because they had no history of disability in their families or because they believed that the disabled child was punishment for the mother. These rationalisations allowed the fathers to distance themselves from their children and from disability. Mothers abandoned their children in favour of another partner who was prepared to look after them but not their disabled children, also younger mothers refused to take on the responsibility of their babies because they either wanted to complete their education or find employment.   Shifting responsibility would take place once the parent gave birth to a disabled child and education becomes a priority. The responsibilities for the children were then taken up by extended family members who addressed the needs of the disabled child and accessed government disability grants. These extended family members who became caregivers were mainly resident in the rural areas of the Eastern Cape.

The reaction of the parents of disabled children in terms of opting to abandon their disabled child shows that the traditional model of disability still prevails amongst the participants since members of the community still believe giving birth to a disabled child is unfortunate and carries stigma. A mother's idea of killing a disabled child due to her distress was also reported. Religious belief within the culture of the study participants proved in this case to be strong enough to avert the action. That a mother had considered such an act, however, shows the enormous stress and difficulty experienced by mothers in this social and cultural group who give birth to disabled babies. This is supported by the Koshti[30] which shows that a 61, 2% depression ratio was found in mothers of children with Cerebral Palsy. Some of the literature also argues that the bias of the traditional model is culturally relativity; scientifically based knowledge is not associated with this model.

Mothers who participated in the study had various perceptions about the cause of their children's disability. These perceptions were as a result of the women's experiences; and not as a result of information or education about their children's conditions. Mothers indicated that abuse, stress, poverty and malnutrition were the causes of their children's disabilities. Unmarried women experienced abuse at the hands of their immediate family or extended family, they were beaten and food was withheld causing the pregnant women physical trauma and stress. The abuse was justified in cultural terms; women who were pregnant out of wedlock deserved such treatment, particularly when the father was absent or unable to pay the woman's family the traditional damages required. One parent gave birth to child with a scar on the head she suspects that she got the scar on the head of the child during the punching and kicking she received from her husband.

The violence is given a name; "*ukwalisa"* meaning the child resembles the features of the father and is not considered abuse. The name given to this abuse is used to normalise beating and kicking during pregnancy, thinking that the features of the child that resemble that of the father of the child is a cause for the rejection and physical abuse. This abuse is the result of a tradition that promotes the abuse of women. Women also believe that it's not a bad thing since the husband cannot fight the feeling of hatred during the period of pregnancy and they believe that sometimes it is a woman who has the same feeling of hatred for her husband until after delivery. It appears that these women devise excuses for the level of abuse within the relationship. Mji[3] stated that, where some aspects of

cultural activities are repressive, they need to be challenged. This needs to be done with a cautious and caring approach as an inquisitive questioning attitude is often seen as deeply subversive in a community with a strong cultural identity. It is suggested in the literature that raising awareness with regard to unacceptable cultural norms or practices can be best attempted by people within the culture itself who have questioned first themselves and have made that shift.[3] This suggests that there is a need to strengthen community based rehabilitation programmes to include those communities where these practices remain entrenched and to discuss both the positive and the negative issues of a culture. Gara stated that forums can be used as a means of raising disability awareness and identifying possible participants in the rehabilitation programme from parents/caregivers of disabled children in the community. [32]

- **Reaction of the community towards disabled children**

The results of the study show that health professionals continue to narrowly adhere to the medical model of dealing with disability at the health care facilities. This puts a strain on the relationship between the practitioners and the parents/care givers of the disabled children. McKenzie[27] argues that, at the same time as medical and welfare professionals undermine parents' confidence in their ability to do what is right for their children, they depend entirely on the same parents to implement what those professionals perceive to be the correct approach to disability in children. The study findings show that the relationship between parents/caregivers of disabled children and professionals can develop positively, resulting in parents/care givers of disabled children sharing information on useful coping strategies and therapists sharing their bio-medical rehabilitation approach to the health related needs of the disabled child.

The study participants reported that the community members in general had negative perceptions about disability and negative attitudes towards disabled children. The perception that disabled children were not quite human was represented in the examples of community members referring to disabled children in animal terms and not wanting their children to play with them because they were 'something else'. This has a deep and long term effect on the socialisation of the disabled child who will one day become a disabled adult. Exclusion is common amongst disability approaches such as the practice of marginalisation of people with disabilities.

Parents/caregivers said they could not leave their children with the neighbours because the neighbours refused to take care of disabled children. They say they are scared to feed children with cerebral palsy. Some parents still lock their children inside the house and lock the gates because they say the neighbours dislike their children. This is supported in the literature. Some Cambodians hold a religious belief that a disability is a punishment. A disabled child to them is shameful for a family. Quite often disabled children are kept at home doing nothing, or sometimes abandoned on the streets to make their own way.[39] As with extended family members, disabled children are often mocked and derided by neighbours, fellow school pupils and even teachers and health professionals.

Parents/caregivers spoke of their children being told they were stupid at school and teachers being relieved to no longer have to teach them. When parents/caregivers took sick disabled children to community health services they reported lack of interest from the health professionals and were even refused treatment because it was considered pointless because of the child's disability. Although the Constitution of South Africa includes disability under Human Rights, disabled people do not seem to be enjoying the fruits of the Constitution. The parents of disabled children see freedom as still being in the far distance because they continue to suffer under a form of oppression from the 'liberated' health professionals. The question remains: who is to blame? Disillusioned parents of disabled children feel as South African citizens that their constitutional rights are being trampled on and thus see the South African Constitution as a useless document if its implementation is not properly monitored.

5. 5. Health and Rehabilitation Problems identified by parents

The conditions of the children of participants/care givers as discussed in full in appendix 1 can be summarised as Cerebral Palsy, Metabolic disorders, Down's Syndrome; Microcephaly and poor cognitive skills. Parents felt that if there had been early intervention programmes some of the conditions of their children could have been corrected. Parents are informed by teachers when their children are 8 years old that their children need to attend a special school. Parents say that at that stage it is too late for them to look for special schools. Borgunn[38] described how parents of children with learning difficulties experience a very tough period when their child reaches the age of approximately 8 years.   Earlier in the chapter, the topic of how parent's denial of their children's disabilities often lead to late diagnosis and prevent relevant treatment.

A shortage of health professionals at the health care facilities poses a threat to the health of disabled children who need constant checkups and physiotherapy treatment. If there were health care centres with physiotherapists in rural communities the complications around disability in children would be reduced. Rudasa[4] argued that many health professionals opt to work in the private health sector and thus the public health sector experiences general shortages, and that it is the rural areas where the shortages are most acute. Gara showed in his study on women who currently have disabled children and live in poverty that mothers of disabled children are especially affected by poverty[31]. Results of the study show that poverty is an added strain on the parents of disabled children who were sickly. Since poor nutrition exacerbated the situation.   The government grant is assisting these mothers with the basic needs but usually in these circumstances the whole family is dependent on the grant and this makes it difficult to save money for transport to the health care facility and for the other needs specific to a disabled child. Hartley[56] showed that inhibitors to coping of parents of disabled children are reported to include financial hardship, stigma, and demands on time, difficulties in care-giving tasks such as feeding, reduced time for sleep, social isolation, less time for recreational pursuits and difficulties in managing behaviour problems.

5. 6. Perceptions & experience of parents/caregivers regarding health and Rehabilitation services

The study indicates that communication, between parents/caregivers, and health professionals, is not optimal. Parents were either not informed that their children had disabilities or if parents were informed, the condition was not explained. This created problems for parents who later came to understand that their children had a disability and in some instances this meant that children were excluded from local schooling. This undermined the efforts of the government to ensure inclusive education for all children. Poor planning at school for the support of the disabled child has the effect of undermining the relationship between parents and teachers.

The perception of all parents regarding accessibility of health and rehabilitation services was not favourable. Lindbald et al[34] supported in the literature that deficit models tend to define communities and individuals in negative terms, disregarding what is positive and works well in a particular population, while asset models tend to accentuate positive capability, to identify problems and activate solutions. According to the findings of this

study; the health professionals perceived disabled children as a burden and less important than non-disabled children. Health professionals are seen to not be willing to devote the time and resources to study how parents may be coping with the disabled child, and did not seek to strengthen their own knowledge nor that of the parents/caregivers.

Parents felt that the health care centres were situated too far away from where they lived. The lack of transport and the distance to the health care facilities in rural communities created a difficult barrier for the study participants to negotiate. The parents felt that they were not respected by the health professionals, they were insulted by the nurses, and doctors were often clinical and insensitive; and they were not given time to ask about health issues or discuss their problems. Some mothers felt that, if more attention had been given to them when they were in labour, their children's disabilities could have been prevented.

In this study parents/caregivers expressed their frustrations with regards to health care facilities where they could take their children when they are sick. The attitude of health professionals undermines the efforts of government to implement and maintain community based health care and community based rehabilitation as part of its health care strategy. Poor experiences with health care professionals can incentivise the use of alternative and unsuitable health systems as they may be more accessible or parents/caregivers are more comfortable in these environments.

The participants shared their concerns regarding the mobile health facilities that are not monitored. They said the staffs at the clinics do as they please and know that no one will report them; the mobile clinics were also not effective because the staff members visited the sites for the mobile clinics only when they wanted to go to their rural homes. They stop at the sites for a while and leave; saying there were no people even if they see people coming running to the mobile vehicles they would not wait.

The negative attitudes of health professionals, and the conversely positive attitude of traditional healers who give parents hope when their children are sick and accommodate them in their houses until the children are better, motivate parents/caregivers to seek out these services over professional health services. The crucial problems of delays in early

detection and inadequate ongoing treatment will continue if health professionals do not change their attitudes. Furthermore there is a need to train traditional health practitioners about good health and safety precautionary measures when treating their patients.

5. 7. Critical health incidents and coping strategies used by parents in the Management of health related problems

Demographic characteristics of parents/caregivers in the study revealed that many live in rural areas, are single and unemployed. Churchill[53] stated that parents of disabled children are at increased risk for depressive symptoms, especially if single and unemployed. Woodgate and Roberta[63] argue that parents of children with special healthcare needs who have better coping skills, have fewer depressive symptoms. In this study, poor coping skills were associated with high levels of unemployment and illiteracy that resulted in a lack of knowledge about available resources, as well as high rates of desertion by husbands and fathers, leaving women single.

The literature Cody[18]argues that coping capabilities refer to the strategies the family uses to manage demands placed on it by various stressors. The mediating factors that influence coping strategies include; family beliefs and perceptions, religious and moral beliefs, overall philosophies and ideologies held by families, family lifestyles and the extent of harmony in the family.

Despite the many difficulties that parents/caregivers of children with disabilities face, there is also much resilience and determination among them to ensure that their children receive what they need as far as is possible. In the literature KaR[44] it is stated that, irrespective of the economic status of families with a child with disability, intervening factors like the mother's personality, optimism, and religious support were found to alleviate the degree of stress and enhance coping capability. These factors, such as a positive attitude, social support and faith in God, help mothers generate psychic energy to cope with the physical, emotional, and financial aspects of care giving. Parents/caregivers in the community where the study was conducted are seen to generate psychic energy to cope with challenges through faith in God and a positive attitude towards disability.

Parents/caregivers use indigenous knowledge and life skills to solve problems. Some reported religion, in particular Christianity, as the cornerstone of their strength and support. Parents/caregivers from all focus groups use the full variety of health practitioners, both formal and informal such as medical doctors, traditional healers and faith healers. The parents/caregivers take the initiative to look for help for their children with referral letters from health professionals.   When parents/caregivers realise that there is a problem with the intellectual capacity of their children they listen to disability awareness radio programmes, or consult the elder generation in their community who have experience with children's development. These actions help the parents/caregivers to make informed decisions and take their children to appropriate schools. Acquiring the relevant information and knowledge of their children's disabilities was a challenge to the parents/caregivers, especially in the early stages of the child's life. This is particularly crucial, as Cornill[53] suggests that early intervention by means of specific motor training programs and general developmental programs in which parents learn how to promote infant development may be the most promising way to promote motor and cognitive development of infants with or at high risk for developmental motor disorders.

In the motivation of how the study may benefit the community, it was mentioned that once parents' coping strategies and indigenous knowledge about coping with the health and rehabilitation needs of their children have been identified, the young inexperienced therapists will come with their bio-medical expertise, and these two will be integrated. The Canadian model[40] of disability supports this as the literature states that a professional culture of occupational therapy holds that individuals should identify goals that are meaningful to them and that the therapist's interventions should be client-centred, assisting the individual to accomplish those goals. These include the individual's cultural preferences, individual or group values, beliefs, and behaviours. It is inevitable that understanding the culture of an individual is central to allow for a health practitioners helpful intervention. The hope is that understanding and incorporating these beliefs into the intervention process will improve outcomes of care. Although this remains to be validated through careful outcomes research, there is certainly a growing body of literature to suggest that this is true.[43]

The study itself also constituted an intervention for parents/caregivers dealing with the stresses of caring for disabled children. Participants reported that the opportunity of

sharing their experiences in the group discussions gave them relief, since they never got the chance previously to speak about their experiences with their children. Having had the opportunity, they felt closure about what they had shared, and consequently, this may explain why none wanted to be referred to the psychologist for counselling, as they felt they did not need any counselling. Following their experiences with the benefits of sharing experience and information, the parents realised the need to form parents' group in their areas. In this respect, the researcher intends to pursue this request.

5. 8. Summary of the chapter

The chapter presented the discussion of all the findings of the data as presented in the previous chapter. All the objectives were covered by participants who were parents and caregivers of the disabled children. The findings discussed were based on the literature review. The next chapter which is chapter 6 will present recommendations and conclusions of the study

Chapter 6

6. 1. Introduction

Recommendations and suggestions on how to achieve the recommendations will be presented in the chapter and how will the study benefit the Community. The chapter will end with the summary.

6. 2. Recommendations

As a result of this study the following recommendations are made to enhance the health and well being of disabled children and their parents/caregivers, and where possible to prevent secondary impairments/disabilities from occurring. Cultural beliefs that condone abuse of women and of pregnant women in particular need to be addressed and the rights and both women and unborn children need to be stressed. The suggestions on handling the topic concerning the cultural beliefs as mentioned in the discussion will be taken into consideration.

Awareness campaigns providing information for the general community need to be provided to educate people about disability and to dispel cultural attitudes that are harmful to disabled children and their parents/caregivers. As mentioned in the discussion, it is important to identify parents/caregivers in the community who will be included in the campaign so as to involve community participation when discussing and referencing culture.

There is a need for incentives to motivate health professionals to work in the rural areas due to the poor conditions. Measures have been initiated by the South African Government, such as compensation for nurses who work in rural areas, but poor management and supervision result in poor quality of service delivery at present. More must be done to improve management and supervision of health professionals to raise the quality of service delivery in the short-term.

Financial motivations should be provided to ensure that physiotherapists, occupational therapists, speech and hearing therapists, clinical psychologists and other specialised health professionals as needed are placed at the health and rehabilitation centres. This is

a long-term goal but it is possible. The Government can motivate students by offering bursaries to students doing health related courses. In 1989 Walter Sisulu University of Technology initiated the programme for Health Education specialists to promote health through primary health care; the programme was sponsored by Government with the condition that all health education specialists who have studied through the bursaries should work in rural areas at least three years. The researcher is one of the products of that programme. The universities should also include disability issues in health related studies, both so that new health professionals gain sound knowledge on disability issues and policies and that they become sensitive about disabled people and take disability as a human rights issue. Due to the distance between communities and health care centres, and the difficulties in accessing transport; pregnant women commonly deliver at home. Training is required on correct methods, including the use of sterile equipment and gloves for the traditional birth attendants. Traditional birth assistants must also be trained to ensure that as soon as possible after delivery all infants must be referred to the nearest community health centre for examination of the mother and child and to start immunisation. This is a short term goal since the Health education specialists are doing awareness campaigns in rural communities with traditional healers and community birth attendants.

Awareness campaigns in the communities should be conducted to educate people about the symptoms and causes of disability. Parents/caregivers should know the symptoms of intellectual and physical disability to enable them to recognise disabilities that do not manifest immediately at birth and to take immediate action. The literature shows documented evidence for the effectiveness of early intervention by means of specific motor training programs and general developmental programs in which parents learn how to promote infants development of the motor and cognitive skills to infants at high risk of developmental motor disorders. Researchers need to do fact finding studies on the qualifications of teachers of the early childhood development programs in South Africa since this is an important developmental phase in lives of all children including disabled children.

6. 3. Conclusion

The study aimed to explore the coping strategies used by parents in the management of the health related problems of their disabled children.   The findings of the study established the existence of a basis for the perception that health and rehabilitation services are often inaccessible to those in most need of care, a perception in line with that of the researcher and one which motivated the study. The results of this study were in line with Fuad's[18] view that strategies adopted to address a social problem are relational and reflect the relationship between the individual and his/her environment in contrast to the unfocussed more traditional trait- orientated approaches and that relational strategies are interactive in nature, linking and integrating a range of stress components The study findings proved that the communities from which participants came perceived disability in terms of the traditional health belief model.

The findings showed that those parents who had stable families and support from their immediate and extended families had better coping skills. The parents who experienced rejection from partners, families and communities had poor coping skills but for some parents who had entertained thoughts of killing their children this option was not considered as a solution as their Christian beliefs both forbade it and helped them to cope with their situation.

6. 4.   How the study will benefit the community

As was discussed in Chapter 1 (1.4) under motivation for the study, it is intended that this study will benefit the community through informing the planning and content of awareness campaigns to be conducted in all the communities in the O.R. Tambo District Municipality which includes areas from which the children at Happy Home come. It is hoped that these campaigns will raise the awareness of the parents/caregivers in these districts that of the preventive role primary health care can play in detecting and treating certain disabilities, so that when parents attend ante natal clinics certain disabilities can be detected early and early intervention can be initiated to prevent possible complications and secondary impairment. It is hoped that the campaigns will assist parents and caregivers to be involved in all the processes of intervention and decision making and provide them with guidelines on how to conduct their own community awareness campaigns. In this way it is hoped that the problems of parents who voiced concerns about the services designed for them by health practitioners will be addressed. All the

researchers involved in this project will be invited and encouraged to do more research on matters related to parenting of disabled children. When the community become aware of the benefits which come from this research, even if they are not material benefits, they will be more open to the researchers when they need information about matters affecting mothers and their disabled children within the community.

Given that the use of traditional medicine that has not undergone reliable testing it can be harmful to an unborn foetus and can lead to disability, it is hoped that the community will be persuaded that the harm done by evil spirits can be prevented by using methods other than by the consumption of untried medicine. They will also be advised to read the instructions for biomedical treatments before use to ascertain whether they are recommended for use by pregnant women. Young inexperienced therapists can make use of the Canadian model can which emphasises the integration of both the cultural and bio-medical approaches with the traditional approach and that therapists should respect different cultural backgrounds.

The recommendations presented are meant to inform both short and long term goals. The report on the findings of the study will be completed two months after the researcher has received the results. A three month period will be used to organise meetings with the relevant health professionals to present them with the findings. Six months later meetings will be organised in administrative areas with the local leaders to address certain cultural issues raised in the study findings. This will be made possible by the fact that there are weekly community meetings in the district where local traditional leaders meet with their communities and at which a slot is given to visitors concerned with health education or community development issues. All recommendations in the study are based on the SMART OBJECTIVES criteria: Specific, Measurable, Achievable, and Realistic with Time frames.

6.4. Summary of the chapter

The chapter presented certain recommendations to address the challenges facing the parents/caregivers of disabled children according to the findings of the study. The conclusion summarised and highlighted the aims of the study, its motivation and the literature reviewed and the relationship of the study to the literature.

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Appendix I

Table of the conditions of Children at Happy Home

The conditions of the children need to be explained so as to understand the rehabilitation needs of the children at the centre. The most prevalent impairment is cerebral palsy which can differ in intensity. Some are profoundly disabled and are not educable; they need constant supervision and regular physiotherapy treatment, while others are able to attend local special schools for children with intellectually impairments. Those that are behind their peers in development are classified as clumsy children according to Fuad[46]. All classifications of disability in children have been taken from the description of conditions by Fuad[46].

Condition	Health and rehabilitation problems	Health and rehabilitation needs
Cerebral palsy (CP)	Young babies may have difficulty in sucking, usually floppy, may develop spasticity or athetosis (involuntary movements). Associated problems may include hearing, speech, vision, perception, intellectual impairment and fits.	It is generally accepted that some advice or treatment should be given at an early stage. Parents' involvement is important. Specialised treatment will depend on the extent of the problem
Clumsy children	Lag behind their peers, in physical activities and make slow progress in learning to read or write. Slow reading and writing may not be due to intelligence but due to difficulties in perception	Children may be referred to a physiotherapist because of poor balance, frequent falls, poor posture and general weaknesses.

Spina bifida	Maldevelopment of the vertebrae and spinal cord. Most frequent in lower dorsal or lumber region. Complications include hydrocephalus, which appears soon after birth. Deformities may be present at birth or may occur later if muscle tension is not balanced.	Rehabilitation is needed since there is a need to manage muscle tension. The weight-bearing and full activity should be encouraged so as to maintain as far as possible, the circulation and stimulation of the bone growth. This can be done with the assistance of a health professional.
Muscular dystrophy	It is the most severe type of disability. The muscle fibres degenerates and are replaced by fatty and fibrous tissue. Sometimes the child is floppy and walks late compared to their peers. When confined to wheelchairs knee flexion deformities are likely unless measures are taken to prevent them.	Physiotherapy is needed to prevent the secondary impairment as complication may result in scoliosis and sometimes deformities of the feet and legs. Respiratory infections are always a danger because of shallowness of breathing and inadequate coughing.
Mental handicap	These children may have poor musculature and balance and they may lack normal facility and variety of movements. Some also have specific physical handicaps associated with brain damage, such as cerebral palsy, sensory	Rehabilitation is in the form of socialisation with other children improves speech and playing with peers improves co ordination.

	defects or optic atrophy. Sometimes no cause is discovered	
Microcephaly	The brain is small and lacks the normal number of convolutions. The head circumference rarely exceeds 7 inches. The child is always severely mentally impaired and often has motor disabilities	Rehabilitation is not suggested.
Down Syndrome	This is the most common identified cause of severe impairment. Extra chromosome which increases the normal number of 46 to 47. They are easily recognised at birth by their typical facial appearance, broad and flattened with small nose and slanting eyes. Tongue may appear too large.	Rehabilitation includes training to do repetitive work. Socialisation is better because they are generally happy, sociable children, fond of music and anxious to join in all that goes on.
Metabolic Disorders	The condition is caused by under-secretion of thyroid gland and may be diagnosed at a few weeks of age. Baby may appear normal at birth and quickly becomes dull, listless and	Rehabilitation is needed; without early treatment secondary impairments may occur, as the brain needs adequate amount of thyroid hormone to develop normally to eat and drink water.

	unresponsive, the skin feels cold and coarse and dry, complexion sallow and lips thickened.	
Brain Damage	Injury may occur at birth e.g. by anoxia or severe jaundice; or later as the result of meningitis, encephalitis, hypoglycaemia, and severe dehydration, metallic poisoning or fracture of the skull.	Children are taken care of by care givers, with the supervision of the physiotherapist.[19].

Appendix II

RESEARCH QUESTIONNAIRE

"THE EXPLORATION OF COPING STRATEGIES OF PARENTS/CARE GIVERS IN THE MANAGEMENT OF HEALTH AND REHABILITATION RELATED PROBLEM"

QUESTIONS FOR FOCUS GROUP DISCUSSION:

The Opening:

- Introduce researcher and give the formal information about the study, confidentiality, informed consent and rights of informants in relation to participation on the study.
- The feedback about the research findings how will it be done and commitment to do so.

1. Ask the age, place where they live e.g. rural/urban, education of the parent, and status whether married, divorced or single
2. Reason for disability- question should be; tell about your child's disability, reason for the onset of the disability, when, and how.
3. How does disability affect the family?
4. Do you consider it a problem to have a child with disability? If yes should explain how?
5. What is the critical health and rehabilitation related incidence in your life?
6. How did you resolve that challenge?
7. Describe how do you perceive the accessibility of health and rehabilitation services in your area?
8. Describe the facilitators and barriers to accessing health and rehabilitation services in your area.
9. If there are no services how do you cope with the health and rehabilitation problems that you face.
10. If you can go back to the same situation what would you do differently today?

Appendix III

INTERVIEW SCHEDULE FOR INDIVIDUAL PARTICIPANTS:

The interview will take an hour.

The Opening:

- Introduce yourself and give the formal information about the study, confidentiality, informed consent and rights of informants in relation to participation on the study.
- The feedback about the research findings how will it be done and commitment to do so.
- Confidentiality of the information and that pseudo names will be used.
    1. Ask the age, place where they live e.g. rural/urban, education of the parent, and status whether married, divorced or single
    2. Reason for disability- question should be tell me about your child's disability, reason for the onset of the disability, when, and how did you find out that your child was disabled:
    3. What was the re action of the family (husband, children etc)
    4. Describe the health and rehabilitation problems you identify in your area
    5. Describe the facilitators and barriers to accessing health and rehabilitation services in your area
    6. How many family members in the household and how many are disabled
    7. What is the source of income for the family?
    8. Does the family help in taking care of a disabled child?
    9. Does the child with disability get disability grant?
    10. Do you consider disability as a health problem?
    11. How and where do you think these problems should be dealt with?
    12. Do you think you need health care services as parents of disabled children?
    13. What is the critical health related incidence that you will never forget?
    14. how did you solve that problem (coping strategies)

Appendix IV

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Diploma in Health Education: University of Transkei, 1991

B. Comm. Education: University of Transkei 1995

Certificate in Project Management: University of Port Elizabeth

Certificate in International Community

Health: University of Oslo, Norway 2006

SUMMARY OF WORK EXPERIENCE:

1 .Jan 1981-Dec 1987:   Executive Secretary Transkei Government

2. Jan1988-Nov. 1990   Student Health Educator, University of Transkei

3 .Dec. 1990-May 1995   Health Educator

4 .May 1995-Sept. 2001   Educator, Ikwezi Tech. Skill Centre, Mthatha

5. Sept. 2001- June 2006: Lecturer King Sabata Dalindyebo F.E.T. College, Mthatha

6. August 2006 to present: Founder and Manager, Happy Home Disabled Children Centre, Mthatha

Appendix V

APPROVAL FOR RESEARCH STUDY AT HAPPY HOME DISABLED CHILDREN CENTRE, MTHATHA:

<div align="right">

P.O. Box 1368

MTHATHA

5099

</div>

4 January 2009

The Hon. Chairperson
Happy Home Disabled Children Centre
MTHATHA
5099

Sir

TITLE: EXPLORE THE COPING STRATEGIES OF PARENTS/CARE-GIVERS OF DISABLED CHILDREN

I wish to refer to the letter of approval by the Board of Directors at Happy Home to do my studies in M.Phil in Rehabilitation at Stellenbosch University. A protocol for the study has been submitted for approval to the Committee for human research at the University of Stellenbosch. The study will commence once the research proposal has been accepted by the committee.

AIM: The aim of the study is to investigate, assess the coping strategies of   parents and care givers of children with disability living in poor conditions

TIME FRAME: February 2009-June 2009 is the estimated time from beginning to the finishing of the study and writing of report

PARTICIPANTS: The participants will be the parents/care-givers of children residing at Happy Home Centre.

The researcher will hold a meeting with parents to advise them about the study, which will be followed by a two days workshop with the research assistance at the centre where they will be empowered with the skills on how to conduct a study and ethical codes concerning collection of data.

If need arises that participants need intervention, the researcher will refer the participants for immediate counselling. The research findings will be made available to your office and a workshop will be held at the centre with your permission to give feed back to participants.

Yours sincerely
VIVIAN VUYELWA DUMA
MANAGER

Appendix VI

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

"THE EXPLORATION OF COPING STRATEGIES OF PARENTS/CARE-GIVERS OF DISABLED CHILDREN IN THE MANAGEMENT OF HEALTH AND REHABILITATION RELATED PROBLEMS"

REFERENCE NUMBER: NO9/06/167

PRINCIPAL INVESTIGATOR: Vivian Vuyelwa Duma

ADDRESS: 32 MSINGAPANTSI STREET, SOUTHRIDGE PARK, MTHATHA

CONTACT NUMBER: 072 1863 083(cell) 047 5372 869(h) 047 5322 348 (w)

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Committee for Human Research at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

> Where will the study be conducted; are there other sites; total number of participants to be recruited at your site and altogether.

> The study will be conducted at Happy Home the total number of parents will be 67 which is the number of children at Happy Home and they will form focus group and from focus group the participants will be identified during group discussion.

> Explain in participant friendly language what your project aims to do and why you are doing it?

➢ The study will be conducted in Xhosa which is the home language of all children at Happy Home and parents/care-givers will be informed that the aim of the study is to understand the challenges of parents/care-givers and their coping strategies in management of the health related problems.

➢ Explain all procedures.

➢ The following procedures will be followed:

➢ Parents will come to Happy Home where the study will be conducted, the transport expenses will be paid and interviews will be done when parents are fetching their children for holidays or bring them back after holidays.

➢ The group comprised of six participants will be sitting at a private place where each will contribute and this is where the group will be interviewed until we reach the saturation point, when there is no new information coming out we will choose the respondents with more information for the individual interview.

➢ Explain any randomization process that may occur.

There will be no randomization all parents/care-givers of children residing at Happy Home will be selected to the study using purposeful sampling.

➢ Explain the use of any medication, if applicable.
There will be no medication involved in the study

Why have you been invited to participate?

Parents and care-givers will be informed that they have been selected to participate to the study as people who took care of the disabled children and it is anticipated that they experienced challenges in management of health and rehabilitation related problems of their children and use different coping strategies that were never put on records. This study will help other parents to learn the different coping strategies from different parents in rural communities where facilities are scarce.

➢ Explain this question clearly.

What will your responsibilities be?

The researcher will listen carefully after explaining about the study and confidentiality and only write down the responses of the parents/care-givers without any interruption. The researcher will not choose what she think is important but to write everything the respondents say. The questionnaire will be followed when asking the question and all objectives should be observed before reaching the saturation point.

➢ Explain this question clearly.

Will you benefit from taking part in this research?

> Explain all benefits objectively. If there are no personal benefits then indicate who is likely to benefit from this research e.g. future patients.

There is no personal benefit to the study but the research will help to understand different backgrounds of the children residing at Happy Home and understand why other parents behave differently from others. This will help in development of the centre and accommodating of each and every child and parents.

Are there in risks involved in your taking part in this research?

There is no risk involved in the study since there will be no use of medicine in the study. Identify any risks objectively.

If you do not agree to take part, what alternatives do you have?

> Clearly indicate in broad terms what alternative treatment is available and where it can be accessed, if applicable.

This is not applicable since there is not use of medicine in the study.

Who will have access to your medical records?

> Explain that the information collected; will be treated as confidential and protected. If it is used in a publication or thesis, the identity of the participant will remain anonymous. Clearly indicate who will have access to the information.

This is not applicable since there will be no medical records to be accessed. The study will be accessed by Stellenbosch Supervisors and the researcher for presentation in workshops and write publication but pseudo names will be used.

What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

> Clarify issues related to insurance cover if applicable. If any pharmaceutical agents are involved will compensation be according to ABPI guidelines? (Association of British Pharmaceutical Industry compensation guidelines for research related injuries which are regarded as the international gold standard). If yes, please include the details here. If no, then explain what compensation will be available and under what conditions.

This is not applicable since there is not use of medicines in the study.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your transport and meal costs will be covered for each study visit. There will be no costs involved for you, if you do take part.

Is there any thing else that you should know or do?

- You should inform your family practitioner or usual doctor that you are taking part in a research study. (Include if applicable)(Not Applicable)

- You should also inform your medical insurance company that you are participating in a research study. (Include if applicable)(Not Applicable)

You can contact Mrs. Vivian Vuyelwa Duma 072 1863 083(cell) 047 5372 869(h) 047 5322 348 (w) if you have any further queries or encounter any problems.

- You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.

- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I ………………………………..…………. agree to take part in a research study entitled "THE EXPLORATION OF COPING STRATEGIES OF PARENTS/CARE-GIVERS OF DISABLED CHILDREN IN THE MANAGEMENT OF HEALTH AND REHABILITATION RELATED PROBLEMS"

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

- I have had a chance to ask questions and all my questions have been adequately answered.

- I understand that taking part in this study is voluntary and I have not been pressurised to take part.

- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (place) ....……......……………. On (date) …………...………. 2009.

...................…………………………   ....…...…………………………
Signature of participant   Signature of witness

Declaration by investigator

I, Vivian Vuyelwa Duma declare that:

- I explained the information in this document to …………………………………..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.

Signed at (place) ....…........……………….. On (date) …………...……….. 2009.

....
Signature of investigator   Signature of witness

Declaration by interpreter

I (name) …………………………………………..……… declare that:

- I assisted the investigator (name) …………………………………… to explain the information in this document to (name of participant) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (place) ....…........……………….. on (date) …………...……….. 2009.

……………………………   ………………………………
Signature of interpreter   Signature of the Witness

Appendix VII

INCWADANA ENGOLWAZI NGOMTHATHI-NXAXHEBA

KUNYE NEFOMU YEMVUMELWANO

ISIHLOKO SEPROJEKTHI YOPHANDO: AMALINGE ABAZALI KWINZAME EZIPHATHELELE KWIMPILO YABANTWANA BABO ABAKHUBAZEKILEYO

INOMBOLO YONXULUMANO : NO9/06/167

UMPHANDI OYINTLOKO: VIVIAN VUYELWA DUMA

IDILESI: 32 MSINGAPANTSI STREET, SOUTHRIDGE PARK, MTHATHA

INOMBOLO YOQHAGAMSHELWANO: : 047-5322348 OKANYE 047-5371869

Uyamenywa ukuba uthathe inxaxheba kwiprojekthi yophando. You are being invited to take part in a research project. Nceda thatha ixesha lokufunda ulwazi oluvezwe apha, oluzakuthi luchaze iinkcukacha zale projekthi. Nceda buza nayiphina imibuzo emalunga nayiphina indawo ongayiqondiyo ngokupheleleyo kubasebenzi besi sifundo okanye kugqirha. Kubaluleke kakhulu ukuba waniliseke ngokupheleleyo yinto yokuba ucacelwe kakuhle ukuba yintoni ebangwa sesi sifundo kwaye ungabandakanyeka njani. Kwakhona, ukuthatha kwakho inxaxheba **kungentando yakho ngokupheleleyo** kwaye ukhululekile ukuba ungarhoxa ekuthatheni inxaxheba. Ukuba uthi hayi, oku akusayi kuchaphazela ukungavumi kwakho nangayiphina indlela. Ukwakhululekile ukuba uyeke kwesi sifundo naninina, nkqu nokokuba uyavuma ukuthatha inxaxheba ekuqaleni.

Olu phando luvunywe ziinqobo ezisesikweni zeKomiti yoPhando Lomntu kwiYunivesithi yaseStellenbosch **kwaye luzakwenziwa ngokwemigaqo esesikweni lophando elamkelekileyo kwiSaziso sehlabathi sika-Helsinki, iMigaqo eLungileyo yoMzantsi Afrika yokuSebenza eKliniki kunye neBhunga lezoPhando ngamaYeza (MRC) iMigaqo yeNqobo yezoPhando.**

Simalunga nantoni esi sifundo sophando?
Uphando yimfunalwazi malunga nengxaki zabazali okanye abagcini babantwana abakhubazekileyo ingxaki ezo ezimalunga nempilo nokucoselelwa kwempilo yabo emakhaya phambi kokuba bafumane uncedo loo gqira kunye namalinge abathi bawenze phambi kokuba bafumane ulwazi lwezengcali zempilo.

> **Luza kwenziwa phi uphando; ingaba zikhona ezinye iindawo; bangaphi bebonke abathathi-nxaxheba abazakugaywa.**

Uphando luzakwenziwa e Happy Home kumzi ogcina abantwana abakhubazekileyo. Inani labantwana abahlala kulomzi bangamashumi amathandathu anesixhenxe loo nto ithetha ukuthi abazali abazakuthatha inxaxheba balinani labantwana.

> **Cacisa ngolwimi oluviwa ngumthathi-nxaxheba ukuba iprojekthi yakho ijonge ukwenza ntoni kwaye kutheni uyenza?**

Uphando luzakwenziwa ngolwimi lwesiXhosa yaye bonke abantu abazakuthatha ixhanxheba ngabantu abalwimi lusisixhosa. Imbangi yoluphando luzakuchazwa ngokupheleleyo lwalwemfuna-lwazi nanjengoko sifuna ukuqonda abazali inzame abazenzayo xabejongene nengxaki ezifuna uqwalaselo lwezempilo ekuncedeni abantwana xa engekho amagosa ezempilo amalinge namatile-tile abathi bawenze.

> **Cacisa zonke iinkqubo***:*

Inkqubo eyakulandelwa yile ingezantsi:

Uphando luzakwenziwe e Happy Home apho bonke abazali bezakuza xa bezekuphuthuma abantwana okanye bebabuyisile ukuvelwa kwiholide. Iindleko zabo zokukhwela zizakubhatalwa ngumphandi.

Iqela ngalinye lizakubanabazali okanye abagcini bantwana abathandathu apho bezakuchaza ngokuthe gabalala yonke inkcukacha ebuziweyo neziganeko abazikhumbulayo. Kuyakuyekwa kusawubonakala ukuba akukho nto intsha echazwayo, kuyakuthi emva koko konyulwe abo babonakalisa ukuba banolwazi oluphangaleleyo ze ke bona bachophele uphando ngabanye ngabanye.

> **Cacisa nayiphina inkqubo engakhethiyo enokuthi ibekho.**

Akukho khetho luzakwenziwa kuba wonke umzali okanye umgcini womntwana okhubazekileyo uyakuthabatha inxaxheba nje kuba enomntwana ohlala kwelikhaya labantwana uzakuba kwiqela okanye athathe inxaxheba eyadwa.

> **Cacisa ukusetyenziswa kwalo naliphina iyeza, ukuba likhona.**
Akukho yeza nelaluphina uhlobo eliyakusetyenziswa xa kuqhutywa oluphando.

Kutheni umenyiwe ukuba uthathe inxaxheba?

Umntu ngamnye uyakucacisela ukuba imbangi yokuba athabathe inxaxheba koluphando kungenxa yokuba ungumzali okanye umgcini womntwana okhubazekileyo nto ke leyo ethi inike uqikelelo lokuba zikho ingxaki athi adibane nazo ekugcineni umntwana lowo ezimalunga nezempilo namatile-tile athi umzali okanye umgcini lowo awenze ukunceda

ngexesha lobunzima kungekho maziko ezempilo okanye amagosa ezempilo akufutshane. Ulwazi esilufumeneyo luzakuthi luncede abanye abazali xa luthe lwashicilelwa.

> Cacisa lo mbuzo kakuhle.

Luyakuba yintoni uxanduva lwakho?

Uxanduva lomphandi kukumamela ngocoselelo yonke impendulo emva kokuba echazile imbangi yokwenza oluphando, ze abhale yonke impendulo yomzali kwinto nganye engahluzi nanye kwizinto ezithethwayo engaphazamisi nomzali amyeke atyatyadule kangangoko anako. Umgaqo uyakulandelwa njengoko ibhaliwe imibuzo ze yonke imibizo iphendule zonke injongo zophando.

> Cacisa lo mbuzo kakuhle.

Ingaba uza kuzuza ekuthatheni inxaxheba kolu phando?

Abantu bayakuchazelwa ukuba akukho nzuzo eyakuthi ifumaneke koluphando koko abazali bangomso bayakuthi bazuze ngolwazi oluyakuthi lufumaneke koluphando ze lushicilelwe lufundwe zizizukulwana, ukanti nesenta i Happy Home iyakuthi ibe nokukhula ngolwazi eliyakufumaneka koluphando nabazali zaziwe iingxaki zabo zishicilelwe zezifundwe nazezinye iintlanga,

> *Cacisa yonke inzuzo ngokungaqhutywa luluvo. Ukuba akukho nzuzo bonisa ke ukuba ngubani onokuthi azuze kolu phando umz. Abazali bangomso.*

Ingaba zikho iingozi ezibandakanyekayo ekuthatheni kwakho inxaxheba kolu phando?

Akukho ngozi inokwenzeka nanjengoko kungasayi kuba namayeza asetyenziswayo okanye ayakuselwa ngapathathi nxaxheba koluphando.

> *Chaza naziphina iingozi ngokungaqhutywa luluvo.*
Akukho ngozi zilindelekileyo koluphando okanye into engabeka ubomi babantu emngciphekweni.

Kuza kwenzeka ntoni kwimeko yesiganeko esingalindekanga sokwenzakala ngenxa yokuthatha kwakho inxaxheba kwesi sifundo sophando?

Akusokuze kubenengozi enxulumene noluphando nanjengoko kungekho mayeza ayakusetyenziswa.
> **Cacisa imiba enxulumene nentlawulo ye-inshorensi ukuba ikhona. Ukuba kukho iindawo ezibandakanyekayo ezithengisa amayeza ingaba intuthuzelo izakuhamba ngokwemigaqo ye-ABPI? (Imigaqo yentuthuzelo enxulumene nokwenzakala kuphando lweManyano yaseBrithane yezoRhwebo lwamaYeza ethathwa njengekwizinga**

> **lehlabathi legolide).** **Ukuba ewe, nceda bandakanya iinkcukacha apha. Ukuba hayi, cacisa ke ukuba yeyiphi intuthuzelo eyakubakhona kwaye phantsi kweziphi iimeko..**

Ingaba uza kuhlawulwa ngokuthatha inxaxheba kwesi sifundo kwaye ingaba kukho iindleko ezibandakanyekayo?

Hayi awusayi kuhlawulwa ngokuthatha inxaxheba kwesi sifundo kodwa isithuthi sakho neendleko zokutya ziza kuhlawulelwa kundwendwelo ngalunye lwesifundo. Akusayi kubakho zindleko ezibandakanyelwa wena, ukuba uthatha inxaxheba.

Ingaba ikho enye into ekumele uyazi okanye uyenze?

> **Kumele wazise ugqira wosapho okanye ugqira oqhelekileyo nje ukuba uthatha inxaxheba kwisifundo sophando** : (AMALINGE ABAZALI KWINZAME EZIPHATHELELE KWIMPILO YABANTWANA BABO ABAKHUBAZEKILEYO)

(Akukho mfuneko)

>
> **Kwakhona kumele wazise inkampani yakho ye inshorensi yamayeza ukuba uthatha inxaxheba kwisifundo sophando**: (AMALINGE ABAZALI KWINZAME EZIPHATHELELE KWIMPILO YABANTWANA BABO ABA
> **Ungaqhakamshelana** noNkosikazi Vuyelwa Duma **kule inombolo yomnxeba** 047-5322348 (w) **okanye unomyayi kule inombolo** (0721863082). **Ukuba unemibuzo engaphaya okanye uhlangezana neengxaki**
> **Ungaqhakamshelana neKomiti yoPhando Lomntu kwa 021-938 9207 ukuba unenkxalabo okanye izikhalazo ezingasonjululwanga kakuhle ngugqirha wakho wesifundo.**
> **Uza kufunama ikopi yolu lwazi kunye nefomu ymvumelwano ukwenzela iingxelo zakho.**

Isifungo somthathi-nxaxheba

Ngokutyikitya ngezantsi, Mna ………………………………………..…………. ndiyavuma ukuthatha inxaxheba kwisifundo sophando semfundo esibizwa ngokuba : **(AMALINGE ABAZALI KWINZAME EZIPHATHELELE KWIMPILO YABANTWANA BABO ABAKHUBAZEKILEYO)**

Ndazisa ukuba:

- Ndilufundile okanye ndalufunda olu lwazi kunye nefomu yemvumelwano kwaye ibhalwe ngolwimi endiliciko nendikhululekileyo kulo

- Bendinalo ithuba lokuba ndibuze imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.

- Ndiyakuqonda ukuba ukuthatha inxaxheba kolu phando kube kukuzithandela kwam kwaye andikhange ndinyanzelwe ukuba ndithathe inxaxheba.

- Ndingakhetha ukusishiya isifundo naninina kwaye andisayi kohlwaywa okanye umntwana wam achaphazeleke sisigqibo sam.

- Usenokucelwa ukuba usishiye isifundo phambi kokuba siphele, ukuba ugqirha wesifundo okanye umphandi ukubona kuyinzuzo kuwe, okanye ukuba andisilandeli isicwangciso sesifundo, ekuvunyelenwe ngaso.

Kutyikitywe e-(indawo) ....…......…………….. ngo-(usuku) ………...………... 2005.

..........………………………………....   ....…………………………………....

Umtyikityo womthathi-nxaxheba   **Umtyikityo wengqina**

Isifungo somphandi:

Mna *Vivian Vuyelwa Duma* ndiyafunga ukuba:
- Ndilucacisile ulwazi olu kweli xwebhu ku-…………………..……………...

- Ndimkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elifanelekileyo ukuba ayiphendule.

- Ndiyaneliseka kukuba uyakuqonda ngokwanelisayo konke okumalunga nophando okuxoxwe ngasentla.

- Ndisebenzise/andisebenzisanga toliki. (*Ukuba itoliki isetyenzisiwe kumele ityikitye isaziso ngezantsi.*

Kutyikitywe e-(indawo) ....…......…………….. ngo-(usuku) ………...………... 2010.

Umtyikityo womphandi .... Umtyikityo wengqina

Isifungo setoliki:

Mna ……………………………………………………………… ndazisa ukuba:
- Ndincede umphandi u Vivian Vuyelwa Duma ekucaciseni ulwazi olu lpha kweli xwebhu ku ……………………………………… ndisebenzisa ulwini lwesiXhosa/English/Afrikaans.
- Simkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elifanelekileyo ukuba ayiphendule.
- Ndimxelele eyona nto iyiyo malunga nokunxulumene nam.

> ➢ Ndiyaneliseka kukuba umthathinxaxheba ukuqonda ngokupheleleyo okuqulathwe loloxwebhu lwemvumelwano eyazisiweyo kwaye nemibuzo yakhe yonke iphendulwe ngokwanelisayo.

Kutyikitywe e (indawo)………………………….ngo(usuku)………………..2010