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FACULTY OF COMMUNITY AND HEALTH SCIENCES
DEPARTMENT OF PHYSIOTHERAPY



**Experiences of caregivers regarding their participation in community-
based rehabilitation for children aged 0-12 years in Botswana**

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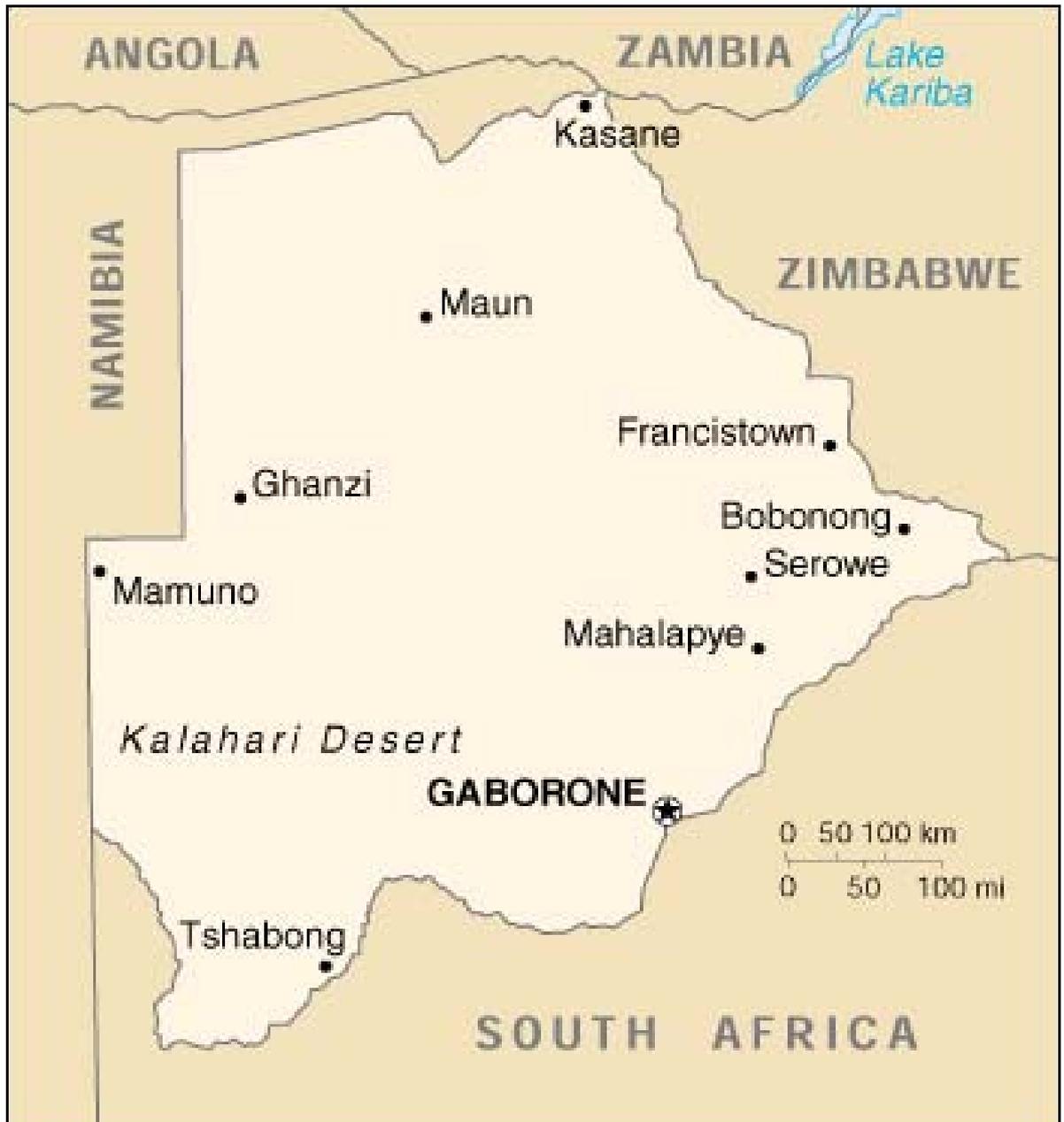
A mini-thesis submitted in partial fulfilment of the requirements for the degree of Master of Science in physiotherapy in the faculty of Community and Health Sciences, University of the Western Cape.

September 2004

Supervisor: Mrs. M. Marais

KEY WORDS: Community-based rehabilitation, Disability, Developing countries, Caregiving, Experiences, Culture, Knowledge, Children, Caregivers and Botswana.

A Map of Botswana



Online. Available <http://education.yahoo.com/reference/factbook/bc/map.html>

KEY WORDS

Community-Based Rehabilitation

Disability

Developing countries

Experiences

Caregiving

Caregivers

Children

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ABSTRACT

Background: Over the last two decades, most countries have been restructuring their health care systems to conform to the Primary Health Care Strategies. Many of these countries therefore, have tended to emphasize community-based health care strategies as opposed to institution-based care. The increasing prevalence of disability globally and the subsequent increase in children with disabilities who need care, means family caregivers and the community are faced with a challenging responsibility of providing this demanding care. The **Purpose** of the study was to examine the experiences of community-based caregivers of disabled children aged 0-12 years in the Republic of Botswana. A qualitative research **method** was chosen to explore the experiences of the caregivers. A phenomenological research design was chosen as appropriate because through the design it was possible to study the meaning of these “caregivers’ world”. A semi-structured interview guide was used to capture the feelings of the carers. **The results** of the study confirmed that caregivers of disabled children in the community experience difficulties while discharging their roles. They lacked support from the community, outside the extended family. Most of the caregivers were overwhelmed by their caregiving roles that consequently had a negative impact on their health and social life. However, the findings indicated that despite the problems the carers encountered, they actively participated in caring for their disabled children. The active participation was often driven by love for their children with disabilities. The study indicated that the carers received enough support from their immediate families but were unhappy with the support they received from the health professionals. The results of the study also indicated that the impact of caregiving went beyond the carer to both the siblings of the disabled child and other members of the immediate family. It is important to recognize that many mothers and grandmothers, even though disadvantaged in terms of resources, knowledge and information are competent and effective caregivers. The findings have therefore, **implications** for intervention. They underscore the necessity for development of caregivers’ support services. These include counselling, provision of material and financial assistance, support groups and respite care. Although the aim of CBR is to make communities less dependent on sustained/long-term specialised professional services, caregivers indicated their need for support from health professionals.

Declaration

I declare that “Experiences of caregivers regarding their participation in community-based rehabilitation for children aged 0-12 years in Botswana” is my own work, that it has never been submitted for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete references.



Jackson M.M. Kilonzo

September 2004

Signed.....

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First of all, I would like to thank the Almighty God for having given me life, the resources and the strength to go through my studies.

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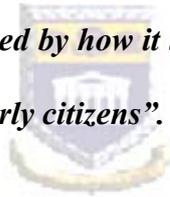
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DEDICATION

I dedicate the work of this thesis to my late son **Dennis Mutinda** who passed-on tragically through a road traffic accident in 1998 at the prime of his childhood.

“The civility of a country is judged by how it treats its children, its persons with disabilities, and its poor and elderly citizens”.



Albrecht, Gary L. (1997).

LIST OF ABBREVIATIONS

ADLs	Activities of daily living
APDDP	Asia Pacific Decade of Disabled Persons
CBR	Community Based Rehabilitation.
CFB	Cheshire Foundation of Botswana
CSO	Central Statistics Office
DRS	Division of Rehabilitation Services
HBHC	Home-based health care
IBR	Institution-based rehabilitation
ICF	International Classification of Functioning, Disability & Health
ICIDH	International Classification of Impairment, Disability & Handicap
IIAS	International Institute of Applied Systems
ILO	International Labour Organization
MCBRC	Mochudi Community-Based Rehabilitation Centre
NGO	Non-governmental Organization
NHIS	National Health Interview Survey
NICCD	National Information Centre for Children with Disabilities
NORAD	Norwegian Development Agency

PHC	Primary Health Care
UN	United Nations
UNESCO	United Nations Educational, Scientific & Cultural Organization
UNICEF	United Nations International Children's Fund
USA	United States of America
WHO	World Health Organization



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CHAPTER ONE

INTRODUCTION

1.0 Introduction

In this chapter the background of the study will be discussed. It will include a review of the global prevalence of disability, the motivation for the study, statement of the problem, purpose of the study and the research questions. The objectives, the significance of the study and definition of terms will also be explained. Finally, this chapter ends with a summary and a brief description of the remaining chapters in this mini-thesis.

1.1 Background information



The study was conducted within the framework of caregiving within Community-Based Rehabilitation (CBR) and Primary Health Care (PHC). PHC dates back to the 1978 World Health Organization's (WHO) Alma Ata declaration, which urged governments to place primary health care at the centre of their health systems. Since then many countries throughout the world placed an increasing emphasis on the PHC arena. It is within the framework of PHC that the concepts of CBR evolved. This will be discussed in more detail in chapter two.

The care and rehabilitation of adults and children with disabilities in developing countries rest mostly on family members or friends in their communities. This could be attributed to a number of reasons. One reason is the unavailability of adequate rehabilitation services. Secondly, even where rehabilitation services are

available, they are inaccessible as a large proportion of these people with disabilities live in the rural areas far away from the rehabilitation services. Finally, there is a lack of infrastructure for social assistance (e.g. disability grants, transport etc), especially in the developing countries, to cater for the disabled population.

Providing care to a disabled family member or a friend and especially a child, can involve a progressive increase in care responsibilities over a period of time since the caregiver has to continue fulfilling other demands such as employment, their own personal needs and those of the other family members. These caregivers provide essential services and yet their contributions are often not sufficiently recognised by the health care system.

Several studies on caregiving experiences in the elderly have been published, but few published research has dealt with caregiving experiences in children. Research has shown that there are striking similarities in the experience of caring for the young and the old (Runciman, 2003). Such similarities include social, emotional and financial difficulties. However, the intensity of care in these two age groups may be different. In the developed countries where caregiving support systems are available it was found that caregivers save the health care system billions of dollars annually. For example, Pringer (1983) as cited by Sawatzky & Fowler-Kerry (2003), established that the annual cost of replacing informal caregivers with paid health care professionals in the United States of America (USA) was \$9.6 billion. A more recent study by Fast & Keating, (2000) cited by

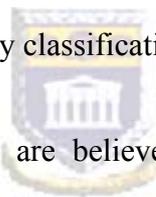
Sawatzky & Fowler-Kerry (2003), reported that in Canada, caregivers of the elderly people save the health care system more than \$5 billion annually.

With the increase of the number of people with disabilities and the expected increase in number of children requiring care, the family and members of the community face the consequential responsibility of providing this prolonged and demanding care.

1.2 Global prevalence of disability

Various ways of quantifying the prevalence of disability have been found in the literature. The United Nations (UN 2002) estimates that more than 500 million people worldwide have various mental, physical or sensory impairments. According to Mitchell (1999a), 7% of the world's population has various types of physical or mental disabilities. The World Health Organization (WHO, 1980) estimated that approximately 10% of the world's population at any given time is physically or mentally impaired. This estimate was based on a number of calculations of the disability rates resulting from diseases, trauma, malnutrition and genetic causes available at that time. Several other surveys were conducted in various countries such as China (with a representative sample of 1.5 million people), Canada, Mali and Great Britain. The prevalence rate has been found to range from 0.2% to 21% in those countries (Helander, 1992). There are however, no common definitions and classifications of disability, which is uniformly applied by all countries. Thus, some invisible disabilities such as deafness, learning disabilities and problems of body functions (e.g. asthma, bowel and bladder incontinence, skin disorders etc) may not be recognized as disabilities or

impairments. This lack of uniformity therefore makes international comparisons of disability data not meaningful. However, the International Classification of Impairments, Disability and Handicap (ICIDH) which was adopted by the WHO in 1980, and more recently the International Classification of Functioning, Disability and Health (ICF) which is a revised version of the ICIDH, has clear definitions of disability which could be used to permit comparison of data across countries (WHO, 1980; WHO, 2001). In the ICF, disability is used as an umbrella term for impairments, activity limitations and participation restrictions (WHO, 2001). This classification calls for greater inter-country efforts to adopt the internationally agreed concepts and definitions. The use of universally agreed methodologies and techniques for identifying disabilities may assist in establishing uniformity in disability classification (APDDP, 2002).



The majority of disabled people are believed to be living in the developing countries. The UN (2002) puts this figure at two thirds of the disabled people; Mitchell (1999a) at 75% while Hutcherson (1991) estimates that one in every seven persons is born with or will acquire a physical, mental or sensory impairment. Furthermore, there is a strong relationship between disability and socio-economic status (Integrated National Disability Strategy, 1997; Anderson & Phohole, 2003). In a survey on people with disabilities in five villages in the Nandi district of Kenya, Hutcherson (1991) also noted a correlation between poverty, educational level, nutrition, gender and the prevalence of disability. In the developing countries less than 3% of these disabled persons receive rehabilitation of any kind (Hutcherson, 1991; Helander, 1992). Several factors are

responsible for the inability of these persons with disability to receive rehabilitation in order to integrate into mainstream society. Some of these are:

- 1) Weakness of an infrastructure or related services for social assistance, health, education, vocational training and placement and
- 2) Constraints that include lack of resources, geographical distance and physical and social barriers make it impossible for many people to take advantage of the available services (UN, 2002).

Millions of children and adults with disabilities in all parts of the world are often excluded from the mainstream of society and experience difficulties in accessing education, employment, health care etc as their fundamental rights. Blackford (2003) observed that because of the increasing number of the disabled persons the field of disability has become important to researchers and policymakers. Policymakers need to be aware of the increasing number of disabled people in order to plan for their integration into the mainstream society. While in the developed countries the trends of segregation and exclusion of children with disabilities from the mainstream of society seem to have changed to greater inclusion over the last two decades, the situation in the developing countries has either remained the same or is worsening (Agosta & Melda 1995).

The impact of physical disability in the developing countries has become a tremendous health, welfare and social issue. The developing countries present many challenges in the lives of these disabled persons. In a review of literature, May-Teerik (1999) identified the contribution of the environment to disability in

developing countries. She noted that poor sanitation, infectious diseases, malnutrition and war are a few of the many factors contributing to disability in these countries.

1.3 Prevalence of disability in Botswana

The Central Statistics Office (CSO) in Botswana assessed the extent and types of disabilities in the country during the 1991 census. The census revealed that 2.2% of the population had physical or mental disabilities (CSO, 2003). A study conducted by Lindsey, Hirschfeld, Tlou & Ncube (2003) indicated that 62% of the population lives in rural areas. This finding does however contradict the CSO's findings, which puts the figure to about 52% (CSO, 2003). The census also revealed that the majority (66.2%) of the disabled people lived in rural areas. A survey conducted by Lundren-Lindquist and Norholm (1993) in a village in Botswana, identified a prevalence of 1.4% which revealed that 22% of the disabled were younger than 15 years of age and 17% were more than 65 years old. A high proportion (30%) of the disabled persons in the same village had parents who were related to one another. The majority of the disabled people (65%) had difficulties with mobility and 21% had two or more disabilities.

1.4 Motivation for the study

The motivation for this study was from my personal experience as a physiotherapist working in a referral hospital in Botswana. The discharge system in the hospital works on the basis that children/patients who have been on rehabilitation are sent home with a therapy programme. The carers are expected to carry out these programmes until the children go back for reassessment in the respective clinics. My observation has been that when the children return they show lack of progress and

sometimes have worse impairments and disabilities than when they left the hospital. Furthermore, there is little research that has attempted to investigate the experiences of these caregivers in CBR in developing countries and particularly in an African setting. Most literature dwells on the experiences of carers in developed countries, which may not be the same in middle developed or poor countries.

1.5 Statement of the problem

The worsening of the impairments and disabilities in children after discharge from hospital is of great concern to the health professionals, particularly the surgeons and physiotherapists. The successful management of these children depends greatly on the home-based therapy provided by the caregivers in the prevention of secondary impairments, disabilities and handicaps. Although many studies have been done to measure burden, coping strategies and related concepts, few studies have examined holistically the caregiving experiences in CBR.

It is therefore important to investigate both positive and negative experiences of caregivers in CBR for children with physical disabilities.

1.6 Purpose of the study

The purpose of the study was to investigate the experiences of caregivers regarding their participation in CBR for children with physical disabilities, aged 0-12 years, in two selected communities in Botswana. The experiences included the impact of disability on the immediate family, coping strategies, enabling factors and barriers to participation in CBR.

1.6.1 The research questions

The study attempted to address the following research questions:

- 1) What were the enabling factors that contributed to the caregivers' compliance with home- based therapy?
- 2) Did the caregivers experience any barriers in the delivery of this prescribed therapy?
- 3) Were there any differences in caregiving between urban and rural settings?
- 4) What was the impact of the child's disability on the immediate family?

1.6.2 Objectives of the study



The following objectives were identified namely,

- 1) To identify the enabling factors that contribute to caregivers' compliance with prescribed home-based therapy.
- 2) To identify the barriers affecting the caregivers' compliance with prescribed home-based therapy.
- 3) To compare experiences of caregivers between two selected regions, namely urban and rural.
- 4) To identify the impact of the child's disability on the immediate family

1.7 The significance of the study

The results of this study could be used to formulate recommendations for improving caregivers' conditions that interfere with their participation in CBR. Such support could enhance their quality of life and that of the disabled children. Rehabilitation workers and managers of CBR resources need to be aware of factors that might have a positive or negative effect on the caregivers' participation in CBR. Health professionals/therapists tend to focus more on the child with disability but very few show interest in the health or coping mechanisms of the carer. This may help health professionals in showing an understanding of the demands placed on caregivers in caring for children with disabilities.



1.8 Definition of terms

Caregiver

Any person who has the responsibility of taking care of the disabled child. He or she may be a parent, relative, friend or paid worker.

Child

Means any human being from the moment of conception to the age below 18 years.

Impairments

According to the WHO impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function (WHO, 2001).

Disability

The WHO defines disability as any restriction or lack (resulting from impairment) of ability to perform an activity in the manner within the range considered normal for a human being (WHO,2001).

Handicap

A disadvantage for a given individual, resulting from impairment or disability, that, limits or prevents the fulfilment of a role that is normal depending on age, sex, social and cultural factors, for that individual. The term was used to describe the interaction between a person, impairment and the environment in which he finds himself. It has been replaced by participation according to the in ICF (WHO, 2001).

Activity limitation

Difficulties an individual may have in executing activities (tasks) (ibid).

Participation restrictions

Problems an individual may experience in involvement in life situations (ibid).

Functioning

Indicates non-problematic aspects of health and health-related states. Includes the physiological and psychological functions of the body systems (ibid).

1.9 Summary of the chapter

The population with disability has increased globally over the past three decades with a subsequent increase in the number of children with disabilities. The increase in the number of children with disabilities means that family caregivers and the community are faced with the challenge of providing long-term care. Caring for a child with disability can involve a progressive increase of

responsibilities because the carer has to continue to meet his or her personal needs and that of the immediate family. Where rehabilitation services are available, the health professional/therapists concentrate mostly on assessment/evaluation and well-being of the disabled child, often disregarding the carer's health and how he or she has been coping with the care of the child with disability. Although effective CBR can be cost-saving to a country, the personal cost on the carer may be immeasurable. The present study therefore set out to explore the experiences of caregivers of children with disabilities in the community.

1:10 Outline of the remainder of the mini-thesis

In chapter two the literature is reviewed. It includes an exploration of the global prevalence of disability with a specific focus on childhood disability and community-based rehabilitation in Botswana. Concepts relating to CBR and caregiving within the PHC context are discussed. A conceptual model of caregiver adaptation and coping in caregiving will be explained. Chapter three describes the research methods that were used in the study and it includes the research setting, the study design, instrumentation, study sample, pilot study, data analysis and ethical considerations. The results are presented in chapter four. In chapter five the results are discussed and it ends with a summary of the main findings, conclusions from the study and recommendations based on the results of the study.

CHAPTER TWO

REVIEW OF THE LITERATURE

2.0 Introduction

The literature review explores the global and local prevalence of disability, including childhood disability, community-based rehabilitation (CBR) and caregiving within the CBR and PHC context. CBR delivery and organizational models will be explained briefly. The concept of caregiving and its impact will be discussed. A conceptual model of caregiver adaptation will be illustrated. Finally, the chapter ends with a summary of the main points that emerged from the study of the literature.

The published studies that were selected for the current study used quantitative and qualitative research methods; the former being descriptive studies, surveys and audits while the latter explored experiences and coping.

2.1 Prevalence of childhood disability

There is a lack of information on the prevalence of childhood disability in the developing countries. The lack of statistics could be attributed to number of reasons namely, (1) there is no common definition of disability in these countries, (2) prevalence studies are costly for these countries of which most of them are poor, (3) many studies depend on predicted disability which tend to exaggerate the prevalence rate rather than confirmed statistics, and (4) no screening for children under two years is undertaken and thus making identification and intervention in this age group critical (Anderson & Phohole, 2003). There are also inconsistencies in the findings

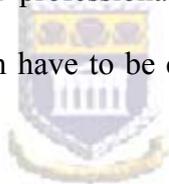
based on epidemiological studies, with some studies suggesting that about 10-15% of all children experience a chronic illness in childhood (Northam, 1997), and others estimating the figure to be as high as 30% (Meyers, Lukemayer & Smeeding, 1998). It has however been agreed that the estimate of childhood disability vary from 2% to 32% of a country's children, depending on the definition of the term disability and chronic illness (Ireys & Katz, 1997).

Large prevalence estimates of disability include all children with conditions that place few or no limitations on the child's functioning, whereas smaller estimates include only children with conditions that place comparatively severe limitations on the child's functioning. For example, recent analyses of data from the United States of America's (USA) National Health Interview Survey (NHIS) suggest that of the 32% of children of the USA, teenagers had one or more chronic conditions in 1988. Nine percent of the children had moderately severe conditions that could result in problematic consequences or some activity limitation; 2% had conditions that cause frequent worry and lead to numerous limitation in ADLs. The most frequently reported conditions among that age group include allergies, asthma and frequent headaches, which generally lead to minimal or no functional limitation (Ireys & Katz, 1997). In 1981, a community-based population sample of families in Ontario, Canada found that 20% of children had either an activity-limiting condition or chronic illness or both (ibid).

Although these analyses, according to the NHIS (1988) and the Ontario Survey (1981) in Ireys & Katz (1997), yielded important prevalence estimates, the data have

serious limitations. The range of estimates reflected a lack of the broadly accepted definition of disability and chronic illness.

Globally there are about 140 million disabled children of whom 97% are found in poor countries where rehabilitation services are lacking or are inadequate (Hurst, 1997). For example, in South Africa, rehabilitation services are mostly found in middle or high-income urban areas, a health service that is greatly needed by many poor rural populations. Furthermore it is estimated that 250,000 of school going age disabled children in South Africa are out of school and only a small number of them receive rehabilitation of any kind (Struthers, 2002). This large number of disabled children that has been left out of school has been of great concern not only to physiotherapists but also to other professionals both in health and education. This means that most of these children have to be cared for at home by their families or friends.



Out of the total number of disabled children globally, about 98% of them lack education and 90% will not survive beyond the age of five years (Hurst, 1997). Children in poor families are at a higher risk of chronic health problems and disabilities, and caring for these children can impose substantial costs to their families (Meyers et al, 1998; Svien, 1999).

2.2 Causes of childhood disability

It is generally believed that about 75% of disabilities in childhood are caused by genetic factors e.g. inheritance of abnormal recessive genes or chromosomal abnormalities etc (El-Hazmi, 1997). A survey conducted in the Republic of China by Chen & Simeonsson (1993), showed that about 22% of cases of disability resulted

from prenatal causes such as developmental malformation, maternal age, maternal disease, drugs, medicines etc); 3% were caused by perinatal factors such as low birth weight, prematurity, obstetric complications, trauma during birth, asphyxia etc); 9% were acquired during infancy and early childhood (poliomyelitis, tuberculosis, meningitis, encephalitis, accidents, malnutrition, environmental factors etc) and 47% had no known cause (ibid). The general prevalence of disabled children was 2.7% and the prevalence rate showed an increase with age. The increase of childhood disability with age can be attributed to domestically acquired injuries and accidents in sport and leisure activities, and road traffic accidents. More recently wars and civil strife have been implicated in the rise of childhood disability, especially in Africa. This includes countries like Rwanda, the Democratic Republic of the Congo, Sierra Leone and Liberia etc.



2.3 Prevention of childhood disability

Childhood disability can be prevented at three levels, namely, primary, secondary and tertiary levels. The three levels of prevention are proposed in a framework for reducing the problem of childhood disabilities in most developing countries (Simeonsson, 1991). Such a model is based on an assumption that: (1) most childhood disabilities are preventable both before and after birth, (2) the causes of childhood disability can be detected and prevented at these three levels, (3) prevention efforts can be made possible by intervening at the right time, (4) at each level of prevention, there are indicated services for the child and linked services for the family, and (5) the levels of prevention in a given country is governed by its attitude, priorities and the resources available (ibid).

Primary level prevention involves interventions with the broad aim of reducing risks of occurrence of developmental impairments and disability. Risk factors can be reduced through better ante-natal care, immunizations, nutrition and health promotion. At secondary level of prevention the goal is to decrease the extent of the manifested childhood disability and shorten its duration. These include infant stimulation and rehabilitation programmes complemented by efforts to encourage the family's ability to promote child development. At the tertiary level of prevention it involves interventions when disability has occurred and is found irreversible. Measures can be taken to prevent the transition of the disability into a handicap.

The intervention programme should be conducted within the context of PHC, relying on the existing services and strengthening the family's role as the central determinant of child health and development (WHO, 1981, Simeonsson, 1991; El-Hazmi, 1997). It should, however, be noted that the responsibility for disability issues are not limited to the health sector alone, but it should include all other sectors involved in social, vocational, educational, legislative and other interventions (WHO, 1981).

2.4 Disability and culture

In many developing countries, the definition of disability is based on cultural beliefs. The term 'handicap' is also defined in relation to contextual factors that are predominantly cultural. The recent tendency by the ICIDH and ICF to categorize all people with different impairments as 'disabled' is a trend, which originated from western societies (Ingstad, 1990; Kisanji, 1995; Coleridge, 2000). The fact that there is no universally accepted definition of the term 'disabled' makes it impossible for most countries in the developing countries to match their definitions of disability

with the three WHO concepts of ‘impairments’, handicap and disability or activity ‘limitations’ and ‘participation ‘restrictions’ (Coleridge, 2000). However in most societies, definitions of disability such as ‘deaf’, ‘blind’ ‘lame’ and so on do exist. Furthermore, what is referred to as ‘disability’ in these societies differ from one culture to another. For example, among the Tuereng in Mali, freckles and small buttocks among women are considered as a serious barrier to marriage and therefore can be considered as a disability (ibid). In other words, the way a society thinks of disabled people is determined by a number of cultural variables, including the nature of the impairments.

In most developing countries, disability is seen as a sign of misfortune not only to the individual but also to the family as a whole. In some cultures it is seen as a symbol of disturbed matrimonial relationships and this becomes a stumbling block to community support. Salas-Provance, Erickson & Reed. (2000), observed that culture plays an important role regarding health and illness. They observed that the way disability is viewed varies in the way communities perceive its severity, its impact on one’s life, beliefs regarding its etiology and preference for treatment. A study by Mweshi & Mpofu (2001) in a peri- urban area in Cape Town in the Republic of South Africa revealed that 47% of the caregivers felt that culture and beliefs affected their rearing patterns of the disabled child. Only 36% knew the etiology of their children’s disability. Struthers (2002) lists cultural beliefs, ‘gods will’ and witchcraft as some of the causes that people living in a peri- urban area of Cape Town in the Republic of South Africa believed caused disability. Disability is still viewed with a considerable stigma attached to it; in some cultures it is often attributed to punishments for past misdeeds (Boyce & Paterson, 2002).

Therefore, these scenarios lead to one very important conclusion, namely, that an understanding of societal constructs regarding disability in a given culture is crucial to the development of strategies in meeting the needs of people with disabilities Yousafzai, Pagedar, Wirtz & Filteau, (2003).

2.5 CBR - The “Top-Down” model

CBR may be defined as

“a strategy for enhancing the quality of life of people with disabilities by improving service delivery in order to reach all in need, by providing more equitable opportunities and protecting their rights. It builds on full and co-ordinated involvement of people with disabilities and their families” (Helander, 1999: 8).



The goal of rehabilitating children with disabilities is to enable them to live at their highest level of function and with a high quality of life (Albrecht, 1997:17).

The initial intention of the WHO’s original model of CBR was to ensure efficient delivery of “low technology” rehabilitation services to areas where services did not exist due to underdevelopment. However, these efforts were often structured “top-down” and rarely incorporated the community members in CBR planning. They only involved the community in programme implementation (Boyce & Lysack, 2001). This mode of CBR, which was sponsored by international agencies and rehabilitation organizations, realized that the CBR models, which were, structured ‘top-down’ encouraged passive and not active community participation from the population. There was therefore a need to adapt CBR strategies that would encourage active

participation of the population (ibid). This model that involves the active participation of the population is what has come to be known as the ‘bottom-up’ model of CBR (Helander, 1999).

The WHO, having considered CBR as a possible compliment to PHC, and after pilot projects having been successfully implemented in Africa, India and south Asia, CBR was formally endorsed in 1978. This followed larger WHO funded projects being established in these areas (ibid). In the late 1980’s and early 1990’s CBR started to emerge as a community development issue as the rights of people with disabilities started being recognized internationally. This meant that all CBR activities started to encompass the principles of power sharing, decision making (including policy) before implementation of programmes. Therefore, it is not until recently that the issues of rehabilitation have been addressed from a community development perspective (ibid). Finally, a joint paper on CBR issued by the three UN agencies namely, the International Labour Organization (ILO), WHO and UNESCO defined CBR as a “strategy within community development for the rehabilitation, equalization of opportunities and social integration of people with disabilities (UN, 1994).

The UN further promoted the ideal of participation by declaring 1983-1992 as the International Decade of the Disabled Persons. This recognition by the WHO was further reaffirmed by the UN’s report entitled ‘the World Programme of Action Concerning Disabled Persons’ (Boyce & Lysack, 2001).

2.5.1 CBR in Botswana

CBR programmes started in Botswana in 1975 under a sub-section of the Ministry of Health. Later, it was upgraded to become the Division of Rehabilitation Services (DRS). In 1996, through a presidential directive, a Policy framework for the handicapped was put in place in the country. The main purpose of the policy was to guide those parties interested in disability issues in order to involve them in the process effectively. This policy document outlines the need for a multi-sectoral approach for effective CBR programme implementation and sustainability. The document further outlines how to respond to the demands for coordinated delivery of services and care for people with disabilities in Botswana. The policy framework spelt out guidelines of the responsibilities of various government departments and private agencies involved in the system of care for people with disabilities. Some of the specific principles of the policy document are:

- 1) Recognition and protection of human rights and dignity of every person with disability
- 2) Participation in the basic entities of society- the family, social grouping and community is the core of existence of human being
- 3) To recognize that the care of people with disabilities is a continuous process requiring more family participation, community involvement and less institutionalization.
- 4) To ensure that the person with disability has a right to determine his/her own well-being.

- 5) To ensure that care of people with disabilities is to be effectively coordinated, in a spirit of cooperation and beneficial interaction (NPCPD, 1996).

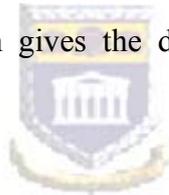
2.5.2 CBR versus Institution-based rehabilitation (IBR)

The UN (2002) describes rehabilitation as a “means of a goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and /or social functional level, thus providing him or her with the skills to change her or his own life”. It can involve measures intended to compensate for a loss of function or functional limitation. Providing a variety of rehabilitation services is a costly task to any country. The health care services find it necessary to provide specialized personnel for services to people with disabilities (Mitchell, 1999a).

CBR is both a philosophy and a strategy of providing more equitable, sustainable and appropriate rehabilitation services to the majority in a community. In CBR, the disabled person, the family, the community and health professionals collaborate to provide needed services in non-institutional settings, and in an environment or community where services for disabled persons are seriously needed or totally absent (Rodgers, 2003).

In contrast to CBR, IBR services are provided in a health or educational institution e.g. hospital or rehabilitation centre either as in-patient or out-patient. Such services usually meet a small number of needs of a small number of persons with disabilities. IBR is therefore a limited approach and could deny people with disabilities their rights to access rehabilitation services. In many instances, where these IBR services are available, they may be cost prohibitive as the majority of disabled persons live in rural areas far away from urban areas where most of these institutions are located.

However, institutional models of rehabilitation are essential for CBR to work effectively. Mpofu (1995) argues that the two models of rehabilitation are not separate but are interdependent of each other. She argues that CBR requires institution-based rehabilitation (IBR) services for referral and assistance of problems that cannot be solved at the community level while IBR requires CBR because of its roots in PHC for referral services. As in PHC, CBR aimed at addressing the inequity that existed in the developing countries due to scarcity of professionals and financial resources. It was therefore, intended to bridge the gap between an increasing “burden” of disability in developing countries. Both PHC and CBR services are provided at the community level but the more difficult cases, which require sophisticated interventions, are referred to secondary and tertiary level health institutions. This referral system gives the disabled person access to specialized personnel and services.



The PHC strategy was identified by the Alma Ata declaration in 1978 as the key to attaining the target of “Health for All” by the year 2000 (WHO, 1978). The declaration defines PHC as:

‘Essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford to maintain at every stage. It is the first level of contact between individuals, family and community with the national health care’ (WHO, 1984).

Although the Alma Ata conference in 1978 does not specifically mention people with disabilities, it does mention that health is “a state of complete physical, mental and social well-being ...as a fundamental human right” (WHO, 1978). However, this definition can be challenged because having a physical or intellectual disability does not necessarily mean one is not healthy.

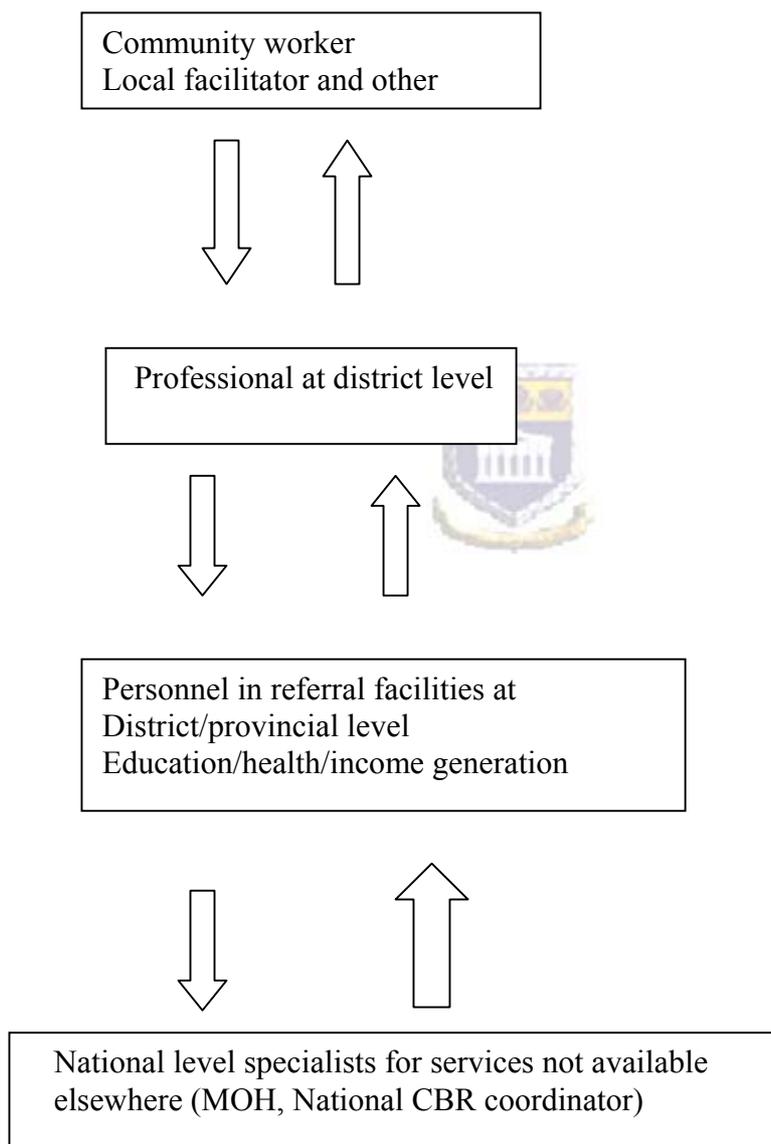
The objectives of PHC are the integration of the following components, namely, preventive, promotive, curative and rehabilitative services through participation of community members and groups at all levels of the societal spectrum (WHO, 1978). PHC include intersectoral collaboration as a key to effective delivery of services. This means it will involve co-ordination from all government departments at national, provincial and district levels (Helander, 1999; Mitchell, 1999b).



2.5.3 CBR delivery system model (Adapted from Helander, 1999)

The model below (**Figure 1**) demonstrates how CBR could be structured for the effective delivery of services to the disabled persons. It shows the different levels role players with the integration of “bottom-up” and “top-down” conceptual models.

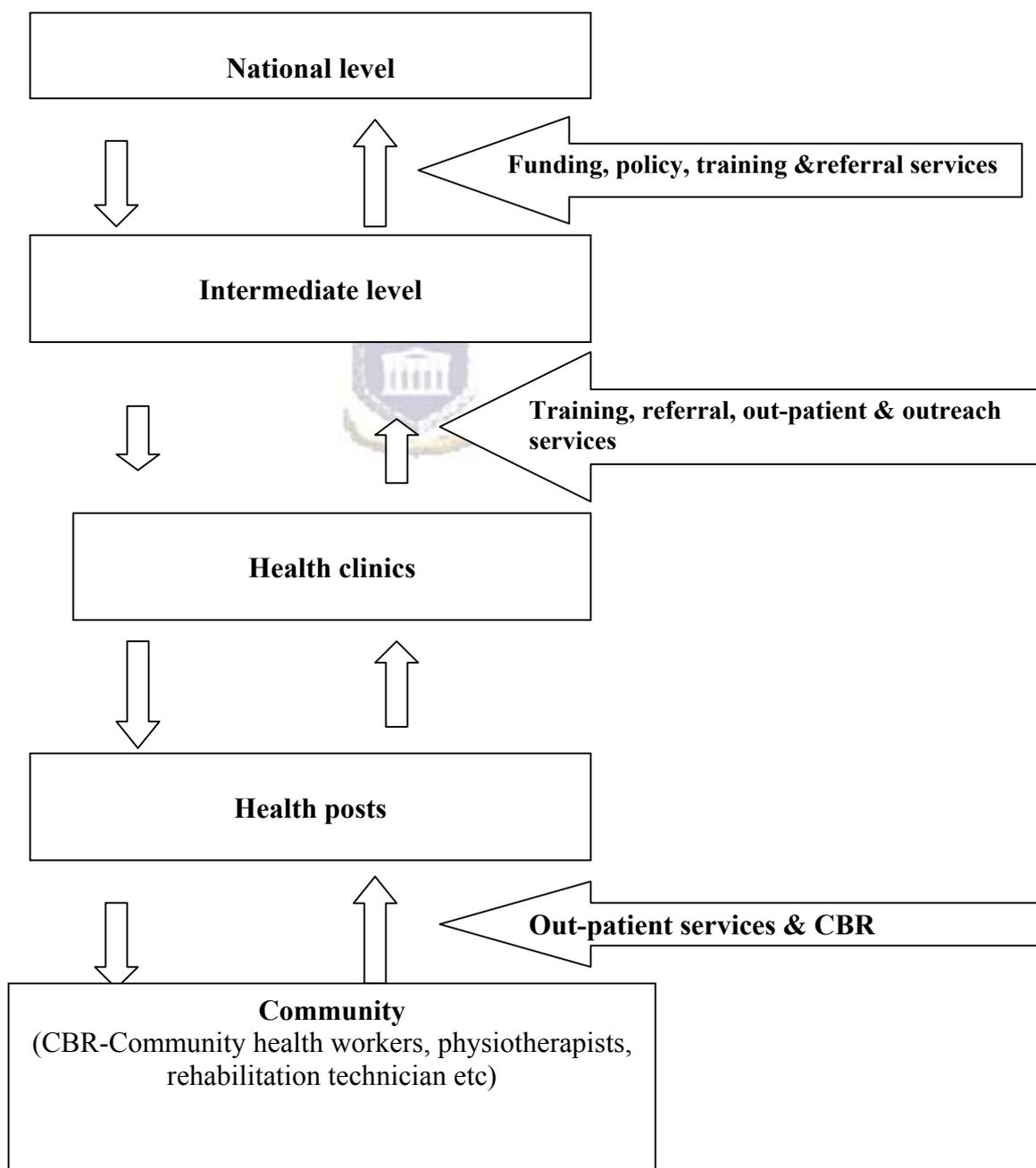
Figure I.



2.5.4 CBR organizational model

Figure 2. (Adapted from Mitchell, R. (1999b).

The model demonstrates the organization of services available at the different levels and the interdependence between the different levels of health care and the community: From top down or bottom up. Difficult cases that cannot be dealt with at the community level are referred to next level. The community level needs the national and intermediate levels for provision of leadership (manpower) and funding.



2.6 Community participation

Community participation is scarcely studied in most sectors such as health, environment, government and rural development. Community participation has however become a prerequisite and strategy for efficiency, equity and cohesiveness in these sectors (Boyce & Lysack, 2001). There are three basic characteristics to note in the concept of community participation; firstly, participation must be active; secondly, people have the right and responsibility to exercise power over the decisions that affect their lives and finally, there must be systems available to allow the implementation of the decisions made by the community (Denhill, King & Swanepoel, 1995:57).

Before the concept of community participation in any sector can be examined, it is necessary to define various relevant concepts used to discuss participation. These factors are believed to have an impact on participation. (Denhill et al. 1995; Boyce & Lysack, 2001).

According to Dryer et al. (1993) as cited by Denhill et al. (1995:56), a community can be defined in its geographical boundaries or social boundaries or both. Woelk (1992), in Denhill et al. (1995: 59), defines a community as “a group of people who live in a particular area and who have shared values, cultural patterns and social problems, as well as a group awareness which facilitates the residents interacting more intensely with each other than they would with outsiders”. However, the definition of a community is still debatable.

The idea of participation is misinterpreted to mean even minimal interactions that take place between people (ibid). Participation is not: (1) where an individual merely takes part in a group activity or, (2) where an individual is merely given information on decisions affecting him or her before it is executed or, (3) where an individual is present at a meeting but has no influence (Boyce & Lysack, 2000).

Boyce & Lysack (2001) have proposed the following definition of community participation in CBR: “Community participation is the organization of activities by groups of persons who have disabilities (or their family members or friends), in conjunction with other relevant sectors, to increase their ability to influence social conditions, and in doing so improve their disability situations”. Although this definition of community participation is in the context of people with disabilities, it could also be applicable to other settings e.g. people with similar issues/ goals, social, developmental, poverty etc. Currently, ‘community participation’ has become a central and essential component of any community-based social model including CBR and is arguably the only viable option of dealing with the needs of persons with special needs (Giacaman, 2001).

2.7 The impact of disability

Disabling conditions have effects that extend beyond the child with the disability to the family, caregiver, neighbours and the community in general. The birth of a child with a disability, or the discovery that the child has a disability can be a traumatizing experience to the family. The siblings, who at first establish a unique relationship with their disabled brother/ sister, soon realize that something is wrong with him/her and the relationship may be affected negatively. The children must then suddenly

adjust to a brother or sister who, because of his or her condition, may require a large portion of family time, attention, money and psychological support (NICCD, 1988). Depending on the degree of disability, modifications in the home and in the parental activities may or may not be substantial.

Any restriction or lack of ability to perform an activity in the manner within the range considered normal (WHO, 2001) will obviously have a direct negative impact on the child involved. The direct impact includes the disabled child's exclusion from mainstream society, stigma and loss of self-esteem (Nocon, 1991; Peshawaria et al., 1998). The emotional effect of the child's disability can interfere with his socializing with other children through play, sports, schooling and other leisure activities for both disabled and non-disabled (Nocon, 1991).

Living with a brother or sister with disability can be rewarding, enlightening, but at the same time it can be confusing and stressful. The siblings express a range of emotions and responses to the disabled brother or sister (NICCD, 1988). The non-disabled children may experience jealousy because they may be required to do family chores, whereas the sibling with disability is not required to do anything despite the fact that he may be able to do them. The negative or positive nature of relationships between siblings and among family members may be influenced by factors such as family's resources, their lifestyle, the child rearing practices, the kind and severity of disability, the number of children in the family and the age differences between children. Other factors include stress-producing conditions that exist in the family and the coping mechanisms used and finally, the kind and quality of the support services available in their community (ibid). The family as a whole is affected

physically, emotionally and financially by caring for the disabled person (Connor & Adams, 2003).

2.8 The concept caregiving

Fisher & Toronto (1990) in Schofield, Sidney, Herman, Murphy, Nankervis & Singh. (1998: 25) observed,

“Caring can be viewed as a variety of activities that includes everything that we do to maintain, continue and repair our ‘world’ so that we live in it as well as possible. That ‘world’ includes our bodies, our selves and our environment, all of which we seek to interweave in a complex, life sustaining web”.

A close examination of the concept of caregiving reveals that the term is often too general and does not recognize the complexity and variable experiences of caregivers ‘Caregiving’ comprises of the ‘caring activity’ and the caring ‘emotions’ (Schofield et al., 1998). Graham (1983) in Schofield et al (1998), differentiated between these two components of caregiving as ‘feeling concern for, and taking charge of the well-being of others arguing that caring demands both love and labour, both identity and activity’. Both Graham (1983) and Dally (1988) conceptualize caregiving as a combination of both ‘feeling and doing’ (cited from Schofield et al., 1998). The level of caregiving depends on the extent to which the recipients of care can look after themselves. The care recipient may be physically dependent on the other for certain activities of daily living.

2.8.1 Family caregiving and gender

The immediate family and relatives play a major role as caregivers of the chronically ill and disabled children in the community, and yet these roles are in most cases not recognized sufficiently by the service providers and in government policies. The family caregivers continue to constitute the backbone of community care and are the most important source of support for their dependent relatives. It is therefore, important to reflect on the emotional cost which caregiving demands from the family (Kausar & Powel 1999).

The family is an enduring social institution found in all societies throughout the world in one form or another and plays a pivotal role in caregiving of the disabled child. In spite of its apparently universal and familiar nature, the family is hard to define. Ravetz (1993) identifies two types of family structure, namely, the nuclear family and the extended family structure. A caregiver may be a mother, father or any other family member who has the direct responsibility of rendering care to the disabled child. However, many children with disabilities will out-live their family caregivers and require community support services in order for them to be maintained in the community. Thus, these caregiving roles extend to community members and the caregivers could include other persons who may be friends, neighbours, volunteers or paid workers (Peat & Boyce, 1993).

According to Helander (1994), the family of the disabled person is his most important resource. Most caregivers in all societies are family members who are mostly women who have to balance this role with other domestic responsibilities and work outside the home (Peat, 1997; Tamm, 1999; Chernesky & Gutheil, 2002). It is

estimated that three out of every four caregivers are elderly women, who themselves are less likely to be cared for by a family member than their male counterparts. It is also estimated that as many as 10% of these women are over 75 years of age who themselves may need some kind of care (Sawatzky & Fowler, 2003; Connor & Adams, 2003).

It is believed that women are main caregivers firstly because ‘care comes naturally from women’. Secondly, most societies globally somehow make caregiving a woman’s responsibility and finally, because in most cases women live longer than men in society (Cancian & Oliker, 1998:45). According to Cancian & Oliker, (1998) caregiving in families stems from biological sex and deep-seated psychological differences between men and women that develop in early childhood. These may be attributed to differences in brain structure or hormones, differences in the evolution process between men and women or psychological differences that occur across the lifespan. They further explain that the natural caring attributes come from inside an individual and not from the outside of a social situation. They explain that women have hormones or instincts that make them good providers of physical as well as emotional care, which most men do not have. In contrast to women they argue that men have hormones and instincts that make them good providers for economic support within the family.

Despite the burden associated with caregiving in terms of physical, financial, and emotional demands, most family members are willing to assume the primary caregiving responsibility. Most of these caregivers are motivated by love for the care recipients (Connor & Adams, 2003). A study by Taanila, Jarvelin & Kokkonen

(1999) on cohesion of parents with a child with disability found that the feeling of togetherness increased in 56% of the families who participated in the study and 67% were fully committed to their families. Seventy percent (75%) valued social support from friends or family. However, physical, emotional, spiritual, social and economic stressors overshadow these positives and the caregivers become susceptible to poor health (Sawatzky & Fowler, 2003). More recent studies have shown that behavioural disturbances in care recipients contribute to a higher level of physical and psychological morbidity in their caregivers. Kausar & Powel, (1999) described personality and physical changes in caregivers of patients of neurological disorders. Personality changes in the care recipients were perceived as more stressful and more threatening than the physical changes. The carers' well-being and self-esteem were more at risk in relation to personality changes than physical changes. It has also been argued that loss of personality as opposed to loss through physical death of their loved ones is more difficult for the caregivers to cope with. (ibid).

2.9 Stress and burden

Stress and burden have provided a leading background for many studies of caregiving as reflected in the extensive literature on these subjects (Kahana & Young, 1990). However, these studies only dwell on the negative outcomes of caregiving. Because of these negative attitudes, most caregiving models fail to capture adequately the diverse and dynamic nature of family caregiving, but what they do is to provide a useful guide of family care (Nolan, Grant & Keady, 1996).

According to Opie (1994), caring is stressful and can be a burden to the caring family but at the same time it should be seen in a positive perspective rather than solely in

negative terms. Opie recognizes that although stress is an inevitable part of caring, and indeed life in general, it can also be a positive experience providing opportunities for growth and challenge. Some caregivers express greater marital satisfaction, a feeling of self worth, a pride in their ability to meet challenges and a meaning in their lives (Kramer, 1997). Caregiving can thus be a satisfying and rewarding experience, characterized by bringing a family closer together and even salvaging relationships that are on the verge of disintegrating (Hooyman & Kiyak, 1999; Patterson & Leonard, 1994).

Although there is considerable evidence to support the notion that caregivers of people with disabilities and chronic illness suffer from psychological and physical stress (Nolan et al. 1996), various studies (Bradshaw & Lawton, 1978; Burden, 1980; Grant, 1990) suggest that the extent to which this is true is doubtful. Taylor (1992), in Nolan (1996), argues that these studies target those caregivers who are most at risk of negative health outcomes rather than having an approach that sees all caregivers as being at risk. Many factors determine the extent to which caregiving is a burden or satisfying experience. Among these are the length and intensity of caregiving, the nature of the relationship with the person needing care, the amount of psychological, social and physical support provided to the caregiver, the presence of professional caregiver, and the self perception and emotional health of the caregiver (Connor & Adams, 2003).

2.10 A conceptual model of caregiver adaptation

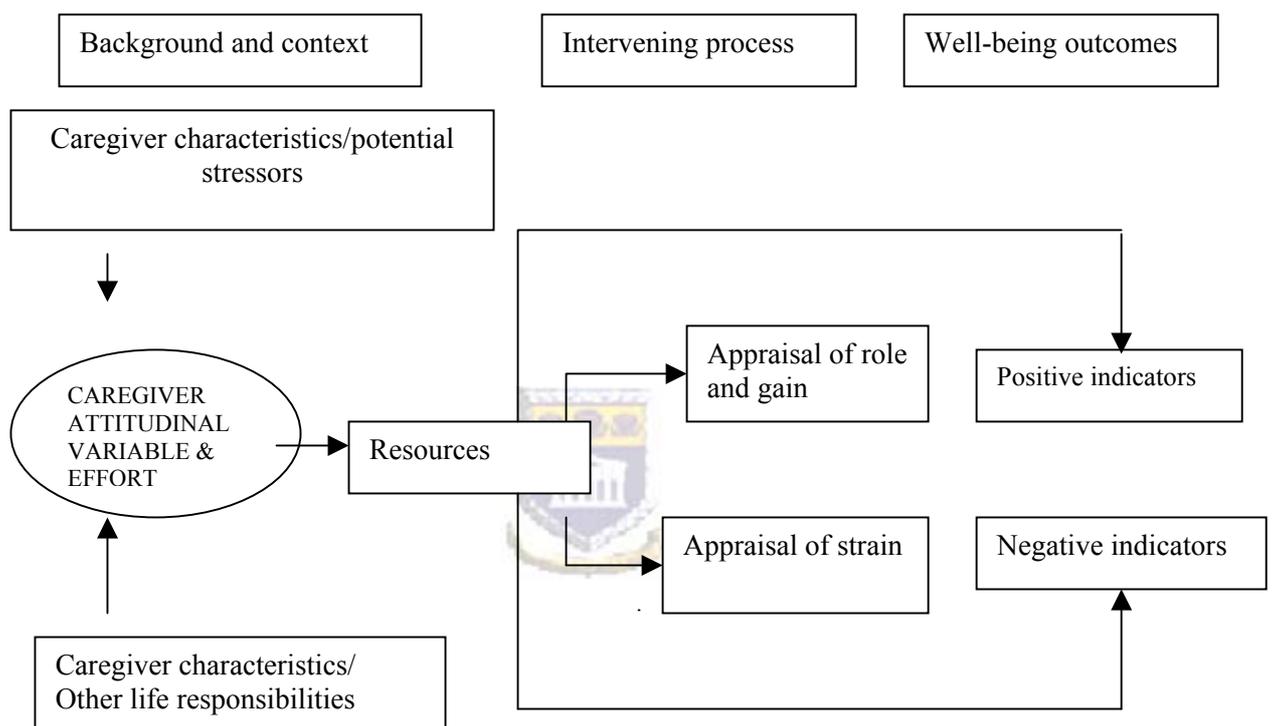
According to Kramer & Kipnis (1995), the characteristics of the caregiver and the care receiver and the context of the caregiving situation potentially play a central role in understanding all other aspects of the caregiver's experience. These contextual variables are conceptualized to determine the types of caregiving activities the individual is engaged in, the type of resources that are available to manage these responsibilities, the appraisal of gain or strain and ultimately the well-being of the caregiver. Individual differences in attitudinal variables, such as motives, value or goals help to explain how a situation can be appraised as stressful by one person and beneficial to another person (Folkman & Lazarus, 1988). Caregivers tend to experience more gains than costs of care when they find the caregiving role as satisfying and if they have effective problem-solving strategies, social support and assistance and are in good physical health (Kramer, 1997). Whether caregiving has positive or negative effects on the family's well-being will depend on firstly, the number and importance of role demands shared between the caregiver and the care receiver; secondly, on the timing of these demands and finally, on the context in which they occur (Kahana Biegel & Wykle, 1994: 13). Multiple roles do not necessarily lead to overload and stress because they may be influenced by family, community or social support, access to finances and acumen of personal competence (Bengtson, Rosenthal & Burton, 1996; Lopata, 1993).

The conceptual model of caregiver adaptation (Figure 3 on page 36) was first developed by Folkman & Lazarus (1984) and was aimed at helping to understand how caregivers adapt to stress. According to this model, adaptation process is made up of three primary domains: background and context; intervening process and well-being outcomes. Caregiver characteristics such as illness severity, type of illness, functional status etc. play important roles in understanding the caregiver experience. Intervening processes include resources e.g. coping, personal control, knowledge, and social support and directly influence role of appraisal and well-being. Appraisal refers to an individual's evaluation of the extent to which caregiving is harmful, beneficial or irrelevant to well-being. Well-being outcomes will consist of a positive appraisal of gain or a negative appraisal of strain.



Figure 3. A conceptual model of caregiver adaptation. (Adapted from Kramer, 1997).

The model illustrates the relationship between caregiver, care recipient and how the associated contextual factors play a central role in understanding the carer's experience.



It is widely recognized that resources play a central role in determining caregiver outcomes. In many research findings, caregivers report much higher scores of negative indicators of well-being (depression, physical illnesses etc.) when compared to non-caregivers (George & Gwyther, 1986). Research on caregiving also shows that many caregivers report caregiving to be an emotional, physical, and at times, financial burden (Orto, Dell & Morinelli 1995:147). For many caregivers, their health, employment, personal freedom, privacy and social relationships are negatively

affected by their role of caregiving (Hooyman & Kiyak, 1999). Significant caregiving problems as identified by researchers include the following:

- 1) Coping with increased needs of the dependent family member caused by physical, and/or mental illness;
- 2) Coping with disruptive behaviours, especially those associated with cognitive disorders;
- 3) Restriction to social and leisure activities;
- 4) Disruption of household and work routines;
- 5) Lack of support and assistance from other family members; and
- 6) Disruption of family roles and relationships.

2.10.1 Coping in caregiving

The concepts in caregiving are as diverse as the coping strategies. According to Sarifin (1994), in Melnick (2002), coping is a cognitive and behavioural response used to deal with a stressful situation. Coping mechanisms differ from one family to another. When a person is in a situation whereby he/she is unable to cope, problems of stress arise. Stress involves a perceived imbalance between the demands of a situation and the resources that a person has to deal with. Coping thus attempts to manage this imbalance between situational demands and the resources available (ibid). Stress can be defined as a response to events or circumstances and can be either positive or negative. The problems associated

with stress are depression, burden, burnouts, lack of sleep, difficulties in memory and concentration, delusions, violent behaviours and hallucinations (Perlesz & Loughlan 1998; Muhlbauer, 2003).

Ingstad (1999) points out that when families are unable to cope with the care of a disabled relative, it is usually as a result of poverty and a lack of knowledge about what can be done to improve the situation, than the result of lack of love or negative attitudes. A study by Mweshi & Mpofu (2001) found that parents and caregivers were not coping with their caregiving roles and were thus susceptible to psychological distress. Another study by Rumano (1994) in Zimbabwe found a lack of understanding of disability and negative attitudes within the community coupled with other roles that the family member has besides caring for the disabled member of the family, as being barriers to effective caregiving. She found that families have little or no time to care for their disabled, especially during rain and harvesting seasons.

Boyce & Lysack (2001) states that disability may not be a community priority, and what is in the best interest of the individual disabled person may not be in the best interest of the community as whole. This means that the disabled person is the sole responsibility of the caregiver. A study conducted in Jamaica by Bischoff, Thornburn & Reitmaier in 1996 found a low degree of practical helpfulness by neighbours of families with disabled children. Atman (1981), Hahn (1983), and Wright (1988), in Gilbride (1993) found in different studies that the consequence of disability is not the reduction of a person's physical or mental capacities, but rather the environmental and social system that are barriers to effective rehabilitation and integration of the individual into society. Both public policy and legislation can be significant barriers or enablers to caregivers of disabled persons.

2.10.2 Coping strategies

Every human being has to acquire some skills to deal with various situations at one time or another in order to survive. How well one deals with these situations will differ from one individual to another depending on internal strengths and resources available. Coping is complex and includes a variety of behavioural efforts in which an individual manages stressful situations. Failure to adopt a coping mechanism may lead to deterioration of health of both the caregiver and care-recipient. Individuals may access more than one coping strategy in their attempt to manage stressful encounters, and these can involve behavioural as well as cognitive disorders (Nolan et al. 1995b).

Folkman and Lazarus (1980), in Rose, Strauss, Neundorfer, Smyth & Stuke (1997), categorized coping strategies into two broad categories. One strategy is problem-focused and includes efforts to manage or alter the stressful situation. The second category is emotion-focused coping and involves efforts to alleviate the emotional distress caused by the stressful condition.

Emotion-focused coping strategy tends to be associated with negative psychological states such as depression, negative well-being and anxiety. Pruchno & Resch (1989), as cited by Rose et al 1997, found that emotion-focused coping strategy is further divided into three coping styles namely, wishfulness, intrapsychic and acceptance. Wishfulness and intrapsychic styles were said to be related to poor mental health of the caregivers while emotion-focused strategy of acceptance was related to better mental health. Haley et al (1987), as cited by Rose et al (1997), however found that problem-focused coping, on the other hand had positive mental and physical outcomes in caregivers. Lazarus (1993) suggests

that all strategies are potentially useful but they must be matched with the nature of the stressor or danger faced.

Coping may be liberating, but at the same time it may also prove to be a stressful experience itself. Therefore, supporting and boosting caregivers' coping efforts should be a major objective when planning for professional support (Nolan et al., 1995).

2.10.3 Coping resources

According to Lazarus & Folkman, (1984), as cited by Nolan et al (1996), coping resources are part of an individual's internal or external environment that is not under direct control and lie dormant until called upon in a stressful encounter. Within a person's internal resources are factors such as personal skills, relevant life experiences and psychological and reasoning abilities (Nolan et al, 1996).

According to Lazarus & Folkman (1984), external resources are more familiar and include income, housing, socio-economic status, social network and support available through such networks. It is argued that men or women could be effective caregivers if resources such as money and time are adequate and if they have learnt appropriate skills (Cancian & Olikier 1998).

2.10.4 Enabling factors and barriers in caregiving

Most of the barriers to effective coping have been inferred from the research on enabling factors to effective coping. Peshawaria, Menon, Roy, Rajam & Gupta (1998) identified better marital satisfaction or support from husband as effective for coping by mothers, while on the other hand, less satisfactory marriages and less support could be inhibitors to effective coping. Baxter (1986), in Peshawaria et al. (1998), identified some barriers to effective coping, namely, additional financial hardships, stigma, lack of time, difficulties in caregiver tasks like feeding, diminished sleeping time, social isolation and lack of recreation.

It is well acknowledged that low-income caregivers have greater needs for support and education and they experience greater caregiver distress than do their counterparts who are better socio-economically. Williams, Forbes, Mitchel, Essar & Corbett (2003) investigated the influence of income on the experience of informal caregiving and concluded that the low-income group felt more overburdened with the caregiver role than those who are not in the low income bracket. This study also found that carers from the low-income group felt more isolated and lonely. They were physically unable to access other service providers (for example psychologists, physiotherapists, support groups and transport), which may explain why they felt isolated. Lack of transportation may also present a barrier to the caregiver who may want to participate in leisure activities, nurture personal relations, or become involved in activities that enhance their ability to cope such as through caregiver support groups (Biogel & Song, 1996, in William, Forbes, Mitchell Essar & Corbett, 2002).

Other barriers identified during this study were, poor physical health of family members (mother, husband, child etc), lack of information regarding the condition, unavailability of services and government benefits, lack of facilities such as transport and hospital; witchcraft and difficulties in admitting the child to school. On the other hand, having faith in God, self-determination, mutual support between spouses, physical support (spouse, friends, siblings, grandmother, neighbours and colleagues etc) has been found to be strong enablers to effective coping (Peshawaria et al., 1998). Research has shown that the attitudes held by the siblings of the disabled child, the medical personnel, teachers and the general public could be limiting factors on the disabled child and the caregiver's success (Gilbride, 1993).



2. 11 Summary of the chapter

The chapter has highlighted the prevalence of childhood disability and also attempted to argue some of the prevailing universal problems faced by caregivers as they undertake their roles. The chapter further attempted to highlight some of the possible similarities between CBR and PHC. Examples of some of these similarities are (1) CBR having evolved from the Alma Ata Declaration in 1978 as an essential component of PHC. (2) Like PHC, CBR was initially promoted as a local initiative to link between the increased burden of disability in the developing countries and lack of professional and financial resources. And finally, services of both PHC and CBR are provided at the community level but more difficult cases that require sophisticated interventions are referred to institutions. The chapter concluded by discussing some of strategies that may be used by caregivers to cope with their caregiving roles. It is common knowledge that these coping strategies differ from one individual to another depending on their environment and resources. Finally the chapter discussed some of the common enablers and barriers in caregiving. The methodology used for the study is described in the following chapter.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

The chapter outlines the methods that were used in the study. Included are the research settings, the study design, instrumentation, study sample, pilot study, data analysis and ethical considerations

3.1.1 Research setting

The study was conducted in the Republic of Botswana at two selected settings, namely, Gaborone and Mochudi. Botswana is a landlocked country in the southern part of Africa. It borders South Africa to the south, Zimbabwe to the north-east, Namibia to the west and Zambia to the north. The country is divided into ten (10) administrative districts. It has a population of 1,661,121 people of whom 810,599 live in urban areas (Central Statistics Office, 2003). Gaborone is the capital city and is located in the Southeast district. Its population is predominantly urban while Mochudi is situated 50 kilometres north of Gaborone in the Kgatleng district and its population is predominantly rural.

According to the International Institute of Applied Systems (IIAS), Botswana has had the highest economic growth in the world of 9% per year since 1966 through 1999 [Online]. Available <http://iisa.ac.at/research>. It was one of the poorest countries when she attained her independence in 1966 with a per capita income of U.S \$ 80. Today her Gross Domestic Product (GDP) stands at U.S. \$ 3600. Her annual budget in revenues and expenditures stands at over U.S. \$ 1.6 billion and U.S. \$ 1.8 billion respectively as per 1996/97 Financial Year. Subsistence farming

and cattle raising predominate. Diamond mining and tourism are also important to the economy. [Available Online].

http://www.photius.com/wfb1999/botswana/botswana_economy.html.

Despite the country's affluent economic growth the majority of the population live in poverty with 62% living in the rural areas. Forty seven percent (47%) of the country's households are female-headed (Lindsey, Hirschfeld, Tlou & Ncube, 2003).

3.1.2 Structure of CBR in the research settings

3.1.2.1 Mochudi

This is a village that is about 50 kilometres north of Gaborone, the capital of Botswana. It is divided into several administrative wards such as Boseja, Makakatlela, and Rashes etc.



It has a small township with facilities such as shopping malls, administrative offices, schools and a primary hospital. Community-based rehabilitation services are mainly provided by a NGO through the Motswedi Community-Based Rehabilitation Centre (MCBRC) in collaboration with the government. The Motswedi Community Rehabilitation programme was founded in 1988 by the Mothers' Union of the Dutch Reformed Church in Mochudi, with support from Botswana Christian Council (Mrs. Ramutsui, Coordinator, verbal communication, 12/12/2003). The founding of this centre was motivated by the number of disabled people who were found lying in their homes without any provision for care or educational needs. The majority of these disabled were children who could benefit from stimulation, welfare and subsequent placement in schools or vocational

training rehabilitation centres. In 1990, a survey conducted and funded by a Norwegian Agency for Development Cooperation (NORAD) identified 680 disabled persons in the village of whom 30% were children of ages 2-16 years (Motswedi general information brochure, undated). The centre offers a variety of services such as CBR, outreach community based services, stimulation school for children intellectual handicaps, day care centre, life skills and vocational training, residential (hostel) programme for disabled children and a support group programme for parents with children with disabilities (known as group therapy programme). Other activities of the centre include group treatments through ADLs and play, provision of assistive devices to children, referral to other departments for services that are not available at the centre, monitoring of children's development and health education to mothers/caregivers, especially on disability and rehabilitation.



For the purpose of rehabilitation services, the centre has divided the village into eight catchment areas namely, Boseja, Clinic 1, Clinic 2, Rasesa, Deborah Retief Memorial Hospital, Makakatlela, Molotwane and Phaphane. In addition to the activities mentioned above, the following activities take place in the mentioned catchment areas:

- 1) Keeping an up to-date database of people with disabilities in these areas
- 2) Visiting people with disabilities in their homes to assess their home environments
- 3) Assessing and planning rehabilitation for these people in their own environments

- 4) Reassessment of old clients for the purpose of updating treatment plans

3.1.2.2 Gaborone

This is the capital city of Botswana and has a population of over 180,000 people (CSO, 2001). The lifestyle of the inhabitants is predominantly urban. Gaborone has the facilities of a modern city, which include shopping malls, schools and health facilities such as health clinics and a referral hospital. CBR is conducted through a government division that deals with the delivery of rehabilitation services and the Cheshire Foundation of Botswana (CFB), which have programmes that cater for disabled people and especially children. There are also other NGOs that have programmes such as Home-Based Health Care (HBHC), and work in partnership with other agencies, which work with disabled persons.

The CFB has a variety of programmes and covers a bigger population. This is a non-profit making charity organization founded in 1989, and is committed to providing quality rehabilitation services to people with disabilities and their families. The Foundation is an autonomous NGO governed by an executive committee whose members are elected each year. The committee members ensure the smooth running of the rehabilitation centre and control its finances on a daily basis.

Presently, the centre operates six rehabilitation programmes for people with disabilities namely;

- 1) Training programme

- 2) CBR programme
- 3) Day-care
- 4) Residential care
- 5) Job placement and
- 6) Outpatient services.

The CBR programme takes services to people of all ages with physical and mental disabilities in their communities. The rehabilitation personnel work with the disabled persons, their families and the community in general in an effort to improve their quality of life. Three rehabilitation officers run this programme in collaboration with the health personnel in their areas.

Through this programme people with disabilities are helped to acquire assistive devices such as wheelchairs, crutches and walking frames etc. However, disabled persons who cannot benefit from the programme are referred for other services elsewhere.

3.2 Research design

A qualitative paradigm based on a phenomenological approach was used for the study. Phenomenology is an approach in which a researcher investigates the ways events of natural phenomena appear without having prior theories and constructs in mind. It studies the meanings of a “person’s world” from the person who lives in it (Huberman & Miles, 2000). A researcher who adopts the qualitative paradigm “believes that events are better described and interpreted than attempting to control them to establish oversimplified causes and effects”

(Domholdt, 2000:155). Furthermore, Rowles in Dickie (2003) describes the presentations of qualitative findings as being a critical determinant of their usefulness. Qualitative findings are typically detailed and to the point. Huberman & Miles (1994:1) agrees that, 'qualitative data are a source of well-grounded, rich descriptions and explanations of processes in identifiable local contexts'.

Qualitative methodology systematically documents, classifies and interprets informants' cognitions and experiences, so that it accurately reflects their lifestyle and knowledge (Sawatzky & Fowler-Kerry, 2003). One of the unique features of a qualitative research methodology is the small number of participants in a study. However, while the number of participants may be fewer, the depth of questioning and richness of data cannot compare with quantitative data (Slauenwhite & Simpson, 1998). Many sociological studies are often based on small samples drawn from one local area, but although these samples may attempt to be representative of a specific category of people, they are not probability samples from which the results can be generalised to the whole population (Arber, 2001).

In qualitative research the researcher relies on his/her ability to describe and write on how events occurred in a manner that brings to mind the events as they happened in the research situation, and in a manner that convey the environmental context and the process involved in arriving at the conclusions (Dickie, 2003).

3.3 Study population

The study population comprised of all caregivers of children aged between 0-12 years with physical disabilities both in Mochudi and Gaborone. The caregivers must have been caring for these children in their communities. A total of 25 and 19 such families were identified in Gaborone and Mochudi respectively.

3.4 Study sample

The sample design was based on a mixture of both probability and purposive sampling as suggested by Arber (2001). Purposive sampling is done when researchers have only sufficient resources to study a small number of people (ibid). In probability sampling, each subject in the population has an equal chance of being selected for the study (Strydom & Venter, 2002). The names of all the participants who met the inclusion criteria were placed in a bucket. Twelve names were then randomly drawn from it, 6 caregivers from each setting.

Where the researcher's aim is to generate theory and wide understanding of social process or social actions, the representativeness of the sample may be of less importance (Arber, 2001). Therefore it is with this in mind that a selected sample of 12 families with a child aged 0-12 years with physical disability were selected from the two study settings. A purposive sample using random sampling was selected from the two study settings, namely Gaborone and Mochudi. The sampling procedure is explained below.

3.6 Inclusion criteria

One main caregiver was selected in each of the participating families with a child with physical and/or mobility problems within the age range 0-12 years. Families with children with intellectual disabilities only were excluded from the study but those with a combination of intellectual and physical disabilities but who had mobility problems were included in the study. The amount of time spent with the disabled child was the criterion of selecting the main caregiver. This was either a member of the family or any other person who was directly involved with the care of the disabled child.

3.7 Instrumentation and data capturing

A semi-structured interview guide with open-ended questions was used with all the 12 participants, each interview lasting between 1-1½ hours, using flexible and in-depth questioning. This provided the researcher with rich information because he could adapt the research instrument to the level of understanding and articulacy of the respondents (Fielding and Thomas, 2001). Two independent persons whose first language is Setswana, which is the widely spoken local language in Botswana, translated the questions from English into Setswana. The participants were interviewed until no new themes emerged. The interview guide for the focused interview consisted of a variety of constructs that were to be covered namely, enabling factors, barriers, experiences, coping strategies and impact of disability to the immediate family. The wording and the order of the questions to the interviewee were kept as basic as possible (Simmons, 2001). Because the researcher has a limited command of Setswana, a research assistant who is a rehabilitation technician was trained and used for translation and taking field notes. The researcher and the assistant each used notebooks and the notes were compared and discussed after each interview to ensure trustworthiness of the responses. A tape recorder to record the interview verbatim was used after seeking written consent from the respondents. Out of the 12 respondents interviewed three opted not to be tape-recorded and only detailed field notes were taken. The three expressed fears of their spouses if they heard what they discussed with the researcher.

3.8 Pilot study

A pilot study was conducted using four families with children aged 0-12 years but who were not to be included in the actual study. Two families were then selected from each setting namely, Gaborone and Mochudi respectively. Some of the questions were not clear and the interview guide was adjusted accordingly. The pilot study was for the purpose of validity and reliability although it is difficult to achieve the latter in qualitative study.

3.5 Procedure

The participants of the study were selected from existing registers kept by the two NGOs that are involved with CBR in these two research settings. The families of disabled children aged between 0-12 years who met the inclusion criteria were then identified from the registers. In Gaborone the participants were sought from the Cheshire Foundation Rehabilitation Centre at Mogodishane while in Mochudi they were sought from Motswedi Rehabilitation Centre. A total of 25 and 19 families that met the inclusion criteria were identified in the registers in CFB and Motswedi rehabilitation centre respectively. A systematic sampling was then conducted in each of the identified families in each research setting and six families were selected in each. The homesteads of the families were then located, the purpose of the study explained to each of the main caregivers and a written consent obtained. Thereafter a suitable appointment for the interview with the main caregiver was made. All the interviews took place at the participants' homesteads. After each interview with a participant, an appointment for a revisit was arranged.

3.9 Data analysis

Data analysis was managed at three levels as suggested by Creswell (1998). Firstly, the data was transcribed verbatim, followed by a description of the account that was as close to the original data originally recorded in order to provide a basis for data indexing, storage, and retrieval. Transcription and translation were done soon after each interview. The transcripts that were in Setswana were then translated to English. To check that English translations of the recordings were an accurate reflection of the responses in Setswana, an independent translator listened to each recording. Secondly, the data was classified systematically by means of coding to identify key factors such as concepts, categories, themes and the relationship between them. After each interview with a respondent, the data was entirely transcribed and analysed, then reviewed for its meaning. The researcher then went back to the respondent with a better understanding of the emerging themes as suggested by Strauss & Corbin (1990). Specific units of data were identified and then assigned categories. Each successive data was then compared with the previously identified units. This meant that data collection and analysis occurred simultaneously as advanced by (Huberman & Miles, 1994).

When all data had been assigned categories, these categories were refined into themes. This early coding gave the researcher guidance on what was to be expected in the other remaining interviews.

3.9.1 Trustworthiness

The data was verified with the respondents for accuracy during a second visit in order to establish the trustworthiness of the information volunteered by the

participants and any additional information added. During the second interview, informants who could read were asked to read through the transcripts to determine if they needed to clarify and elaborate on the responses from the first interview. For those who could not read, the transcripts were read to them and also asked to ascertain whether that was their correct responses. They could clarify or elaborate on their previous responses. Subsequent questions evolved which prompted the investigators' need to know more about the personal experiences of the respondents. Finally, the data was interpreted in order to get its essential meanings.

Although validity and reliability are of importance in all studies, methods of achieving reliability in qualitative studies differ from those used in quantitative research. Reliability in qualitative research is concerned with consistency and repeatability of informants' accounts, as well as the ability of the researcher to collect and record information accurately (Cresswell, 1998:197). Creswell (1998) believes that validity in qualitative research is concerned with the confirmability and truthfulness of scientific findings. Huberman and Miles (1994:11) concur with Cresswell (1998) and reaffirm that 'the meanings emerging from the data have to be tested for their plausibility, their sturdiness, their "confirmability"; that is, their validity'. Confirmability requires that the findings, conclusions and recommendations be supported by the data collected and the researcher's interpretations are as close as the actual responses (Cresswell, 1998: 143-144). In qualitative data the equivalent of validity and reliability is therefore its truthfulness and trustworthiness.

3.10 Ethical considerations

Permission was sought and obtained from the Senate Research Committee of University of the Western Cape to carry out the study. The purpose of the study was explained to the caregivers. Permission was also sought from the caregivers' partners/husbands. Written consents were obtained from all the participating caregivers. They were informed that their participation in the study was entirely voluntary, and that they could withdraw from the study at any time, and that they did not need to give any reasons or explanations for doing so. They were assured that if they chose to withdraw, that would have no effect on their relationship with the researcher.

The participants were also informed that because of the study there could be violations of their privacy. The participants were further informed that they might not receive direct benefit from participating in the study, but that their participation may help others in the future. Consent to tape-record the interviewees was also obtained from each participant and field notes were taken from those who objected to being tape-recorded.

The participants were assured of anonymity and total confidentiality of information, and that any information obtained from them was solely for the purpose of the study. A counsellor (Social Worker) was approached to attend to the participants who might have been emotionally affected during or after the course of the interview. Although most of the participants were affected emotionally during the interviews, none required the intervention of the Social Worker. Written permission to use the two agencies registers was also obtained

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from Motswedi and Cheshire Foundation Rehabilitation centres respectively which was granted.



CHAPTER FOUR

RESULTS

4:0 Introduction

In this chapter the results of the study will be presented and described. Included will be a description of the study sample and its characteristics, and a discussion of the main trends, patterns and connections that emerged during the study. Finally, the chapter ends with a summary of the main results.

4.1 The study sample and its characteristics

The purposive sample for this study consisted of twelve (12) African Black caregivers from both Gaborone and Mochudi. The ages of the disabled children in their care ranged from 2½ to 11 years and all, except one, had severe disabilities. The most common disabilities were cerebral palsy with delayed milestones, representing 58% (7) of all children of the participating caregivers. Other disabilities included spina bifida (1), poliomyelitis (2), encephalitis (1) and one with a disability of unknown cause. It was also interesting to note that the 12 caregivers were all females. Their ages ranged from 21 to 79 years and 8 of the participants were biological mothers of the disabled children while the remaining 4 were grandmothers. The caregiving experience of the 12 participants at the time of the interview (December/January 2003) ranged from 1½ to 11 years, representing a total of 72 caregiving years.

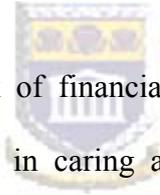
The literacy level of the participants ranged from ‘not been to school (illiterate)’ to form 5 (Grade 12).

4.2 Description and summary of the main themes

The responses of the caregivers were thematically analyzed and the following themes emerged which describe the nature of the experiences of caregivers of disabled children in the community. The themes and categories are tabulated below. Table 1 presents a summary of the main results.

- Impact of caregiving
- Support
- Social isolation
- Knowledge and beliefs

It is important to note that lack of financial resources and time management emerged as crucial determinants in caring across these themes and therefore, impacted on most of them, namely impact on caregiving, support and socialization.



4.2.1 Impact of caregiving

4.2.1.1 Caregiving tasks

In spite of all the participants having multiple roles in the family, they were able to attend to their household chores, and at the same time attend to their disabled children in their care. All the participants were able to perform exercises to their children at least twice a week even though some of them spent as little as five minutes to do so as prescribed by their rehabilitation worker. One caregiver said:

“I like exercising my child because since I started I have seen a lot of improvement...one session would take anything from 5 minutes depending on the availability of time and on how my day has been. You know sometimes you would come home so tired and the only thing that you need is a rest...”



Another expressed:

“I exercise him twice a week because I have other domestic chores to do and so I feel each domestic duty must be attended to”

In addition to the exercises, other assistance given to the disabled children included feeding, bathing, cognitive stimulation, toileting, and transfers to bed, mat, chair and turning positions. Most participants said they liked every task that they did to help their disabled children. However, some of them said there were some tasks that they were not comfortable with. All these participants who said they did not like some of the tasks they did to their children identified toileting as the task they disliked most. One of these participants said, when probed, why she did not like helping in toileting:

“...with no money to buy diapers it means I have to keep on cleaning him and washing his linen...”

4.2.1.2 Finances

Most caregivers felt that they had to leave paid employment or income generating activities to devote their time in caring for the disabled children. One caregiver said:

“I had to leave my work in 2002 to concentrate on caring for this child...now it is only the father who works to support us and it is really hard”

Other two caregivers had the following responses respectively:

“If it were not for this child I would be doing some income generating activities to help my family...before this child got sick I would go to South Africa or Zimbabwe to buy things to come and sell here in Botswana..”

“...She has changed my life into a misery.... I am not working because of the child.... I cannot go anywhere because of this child...I do nothing to help my family because of this child”.

4.2.1.3 Family

Some caregivers said that due to the great amount of time they devoted to their disabled children, other siblings started feeling disadvantaged. One caregiver said that one of her non-disabled children had been complaining why his disabled brother was not given household tasks. She said:

“...The young brother is not happy because he is the only one who helps in the housework...I have to buy him some presents to keep on helping”

Another caregiver said one of her daughter felt they were suffering because of her disabled sister. She felt that if it were not for the disabled sister, the mother would look for work and help her father in supporting them.

4.2.1.4 Caregiver's well-being

Most of the participants indicated that their caregiving roles have had a negative impact on their physical and psychological health. Many of them said they felt stressed while one of them complained of backache that she associated with carrying her disabled child. It was evident even from the narratives of these caregivers that their roles had a negative impact on their health, especially their mental health. The following responses were elicited from the participants:

“...I think about it...I sometimes feel like I am getting insane”

“... I have even lost weight because I am stressed when I think of my future and that of this child....”

“...I do not live happily because of this child...sometimes I worry...supposing I die today how will her life be as a grown-up woman”

“...I have been sick since 2002...I have been having this backache which I believe is caused by carrying her”

The above responses from the caregivers suggested that they were stressed and their caregiving roles had become a burden.

4.2.1.5 Attitudes

It was interesting to note that despite the problems that these caregivers were going through most of them felt their children should be cared at home but not in an institution. These feelings were based on love for their children as expressed below:

“I am against the idea of my child staying in a centre... I feel the child will suffer in the centre because she won't be free to ask for any help like she would ask freely here at home”

“I feel it is better when he stays here at home because at the centre I have to keep on visiting him regularly and have I no money”

“I feel he should stay here at home because this is the place he is used to”



“I do not think this is a good idea because she is fully dependent and I feel can do better here at home as mother”

4.2.1.6 Coping

Support or lack thereof may affect the ability to cope with the demands of caring for a child with disability. Most of the participants said that they were not coping with their caregiving roles. The expressed lack of support from the health workers, social support systems and lack of financial resources were identified as some of the factors that made it difficult for the caregivers to cope. One caregiver summed it up as follows:

“...I am not coping...I always try my best but it is not enough...I earn 1200 ²Pula a month and I have to pay for this house, water, electricity, maid and special meals for the child because she cannot eat hard foods...I have even lost weight because I am stressed.... I always think of my future and that of this child.... I have no parents and therefore I have to go it alone...”

Another caregiver said that she was coping but expressed it as follows:

“...I am coping but things are hard on me...I have no way out...”

The caregivers also identified transport and lack of assistive aids and devices such as wheelchairs and crutches for their disabled children as the other problems that they faced and thus made their coping with caregiving roles difficult.

4.2.2 Support

4.2.2.1 Institution vs. home care



Although time division emerged as crucial factor in these caregivers' roles, most of them were happy to continue caring for their children at home. Those who felt their children should be institutionalized expressed those feelings firstly, because of lack of enough time to give the required care, and secondly, because of lack of knowledge on what to do and finally, because of lack of resources to sustain the care. However, they were also against long-term institutionalization. This was highlighted by responses such as:

“...Yes I feel he should stay in a centre...he once stayed at a centre and the improvements were great...I have not enough time to give the

² The local currency in Botswana (1US\$=Pula4.9)

necessary care because I have two other children to take care of plus other domestic chores”

“I feel he should stay in a center...because he can get better therapy there and it will also be a relief for me to look for a job”

“... I have no problem if he is put in a centre as long as it is not for a long time”

“ I feel she can benefit if she can be rehabilitated in a centre where there are other children during the day and then comes home in the evening but I won't like her to stay there...you know she is my last born and I love her so much...”



4.2.2.2 Support from immediate family

All the participants interviewed acknowledged the support that they received from their families and especially from children and spouses/male partners. Children were cited as supporting the caregivers in respite care. Three of the caregivers who had spouses however, said they did not receive support from their spouses/male partners. The following were elicited from the caregivers:

“First of all, the father of this child left me...I believe because of the disabled child and he does not support me”

Another caregiver who was caring for her grandchild said:

“The father of the child has run away from the mother...so I have to support my daughter in looking after the child”.

Another caregiver who was caring for her daughter said, when asked if she received help from her husband:

...No he left me... I believe because of this child...he does not support me...I want to take him to ³kgotla.”

All participants were happy about the support that they received from their children. They helped with house work and caring for the disabled child. This was confirmed by responses such as:

“On weekends the children are able to care for the child and I am able to attend church services and see friends...the mother of the child works and therefore she is able to buy some groceries”.

“The children help in bathing...and all other things that I do for him...the father also supports in most of the activities plus financial support”.

“...They help me...especially my children...the father is somehow supportive”.

4.2.2.3 From Community and Health workers

Among the respondents who participated in the study, only two acknowledged some support received from their neighbours. All the others said they did not receive support of any kind, not even from members of the extended family. One caregiver said she received help from neighbours in form of respite care and the other received foodstuffs and also respite care. The following responses were elicited from the caregivers:

³ A village court usually under the jurisdiction of the local administration

“...Yes sometime they help in caring for the baby to give me some rest...and sometimes they buy me some groceries”.

“There is only one neighbour who helps me...you see that one (*pointing at the neighbour's house across a fence*) helps me sometimes”.

All the participants expressed lack of support from the government health workers. Most of them said that the lack of support from government health workers was the main reason why they had decided to concentrate in caring for their children at home. The caregivers were happy about the services and support of the local CBR agencies operating in their communities. This was highlighted by the following responses:

“...I only receive help from ⁴Motswedi and not from not from ⁵DRM”.

“I used to take the child to DRM with no improvement...those people do not care ...that is why this friend of mine introduced me to Motswedi”.

“...Motswedi has been very supportive...they even come to see the child here at home”.

Another caregiver, when asked of her views of having to do the exercises at home, responded:

“I find it O.K because even when I used to take the child to ⁶Marina those workers used just to watch me as I exercise her...they never helped...but I think I need someone to help me here at home”

⁴ Motswedi Community Based rehabilitation Centre

⁵ Deborah Ratief Memorial Hospital is a mission facility funded by the government

⁶ A local referral hospital

4.2.2.4 Urban versus rural experience

All the participants from Mochudi were aware of a local support (group) programme and services that were provided by MCBRC. All, except one, felt the programme was helping them in coping with their caregiving roles. The caregiver who felt that the programme was not beneficial had only attended the group sessions once.

In contrast all the participants from Gaborone, an urban area, said they were not aware of such support groups in their neighbourhoods. Gaborone being the capital city of the country and with its good infrastructure networks, one would expect better support systems of the caregivers.

4.2.2.5 Religion

Some caregivers expressed satisfaction with the role of their religions played in helping them to cope with their caring for the children with disabilities. They felt that their constant belief and trust in God had kept them motivated. One caregiver when asked what motivated her to keep on helping the disabled child had this to say:

“I like helping her... my belief and trust in God kept me ‘goingmy pastor and the church members have been praying for us...they sometimes come here at home to pray with us”

Another caregiver said:

“...I have set my trust in God....since I joined the church things have been much easier”

4.2.3 Social isolation

Social isolation can be seen as a barrier to coping in caregiving. Most participants expressed feelings of social isolation. There were several distinct scenarios in which the participants expressed these feelings. Firstly, they expressed the lack of support from social services, from family members and health workers; people who they expected to show understanding of their roles as carers of children with disabilities. One caregiver expressed the following sentiments:

“...eeh I am not coping...I have tried to go to Social Workers for help but nothing has come...I have decided to go it alone...”

Another caregiver responded:

“...but now I cannot...I even have no time to go to *masimo* because of him”

Secondly, the feelings of being ‘tied’ down to the house sometimes because of lack of respite care meant that these carers had to drop most of their other activities outside home. This included not visiting friends and going to the *masimo*. Going to *masimo* is an opportunity for these carers to get away from their homes to cultivate their land and interact with other people. This was evident from the responses such as:

“...I cannot do other domestic and social chores because of this child”

4.2.3.1 Immobility

Immobility of the caregivers was a significant contributor to the caregivers' feeling of isolation. Some participants said they could not take their children with them whenever they were to travel because public transport is not accessible to persons and children with disabilities. This resulted in frustration in most of the participants.

Lack of regular income also contributed to the caregivers limited mobility and hence their social interactions. Three of all the participating caregivers had limited sources of regular income, which was not enough to sustain caring for the disabled children and the rest of their families. Other participants said they could not take their children to hospital for physiotherapy because of lack of money to hire private taxis. This meant that they had to exercise their children at home without taking them for reassessments.

One caregiver expressed:

“...I have been exercising her here at home because I cannot be able to take her for physio because of transport problems and lack of money...”

4.2.4 Knowledge and beliefs

4.2.4.1 Expectations

Most participants showed lack of understanding of the permanence of their child's disability. They did not know that it was not possible for their children to be like other non-disabled children. This was elicited by the carers' belief that they were

helping their disabled children because they wanted them to be like other children.

One caregiver said:

“...I feel it is my duty to help my child.... because I want her to be like other children”

Two other caregivers expressed the same sentiments and this is what they said:

“...For me...it is O.K because I want (name of the child withheld) to be like other children”

“...As a mother I feel it is my duty to help my child...as a parent I have to do it and hope one day he will be like other children...”

In such circumstances, it makes it difficult to cope because the parent/caregiver has not come to terms of believing that his/her child cannot be like other non-disabled children. It also shows lack of knowledge of the etiologies of most disabilities.

Most participants understood the benefits of exercises to their disabled children.

This was expressed by responses such as:

“...Exercises will make him improve”.

“...Because I want him to be independent”

“I am happy to be doing the exercises here at home because they help her”

“...Yes before the exercises the child’s spine was bent and now has got better...her head and neck control was weak and now has got better”

Although the participants appreciated the benefits of exercising their children regularly, most of them did not know the types of disabilities their children had. Some of them did not understand why they were exercising their children and were doing so because they had been advised by their rehabilitation workers to continue with the exercises. In other words, they were ‘performing duties as instructed by the rehabilitation workers’. This was evidenced by responses such as:

“ I have no problem with exercising him because I know the exercises has to be done”.

4.2.4.2 Beliefs

Beliefs of witchcraft or punishment were found among some of the participants. When the caregivers were asked whether they knew the types and causes of the disabilities in their children, the following responses were elicited:

“ I don’t know but I think witchcraft is the cause”

“I don’t know...⁷*Baloi* wanted me and my child to die because they find I am living well...with a good family and home”

“No... no one has ever explained to me.... even at the hospital”

One caregiver, when asked whether she knew the type of disability her child was having, answered in the affirmative, but when probed she gave the following response:

“I think witchcraft has something to do with her problem because the child was O.K until one year later...I am a prophet and I know my child

⁷ People associated with bringing misfortunes in Batswana culture

is bewitched...my sister bewitched my daughter because she did not want me to marry the father of the child”

These responses confirm that disability is still associated with superstitions and witchcraft. Most of the caregivers/parents said their compliance to the prescribed exercises was based on the love for their children or grandchildren and wanted them to improve and be like other children as confirmed by the responses above. They expressed that the love for their children motivated them to continue helping them. One caregiver said:

“I love my child and it is his right to get the care...as a parent I have to do it ...”

4.3 Urban and rural comparison



The participants of the rural setting were aware of and utilized facilities of a support group in their areas. Most of them said the support group was helping them to cope with their caregiving responsibilities. In contrast the urban participants were not aware of such support groups in their neighborhood. Apart from these differences, which can be attributed to how CBR was structured in these two study settings, I found no significant differences in caregiving experiences between the participants.

4.4 Summary of the main results

The results of the study indicated that despite the problems the caregivers were encountering, they were willing to help their children with disabilities. The caregivers were found to be compliant with therapy as prescribed by their rehabilitation workers. Many of the caregivers acknowledged the support they received from their immediate family but were unhappy with the available health and social support systems. Lack of support services also caused many of these caregivers to feel isolated and fatigued. The results also indicated that the carers had little knowledge and information about their children's disabilities. I also found no significant differences in caregiving experiences between the rural and urban participants. Finally, the multiple roles of these caregivers had a negative impact on their mental and physical health.



CHAPTER FIVE

DISCUSSION, RECOMMENDATIONS AND CONCLUSIONS

5.0 Introduction

This chapter details a discussion of the results i.e. the themes in relation to the purpose and objectives of the study (Refer to Table 1 p 58). The study had certain limitations and these will also be discussed. Finally, the chapter provides recommendations and conclusions based on the results of the study.

The objectives of the study were (1) to identify the enabling factors that contribute to caregivers' compliance with prescribed home-based therapy, (2) to identify the barriers affecting the caregivers' compliance with home-based therapy, (3) to identify the impact of the child's disability to the immediate family and (4) to compare experiences of caregivers between two selected regions, namely urban and rural.

5.1 Enabling factors and barriers

The results of this study examined issues about the experiences of caregivers of disabled children in the community. The findings confirm that caregivers of disabled children experience difficulties in their caregiving roles. Despite the problems these caregivers were going through, they were actively participating in caring for their disabled children. These findings contradict a previous study by Unger, Jones, Park & Tressel (2001) that found caregivers who experience family problems might participate less in programmes of children with disabilities in the community. The difference between the current study and the one by Unger et al.

(2001) is that the latter was carried out in the USA, a developed country. One would expect caregiving to be “less of a problem” in developed countries because they are perceived as having more resources than their counterparts in the developing countries. Because of the limited availability of resources in the developing countries, one would have also expected less participation of caregivers in caring for their children with disabilities.

One of the motivations for this study was why children, after discharge from hospital, returned with worsening disabilities. I, however, found that all the 12 caregivers were compliant with their roles of doing the home-exercises to the children in their care, as was prescribed by their community rehabilitation workers. The compliance of all 12 caregivers could be due to a possible sample bias as all of them were recruited from CBR agencies. Thus, the study design was not suitable for identifying associations between poor caregiver compliance and worsening disabilities in the disabled children. The caregivers were able to exercise their children three times or more in a week despite the multiple roles they fulfilled in their families and the problems that they faced on daily basis. The compliance in these carers can be attributed to several reasons. Firstly, they were hoping that their children would be like other non-disabled children; this indicated their lack of knowledge and insight into the permanence of the disabilities; Secondly, the compliance can be attributed to the love that most of those caregivers have for their children. I found that love motivated these carers to continue performing the exercises regularly to their disabled children, which concurs with what is advanced by Connor & Adams (2003). Thirdly, because of the prolonged periods of care, these carers developed strong bonds with their children with disabilities, which resulted in special relationships between them.

Finally, for some caregivers, the compliance could be attributed to “obeying instructions” as was given by their rehabilitation workers. This was confirmed by the responses such as:

“...I have no problem with exercising him because I know the exercises have to be done”

Such a response indicated that the carer did not have precise reasons as to why she kept on performing the exercises but understood that they should be performed because she was shown the exercises by someone in authority, namely the rehabilitation worker.

Studies on caregivers’ compliance to prescribed rehabilitation or therapeutic programmes are scarce in the literature. However, the findings of the current study indicated that the compliance of the caregivers was facilitated by the constant support that most of them received from their immediate family and the local community-based rehabilitation programmes in their areas. The community rehabilitation workers made frequent visits to these caregivers to monitor both the progress of the caregivers in doing their roles and that of the children.

In contrast to the above the results of the study indicated that the caregivers were not receiving enough support from their communities and, especially from the extended families and neighbours. This contradicts the WHO’s concept that assumes that the community is a readily available source of support. However, these findings concur with the study by Bischoff, Thornburn & Reitmaier (1996). They found a low degree of support of caregivers of disabled children from neighbours in a Jamaican village.

Although the current study revealed that the caregivers experienced stress and conflict in their multiple roles, the social support of the immediate family (children & spouses/male partners) provided the much-needed support. The majority of them were satisfied with the support that they received from their children and spouses/male partners and this was helping them to cope. This is also consistent with what has been advanced by Peshawaria (1998) who identified good marital relationships or support from husband as enabling factors to effective coping in caregiving. I also found that the presence of a disabled child in a family disrupted family relationships. Some caregivers reported that their spouses/male partners left them on realisation that they had children with disabilities.

Most of the caregivers from Mochudi were aware of a support group for parents/caregivers of children with disabilities.. According to Helander (1999), these findings are consistent with the WHO's original model of CBR which was to ensure delivery of rehabilitation services to areas where such services were unavailable due to underdevelopment. This finding can be attributed to the structure and the management of the CBR programmes in the rural setting, which seemed to be close to the community in which they served. The close relationship between the rehabilitation workers and the community members enhanced the workers' understanding of their needs. In contrast, the caregivers from Gaborone, an urban area, said they were not aware of such support programmes in their neighbourhoods. One would have expected Gaborone, being an urban area, to have better community support assistances.

The caregivers of this study also had some barriers or factors that interfered with their efforts in caring for their disabled children. The results of the study indicated

that the caregivers of both rural and urban settings were not getting enough support from the formal health and social services. They complained of the quality of care and lack of attention that they encountered in health institutions whenever they took their children for medical check-ups. They also complained of the problems they encountered whenever they wanted to travel because of lack of accessible public transport for persons with disabilities.

The lack of support from neighbours, social and health services contributed to the caregivers' inability to cope with their roles. According to Schwarz & Roberts (2000), social support minimizes the adverse consequences of stressful situations and thus may contribute to helping the caregivers to cope with their roles. Social support may also contribute to caregivers' feelings of control and self worth. These findings also concur with an unpublished study by Thejane (1999) in the Qwa-Qwa region of the Republic of South Africa. It found lack of emotional and social support of families with children with disabilities from the community as significant barriers to effective rehabilitation of those children.

Lack of resources contributed significantly to the caregivers' inability to cope. According to Lazarus & Folkman (1984), resources such as money and time may help an individual's coping mechanisms. I however, found that most caregivers had coping mechanisms. Some participants relied in the trust of their religions, beliefs in God and prayers. Although these may not have been effective, they were helping them to cope.

Kahana & Young (1990) caution that in most cases research on caregiving focuses on the negative outcomes of caregivers, but it is evident from the participants' responses that they were overburdened by their roles as carers. Their burden in

caregiving could be attributed to a number of reasons; firstly, the duration of the caregiving roles; all the caregivers had been caring for their disabled children from between 1½ and 11 years. Secondly, the intensity of the care was made greater by the severity of the disabilities that their children had. All the children, except one, had severe disabilities, which made them fully dependent. Thirdly, in addition to the lack of financial resources, which contributed to their burden, the caregivers also received no support from the health and social services, thus making the caring roles their sole responsibility. Unlike in most developed and some developing countries, Botswana does not have social support services such as disability grants, but persons with disabilities who need assistance are aided through government and civic social service departments. Such aid may be in form of mobility assistive devices, food, vocational placement etc. One caregiver stated that she was unable to feed her disabled granddaughter and at the same time feed her own family members. Poor nutrition can be harmful to the health of both the caregiver and the growing child.

The findings of the current study also concur with studies by Aneshensel, Pearlin, & Schuler, 1993; Orto, Dell & Morinelli, 1995; Lindsey et al., 2003) that established that many caregivers report caregiving to be an emotional, physical and financial burden. The reason for these may be attributed to the fact that most the caregivers were older women who had no regular income and themselves might have needed care due to the effects of old age such as illnesses and degenerative changes. Brody (1985) argues that whether the main caregiver assumes the responsibility of caring voluntarily or assigned by the family members he or she is more vulnerable to burden by virtue of the responsibilities

assumed. Most carers will assume the responsibilities not by choice but because there is no alternative.

5.2 Knowledge and beliefs

Despite the willingness of these caregivers to help and support their children, I found that they had little knowledge about the nature of their disabilities. The lack of knowledge meant that they did not understand the permanence of the disabilities of their children. This was confirmed by responses that indicated that they were helping their children in the belief that they “would be like other children”. This is consistent with study by Mweshi & Mpofu (2001) that found a low degree of knowledge on disability amongst caregivers of disabled children. Cultural beliefs such as witchcraft and ‘god’s will’ were also found as some of the causes of disability among people living in a peri-urban area of Cape Town (ibid). Beliefs of witchcraft have also been found in other previous studies e.g. in Jamaica by Thornburn (1998). In a study on attitudes towards childhood disability in three villages in Jamaica, Thornburn found a significant relationship between supernatural beliefs and disability.

Several studies investigated the impact of cultural beliefs on disability. In many communities in the developing countries, culture plays an important role in understanding disability (Kisanji, 1995; Coleridge, 2000). Cultural factors influence the attitudes of most communities towards most of what happens around them, including their attitudes towards disability and rehabilitation. Despite the significance of culture in most developing countries, CBR programmes fail to recognise them sufficiently and therefore, expose themselves to higher risks of failure. The understanding of disability in a cultural perspective is therefore of

critical importance if CBR resource managers and rehabilitation professionals have to understand what is true about disability and what is unique in some specific cultures. From this knowledge, change can be advocated through the local people if negative practices do exist.

5.3 Impact of disability

This study indicates that caring for disabled children had a negative impact on the health and wellness of the participants. I found that many caregivers had been affected both physically and psychologically by their caregiving roles. Most caregivers felt stressed and one of them developed backache as a result of her caring roles. The stress these carers experienced can be compounded by the burden that resulted from most of them not able to cope with their roles. These findings are concurrent with George & Gwyther (1986) that found caregivers reported negative indicators of well-being, namely depression & physical illness. A recent study by Lindsey, et al. (2003) on caregivers of HIV/AIDS and chronically ill patients concur with the findings of the current study. Their study set out to measure the experiences of older and young girl carers of HIV/AIDS and chronically ill patients in home-based care programmes in Botswana. The study showed that the caregivers in these programmes were feeling overwhelmed with the magnitude and the multiplicity of tasks they had to perform. They also reported that the caregivers were also feeling exhausted, experienced poverty and often neglected their own health.

All the caregivers of my study were women. The African culture, like in most other societies, assumes caring is a basic duty of women (Cancian & Oliker 1998; Giacaman, 2001). This role exacerbates an already existing exclusion of women

from social and economic activities. This therefore, brings about conflict between the needs of two disadvantaged groups, the children with disabilities and the caregivers.

Caring in itself could have resulted to caregivers' isolation, which could be attributed to lack of enough financial support and respite care. Feelings of isolation included most of the caregivers neglecting their personal needs and social contacts outside home. Their caregiving responsibilities also prevented some of them from taking paid employment. One caregiver had left paid employment to devote her time to the care of the disabled child. These findings concur with Seymour's (2001) study that found that most caregivers live in poverty because they are prevented from taking paid employment by their caring roles, and thus are left isolated. Many of them ended being stressed and fatigued. In the United Kingdom (UK), one out of every five caregivers has had to leave or declined to take-up paid employment because of caring responsibilities of their disabled children (Mellow, 2004). This finding is also consistent with previous study by Doland & Sims (1996), who measured experiences of the family caregiving at home. The study of Doland and Sim's (1996) found significant evidence of isolation and loneliness among the majority of the caregivers and described their caregiving experiences as "solitary journey". The health workers, family members and church or similar religious groups could ease such feelings of isolation if the carers received frequent visits.

Caring for disabled child did not affect the caregiver alone. I found a negative impact of disability on both the caregiver and the immediate family. The presence of a disabled child in a family caused separation of spouses/partners. I also found that the siblings were affected by their sister /brother with disability. Some non-

disabled children felt that their mothers/grandmothers spent so much time with their disabled sister/brother, which made them feel disadvantaged in terms of attention given to them by the parents. Some felt they had to do the household tasks when their disabled sister/brother did not do any tasks. Research also found that the siblings of the disabled child would like to emulate the disabled brother/sister in order to seek attention from the parents. This leads to a phenomenon that has been described by Burke (2004) as “disability by association”. Burke (2004) argues that the experience of living with disability results to the siblings being excluded from main ‘stream activities’

5.4 Rural: urban comparison

One of the objectives of the current study was to compare the experiences of caregivers between urban and rural settings. The only difference was that the participants of the rural setting were aware of a support group in their neighbourhood that was helping most of them to cope with their caregiving roles. In contrast all the participants from Gaborone, an urban area, said they were not aware of such support groups in their neighbourhoods. The rural community also had a better CBR outreach infrastructure. Gaborone, being the capital city of the country and with its good infrastructure networks, one would have expected better support systems for the caregivers. Except for the differences above, the experiences of the caregivers from both the selected rural and urban settings were similar. However, it should be noted that all the participants of the urban setting came from lower-income groups that put them in a relatively similar socio-economic category as their rural counterparts and this could have affected the findings of this study.

5.5 Limitations and weaknesses of the study

It is important to emphasize the limited scope of the study design in relation to the observed outcome. Firstly, the credibility of this study would have been enhanced if a combination of data collection methods (triangulation) were used, for example, by employing focus group discussions among the participants. This was logistically not possible because the participants of the study were scattered all over the research settings and that made it impossible to bring them together for such discussions. Secondly, biases would have somehow influenced the findings of the study because of the researcher's and the research assistant's persistent involvement with the respondents.

Although every effort was made to minimize sampling bias, another source of bias could be the fact that the sample only recruited people that had contact with CBR agencies. It could also be that the sample consisted of mainly pro-active caregivers who used the opportunities provided by the existing services. The outcome of the study could have been worse if the sample had been identified in a different manner. Although every effort was made to minimize biases by employing a probability sampling method when selecting the participants, all the caregivers of this current study comprised a lower income group that could have affected its findings. The relationship between disability and poverty is complex and multifaceted. Being born with disability in a family increases the chance that one will be poor because of the unfair discrimination that those persons with disabilities encounter. While disability and poverty are present throughout the world, significant differences exist between developing and developed countries. It is estimated that the majority of the world's poor and proportionately more

individuals with disabilities live in developing countries. This again exacerbates most families' efforts to free themselves from the chains of poverty.

Finally, the truth of responses is a concern of data collection through interviews. Prior knowledge about the purpose of the study may have influenced the participants into giving me experiences that would fit. However, exploring questions and reflective summaries were used to elicit truthful responses and reconfirm statements from participants.

5.6 Recommendations

It is important to recognize that many mothers and grandmothers, even though disadvantaged in terms of resources, knowledge and information, are competent and effective caregivers. Their competence can be enhanced if they are given the necessary support services available both from the formal health care systems, private sector, religious institutions, and in their communities. It should be noted that CBR cannot operate effectively without the support of the formal health sector (Mpofu, 1995). From the responses of the caregivers in this study, the following recommendations were formulated which summarize their needs:

- Health care policies should recognize caregivers as partners in the delivery of primary health care and are therefore, essential to the success of community based care programmes. The rehabilitation workers and health care professionals should recognize the burden associated with caregiving responsibilities. The rehabilitation and CBR managers should be aware of the factors that impact both negatively and positively on the lives of caregivers.

- From the findings of the current study, it appears that the health care system does not acknowledge, nor appreciate sufficiently, the contributions of caregivers of disabled children in the communities and therefore, there is need to accord them with the necessary assistance to facilitate their caregiving roles. There is also a need for more support services that should be commensurate with the needs of the caregivers and that of their disabled children.
- Respite care services such as day care centres could possibly be made essential in planning better services for the caregivers. Such services will provide time for rest and social activities for the caregivers. This will eventually reduce the amount of stress that engulfs them and thus, they will be able to maintain their health for a prolonged care provision
- Policy makers should work out a compensation plan for caregivers of children with disabilities as a show of appreciation for their contributions to the health care system. This can be achieved through childcare grants, tax relief incentives, credits to start small businesses, disability grants and pension benefits. Rehabilitation professionals such as physiotherapists, occupational therapists etc are in ideal positions to advocate for these caregivers' needs.
- There is need to support and redistribute resources equitably from institutions to community-based care programmes, so that care can become effective and accessible to many disabled children and their carers. Such redistribution should include rehabilitation professionals such as physiotherapists, occupational therapists etc. who are currently

concentrated in health institutions in urban areas at the expense of the majority of the rural populations. Such moves will be in line with the PHC philosophy that requires governments and policy makers to make health care accessible to the majority of their populations who live in the rural areas. From the results of the current study, the rural community enjoyed a better CBR support services than their urban counterparts. There is therefore need to redistribute services equitably in both rural and urban communities where they are needed. In an attempt by the developing countries to establish high quality and high tech tertiary health services comparable to those in the developed countries, there has been a tendency to shift resources to tertiary health care at the expense of the PHC.

- Training and provision of information to caregivers on coping skills and disability issues is essential to enable them find solutions to the problems that they encounter in daily basis. This will subsequently assist them to cope better with their work.
- There is need for educating carers about disability, common causes, their etiologies and treatment. With such knowledge, caregivers would be able to understand the permanence of disability and those with cultural beliefs and practices, which create negative perceptions, would be able to change these.
- Although many studies have been conducted to investigate burden and coping strategies in informal caregivers of adults and especially the elderly, few of them have holistically measured these constructs in caregivers of disabled children in CBR. The results of the current study

therefore underscore the need for more research in this field. There is also need for research on modalities of realizing possible integration of caregivers of disabled children into formal health care system within the framework of PHC. This could be through continued recognition and support from the formal health care system.

5.7 Summary of main points of discussion

The present study addressed issues about the experiences of caregivers of children with disabilities in the community. The results confirm that these caregivers experience difficulties while discharging their roles. These problems are exacerbated by the multiple natures of the tasks that they have to fulfill to their immediate families besides that of the disabled children. Their caregiving roles resulted in stress, financial burden, feeling of isolation and had negative impact on their health.



There is thus a need to accord the caregivers with the necessary support in order to facilitate them in performing their work. This will eventually reduce the amount of stress that they experience, and thus they will be able to maintain their health for better provision of care to their disabled children. Rehabilitation professionals should be aware of the factors that impact both positively and negatively on the lives of the caregivers. There is also need for policy makers to recognize the caregivers as partners in the delivery of PHC and award them with incentives such as pay for their work, pension benefits etc.

5.8 Summary of the study

A qualitative research design was used to explore experiences of the caregivers of disabled children in the community. The purposive sample consisted of twelve (12) African Black caregivers both from Gaborone and Mochudi. The ages of children with disabilities under their care ranged from 1½ to 11 years. All except one child had severe disabilities. The literacy level of the caregivers ranged from illiterate to form 5(Grade 12). The responses of the caregivers were thematically analyzed and four major themes emerged, namely, (1) impact of caregiving, (2) support, (3) social isolation and (4) knowledge and beliefs.

The results of the current study confirmed that caregivers of disabled children in the community experienced difficulties. The carers had little knowledge of disability and caregiving issues, and their caregiving roles had a negative impact on their health. Caring, however, had one positive aspect for both the carer and the care-receiver. Due to the prolonged contact between the carer and the care-receiver, the caregivers developed love for their disabled children. However, Sawatzky & Kerry-Fowler, (2003) noted that this positive aspect of caring could easily be overshadowed by the difficulties that these caregivers were going through. Some of these difficulties could be minimized if the health care policies recognized sufficiently the contributions of caregivers of children with disabilities towards PHC. There is need to give caregivers of children with disabilities the necessary support to enable them to perform their roles with minimal difficulties.

5.9 Conclusions from the study

The researcher succeeded in identifying some of the positive and negative experiences of caregivers of children with disabilities in two selected communities in Botswana. Minimal differences were found between the caregivers from the urban and rural settings.

The carers felt stressed, overburdened and isolated by their roles. They often neglected their own needs, which also impacted negatively on both their physical and mental health.

The caregivers lacked the required resources, knowledge and information on disability issues and caregiving skills. Their caring responsibilities were intricately linked with other responsibilities in the home. However, despite the difficulties and problems they were going through, they still performed their caring duties competently and effectively. The results of the study have implications for intervention as recommended. It is essential to recognize the role of caregivers in healthcare and rehabilitation, but they should be given adequate support such as counseling services, provision of material and financial assistance; support groups and respite care services in order for them to fulfill these roles.

Most support groups are not consistent with caregivers' cultural values and beliefs. There is need therefore to facilitate social assistance infrastructure that would be readily acceptable to caregivers e.g. church, social groups etc and that most them would likely participate actively. This was evident from the caregivers'

trust and faith in their religions and cultural beliefs in helping them to cope with their roles.

Policy makers, health care professionals and the society as a whole have a significant part to play in that regard. They should recognize that “health is part of every day living, and an essential dimension of everyone. The caregivers should be given an opportunity to make choices and to gain satisfaction from living” (Cited from Sawatzky, & Kerry-Fowler, 2003:285).



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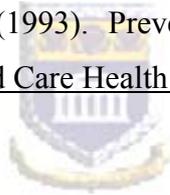
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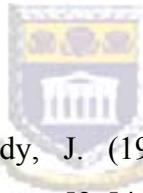
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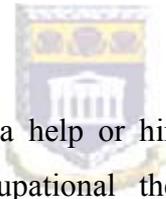
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Appendices

Appendix 1

Letter to respondents

University of the Western Cape



August 2003.

Dear Respondent,

Re: Research on experiences of caregivers regarding participation in Community-Based Rehabilitation for disabled children aged 0-12 years in Botswana.

I am a post-graduate student currently registered at University of the Western Cape in the department of Physiotherapy. The research I am doing will be submitted to the University of the Western Cape Senate in partial fulfilment for the requirement of a Masters of Science degree in Physiotherapy.

I am humbly asking you for your voluntary participation in the research because it is essential for me to know about parents and caregivers of our disabled children in society so that I may understand your thoughts and feelings about caregiving experiences.

The discussion will take between 45 minutes to one hour with a possibility of coming back to you for verifications of what we will have discussed. The answers to the questions that I will ask you will be helpful in finding ways of improving our services in helping both the disabled child and you the caregiver in your area and in Botswana as a whole. Every discussion will be kept confidential and will only be used for the purpose of this study.

Thank you!

Jackson MM. Kilonzo.

CONSENT FORM

I, _____, agree to participate in this research project on “Experiences of caregivers regarding their participation in Community-Based Rehabilitation (CBR) for children aged 0-12 years in Botswana”.

I understand the study involves face-to-face interview and will discuss my general ideas about the topic.

I understand that my participation in this study is entirely voluntary, and that if I wish to withdraw from the study, I may do so at any time, and that I do not need to give reasons for doing so. If I withdraw from the study, I understand this will have no effect on my relations with the researcher.

I understand because of this study, there could be violations to my privacy.

I understand that I may not receive any direct benefit from participating in this study, but my participation may help others in the future.

I understand the information I give will be kept confidential to the extent permitted by law.

I have read and understand this information and agree to take part in the study.

Today's date

Your signature

Appendix 2

Semi-structured interview guide:

University of the Western Cape

1. DEMOGRAPHIC INFORMATION OF THE DISABLED CHILD:

Age----- GENDER: Female Male

For how long have been caring for this child?

Relationship to caregiver-----



If you are a parent from what age was your child diagnosed with the disability?

Nature of disability: Mild (capable of performing personal care tasks, i.e. wash, dress, eat independently), Severe (total dependence).

Age of caregiver----- Gender: Female Male

1. ASSISTANCE GIVEN TO THE CHILD

(a) What assistance/exercise do you give to the disabled child? Probe!

- (b) What are your views on having to carry exercises/home programme with your child?
- (c) Do you think your/this child should be in an institution where he/she could receive regular therapy without you having to do the exercises at home? Probe!
- (d) Do you think your/this child be taken to an institution where he/she could receive therapy on outpatient without you having to do the exercises at home? Probe!
- (e) How many times in a week do you give this exercises/assistance? Probe!
- (f) What makes it easier for you to care for this child? Probe!
- (g) How long (in minutes) does it take you to assist/exercise the disabled child?
- (h) What motivates you to give this exercise/ assistance? Probe!
- (i) What assistance/tasks do you like most? Probe!
- (j) What assistance do you dislike most? Probe!
- (k) Do you receive help from the family members?
- (l) Do you receive help from your neighbours? Probe!
- (m) Do you have any support groups for parents/carers of children with disabilities in your community?
- (n) Do you receive enough support from:
- Physiotherapists
 - Occupational therapists
 - Social workers
 - Doctors

Do you experience any problems in caring for the disabled child? Probe!

Does the disabled child attend school? Probe!

2. IMPACT OF DISABILITY:

(a) Do you know what type of disability the child has?

(b) In your opinion what caused the disability in this child?

(c) Has anyone explained to you the nature of child's disability?

Probe!

(d) Has the child affected his/her brothers and sisters?

Probe!

(e) Has the presence of this child affected your life? Probe!

(f) If you are a parent, has the presence of the disabled child affected your relationship with your spouse?

(g) Why do you think your child is disabled?

(h) Do you think the exercises are beneficial to the child?

(i) Are there any problems you would like to discuss?

Appendix 3

1. KITSISO KA YA NGWANA YO NANG LE BOGOLE

Dingwaga-----

BONG: Mosetsana: Mosimane:

O na le lebaka le le kae o tlhokomela ngwana yo?

Ngwana yo o tsalana jang le wena o le motlhokomedi?

Fa e le gore o motsadi, bokowa jwa ngwana wa gago bo lemogilwe leng ke ba bongaka?

Bokowa jwa ngwana bo tseneletse go le kae: O kgona go itirela ditiro tse di motlhofo jaaka go itlhapisa, go ja le go ikapesa, kgotsa bokowa ja gagwe bo dira gore a tlhoke thuso le mo ditirong tse di motlhofo?

Dingwaga tsa Motlhokomedi:



THUSO E E FIWANG NGWANA

- (a) Ngwana o mo fa thuso/tlhokomelo efe? Tlhalosa!
- (b) O ikutlwa jang ka katiso/tlhokomelo e o tshwanetseng go e fa ngwana ko gae?
- (c) A o bona ngwana yo o tshwanetse nka bo a le ko lefelong/legaeng la tlhokomelo, go na le gore o ka bo e le wena o mo thusang/katisang mo gae? Tlhalosa!

- (d) A o bona go tlhokafala gore ngwana yo a tlhokomelwe jaaka molwetse yo o eteleng lefelo la tlhokomelo, go na le gore e ka bo e le wena o mo thusang ko gae?
- (e) O thusa/katisa ngwana ga kae ka beke? Tlhalosa!
- (f) Ke eng se se tlhofofatsang tiro ya go tlhokomela ngwana yo? Tlhalosa!
- (g) Go tsaya nako (metsotso) e e kae mo letsatsing go fa ngwana yo tlhokomelo/katiso?
- (h) Ke eng se se go fang moko wa go tlhokomela ngwana yo? Tlhalosa!
- (i) Ke dithuso kgotsa dikatiso dife tse o ratang go di fa ngwana yo? Tlhalosa!
- 
- (j) Ke dikatiso dife tse of sa di rateng? Tlhalosa!
- (k) A o bona thuso go tswa go ba lelwapa kgotsa masika? Tlhalosa!
- (l) A o bona thuso go tswa go baagisayi? Tlhalosa!
- (m) A go na le makalana a thuso a a tlamilweng ke batsadi kgotsa batlhokomedi ba bana ba ba nang le bogole?
- (n) A o amogela thuso e e maleba kgotsa e e lekaneng go tswa go;

- Dingaka

- Dingaka

- Bommaboipelego

- Baoki le ba bongaka ka kakaretso

- (o) Go na le mathata mangwe a o a kgabaganyang fa o tlhokomela ngwana yo? Tlhalosa!

(p) A ngwana yo o tsena sekole? Tlhalosa!



2. TSENELELO YA BOGOLE

- (a) A o itse gore ngwana yo bogole jwa gagwe ke jwa mofuta mang?
- (b) Go ya ka wena ke eng se se tlhodileng bogole jo?
- (c) A go na le o kileng a go tlhalosetsa mofuta kgotsa mokwa wa bokowa jwa ngwana yo? Tlhalosa!
- (d) A ngwana yo o amile bomogolowe/bomonnawe?
- (e) A ngwana yo o go amile kgotsa o fetotse botshelo jwa gago?
- (f) Fa o le motsadi, a go nna teng ga ngwana yo go amile kamano kgotsa tsalano ya gago le mogatso?
- (g) Go ya ka wena ke eng ngwana yo a na le bogole?
- (h) A go ikatisa go thusa ngwana yo

Appendix 4



University of the Western Cape
Hector Peterson Residence
Block P Room 10
P/bag X17 Bellville 7535
South Africa.
28/12/2003

The project coordinator
Motswedi Community Based Rehabilitation centre
P.O Box 1396
Mochudi
Botswana.
Dear Sir/Madam,

Re: Permission to conduct research on experiences of caregivers regarding their participation in Community-Based Rehabilitation for disabled children aged 0-12 years in Botswana.

I am a post-graduate student currently registered at University of the Western Cape in the department of physiotherapy. The research I am doing will be submitted to the University of Western Cape Senate in partial fulfilment for the requirement of a Master of Science degree in physiotherapy.

I am humbly requesting you to allow me use your centre's registers to locate families with disabilities who meet the inclusion criteria of this study. I am particularly looking for families with physical disabilities and who have mobility problems in addition to the above age category.

Written consent will also be sought from the participating families and total confidentiality will be adhered to, as stipulated by the Faculty of Higher Degrees Committee of the University of the Western Cape.

Enclosed please find the acceptance letter from the university's Higher Degrees Committee acknowledging my request to do the study and a draft copy of the written consent to the respondents.

I remain optimistic and thank you in advance for your support.

Sincerely,

J.M. Kilonzo.

Supervisor: Mrs. Margaret Marais



Appendix 5



University of the Western Cape
Hector Peterson Residence
Block P Room 10
P/bag X17 Bellville 7535
South Africa.
28/12/2003

The Executive Director
Cheshire Foundation Rehabilitation Centre-Mogodishane
P.O Box 1232
Gaborone
Botswana.
Dear Sir/Madam,



Re: Permission to conduct research on experiences of caregivers regarding their participation in Community-Based Rehabilitation for disabled children aged 0-12 years in Botswana.

I am a post-graduate student currently registered at University of the Western Cape in the department of physiotherapy. The research I am doing will be submitted to the University of Western Cape Senate in partial fulfilment for the requirement of a Master of Science degree in physiotherapy.

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