

CHILDHOOD DISABILITY IN RURAL ZAMBIA:
A QUALITATIVE STUDY ON THE USE OF
HEALTH CARE SERVICES

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Abstract

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There are approximately 650 million people living with disabilities worldwide, an estimated 200 million of this number are children. A majority of disabled children live in poverty and lack access to basic health services and rehabilitation opportunities from being excluded from the allocation of resources. As such, they are highly susceptible to the risk of missing out on essential developmental opportunities. In Zambia, poverty levels are high and a national policy about disability is yet to be implemented, thus the care for disabled children falls on the families alone. This study explores how the health needs of disabled children are understood and managed through explanatory models within a framework of structural violence.

In this qualitative study, observations and interviews with 16 parents of disabled children and 13 health workers in the Kazungula District, Zambia were carried out. Facilitating factors and barriers to health care were explored, formal and informal health services identified and reasons for the choice of services examined. Systematic Text Condensation was used to analyze the material.

The primary caregivers of disabled children use the rural health centers, but rarely for an assessment of their disability. Family members attend rural health centers without bringing the disabled child, thus further management of the child is based solely on information from the relatives. The main barriers to health care are long distances, lack of available transport and shortage of staff, equipment and skills at the rural health centers to manage childhood disability. Referral to higher-level health facilities is done extensively, but is difficult for families to make use of. Parents become tiered of trying to respond to episodes of illness and they consequently give up. Primary health care in Zambia is not able to provide adequate care for disabled children, and their health needs are therefore assessed and managed within a family unit strongly influenced by poverty. Throughout this study, it will be argued that a combination of individual health beliefs and social and structural factors influence health behavior and must all be taken into consideration.

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1.0. INTRODUCTION

“No diseases pass him by”

These are the words of a young mother with a severely sick 16-month-old child. The son had multiple disabilities, was severely malnourished, had few voluntary movements and needed extensive care. She described a prolonged labor for five days that started at home; after two days of labor she was taken to the rural health center, and then finally referral to a hospital where a forced labor was performed. She exemplified a dramatic birth, which provided her with reason for the condition of her son. People in her village suggested consultations with traditional providers to find a cure. The mother, conversely, didn't believe the son could be assisted in such a way. She said she preferred treatment from the hospital in town where she had spent one month with her son earlier. Little improvement was experienced.

The mother and her son used to stay with the father, but a lack of support from him made her move back to her parents with her son. She expressed sadness at the lack of support from her own family, who advised her to not take her son to the hospital. The family believed that they had tried enough, and nothing more could be done. They put their faith in the hands of God.

We met the mother and her son at home; they lived in a mud hut in close proximity to other family members. She only left her son with other family members when she collected water. The rural health center was one hour away on foot; they had provided her with a referral letter to the hospital in town. She could not afford to go there, as transport and upkeep in town was expensive and she could not find money. She provided care for her son at home, planning ways to generate income so that she would be able to provide him with much needed specialized health care. She was not able to achieve this and the consequences were grave; at the age of 17 months, her child passed away in their home.

This mother's story is explored with the aim of illuminating the complex interplay of individual agency, and the structural barriers that take place in a rural Zambian family strongly affected by poverty. To what extent did the restrictions she was confronted with in managing the complex condition of her disabled child explain the unfavorable outcome? And to what extent did her own perceptions about the illness influence the actions she planned and carried out in the process of finding sustainable solutions to the disability? This thesis aims at

exploring these questions in order to gain a more comprehensive understanding of the use of health care services for children with disabilities and their families.

1.1. Background

There are approximately 650 million people living with disabilities worldwide and an estimated 200 million of these are children (World Health Organization [WHO], Concept Note, n.d.). 80% of disabled people reside in low- and middle-income countries, and the number continues to increase (WHO, 2005). A majority of disabled children live in poverty, and many lack access to basic health services and rehabilitation opportunities; often being left out in the allocation of resources (The United Nations Children's Fund [UNICEF], 2006). As such, they are highly susceptible to the risk of missing out on essential services and protection (UNICEF, 2009).

The Declaration of Alma Ata in 1978 called for urgent attention to the importance of primary health care and the substantial need for immediate action throughout the world, with the primary aim of "Health for all by year 2000" (Declaration of Alma Ata, 1978). More than 30 years later, health for all has not been achieved, and with the Millennium Development Goals (MDGs) for 2015 entering the international arena, new attempts have been planned to achieve better economic and social conditions among the poor people of the world (United Nations Millennium Declaration, 2000). The prospect of universal access to health through acceptable, accessible, appropriate and affordable health care has not been realized, and one main critique of the MDGs is that equity and social injustice are not reflected (Walley et al., 2008). The targets do not adequately take into account the poorest of the poor or address a reduction of inequality (Langford, 2010). The Convention on the Rights of the Child is an important tool in empowering children and in addressing the importance of increased accessibility to health services for children with disabilities (UNICEF, 1989). This should also contribute to the reduction of the inequalities that highly influence the MDG targets.

1.1.1. Zambia

Zambia is a landlocked country in Southern Africa with a population of 13.3 million (Government of Zambia [GRZ], 2011). The majority lives in rural areas where more than

80% get their income from agriculture (Jorgensen & Loudjeva, 2005). The country is ranked number 150 out of 169 countries in the Human Development Index with an estimated 63.7% living in multidimensional poverty (World Bank [WB], 2011). It is reported that 64.3% of the Zambian population live below the poverty line of USD1.25, and 81.5% are below USD2. In Zambia, 79% of small-scale farmers in rural areas live in poverty, with 66% belonging to the group of extremely poor (Miller & Ziegler, 2006). Looking at rural households, the majority depend on their own production of food, which is strongly affected by climatic conditions such as drought and floods.

Economic growth has improved in the last decade, but has not contributed to poverty reduction and improved living conditions for most Zambians (GRZ, 2011). Economic development depends highly on foreign aid but is susceptible to extensive corruption, with assistance not profiting those who are supposed to benefit (Husmann & Chicalanga, 2007). Transparency International Zambia report 65 billion euro misused, stolen or mismanaged yearly (Husmann & Chicalanga, 2007).

As a consequence of poverty, preventable and treatable diseases have negatively affected the poorest people who do not have access to professional healthcare, health information, safe drinking water and sanitation, education, decent housing and secure employment. This has placed an increased pressure on an already constrained health sector (Ministry of Health [MoH], 2006). Further, it has been shown that even though the poorest in Zambia are disproportionately affected by diseases that could have been prevented, they are less likely to use health care services (GRZ, 2011).

1.1.2. Disability in Zambia

An estimate of one to two million disabled people in Zambia is based on a general projection of 10% provided by the WHO (Miller & Ziegler, 2006). A survey on living conditions among people with disabilities (Loeb & Eide, 2010) found the prevalence of disability in Zambia to be 13.3%. The magnitude of childhood disability in Zambia is not known. There is limited information about available services for disabled children and disabled children in Zambia have severely limited opportunities to access health care (UNICEF, 2008).

Zambia has to some extent worked to highlight issues related to disability and promote awareness by developing the *Persons with Disabilities Act* No. 33 of 1996, and with the signing of The United Nations Convention on the Rights of People with Disabilities (2006). However, while the development of a national policy on disability has been accomplished, it is yet to be implemented. The Zambia Government has initiated few interventions and the results have largely been that the responsibility of taking care of people with disabilities falls on the family alone (Miller & Ziegler, 2006). The family is often the only provider of care in poor, rural areas; therefore, the composition and resources of a household will have a considerable impact on the abilities to manage childhood disabilities and make use of available health care services (Ingstad, 1997).

The Sixth National Development Plan states that in order to improve the lives of people with disabilities, a scale-up of disability mainstreaming is planned for, including user-friendly infrastructure, to make services more accessible (GRZ, 2011). Poverty, as a fundamental characteristic of a large majority of rural populations, threatens the survival and development of children and poses as a significant obstacle in securing basic living standards (UNICEF, 2008).

1.1.3. Kazungula District

The Kazungula District has a population of 94 494 and is found in the Southern Province of Zambia (Shankwaya, 2009). The area is strongly affected by poverty, and the large majority does not have formal employment or an income. They depend on small-scale farming for production of their own food. The infrastructure in the Kazungula District is of poor quality, and some areas are inaccessible as a consequence. The area has been affected by droughts since 2004, and this has limited opportunities to utilize and farm the land (Shankwaya, 2009). As a consequence, families experience hunger, because the small production of food will not sustain the needed consumption throughout the year.

The Kazungula District has five traditional chiefs who are highly respected, and play a major role in decision-making. They have control over political, judiciary and social issues, and are consequently responsible for the distribution of resources and information within their areas. They are key entry points in matters related to delivery of health care services and play a powerful role in mobilizing the local communities (Shankwaya, 2009).

1.2. Rationale for the study

In the process of deciding on a topic for a master's thesis, my experiences from the last 10 years working as a physiotherapist for children influenced substantially the way forward. In 2007 and 2008, I had the opportunity to work in Zambia where I met disabled children and their families, and observed the challenges they faced due to poverty on a daily basis. Their perceptions of health and illness frequently differed from mine in a context where access to health care facilities was influenced by a variety of circumstances stemming from both personal and structural factors. Children with disabilities were rarely seen at the rural health centers (RHCs) and this led to a wish for a more comprehensive understanding of the health behavior of these families in order to better comprehend the reasons behind the situation. The assessments and intervention strategies put forward, together with the rural health centres, were often not well enough adapted to local conditions and lacked sufficient sustainability. This had led to a desire to have a more systematic, in-depth understanding of the situation of disabled children and their families in regard to their use of health care services in Kazungula, thus resulting in the following research question:

“How do children with disabilities and their families use health care services in rural Zambia?”

There is no comprehensive health approach that targets disabled children specifically in low-income countries, and little has been evaluated in terms of the quality of care for this particularly vulnerable group (WHO, n.d.). The literature points out that these children lack access to health care services, and highlights the potential negative impact this could have on their developmental opportunities (Damstand & Maulik, 2007; Grantham- McGregor et al., 2007). As such, the upcoming UN World Report on Disability and Rehabilitation (launch June 2011) which was called for on the basis of limited research and awareness within the field of disability will be important and influential in assessing the current situation of children with disabilities (WHO Concept Note, n.d.). Little is known about how childhood disability is managed in Zambia, and how they make use of and experience health care services. As such, there is a need for increased understanding of the management of childhood disabilities within families in rural Zambia.

This study aims to provide knowledge about how parents see the health needs of their disabled children and how they reason in dealing with it. This thesis will give valuable insights into a field where more research is called for and will contribute to an increased

understanding of how childhood disabilities are management in rural Zambia. To increase the base of knowledge within this field is of great value in order to plan and evaluate services and influence policies and strategies to strengthen primary health care and implement adequate health care and rehabilitation services for this group of children.

The main objective of this study is to explore how disabled children and their families use health care services in rural Zambia. The specific objectives are to:

- Gain a broader understanding of the health needs of disabled children
- Explore barriers and facilitating factors to health care
- Identify formal and informal health services
- Explore the reasons for their choice of services.

1.3. Structure of the thesis

In Chapter 2, a theoretical framework will be presented where relevant concepts and literature is included. Thereafter, in Chapter 3, a description of how this study was carried out is outlined. Chapter 4 presents the findings from in-depth interviews with parents and health workers, together with findings obtained from the community meetings. Chapter 5 contains a discussion of the findings in relation to the theoretical framework, followed by the conclusion and future recommendations in Chapter 6.

2.0. THEORETICAL FRAMEWORK

In this section, a presentation of the important concepts for the objectives of this study will be outlined, and an overview of the literature introduced.

2.1. Disability

The concept of disability has changed over the last few decades; a medical model that focuses on individual, bodily impairments with a strong emphasis on diagnosis has been replaced by a social model. A social model of disability incorporates complex processes including limitations in functioning and participation, and posits society as the main factor contributing to disability (Grut & Ingstad, 2007). In this study, an understanding of the social model of disability will be used.

Disability is a broad term, and the actual perception of disability depends on complex social and cultural situations (Helander, 1993; Whyte & Ingstad, 1995). Accurate and reliable numbers are difficult to obtain and interpret, causing estimates of prevalence to vary significantly (Loeb & Eide, 2008). In general, the WHO definition found in the International Classification of Functioning, Disability and Health (ICF) is well acknowledged (WHO, 2001). It states that disability is “the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives”. Disability cuts across all aspects of an individual's life and, with its transient nature, can have very different implications at different stages of the lifecycle (Ingstad, 2007).

2.2. Poverty

There is no one single definition of poverty, because poverty exists on many different levels. *Extreme poverty* is generally defined as living on 1,25 USD or less a day, The World Bank estimates that 1.4 billion people in developing countries were living in extreme poverty in 2005 (WB, 2011). *Relative poverty* is more context-dependent in that the poverty levels depend on, and are being defined within, the community, region or country (Townsend, 1979). Although relative and absolute poverty differ in terms of definitions, it is important to note that in practice people with disabilities are often the victims of both.

These income-based poverty indicators are limited in the sense that they do not capture the multidimensionality of poverty and, as such, the UNDP introduced a Multidimensional Poverty Index (MPI) in the Human Development Report 2010 (Klugman, 2010). This was done to complement the narrow, income-based poverty measures traditionally used. The MPI identifies the number of people living in multidimensional poverty for the three dimensions of health, education and living standards, and thus takes into account multiple deprivations and gives a more diversified representation of poor people at the household level. Poverty in this study will be viewed as a multidimensional phenomenon.

2.3. Structural violence

Structural violence describes situations where violence is not performed by an individual, but is built into a structure and creates a gap between the potential and the actual resources utilized by people within that system (Galtung, 1989). Therefore, violence is committed when something that could have been avoided is not, as a result of established systems sustaining an order where people suffer from not being able to utilize their capacities. Examples of this are unevenly distributed resources in income, education and health. These established systems endorse limitations; they are close to invisible and are viewed as ordinary in the interpretations of reality through being embedded in existing structures, for example access to health care. The forces of social nature are outside of the control of those affected, and have ramifications for the overall lives of poor people. As such, structural violence can be seen as a strong regulator in keeping poor people poor and will consequently impact their health negatively.

This is further described by Paul Farmer who states that, “*structural violence is visited on all those whose social status denies them access to the fruits of scientific and social advances*” (Farmer, 2010a p. 313). Farmer writes about the powerlessness that is part of the lives of poor people in their everyday encounters with systemic barriers in the utilization of their capabilities. Poverty, as a restricting force, limits the minor and major choices available to individuals. The poor people of today are the main victims of structural violence, “*... the poor are not only more likely to suffer; they are also less likely to have their suffering noticed*” (Farmer, 2010b, p. 344). Thus, poverty and inequality are structured and legitimized over time.

Structural violence theorists describe the world as disproportional where the differences between rich and poor people are amplifying, both between and within countries (Pogge, 2002). The power to make decisions about the distribution of resources is profoundly asymmetrical and this economic arrangement is pivotal in generating structural violence. From this line of reasoning, (Uvin, 2010) argues that development aid contributes to social inequality by favoring a pattern of spending that benefits the already well-catered-for parts of the society. From a community health perspective, these social determinants of disease are important to take into account and try to understand in an effort to contest structures where affected people are made powerless and the structures continuously produce inequality and suffering. When looking at the root causes of disease, Farmer (2010a) advocates the importance of addressing social forces, including poverty.

The concept of structural violence is useful in understanding complex situations and highlighting the social determinants of disease and their implications on the lives and health of people in resource-poor settings with a limited power to choose. Such a framework will be used in an effort to understand the social life of families with disabled children and the external forces influencing their opportunities to seek adequate health care for their children. Childhood disability can be seen as a complex challenge to those involved in the management of providing care, and will only be sufficient if the social determinants of health and disease are addressed.

2.4. The reciprocity of disability and poverty

Disability and poverty are strongly interconnected. They influence each other mutually and form a vicious cycle that will continuously challenge the life of those affected (Yeo & Moore, 2003). Poverty is seen as a factor that will contribute to an increase in disability and simultaneously the presence of disability will potentially create poverty. There is a growing literature on the interrelationship between disability and poverty (Filmer, 2008; Hoogeveen, 2003; Ingstad & Grut, 2007; Trani & Loeb, 2010), which describes a probable interdependency between disability and dimensions of poverty. People with disabilities in low-income countries are over-represented among the poorest of the poor (Bonnell, 2004). The UN Millennium Development Goal to eradicate extreme poverty and hunger will only be met if people with disabilities are included in the efforts to reach the proposed targets (Bonnell, 2004). The reciprocity of disability and poverty illustrates the dynamics of how the presence

of impairments affects the economic and social life of people (Bonnell, 2004). As a result, chronic poverty with its increased risk of illness and additional impairment will contribute to lower levels of human development (Miller & Ziegler, 2006).

2.5. Health care system

The model of health care systems presented by Kleinman (1981) will be introduced with the intention to apply his abstraction of health care systems to the health care system found within a rural Zambian society. The model presents three overlapping and interrelated sectors of health care: the popular, the professional and the folk sector. Kleinman's model of health care systems is useful in studying societies to understand the reasons for individual health behavior. Kleinman (1981) refers to health care systems as socially and culturally constructed and shaped by cultural rules and meanings. The interaction between the systems emerges as a result of people moving freely between the three sectors (Helman, 2007).

Within Kleinman's popular sector, care is provided in homes and local communities and the main area of health care is within the family (Helman, 2007; Ingstad, 2007). The large majority of health care takes place in the popular sector, where definitions of illness are first recognized and defined, before health care activities are initiated (Kleinman, 1981). There is an exchange of culturally known and accepted ideas about diagnoses and treatments before choices are made about where to seek help (Ingstad, 2007). Hence, the popular sector can be viewed as a focal point for all sectors, incorporating entrance points, exit strategies and interplay between the different sectors. When people use other sectors, their choices are already embedded in the popular sector. Experiences gained in using the other sectors will eventually be brought back to the popular sector in an effort to evaluate, seek opinion of and decide what to continue with further.

The second sector is where the professional, more organized medical health care is being carried out (Kleinman, 1981). This sector is often referred to as a biomedical system, where health care activities are authorized and strongly regulated. The underlying cultural values of a society also play a part in determining how disease is diagnosed and treated within this sector (Helman, 2007).

The third sector in Kleinman's model is the folk sector, where different types of providers operate. This sector is often a part of the same local community as the patient and thus has

extensive knowledge about people in the community (Ingstad, 2007). Folk healers do, to a large extent, share the basic cultural values and worldviews of the communities in which they live (Helman, 2007). This could create a positive environment, as well as be advantageous for understanding, defining and treating illness.

In all societies the multitude of health care activities are more or less interrelated (Kleinman, 1981) and form a variety of alternatives for individuals in their efforts to stay healthy, prevent sickness and treat illness. This is often referred to as medical pluralism (Helman, 2007).

Medical pluralism exists as a result of different actors operating within the health care system, offering patients their own particular way of explaining, diagnosing and treating ill health.

These various actors coexist within the same health care system; however, they can give very different explanations and rationales for ill health. For example, to the individual patient these explanations may not be as important as their efficacy in relieving suffering (Helman, 2007).

When given a set of options, patients use different elements from various systems of health care in order to get a more comprehensive approach to their own situation (Ingstad, 2007). As such, medical pluralism gives a range of therapeutic options for patients to consider. In most societies, patients and care-givers resort to different kinds of therapies, even when these therapies have mutually incompatible explanations for an illness (Helman, 2007). This implies that for users of a health care system, a combination of different strands of expert advice is developed into one meaningful entity where consumers make decisions about which providers they wish to use in given situations (Helman, 2007).

2.6. The health care system in Zambia

Since 1992, Zambia has implemented major health sector reforms with the mission to

...provide the people of Zambia with equity of access to cost-effective, quality healthcare as close to the family as possible in order to ensure equality of access in health service delivery and contribute to the human and socio- economic development of the nation... (MoH, National Health Strategic Plan 2006- 2010, p.1)

A decentralization process has been carried out within the Zambian health sector with the aim of moving resources from central level health facilities to more operational levels of the health care system in an effort to be more functional where the majority of the people are

(MoH, 2006). In 1994, user fees were introduced but this system of payment for primary health care services was terminated in 2006 with the goal of increasing access to health care for those incapable of paying (GRZ, 2011).

There are several providers of health care services in Zambia. According to the Ministry of Health (2006), the main providers are public health facilities served by the Ministry of Health, hospitals within the mining industry, mission hospitals and clinics, private hospitals and clinics, Non-Government Organizations and traditional healers. The rural health centers under the MoH are supposed to cater for a population of 10 000 within a radius of 29km. Under each rural health center there are several health posts serving 500 households within a 5km radius. There are 17 178 health workers employed in the public health sector. This number is lower than the recommendations from the WHO (GRZ, 2011).

The delivery of health care in Zambia is constrained by a number of factors, including the critical shortage of essential human resources within the work force of the health sector, inadequate funding, the deprived state of existing health facilities and available equipment, inadequacies in the empowerment of local communities to gain better health, geographical access barriers particularly in the rural areas and a lack of information about traditional medicine (MoH, 2006). The human resource crisis currently taking place within the Zambian health sector is largely influencing the ability to provide the population with basic health care services. In many rural health centers there are no staff employed and untrained personnel are managing the centers. The opening of new facilities has been activated without the required staff to run the centers.

Although a majority of research shows that there is limited access to health care for disabled children in low-income countries (UNICEF, 2006; WHO, n.d.), a survey of living conditions in Zambia found that health services were available to a large majority of those with disabilities (Eide & Loeb, 2010). In a study by Birbeck and Kalichi (2004), 700 people with epilepsy were identified in a rural catchment area in southern Zambia. Information from hospital registers indicated that only 32 people with epilepsy had received chronic care for their condition. Hjortsberg (2003) argues that the providers of health care in Zambia have embedded in their system a priority between both diseases and individuals, thus, affecting how people anticipate medical services. This could explain the differences found in the use of health care services as a result of purposeful or unintentional health policies.

The health care system in Zambia can be viewed as not being structured to provide equal opportunities to those in need of assistance (Hjortsberg & Mwikisa, 2002). People who have the financial means available are more likely to seek health care than those who lack that capacity (Hjortsberg & Mwikisa, 2002). There is a higher burden of disease reported among the poor, and yet they use health services to a lower extent than the non-poor (GRZ, 2011). Additionally, residing in a rural area, as well as other factors resulting from poor infrastructure, has a negative impact on health-seeking behavior. Those with higher incomes tend to live in urban areas, so their physical and financial access to those health facilities with the capacity to diagnose and manage chronic illness is greater (Diop, 1998). Hjortsberg and Mwikisa (2002) also found inequalities between rural and urban areas and points out that the differences in distance are particularly imbalanced, thus creating situations where people in rural areas pay more in relation to their income for using primary health care. The costs related to long distances for people seeking health care are high for people residing in rural areas, particularly during the farming high season. Consequently, the distance to a health care facility can be seen as a significant factor when decisions are made about whether to seek help or not. Poor infrastructure and lack of transport make rural health centers less accessible for the rural population, walking is often the only feasible way of reaching the rural health center, and this can take a considerable amount of time. Hjortsberg and Mwikisa (2002) found that these components have created inequity to a larger extent than the removal of user fees in the Zambian health sector.

One study (Evans & Young, 1988) notes the seasonal nature of income and describes the situation of Zambian women who cannot afford to get sick because transporting themselves to the RHC will mean that they have to stay away from productive activities. Rural households depend strongly on income from the land, and a loss of time working in the fields will directly influence the food availability and income situation (Evans & Young, 1988). In rural Zambia, a study about children on Antiretroviral Therapy found that a lack of money, transportation, poor road conditions and long travel time influenced the use of health care (Van Dijk et al., 2009). Furthermore, more than 90% of children with HIV-infection were reported to travel more than one hour to reach a government health facility and more than 25% traveled more than five hours. Malama, Chen, De Vogli and Birbeck (2002) reported that user fees were a barrier to hospital admission for girls between the ages of 3 and 6 years. Birbeck and Munsat (2002) found similar barriers to consultation with a physician for people accessing neurological services: high cost of transport to the referral center, lack of money to feed and

house those family members accompanying the patient, overworked staff, long waiting times and little feedback on how to proceed after consultation.

Some studies from other countries with similarities to Zambia should also be mentioned, since literature within Zambia is scarce; A study from rural Tanzania found that poor families with sick children sought health care more rarely than wealthier families, also in communities viewed as uniformly poor (Schellenberg et al., 2003) Wealthier families had more knowledge about the danger signs, they were more likely to bring sick children to a health facility and had shorter journeys to the health facility compared with poorer families. Ingstad's (2007) description of access to primary health care in Botswana, defined as being reachable by walking distance, illustrates the systemic barriers for those who do not have the ability to walk. In another study, Ingstad and Grut (2007) report poor rural families in Kenya to have lost the spirit to fight, they have become overwhelmed with constraints in everyday life and consequently give up. Primary health care in Kenya is not capable of attending adequately to disabilities and the families play a vital role as provider of care. As a result, traditional medicine is an option for many, and attractive in offering a cure, and as such becomes a barrier to modern health care (Ingstad & Grut, 2007).

Traditional providers play a central role in the provision of health care in Zambia (Baskind & Birbek, 2005), and are important components of the health care system in a rural Zambian context (Stekelburg et al., 2005). The total number of traditional practitioners is 40 000 (Sugishita, 2009) and they are more evenly distributed than the government health facilities, which means they are often closer to where people live (Stekelburg et al., 2005). They are more accessible, and more in-line with culture and concepts as perceived by the families (Baskind & Birbek, 2005).

A traditional practitioner in Zambia is commonly referred to as a ng'anga. The term ng'anga can be translated to a traditional "doctor", and they often use herbal medicine in their practices. They deal with problems of a physical nature, economic challenges and interpersonal difficulties, and they often claim to be of assistance in responding to episodes of "witchcraft". Sugishita (2009) reports that problems caused by witchcraft can only be dealt with through a ng'anga, who also has the ability to identify the person behind the bewitchment. In most cases the bewitchment has been caused by the jealousy of a relative, friend or neighbour.

There is a system of home-based care (HBC) within the Kazungula District (Shankawaya, 2009). The role of the HBC is to focus on chronically ill individuals. Children with disabilities are not included in this category, with the main focus being on people with HIV/AIDS and tuberculosis. Another important local institution is the neighborhood health committee, described as being a bridge between the community and the RHC. This committee has a strong influence in defining health needs and priorities within their local communities.

The Kazungula District does not have a referral hospital and, as such, the rural health centers are the highest level of health care provided within the district (Shankawaya, 2009). All rural health centers in the Kazungula District provide maternal and child health services. In the rainy season from November to April, some areas within Kazungula are cut off from health services as a result of inaccessible roads.

2.7. Explanatory models

The driving force of the health care system is explanatory models, which give important answers to questions of etiology, time and mode of onset of symptoms, severity, treatment and prognosis (Kleinman, 1981). Explanatory models are used by individuals to explain, organize and manage particular episodes of impaired well-being; both users and providers of health care bring with them their own explanatory models. These individual models work as facilitating factors and barriers in the health and illness process, responding to a particular episode of illness (Ingstad, 2007). The explanatory models of patients are changeable and strongly influenced by personality and cultural factors (Kleinman, 1981). As such, people within a patient's network affect the choices they make because these people's perceptions of the present situation are taken into account to a large extent.

Characteristics of the explanatory models of patients are often related to vagueness, multiplicity of meanings, frequent changes and a lack of sharp boundaries between ideas and experiences (Kleinman, 1981). As a result, different explanatory models will often occur. For example, physicians who base their explanations on scientific logic, and follow one path of reasoning for clarification of a disease, may find it difficult to grasp the patient's perspective of illness. Thus, the distinction between illness and disease is important to address in order to identify a gap between what patients seek to get and what the health personnel will provide.

In general, biomedicine is often used as a first choice of action to address acute, critical conditions while chronic conditions are often dealt with by folk medicine (Ingstad, 2007). There are, however, some distinct differences in terms of the legitimization of different sectors of health care within the explanatory models of patients. Biomedicine has to prove effective for people to see the point in using it. Folk medicine, on the other hand, exists as a logical part of a culture and does not have to justify its existence to the same extent (Ingstad, 2007). And, moreover, it is very natural to turn to other solutions if the first choice made is not working, or the solution applied did not have the expected outcome (Hjortsberg, 2003).

The decisions people make in the health-seeking process are strongly influenced by how people perceive the illness (Stekelburg et al., 2005). In Stekelburg et al.'s study (2005), 86% of respondents would consider attending hospital after an unsatisfactory treatment from a traditional healer, and 45% would consider a traditional healer after dissatisfaction with treatment from a hospital. In their study in rural Ghana, Hill, Kendall, Arthur, Kirkwood and Adjei (2003) found that the ability of mothers to recognize certain signs and symptoms was an important factor in determining health-seeking behavior. Some illnesses were described as not-for-hospital and, as such, not treatable by modern medicine.

The treatment of children with disabilities depends on the beliefs about the nature and cause of the disability, as perceived by the primary caregiver (Danesco, 1997; Diken, 2006; Maloni, et al., 2010). Maloni et al. (2010) report a multitude of treatment options used when seeking help for disabled children; all respondents in their study had been to traditional providers before establishing contact with formal medical services. Communication between the health care provider and mothers was identified as a barrier to seeking treatment for the disabled child. Diken (2006) found that mothers used both biomedical and traditional beliefs when making sense of the cause of their child's disability. Devlieger, (1995), describes situations where no other relationships can be used as explanations, and where the cause of the disability is then attributed to God. God is the reason when no other cause can be found, and is regarded as the absolute power and the ultimate cause of the disability.

One important aspect that Grut and Ingstad (2005) report in their study from Kenya is that a lack of information and knowledge about disabilities create situations where parents are unaware of where to seek guidance, and lack the knowledge on how they can best help their children. Parents are not informed about potential improvements in their child's condition or how they can contribute to training and stimulating them.

In Sugishita's study (2009), health workers in Zambia believed that sick people would initially consult the traditional practitioners (ng'anga), and when the condition worsened they would go to the clinic. This was not in-line with what people in need of health care said; only 8 out of 46 people in the study said they consulted a ng'anga before biomedical treatment was chosen. In a study about epilepsy in Zambia (Baskind & Birbeck, 2005), traditional healers were interviewed about their experiences with the condition, and highlighted the importance of giving explanations to the patients regarding the seizures.

3.0 METHODOLOGY

This chapter will present how the study was carried out and will begin with the choice of methods and background for selection. Following this, the methodology related to the study site, access and sampling will be described before data collection procedures are presented. Thereafter will follow a section on reflexivity, before a discussion of the methodology and the trustworthiness of the study are described. Ethical considerations are then presented before the methods used in analyzing the data are outlined, combined with a short description of the dissemination of the results.

3.1 Study design

The chosen of method to investigate a phenomenon will depend on the objectives of a study (Varkenvisser, Pathmanathan & Brownlee, 2003). A qualitative study design makes it possible to understand why people act the way they do and, at the same time, glean a deeper insight into how they experience and interpret the world in which they live. This type of study also allows the participants to answer questions of an explorative nature such as why, what and how (Malterud, 2008). The concepts of health, illness and disease are dynamic; their substance depends on social, cultural and individual aspects of life. Thus, the uniqueness of individuals within a given context needs to be addressed in order to gain a better understanding of the mechanisms influencing health and the behavior related to it. Therefore, a qualitative method was adopted for the current study in an effort to gain a more comprehensive understanding of the situation of disabled children and their families in rural Zambia. In-depth interviews, observations and community meetings were carried out to contextualize the findings and contribute to the understanding of the phenomenon under study from different angles. Studies that are qualitative in nature can enrich our understanding of the complex and multifaceted nature of the use of health care services among disabled children and their families, in a continuous effort to comprehend explicit encounters, actions and perspectives into a broader and more meaningful context.

3.2 The study sites, access and sampling

3.2.1 The study site

The study was carried out in the Kazungula District in Zambia's Southern Province. Kazungula is a rural district with 19 rural health centers (RHC) and health posts. Five RHCs in the Kazungula District were initially chosen, in collaboration with the Kazungula District Medical Office (KDMO), based on the following criteria: the researcher did not have experience with the rural health center from previous work in Kazungula District, it was accessible during the rainy season and there was accommodation available for the research team. The included RHCs were situated between 35 and 85km from the administrative center at KDMO.

One of the RHC identified was changed due to being inaccessible as a result of heavy rains and was replaced by another accessible one within the same area. During data collection in one of the selected RHCs, five families with a first language other than the local Tonga language were recruited. The interpreter of Tonga origin found it challenging to interpret another local language, therefore, a decision was made to exclude the parents in this catchment area. However, home visits and informal interviews were carried out with the identified families and translations conducted by a community volunteer. The families were given information about the project and our presence in the catchment area, thus creating expectations about participation which needed to be clarified. Additionally, experiences and perceptions from these families were seen as useful information in the overall understanding, even though they were not used as part of the interviews in the study.

By recruiting participants from four different areas of the Kazungula District, the risk of recognition of the participants was reduced. Variation within the Kazungula District was also addressed using this approach. At the same time, the number of disabled children within each area was expected to be low. Choosing multiple sites restricted us in not being able to know one study site in greater detail.

The RHCs chosen were served by one or two nurses, and two out of the four had a midwife among the staff at the time of study. There was also an additional classified daily employee who was carrying out a variety of tasks including cleaning, screening of patients and distribution of medicines. The classified daily employee operated the RHC when the health

workers were not present. Each of the RHCs offered services to a population of between 3000 and 5000 people.

3.2.2 Access

The study was approved by the Regional Ethics Committee in Norway in June 2010. The Tropical Diseases Research Center, Ethics Review Committee, Zambia approved the study on November 3rd 2010. The study was also approved by the Southern Province Medical Office and the Kazungula District Medical Office (KDMO). One representative from the KDMO was assigned to assist in realizing the project locally. She accompanied the research team (the researcher and the research assistant who also was the interpreter) to the study's chosen catchment areas and made official introductions to local community leaders prior to data collection. Presentation of the research team was carried out and the purpose, effectuation and ethical considerations in the research project were discussed before approval was obtained locally.

Health workers were identified through the KDMO, and the plan was to interview health workers at the four chosen RHCs. The research team approached them in person and provided verbal information about the project. The health workers were given a written information letter and time to read and decide whether to participate or not. Only three health workers were recruited through this process. Another three health workers were given information letters at the RHCs, but for various reasons, they were not available for later interviews. Many health workers posted at the four RHCs were not present at the RHC when the research team was there due to being on leave from work or because they were attending workshops outside of the catchment area. The KDMO assisted in the further recruitment of health workers by informing other health workers about potential participation in the study. Health workers from the RHCs came to the KDMO once a week to report their activities. The research team spent those days at the KDMO in an effort to meet with health workers and make requests about participation. Information about the project was provided beforehand and the health workers had time to consider their participation. Two of the health workers were recruited and interviewed shortly after information was given verbally and in writing. This was due to practical challenges in finding a time and place to meet again for interviews.

Parents and grandparents (hereafter referred to as parents) with disabled children were identified through the staff at the four RHCs included in this study. In some situations they were not aware of any disabled children within their catchment area and had to consult community volunteers. The staff and the community volunteers were given information about the research project and asked to recruit parents with disabled children within their catchment areas. No specification was made as to the disability of the child, be it diagnostic or functional, leaving it to the staff at the RHCs and community volunteers to include children they regarded as disabled within their catchment areas. The research team was then taken to the homes of the selected families for introduction, and information about the study and the research team was given. Verbal information, together with an information letter in English, Tonga or both was presented, including a request for the primary caregiver within the family to participate in the study. The participants were given the opportunity to ask questions and time to discuss with the family before making a decision. The research team came back one or two days after the first visit to the families to conduct the interviews. This was done to better secure voluntary participation, to give time for the families to read through the information, understand it and share it with the family. Moreover, this created better opportunities for the families to turn down the request if they did not wish to participate.

The research team used public transport to reach the RHCs included in this study. This was done in an effort to experience the available transport facilities for people living within the catchment areas and, as such, provide a better understanding of what they have to go through. Using public transport is a good way of meeting local people in their everyday lives, thus creating an arena where valuable information about local conditions can be shared. During data collection, the research team was accommodated locally, either at the RHC, in the house of a health worker or in the house of other community members. This provided us with interesting encounters and insights into rural Zambian lives. It also created opportunities for us to get to know each other better and provided us with valuable time to share and discuss our experiences.

Within the data collection catchment areas, we used our feet as the mode of transport to reach the participants' homes. In that way, distances and terrain used by the participants in their efforts to reach the RHC were experienced. Moreover, it proved valuable in providing time to get to know the community volunteers escorting us. They remained with other family members while we conducted interviews with the parents in privacy.

3.2.3 Research participants

Two different samples were chosen for this study: parents/grandparents with disabled children and health workers employed at a RHC under the KDMO. The parents were chosen because they can provide vital information about the health situation of their own children with disabilities and share their rationales for decisions made in the process of seeking help. Health workers were chosen on the basis of their key role in providing local communities with health services. Their perceptions and experiences with childhood disability were seen to provide the study with a more nuanced understanding of the situation, and at the same time contribute with a different perspective. Moreover, their apprehension and awareness could shed light on aspects of the health needs and health behavior of children with disabilities and their families. The two different samples, parents and health workers, provided the study with diverse perspectives and contributed to the complex understanding of the situation of disabled children in rural Zambia.

In this study, the health workers interviewed were nurses, midwives and one clinical officer (trained non- physician clinicians). They had between 1 and 12 years experience working for KDMO, and most of them had been working for other government institutions for a number of years prior to this.

The parents (and grandparents) had disabled children between the ages of 8 months and 15 years. Mothers were most commonly interviewed with the exception of two fathers and three grandmothers. The level of education among the parents within this study varies between 3rd and 12th grade and few of their disabled children go to school regularly. Their children, 7 boys and 7 girls, represented a wide variety of conditions: epilepsy, cerebral palsy, hydrocephalus, seeing impairment, hearing impairment, congenital limb deficiencies, Down syndrome and developmental disabilities. They also differed substantially in functional abilities and in their social participation, both within the family and in the community at large.

3.2.4 Sampling

The selection of the participants was based on their ability to provide in-depth information about the topic under study, referred to as purposive sampling (Patton 2002). Such sampling makes it possible to find participants that will reflect on the topic and the data will enlighten the objectives of the study by consisting of relevant and adequate information.

The size of the sample in a qualitative study depends on the complexity of the questions, how relevant the purposive sampling has been and the quality of the information found through the data collection process (Malterud, 2008). The exact number of participants in this study was determined during the data collection. Further data analysis was done throughout the data collection process, and a saturation point was reached when new data did not contribute with new knowledge. Twenty-nine participants were recruited for this study: 16 parents and 13 health workers. Individual interviews were conducted with all 13 health workers and with 12 of the 16 parents. Two of the parents requested to have another family member present during interviews; thus, including a total of 16 parents in this study.

Health workers that knew me from my earlier work with the KDMO were excluded from participating in this study. Parents were recruited from areas other than those I knew from previous job experience in an effort to avoid meeting families that I had had previous contact with. This was done in an effort to minimize the expectations of research being therapeutic and seen as an adjunct to the medical care they were already receiving.

The plan was to interview parents and health workers in a stepwise process, having participants from one group shed light on the other group and vice versa. This was not feasible initially as a result of challenges with the recruitment of the health workers. The first six interviews were therefore conducted with parents before any interviews had taken place with a health worker.

3.3. Data collection

3.3.1. Interviews

In qualitative research interviews, attempts are made to understand the world from the perspective of those interviewed and give details about the meaning behind their experiences (Kvale & Brinkmann, 2009). In-depth interviews with parents with disabled children and health workers were conducted. This was done in an effort to gain knowledge about the experiences and perceptions of the health situation of disabled children and the use of health care services. However, through in-depth interviews, it was to some extent up to the participants to determine what type of information they would give and how they presented their opinions and attitudes. A semi-structured interview guide with themes was used, giving room for flexibility. Open-ended and probing questions were used to facilitate free responses

in the participants' own words. Moreover, new themes that were not initially thought of during the planning of the study emerged, and provided valuable new insight to the research team in understanding the objectives of the study.

Summarizing the main results at the final stage of the interviews was done in an effort to corroborate the understanding and interpretations of the research team, thus providing a better congruence with the information provided by the participants during the interviews.

Interviews with health workers were conducted in English, as English is the official language of Zambia and people with health education backgrounds have good English skills. The use of concepts and terminology was more harmonized given that I am also a health professional. Additionally, the research assistant was also present, subject to approval by the health workers recruited for the study, with the exception of one health worker who had to be interviewed at a specific, unplanned time. The aim of having the research assistant also present, was to strengthen the interpretations, and enabled the research team to view the interview situations from different perspectives. This opened up for a comparison of experiences and gave more nuanced interpretations of interview situations. On the other hand, having the research assistant present might have created an atmosphere where the participants were less willing to share information. Interviews with parents were conducted in Tonga with an interpreter.

Interviewing the participants twice would have strengthened the study, and was considered during the planning phase of the study. Due to limitations in time, however, this was not carried out. As a consequence, interesting issues that were brought forward in the first interview would not be elaborated on in a follow-up interview and clarifications of uncertainties during the first interview were not sought, thus potentially influencing the quality of the study.

There is no way to completely guarantee that what is conveyed is actually what is being said by the informants (Patton, 2002). This was addressed by listening to all of the interviews afterwards, the research assistant translated once more orally, and a comparison was made to the translations already on the tape recorder. This opened up for a more thorough understanding of what had been said in the interviews and was a quality check of what had been translated. Non-verbal communication was also discussed after each interview. This gave a more comprehensive and nuanced understanding, as the research assistant had the cultural competencies in interpreting non-verbal communication. The information was not

used directly, but gave valuable background information during the methodological reflections undertaken after each interview.

3.3.2. Interview guide

An interview guide is a list of the questions or themes that will be explored during an interview, and provides a systematic way of approaching the issues under study (Patton, 2002). Two different interview guides were used in this study: one for parents and one for health workers (Appendix 6 and 7). The two interview guides were evaluated by two experienced health workers within the field of childhood disability, and by an experienced health worker with an extensive knowledge about disabled children and their families in the Kazungula District. On the basis of these people's responses, adjustments were made to make it more relevant within a rural Zambian context. Their extensive knowledge within the field of childhood disability might have lessened the relevance for those health workers with less experience with disabled children. An initial broad scope in the interview guide was adjusted for some of the health workers and more concrete questions added. The interview guide for parents was tested on two mothers with disabled children at Cheshire Home in Livingstone. They provided valuable feedback as part of an effort to strengthen the relevance and comprehension of the interview guide before data collection, but may have been influenced by the fact that these mothers were living in a more urban setup. The testing of materials proved also to be beneficial through the collaboration between the research team prior to data collection. It allowed for adjustments in the dynamics within the interview setting, in particular in relation to translation. The two interview guides were revised during fieldwork when we acquired new insights.

3.3.3. The use of an interpreter

In this study, the use of an interpreter was essential during interviews with parents, and since the interpreter also acted as a research assistant prior to, during and after data collection her role needs to be addressed. When making use of an interpreter, challenges arise both in translating the words of the interviewer and the informants, and in determining to what extent the views of the interpreter are included in the translation. This could potentially threaten the

quality of the study by not obtaining the true perceptions of the one being interviewed (Patton, 2002).

In the process of finding an interpreter for this project, the characteristics of fluency in the local Tonga language and a university degree within the field of health or social sciences were primary qualifications. Advertisement for employment was done in the local church of the convent where I resided and at David Livingstone College of Education in Livingstone, one of few higher education institutions in the area. Four people responded, and all were interviewed. One was finally selected based on her Tonga background and her academic qualifications. She is of Zambian origin with one parent of Indian background, is 28 years old, has a university degree in microbiology and is doing postgraduate studies in public health, which has included an introductory course in qualitative methodology. When using an interpreter it is important to address her pre-conceived notions of the topic (Patton, 2002). The chosen interpreter had experience working as a quantitative research assistant, but no interpretation background or experiences within the field of disability. The issue of gender was also relevant in the recruitment process since I expected to interview mothers as primary caregivers and had a preconception that having a man present during the interviews could restrict mothers more than if only women were present. At the same time, we had to share accommodation during data collection, thus adding a practical dimension to the aspect of gender.

Two months were spent introducing the project and getting to know each other, while waiting for ethical approval of the research project. We spent time together at Cheshire Home, Livingstone where work with disabled children is carried out on a daily basis. The research assistant was also provided with the relevant literature in order to obtain more knowledge within the field of childhood disability. The research team took part in outreach activities with Cheshire Home as part of creating a broader base of understanding.

3.3.4. Interview settings

Interviews with parents were conducted in the homes or gardens of the participants. Most families had prepared sitting arrangements inside their houses or in a quiet location outside. The home environment of the parents was chosen in an effort to interview the participants in a familiar atmosphere where they would feel safe. Moreover, conducting the interviews within

the homes could make it more convenient for the parents to participate by taking up less of their time. It could also provide the research team with information about the home environment of the participants and contribute to a more comprehensive understanding of their situation. On the other hand, having strangers within their domestic area could have created unease and was addressed by visiting twice.

Conducting interviews in someone's home environment creates challenges, especially in terms of anonymity. We were two outsiders accompanying a community volunteer in walking to reach the homes of the participants. We met many curious individuals on our way through various villages who wanted to know who we were and what we were doing in their villages. The community volunteer would tell them we were part of a project about disability, this was appreciated and when reaching the homes of families with disabled children, we were never followed. During many of the interviews, we sat quietly outside with the only disturbances being children playing and animal sounds. One challenge that did emerge was situations where the community volunteers did not know the exact location of the homes of the families we were to visit. They had to ask for directions, thus making it impossible to keep the identity of the families hidden.

The health workers were interviewed at the RHC where they were located if comfortable with such a situation. This seemed to be the most convenient environment, particularly since the health workers spent long hours attending to patients in and around the RHC area. However, this could jeopardize participant confidentiality, and some of the interviews were done in the homes of the health workers. This was also beneficial in limiting disturbances. Since we were not able to recruit enough health workers during the visits to the four RHCs chosen for this study, some health workers were interviewed in their rooms while attending a workshop at a lodge. Some were also interviewed in a private room at the KDMO. These participants could have chosen to be interviewed in the house where I lived, located close to the KDMO to avoid the risk of others listening in, but none of the participants chose to do so.

3.3.5. Information letter and informed consent form

Information letters and informed consent forms were distributed before conducting the interviews (see Appendix 1- 5). The research assistant translated the material for parents from English to the local Tonga language. In this process, the concept of disability was found to

have a negative meaning in the local Tonga language and the more neutral word *Ulibâbu* was chosen, which means condition. The translations were checked by another person to ensure its quality. Information letters included our telephone numbers (the researcher and the research assistant), and arrangements were made with community volunteers who had telephones available in case parents wished to contact us.

3.3.6. The use of a tape recorder

A tape recorder is used in such studies to document and thereafter analyze the interviews (Kvale & Brinkmann, 2009). In the current study, two tape recorders were used to avoid technical difficulties. All participants were informed about this in advance and were asked for permission. They were told that they could turn off the devices at any point during the interview, or erase taped material afterwards. Information was given about the further use of the audio-taped material, and that it would only be made use of by the research team, and deleted at the end of the project. The use of tape recorders may have influenced the openness of the participants in terms of what they were willing to share.

3.3.7. Transcription of interviews

To transcribe interviews means to transform the oral content of what people have been sharing into written form (Kvale and Brinkmann, 2009). All interviews in this study were transcribed word-for-word. I transcribed all interviews with health workers and the English parts of the interviews with the parents. The research assistant transcribed the local Tonga language parts of the interviews with parents, and controlled the already transcribed English text by me. The transcribed interviews with parents were read by a third person fluent in the local Tonga language with experience in translation and transcriptions to strengthen the quality of the transcripts.

The transformation from spoken word to written text gives an incomplete picture of the phenomenon under study, and the meaning as communicated by the informants might have been changed in the process. Therefore, the research team present at the interviews also carried out the transcriptions. This proved valuable in being able to recognize the context in which things had been said and added valuable information to the further analysis. Names of individuals and places were changed in the transcribed material to secure anonymity.

3.3.8. Observation

Observation can give first-hand involvement in the social world under study and be a complementary method to get more accurate information on behavior (Patton 2002). In contrast to observation, when research is conducted through in-depth interviews, the information obtained will depend heavily on what informants are willing to share; there is usually a discrepancy between what people say they do and what they actually do (Malterud, 2008). Hence, observation can lead to a broader understanding of the issues at hand.

Observations were carried out in public places in the catchment areas with special attention given to the areas around RHCs. Being an outsider made it possible to interpret the situations under study differently from those participating (Patton, 2002). Such observations provided me with an overview. The composition of the research team proved valuable in providing various perspectives, the research assistant being less of an outsider as a Zambian, but also with another background in terms of urban residence and education. However, being part of the environment under observation poses challenges, both in terms of influencing the surroundings to some degree just by being present, and also in terms of only seeing or hearing findings which are interesting. It is possible that one can miss or misinterpret information that is critical to the research (Patton, 2002).

3.3.9. Information meetings

One information meeting was held at each of the four RHCs after all interviews with parents and health workers had been carried out. Parents, health workers, community volunteers, representatives from other families with disabled children and local leaders were invited to the RHC for a presentation of the preliminary findings from the perspective of the research team. A 30-minute presentation of the main findings was carried out by the research assistant in the local Tonga language and the debate afterwards was facilitated by the research assistant, while a third person translated to the researcher from Tonga to English. This was done in an effort to create a dynamic process without interruptions in English, which was not understood by the majority of the participants. Questions and comments from the local communities proved valuable in an effort to validate findings.

The information meeting also had another important purpose: to provide the participants and the research team with an opportunity to meet again after the interviews, particularly the parents since they had few resources to make contact with the research team themselves. Time

and space was provided for the participants of the study if they wanted to meet with us in a more private setting. Three of the parents used this opportunity. Representatives from families of 12 out of the 14 children in this material attended the information meetings. Two families had not been notified about the information meeting and did not participate. In some cases, the parents who had taken part in the interview could not attend the information meeting, but had sent another family member in his/her place. Only 3 of the 13 health workers participating in this study were present at the information meetings. An additional information meeting was therefore planned at the KDMO, but was not carried out due to the official invitation necessary from KDMO for them to attend, an invitation that could have jeopardized voluntarism. The information meetings were conducted in an effort to reduce the bias of the research team having a monopoly on interpretations from interviews.

The information meetings were taped with an audio recorder and permission to use it was asked at the beginning of each meeting. After each meeting, the research team listened through the tapes, and the main topics were discussed.

3.4. Reflexivity

In every step of the research process, the positions and perspectives of the researcher were of influence (Kvale & Brinkmann, 2009). The effects this had on the research process and for the outcome of the study must be assessed. The issue of how the researcher can influence a research process is called reflexivity (Patton, 2002). Openness about subjectivity through reflexivity is important in strengthening the trustworthiness of a study (Malterud, 2001). Results are only one way of analyzing the materials gathered and there is no guarantee this “truth” will fully emerge with the views of the participants themselves (Malterud, 2008, Patton, 2002). Therefore, it is possible that observations and interpretations of situations may not match the participant’s understanding of the same issues, particularly in this study where I came from a different culture, had never been affected by poverty, spoke a different language and had a professional background which might have created a distance in the interviews and may have influenced what was shared. This lack of balance might have been adjusted by the researcher being young, not married and without children of her own, in addition to belonging to an egalitarian culture, and with no personal religious beliefs. The background as a health worker may have created closer cultural proximity with the health workers participating in this study in combination with the shared English language.

Having said that, one way of reducing the natural differences in mind-set and gain more accurate understandings is to acknowledge that the differences exist and make a habit out of continually checking analysis and interpretations with the participants during interviews. By doing this, it was possible to strengthen common ground and obtain important reflections on their reality. The research team also used *chitenges* (a cloth to wrap around the waist) which are worn extensively by women in Zambia and are seen as a respectful gesture when entering people's homes.

One important dimension which has had a central role throughout the process of planning and executing this study is that I worked in the Kazungula District under circumstances very similar to the context in which this study took place. Prior experiences were useful in understanding the complexities found within childhood disability in the Kazungula District. One challenge I knew would arise was the likelihood of perceptions about me being white and rich, and as such could influence the families to participate. We tried to reduce such expectations by giving extensive information about the study during the initial meetings with local leaders and in the first meeting with families in their homes. During the later information meetings, the communities gave us good feedback on such an approach, since they are used to situations where the presence of people from other cultures could mean some type of benefit.

3.5. Trustworthiness

To be able to say something about the relevance of this study, it is necessary to look at how it was carried out and how this has influenced the material. To have a critical approach to the methods and how they were used throughout the entire research process will give information about what has been found and the implications this has (Malterud, 2008). Since this is a qualitative study, the aim is not to come up with one single truth; therefore, the concepts of validity and reliability as used in quantitative studies will not be used. Trustworthiness, as described by Guba and Lincoln (1985), will be used instead through the concepts of credibility, transferability, dependability and confirmability. This allows for a critical approach to the relevance of the method applied within a social world in constant change.

3.5.1. Credibility

To investigate credibility means to look at the appropriateness of the methodology and if the study has been conducted according to good practice (Patton, 2002). Throughout this study, methodological and ethical concerns were constantly evaluated. Another aspect of credibility is to submit findings to the participants in the study so they can give feedback on the interpretations made by the researcher and check their own interpretations (Guba & Lincoln, 1985). This concern was addressed through the information meetings held with local communities, following the in-depth interviews. What became apparent during information meetings were that very different voices were heard in the different meetings. One meeting had a strong influence from local leaders where the voices of parents were rarely put forward. Another meeting where the headman present had to leave early opened up for more activity from the parents of disabled children, yet another had a very active traditional healer who was also a father of a disabled child. Triangulation was also used; multiple sites, two different groups of participants, and observations complementing the in- depth interviews.

Trustworthiness must also be based on what the informants are willing to share and how they share it (Lincoln & Guba, 1985). The informants have their own reasons for participating, and may have shared what I have interpreted as their own genuine experiences and opinions which could be affected by them telling me what they think I would like to hear. At the same time, informants may have a desire to justify their own actions. In this study the parents may have seen the research team in connection with the rural health center and as such overemphasized the use of it. Another aspect which also has to be considered is the recall bias in that parents in this study have had disabled children for a long period and their perceptions of what has taken place will be shaped over time and influenced by new experiences. It is also important to address the two interviews were two participants were present simultaneously and acting as participants in the same interviews. This would influence what the participants are willing to share and they might hold back information. It is also possible that having another family member present created a more secure environment and as such facilitated open responses.

Throughout interviews I checked with the participants if I had understood them correctly, however I did not make this a continuous habit, only in situations that were unclear to me. Therefore, there may have been situations where my understanding should have been checked. There were situations with both health workers and parents where they changed their

minds and their attitudes. This may have been as a result of how the questions were asked by the researcher, and not necessarily as a consequence of the participants changing their opinions (Kvale & Brinkmann, 2009). We made summaries at the end of interviews in an attempt to ascertain whether we had understood what the participants had said.

The concept of disability was not pre-defined, but used freely so as to retain the perceptions of the informants in determining what was said, and what falls under the definition of disability as seen from the view of the participants. This could have influenced both the recruitment process and what the participants wanted to share depending on how they perceived disability. This raises questions not just about whether the participants were telling the truth, but what they are telling the truth about (Malterud, 2008). The aim of not using a more narrow definition of disability was to acknowledge that the concept depends on context and a favorable definition by the researcher might not have matched the perceptions of the participants. At the same time, very few had a formal diagnosis, and therefore the local Tonga language term equivalent to condition was used for the parents, and disability as a concept with health workers. It is therefore important to acknowledge in this study that the participants were referring to their own perceptions of disability, and this will influence what the participants say something about. For instance, when the health workers said they had not seen children with disabilities at their RHC, one must take into consideration their perceptions of disability as a factor influencing their answer. Two of the health workers made extensive references to mental health throughout the interviews which could be interpreted as a particular interest, but could also say something about what the concept of disability consists of to them. The diagnosis used in describing the children further in this thesis stems from a combination of what has been reported by parents and health workers, and the view of the researcher.

3.5.2. Transferability

Transferability refers to giving a comprehensive account of the research process so that others can evaluate the relevance of applying the findings to other circumstances (Lincoln & Guba, 1985). Within this study, the sample was small, and the aim was not to make generalizations to large populations, but to point to something that others can recognize. By gathering a variety of information about a small sample it is possible to transfer important findings about phenomena to similar groups under comparable conditions. Trustworthiness would have been

strengthened by recruiting people who were not known to the RHC. Recruitment through the RHC and community volunteers could have influenced the sampling. In the current study, we only met with those people who had actually used the RHC, which means the conclusions are based solely on their experiences. Families with no contact with the RHC or community volunteers might have provided this study with different perspectives.

3.5.3. Dependability

Dependability can be compared to the term reliability in quantitative research, which refers to whether it is possible to repeat the findings and outcome of the study if it was measured again (Lincoln & Guba, 1985). Such replication is not possible to achieve in qualitative research where the social world under study is changeable and never fixed. Therefore, dependability is used instead, by giving comprehensive information about all stages in the research process in the ever-changing context where the research has taken place. This is done in an effort to accomplish transparency to meet the criteria of dependability, and has been tried in every step of the research process.

3.5.4. Confirmability

Confirmability refers to neutrality in the research process, and can be difficult to achieve in qualitative research (Lincoln & Guba, 1985). A unique perspective is brought into the research process by the researcher and, as such, reflexivity is a strategy to raise awareness of how the research has been influenced. The subjectivity of the researcher was always present and will influence the results, which makes reflexivity important in the validation of the study (Patton, 2002). With the research question in mind, findings and discussion were based on what the researcher found relevant. Supervision from an experienced researcher throughout the entire research process has therefore been vital.

3.6. Ethical considerations

The participants must understand and be informed about the possible risks and benefits, the concept of voluntary participation, confidentiality, the purpose of the research, how they were

chosen to participate, procedures for data collection and who to contact with questions and concerns (Ulin, Robinson & Tolley, 2005). In the following I will look into these ethical dimensions.

3.6.1. Informed consent

Informed consent is viewed as the cornerstone of medical ethics and a major principle of all medical research (Nuremberg Code, 1949). Munhall (1988) used the concept of process consent to describe what is going on within qualitative research and she argues that informed consent has to be a continuing process when research is conducted within a constantly changing field.

Within the concept of informed consent one of the main pillars for the participants to understand is the nature and purpose of the research. In order to do this, one predetermining factor is that researchers must do what they say they will do (Benatar, 2002). Through a qualitative study with in-depth interviews as the main method for collection of data, new insights throughout the process emerged. Such new information can impact the outcomes and make it difficult to notify the participant about all relevant aspects in advance, and fully prepare them for what might come up during interviews. The importance of assuring that the participants understood the possibility of unconditionally dropping out if they wanted to, and to look at informed consent as something they had to give continuously, were strategies that could minimize discrepancies. During some of the interviews, due to unforeseen circumstances, the researcher stopped the interviewing and asked the participants if they wanted to continue. When the conversations changed character, the participants were asked for new permission in an effort to meet the criteria of viewing informed consent as an ongoing process.

Written informed consent was obtained from all participants. All necessary information about the study was explained to the participants in the local Tonga language or English before they made their decision to participate or not. The participants were given information so that they knew what they were consenting to, to clearly state that they could withdraw from the study at any stage and that their decision would not affect their future chances of receiving health care. They were given time to consider participation and to ask questions. The research assistant

read through the informed consent forms in the local Tonga language before signatures were obtained from the parents.

3.6.2. Confidentiality and anonymity

In qualitative studies there is always the possibility of recognition of participants (Goodwin, 2006). As such, the principle of confidentiality must be addressed. Confidentiality means that the information informants give during interviews will not be traced back to them or made available to others (Goodwin, 2006). Thus, efforts were made to discuss the challenges which arose when the researcher used quotations and wrote about a small number of informants in her own voice. By doing so, the informants were able to take this into consideration when sharing information during interviews.

In the research process, the names of informants and locations were changed in order to reduce the probability of recognition. Such a task might seem straightforward, but is challenged when groups of informants belong to small and transparent communities (Goodwin, 2006). One way to meet the criteria of anonymity was to recruit participants from various catchment areas. Moreover, when using quotations in the text and when writing about the participants, the terms “health worker”, “parent” or “grandparent” have been used so that information cannot be linked to the person it refers to.

3.6.3. Risks and benefits

The potential harm and benefits to participants as a consequence of participating in research need to be approached and potential benefits should outweigh the risk of harm (Kvale & Brinkmann, 2009). Research participants may experience anxiety and distress not anticipated during the planning of the study or covered when information is given to them (Richards & Schwartz, 2002). The risk of a power imbalance is also an underlying factor, which can potentially cause the exploitation in the relationship between the research team and the participants (Richards & Schwartz, 2002). This could have led to situations where participants felt obligated to participate. There is also a possibility of seeing the interview as a therapeutic session where participants may say more than they had initially thought they would when consenting to participate. Within this study, parents may believe that they will experience changes in the situation of their disabled children through contact with the research team, a

factor that may have motivated them to participate. Further, emphasis has to be put on security in terms of respecting the participants, not only according to the researchers' own perceptions of respect, but also in-line with the participants' limits and interests (Malterud, 2008).

One way of overcoming these challenges was to obtain as much knowledge as possible about the situation of the participants before the interviews took place. Another point to consider was making sure of the wellbeing of the participants during interviews, which can be assured through a mutual trust and respect where the participant feels safe without being pressured or invaded. Another way of reducing the likelihood of stepping over the boundaries of the participants was to inform them adequately about the study, and be completely open about how the information will be used. Arrangements were made with community volunteers to contact the RHC if parents needed to be followed up in relation to participation in interviews.

As the participants invested time and gave their stories and perspectives in participating in the study, compensation should be given to value their contributions (Patton, 2002). Each of the parents in this study received two chitenges (long cloth to wrap around the waist), given to the participants after the interviews to decrease the risk of participating solely for the incentives. They had not been informed about this in advance since they live in extreme poverty and any kind of means could have been viewed as incentives to participate. The type of compensation was discussed with the KDMO and two chitenges were seen as appropriate. The health workers were not compensated for their participation since they were interviewed in relation to their work.

It was important for the research team to get feedback from the local communities of the preliminary findings. It was discussed to do this only with the informants, but this could have been a way of identifying them. We therefore decided to invite the participants together with staff at the clinic, community volunteers, local leaders and other parents with disabled children who had not been included in our study. This was done in an effort to have the voices of the local communities heard since the initial permission for carrying out the study was done on a community level before the participants were recruited. Another important aspect of conducting a village meeting was the very likely lack of access to the results experienced by the parents. They would not be able to read the final thesis in English.

A valid research design involves beneficence (Kvale & Brinkmann, 2009). During the interview situation, participants may consider and think about issues that have not been

apparent to them earlier (Richards & Schwartz, 2002). The answers provided by the participants might make them reflect differently and question issues that they earlier took for granted. This could potentially increase the knowledge within the participant. Another possible benefit could be that it will be meaningful to the participants if what they say and do will give others an increased understanding of the situation for disabled children and their families.

It is possible that a risk for disabled children and their families as a group could emerge if the findings of this study create stigmatization within the community by focusing on their situation specifically. On the other hand, it could also be beneficial to center attention on their situation and create a greater understanding of their circumstances. Interviews with health workers could therefore create more focus on the health care of disabled children and increase awareness in addressing their needs.

3.7. Data analysis

The data was analyzed through Malterud's modification of Giorgi's phenomenological method (Malterud, 2008), a four-step approach which can be useful in developing new concepts and descriptions across a material of several informants (Malterud, 2001). The method can be applied to the text with the aim of uncovering meaning as experienced by the informants (Malterud, 2008). Data analysis is a continuous process, and occurs also during data collection. The first step is to gain a familiarity with the material as a whole (Patton, 2002). A wide scope was initially applied in this study as the first step recommended by Giorgi. This was done to lessen our own influence on the material, and bring forward the voice of the informants. In the next step, meaning units were constructed from what the participants had been sharing; for example, traditional medicine, expectations, referral system, explanations and barriers. The meaning units were then organized into codes by using the NVivo 9 data analysis software. Examples of codes used were are; workload, cost, traditional beliefs, religion and social support. Some codes were more specific than the meaning units and various meaning units changed character as a result of the coding. In step three, the meanings were abstracted from the codes and were viewed in relation to the purpose of the study before themes were tied together into descriptive statements in the final step. The researcher has limited experience with phenomenology, and no former experience in carrying

out this type of analysis, therefore the analytic process has been less systematic than what the model describes.

3.8. Storing of collected data

Data material was stored in a locked closet and kept separate from any key information about the informants. The informants were given codes HW 1-13 (health worker) and PC 1-16 (primary caregiver) when verbal material was transcribed and stored to avoid recognition of informants.

3.9. Dissemination of results

This thesis will be distributed to the Ministry of Health, Zambia, Southern Province Medical Office, the Kazungula District Medical Office, The Norwegian Association for Disabled, The Norwegian Association for People with Developmental Disabilities and Opportunity Zambia. A dissemination seminar is planned with stakeholders within the field of disability in different parts of Zambia. A short version of the thesis will be translated into the local Tonga language and disseminated to the local communities where the study was carried out. As the primary investigator, I also plan to turn this master thesis into an article.

4.0. PRESENTATION OF FINDINGS

The presentation of findings will commence with an introduction to the main findings. Thereafter, the findings from the interviews with parents and health workers will be presented separately, and findings from the information meetings will then be given.

4.1. An overview of the main findings

The families of disabled children have the main responsibility for taking care of their children and management is carried out within the household. Parents of disabled children use the rural health centers when their children are affected by common conditions, but rarely for the assessment of the disability. In such cases, they are more likely to seek help from traditional providers. They often leave their children at home when the RHC is consulted. The main barriers to health care are explained by long distances, lack of available transport, inadequate assistance at the RHC, the RHC is not adequately staffed, equipped or empowered to handle comprehensive health needs. Poverty is an underlying factor influencing all of these barriers and contributes to resignation in health behavior. The parents are fluctuant in their health-seeking behavior, and are willing to try a myriad of providers and treatment options, often simultaneously, in the process of finding explanations and a cure for their disabled children.

4.2. Findings from interview with parents

4.2.1. The disabled family

In this study, parents had different experiences when describing how having a disabled child influences their families. The father of an 8-year old boy with visual impairment described his situation in this way:

“When you are keeping a disabled person, you are also disabled”.

This family has 10 members, the parents and 8 children, they live by themselves, separated from other people in the village and they share the responsibility among themselves in caring for their disabled family member. The father described the disability of his son as something projected onto him and the rest of the family and, as such, is highly influencing to the family.

The boy is not in school and needs to be looked after continuously. According to the father, they bring the son with them when they have work to do, but he needs extra attention since they fear he will hurt himself if he is not properly looked after. The family wants him to go to school, but a lack of resources and long distances prevent him from attending. In the event of the son becoming sick, the family will sit down together, discuss the reasons for ill health and negotiate possible solutions to the problem, which can include the allocation of financial resources and further management. Then one family member, usually the mother, will take the child to the RHC and explain what the family has already discussed. This family has taken their visually-impaired son to the RHC on many occasions in an effort to seek help for his condition. During his younger years they were often told to wait and see, something they did but saw no improvements. Now, the RHC has told them that the provision of help is not possible from their side, and they have requested the family seek help at a specialized hospital. This was not possible due to a lack of money, and the family has made arrangements amongst themselves to make sure the son is always looked after, and to make sure he gets the assistance he needs from the family.

The social support available within the families and communities varies greatly according to the participants in this study. Some of the parents have extended families where the responsibilities for caretaking and provision of financial means are shared. Others describe situations where their husbands have left the family, moved to another village and remarried, thus leaving the responsibility of the disabled child to the mother alone. One mother married a new man after her first husband (and the father of her disabled child) passed away. The new husband stayed in another village, so she went there with her disabled child to live with him and his family. The new husband was not supportive, he complained about the son contaminating his children by having a disability, and that made the mother feel uneasy about the situation. She described it in this way:

“There is no way you can just love me and not my children”.

She felt she could not be in such a relationship and a decision was made to separate. She moved back to her parents with her disabled child where she now lives in a separate house with her son. Her parents provide her with the means for her to be able to sell fruit and vegetables so that she can take care of herself and her son.

One of the grandmothers interviewed in this study shared her experiences in having responsibility for her four-year old granddaughter with cerebral palsy. The reason for the

grandmother being the primary caregiver is that her daughter, the mother of the child with the disability, is sick and is being cared for by the sister of the grandmother in another village. Another grandmother had responsibility of her grandson as a result of his parents trying to make a living in a town, and he can be better looked after by the grandmother in the village. There are a variety of reasons for disabled children residing with different family members, and the explanations parents often gave was to provide as much care and assistance as possible for the disabled child. Mothers described strong obligations to bring their children to work instead of leaving them behind at home by themselves, and impacted on the ability of the parents to work, produce food and earn an income.

Parents expressed opinions about the responsibility of a disabled child as something kept within the family; the local communities are rarely involved. One mother explains:

“... the people were saying if the doctor who helped you deliver saw it and did nothing, what else can we do?”.

The RHC cannot provide help, and the local community is, as the mother puts it, not interested in the girl. They may ask how she is doing, but they would never take steps beyond that. The girl is, therefore, either looked after by her mother or father, and the mother usually carries her on her back when she collects fruits to sell by the roadside.

Parents also expressed that having a child with a disability is a natural situation within their family. Everyday life for them includes taking care of a child with extra needs and this is regarded as ordinary within the family. Additionally, parents articulated concerns about the future of their children and the fear of dying themselves leaving their disabled child to be looked after by others. One mother explained it like this:

“I will leave her to suffer if I die”.

This mother is the head of a small household with a 10-year old girl with epilepsy to take care of. She makes the decisions on behalf of her family and earns respect in that manner. The father is a polygamist and spends most of his time with his other family in another village. He comes to visit once in a while and supports the decisions she makes in regard to the condition of her daughter.

4.2.2. The rural health center

The parents interviewed in this study stated that they had been to the rural health center with their disabled children. The main reasons for going were to have their children vaccinated, to get help for common conditions like fever, diarrhea, headache and stomach pain, and to collect medicines for children with epilepsy. In many situations, the sick child was not brought to the clinic in person, but the parents or other family members were sent to collect drugs after explaining the signs and symptoms to the health worker at the rural health center. This is mostly due to the challenge of carrying the children for long distances when assistance is sought.

The parents described situations where the disability was not assessed and treatment was not given. One exception was parents with epileptic children who reported a reduction in the number of fits seen in their children and who explained that they collected drugs once a month. The lack of assistance makes the parents dissatisfied and they explained that they no longer made use of the rural health center in the management of the disability, as one mother explained:

“...they just wrote her name down but they didn't do anything or say anything”.

This woman has a three-year old daughter with cerebral palsy, and the family has stopped taking their disabled child to the rural health center because they do not believe that any help is provided. They must walk for approximately one hour to get to the center, and since the girl is not able to use her feet, the mother has to carry her all the way. The family does not believe that the rural health center meets their needs. This description of a situation where they come to the rural health center for help and do not receive what they perceive to be adequate treatment, was often described by the parents.

Few parents had the condition of their child explained at the rural health center. The only informants in this study who said they had the condition explained were the mother and grandmother of an eight-month old boy with hydrocephalus who were interviewed together. The family had been to a referral hospital where they were told that the reason for the boy's large head was water inside his head that would not go away. Another mother with a physically disabled girl as a result of malformation of the feet did not get the same treatment when she gave birth to her daughter. The doctor taking part in the delivery hid the baby away from the mother so that she was not able to see her newborn daughter for some days. It should

be noted that most of the parents mentioned that they did not actively ask about the condition of their child when they saw the staff at the rural health center. The reasons for this were various; some mentioned that they didn't want to take up too much time with the health workers when others were waiting, while others didn't see the point in asking questions, they had come with a particular purpose, so they explained why they had come and were given the medication to treat symptoms.

When asked what kind of assistance they had received from the rural health center, the parents described situations where the health workers had not been able to provide any assistance. One father stated that:

"... at the time we went to the clinic, they said they couldn't help him in any way because he was still too young".

He explained that he or his wife had taken their 8-year old son to the rural health center on numerous occasions. The son is blind, and was taken to the rural health center for the first time when he was one-week old. The mother gave birth at home, and the parents could see that something was different with his eyes, as they appeared white and cloudy, but they took it to be the natural appearance of a newborn. When the cloudiness did not disappear, they decided to ask for advice at the rural health center. During the first years, they were asked to come back again and again, but as their child grew older, the clinic made it clear that they could not assist with his blindness and they were told to seek more specialized care at the nearest hospital, two hours away by car, which was not possible.

To make use of referrals was difficult for the parents in this study. A mother with a 10-year old deaf daughter had these experiences in generating money for medical treatment:

"... we'll take her when we find money, but the father also got sick and then he passed away, so there hasn't been like money to go back".

She remarried and moved to live her new husband while her disabled daughter remained with other family members who take care of her. The mother stated that her new husband is morally supportive, but he does not earn money himself and has to provide for his own children as well. He is, therefore, unable to contribute any money to help her daughter. The family brought their daughter to a more specialized hospital when she was younger, where she was given medicine to put in her ears the three times she was there, but they were not able to locate more money and were prohibited from returning. Transport is rarely available, and the

cost of transport is high, particularly when compared to the resources available within their household. This view was shared by all of the parents who pointed out that a lack of transport and the costs involved in both transport and upkeep was a major challenge for them.

All of the parents spoke of referrals as the only treatment option offered by the rural health center, however they rarely had the opportunity to follow this up as a result of costs and time involved in taking the child for more specialized care. Some parents had already taken their children to higher-level hospitals and described situations where they were not treated well and discharged unsatisfactorily. Others shared future plans for going for specialized care when their economic situations changed. They will be provided with a referral letter from the rural health center when they have located enough money. This they hoped to achieve with the help from other family members or through a good harvest, as this mother explained:

“It can take a while because we need to plant, and then we harvest and sell, so it will take some time”.

The parents had to plan such activities some time into the future to be able to generate money beforehand so that they would be able to bring their children for attention at a referral hospital.

4.2.3. Other providers

Many of the parents within this study had used the services of traditional providers in their efforts to find a treatment for their children with disabilities. At the same time they described unsatisfactory results from these consultations with traditional practitioners. Some had experienced light improvements, but they rarely attributed it to the traditional practices alone. One exception to this came from an older mother who was advised to try herbal remedies when medication from the hospital had failed:

“She was born ok, but then she developed some cerebral malaria and the fitting also started. So she was taken to the hospital, there’s a psychiatry section there. So they gave her some medicine but it just got worse. Someone advised to try traditional herbs, they help. She (the mother) stopped taking her to the hospital and tried traditional medicine. They helped and she stopped fitting. But just the speech hasn’t come back”.

She said she cannot be sure whether the herbal medicine was the only reason her daughter stopped fitting, but she said that she believes the fits took most of the brain away from her daughter and that's why she was not able to speak today.

The parents in this study reported that their children had been cured from traditional treatment, but several of them had been promised complete healing. The majority of the parents had traditional explanations for the condition of their child, and bewitchment was often described as the cause. For the child to become well again, several witchdoctors were consulted with no change in the situation of the child as a result.

One mother explained the reason for the condition of her 10-month old son with hydrocephalus through the narrative of someone putting medicine out to trap her. The mother stepped on that medicine when she was pregnant and that is the reason for her son's condition. The family accepted this explanation and traditional doctors had been consulted in an effort to treat the boy. Another father believed that the soul of a community member had slept with the mother while she was pregnant, causing the child to be born with a disability. Another mother explained the situation of her 15-year old daughter who, according to several traditional healers, was bewitched by a person that was actually staying in the village. The soul of her daughter was taken away and just her body remains. For this situation to be reversed they must find out who did this to her daughter and make sure that person dies.

Often other family members suggested that the disabled child be taken to a traditional healer for treatment, and while many of the parents expressed skepticism during the interviews regarding this type of treatment, they were often willing to try since other family members thought it would be useful in the process of getting a healthy child.

One mother explained her belief in traditional medicine in favor of health services offered at the rural health center: her daughter had epilepsy and was given anti-epileptic drugs from the local clinic with the result that her fits reduced. However, the fact that an element of her daughter's condition still remained was difficult for the mother to accept, and so the family took the girl to traditional providers in an effort to cure the condition completely. At the time of this study, the complete cure had not yet been realized, but the mother would not settle for a temporary solution, she believed her child would be completely healed at some point in the future if the right traditional provider could be found.

Religious beliefs played a very important role in the lives of the parents and families taking part in this study. As one mother pointed out:

“I just pray to God, but I don’t know how God has planned this thing, how it’s going to be”.

She had numerous people telling her a variety of reasons for her daughter’s condition. The mother described herself as a praying person and she had seen powerful results from her prayers:

“If I look back at the start of the fits, I have noticed that God listens to my prayers”.

Her daughter used to fit a lot and this has now reduced, all that remains is a hand that shakes and some pain in her legs. The mother believes that the condition has changed for the better as a result of her prayers.

Parents attributed many of the improvements seen in their children’s disabilities to God; He is the only one who knows, He has a plan and it is in His hands. They all had their prayers heard in various ways and they explained the interference of God as the main reason for improvements in the functioning of their children. One mother was grateful for the help she received from God; now her three-year old daughter stands with support, where in earlier days she couldn’t. Only one family, the mother and grandmother already introduced, said they had not seen any help from God at this point, but as time passed, they hoped to see positive changes. People from their local church came and prayed with them regularly and they said they appreciated this.

The parents also pointed out the importance of support from members of their church in caring for their disabled child. Through their various congregations they are encouraged to continue trusting in God and to pray. These parents talked about the presence of God as being of enormous help in difficult situations, not just in connection with the disability of their child, but also in providing the family with the necessary means for survival. Some parents stressed the importance of combining the faith in God with actively seeking help elsewhere for the condition of their child.

Throughout conversations with parents they did not express a fixed chronology of where to seek help first. Some had been to traditional providers before they decided to seek help at the RHC. Others initially went to the RHC before they consulted other providers, and under many circumstances there was an overlap in the use of available treatment options. The one thing

that stood out as an important factor was the wish they had to find sustainable solutions with the aim of improving the situation for their disabled children. At the same time, the parents communicated that they were willing to try any means possible to improve the condition of their child. One grandmother put it like this:

“... when you have a patient, you try everything”.

She had responsibility for her 6-year old grandson with cerebral palsy, and described numerous efforts taken by herself and other family members in responding to his needs. They live nearby the clinic and he had been to the rural health center on many occasions. The family had also taken him to a specialized hospital, but they said he only got worse, and they had brought him back home. Now, the grandmother described his condition as being stabilized, and she does not see any reason to use such services again; what he needs, he can get at home.

4.3. Findings from interviews with health workers

4.3.1. The disabled family

There was a common view among the health workers that children with disabilities can be viewed as burdens to their families. This was underpinned in cases of severe disability, and two of the health workers expressed that the death of a disabled child might serve as a relief to the involved families. According to many of the health workers, these children were treated differently within their families and local communities, negligence and a lack of priority were common occurrences. One nurse explained:

“And the mothers also they don’t come out in the public to show or to say this is the challenge that we are having at home, maybe they don’t have food, maybe the clinic can help in a certain way but they cannot come because of that child who is disabled”.

In terms of the pattern of seeking help for the condition of disabled children, most of the health workers believed that these families first seek treatment from traditional providers before coming to the clinic. Moreover, they accredited the reasons for coming to the clinic as a result of failure from other providers; experiencing a lack of improvement in their children from other sources drove them to seek assistance at the rural health center. Their reasons for seeking traditional treatment, according to the health workers, were local beliefs and

understandings about disability in combination with pressure from relatives and local communities.

4.3.2. The rural health center

Health workers within this study reported that they rarely saw disabled children at the rural health centers. Some of the health workers reported that they had seen only one or two disabled children in their present work. In cases where families brought their disabled children, they generally came to get help for common conditions like fever, diarrhea, headache and vomiting. They described a lack of strategies to identify, administer and follow-up with children with disabilities, and provision from the RHC was often only through the management of common conditions. One health worker put it like this:

“And maybe there is also poor identification. At times when someone maybe comes to the clinic you just look at the presenting part, maybe has got fever what and what. But you are not going to consider maybe the disability of that individual so times the care we tend not to assess these children properly, at times we just maybe concentrate if someone comes, maybe the woman will bring a child, you just ask what is the problem, they’ll tell you no, the child has got diarrhea but you have not assessed the other disability the child has so that you are able to identify. That is such a problem also. I think that one we are not doing very well”.

This health worker here made a distinction between the disability and other conditions, with the disability being left out and, as such, is contributing to the poor identification he describes in the beginning.

According to the health workers there were many children with disabilities within the catchment areas that are not known to the rural health center. The reasons stated by the health workers for these children and their families not coming to the clinic were one or more of the following factors: lack of knowledge within the families both in terms of the condition of the child and in terms of facilities they can find at the clinic, long distance, lack of money for transport, inadequate services offered at the rural health center, traditional beliefs, and families not wanting to come out into the open with their disabled children. One health worker gave this statement:

“There are so many people with disabilities who have not been followed up, who have not been identified, and who have not been taken care of”.

He pointed out the shortcomings experienced by health workers in trying to meet the needs of disabled children and their families. The health workers in this study emphasized the important role of the neighborhood health committees and community volunteers within their catchment areas in identifying disabled children.

The health workers stated that they had heavy workloads with many patients to attend to on a daily basis and time constraints limit their ability to assess and enquire about issues outside of what the parents present as signs and symptoms in their child. The health workers depend significantly on information from parents in the process of decision-making and for further management. They communicated that they might have attended to disabled children at the rural health center without being aware of the condition of the child, and they explained this as a consequence of a high workload and a lack of adequate training in identifying these children. As one nurse stated:

“And maybe the parents will not explain the other problem that the child is facing. They will only focus on the presenting part at that particular time. But what has been experienced before they will not talk about it, to them they will just take it to say it’s normal”.

The assistance that can be offered by the rural health centers to disabled children and their families is described as being insufficient by the health workers. They said that the service they can offer is limited, and they explained that such a situation can be a barrier for parents in bringing their disabled children. In many cases, the only treatment option available to attend to the disability is a referral to a higher-level hospital. The responsibilities of the RHCs in such cases are to provide the child and the family with a referral letter, and then leave it to the families to decide if they can go. The health workers described situations where they referred, even though they knew that the families would never be able to take their children to town for further management. They described various reasons for this inability, including long distance, lack of transport money, fear of not being able to provide resources for upkeep in town, general unwillingness to go to town and a bad reputation of higher-level facilities. These factors all contributed to the prohibition of these families seeking further help for their children. This was described by a nurse running one RHC:

“There are people who come very poor, you refer them to General Hospital and then they say we have no money to go, then they decide to go back home, and it’s very sad, we feel like we are failing in our duties”.

This nurse described the services they offer at her rural health center as inadequate when parents are not able to follow-up on their recommendations.

In addition to referrals, they can prescribe medication, in particular for children with epilepsy and for general conditions like fever, diarrhea, headache and body pains. Health education was mentioned as a service offered at the rural health centers, however, how this health education is given and what it contains differs from health worker to health worker. The components mentioned were awareness of how to handle a disabled child, nutritional advice, and the importance of integrating the child into the daily activities of the family and the community.

The health workers noted the importance of good examples in the local communities for the creation of a better reputation for the RHCs, which will increase the number of people who access health care. The HWs had experienced the opposite situation, where they had been faced with great challenges in not being able to help children with disabilities adequately. Within their local communities, knowledge and ideas are shared in such a way that positive and negative experiences among others will influence the pattern of seeking health care. Family and community ties are strong and people usually know what is going on, what has been the outcome of interventions and what has not been successful for other members of the community. Some of the health workers highlighted the efforts they had made in trying to meet the needs and expectations of families with disabled children. They focused on the importance of adequate treatment for conditions of a more generalized character, conditions that are often easier to treat because they are less severe, and the RHCs have regiments and medication available to address such conditions. The effects are reported shortly after, and the families have seen that there are positive outcomes of treatment for less severe illnesses at least. According to the health workers, this could act as a catalyst for families to use the RHC more extensively than what is being described. Some suggested that this strategy could be used to create an environment of trust between the families and the RHCs and therefore facilitate these families bringing their children to the RHC more often.

Health workers expressed beliefs about these families having a need to explain the condition of their child; something out of the ordinary has taken place and this needs to be made clear in

some way or another. Some pointed out the challenges in transforming medical explanations into local understandings. Others described situations where they were challenged in communicating about a condition that is also new to them. They often work alone at their RHCs with limited access to sources of information on topics like disability. Moreover, they have priorities to follow and targets to reach in order to fulfill their duties, which can impact on the time available to talk about complex conditions.

The health workers experienced families with disabled children having high expectations about the outcome of services offered at the RHC. One clinical officer expressed it in this way:

“So they are too expectant when they come. They rely so much on us and at times they explain things and at times to you it’s a challenge but to them they think you are like God, they expect actually the best actually from us, they expect to get well, they think we can treat anything”.

He described situations where the local community complained about the RHC and said they were not doing enough to meet the needs of these children. According to him, there was a wish among families that these children should be better as soon as possible after consultation at the RHC, and the work he was doing in sustaining the situation and preventing it from worsening, which was often the best he could offer, was not seen as good enough in the eyes of these families. The health workers reported that the families often asked for medication, which was usually given in the form of light painkillers.

4.3.3. Other providers

Among the health workers in this study, there was a common opinion that some parts of traditional medicine are accepted. The use of herbs was acknowledged to be of benefit, and some of the health workers stated that they had seen positive effects from this type of treatment. Witch doctors and witch finders, in contrast, were not recognized as serious providers. One nurse addressed the issue in this way, when asked about her opinion on traditional medicine:

“On that one we preach them about Jesus Christ, that’s what we do when we fail at the clinic, just tell them that it’s not about going to the witch finders or witch doctors, just take your complaints to God”.

This mention of God as a force in the treatment of disabled children was described by other health workers as well, who had told families with disabled children that they must have faith in God. When they realize that they do not have adequate treatment to offer, and have acted to the best of their knowledge, they tell the parents to continue praying and believing in God.

4.4. Findings from community meetings

Many new stories from other parents with disabled children were shared during the meetings, and some new aspects and issues turned up which were out of the scope of this study. Parents expressed that being brought together gave them new insights into their situations, particularly with regards to the fact that there are other families in similar situations. Some of the parents said that they thought they were the only ones with a disabled child. Such new information will not be described further, but has been taken into consideration throughout the analyzing process.

In all four meetings, it was expressed that the main barriers to seeking care at the RHC were a lack of financial means, unavailable or non-existent transport, long distances and the fact that the RHC did not have the services to handle disabled children. Parents said that the RHC might not explain the condition of their children well enough, and they believed that can influence the quality of help received there.

The families told of how they sought help for common conditions and for the practice of extensive referral from the RHC. The RHC was said to be the starting point for disabled children, and parents expressed challenges in being able to utilize the referral letter they were given from the RHC. They said that they wanted to use the referral, but a lack of money prohibited them doing so. This made the use of traditional providers more convenient, and it was pointed out that such services were often free of charge. Another point mentioned was the notion that people had about bewitchment as the cause of the disability and the understanding that the condition of the disabled child was something believed to be “from the hands of people”, from a person wanting to inflict harm on the parents.

The treatment offered from any provider, be it from the RHC or traditional providers, was seen to be of little benefit to disabled children, and a combination of treatments was described to be common. Since no help was found, the families ended up staying at home with the child

until the child would get better. There are no programs specifically targeting disabled children and this was commented on as being a reason for children remaining at home.

One important new element that was raised during the information meetings by several of the new parents we met who had not participated in the study was that they didn't realize they could bring their disabled child to the RHC; they had not known that was an alternative open to them.

5.0. DISCUSSION

People interpret their world and the reasons for their actions based on a variety of social and personal factors. These factors play an important role in bringing into existence the explanations for health and illness, and guide choices and activities undertaken by individuals and families in the process of using a health care system. Social and cultural circumstances will change over time and thus create a dynamic environment for action. Within a rural Zambian context, the dimension of poverty will have a significant impact on the opportunities for action. Poverty can be seen as a major health determinant, well beyond the control of families with disabled children and health providers operating within a local health care system, thus it acts as a strong regulator in the determination of access and utilization.

The discussion will be carried out in terms of two different paths profoundly interlinked. In the following section, the main findings of this study will be discussed within a framework of structural violence in an effort to understand the external forces influencing opportunities to make independent choices. I will attempt to address the structural barriers within a rural Zambian context, and try to get a better understanding of the impact these barriers have on health behavior. Furthermore, the understanding of explanatory models for health behavior within a local health care system is addressed with reference to Kleinman (1981). This is done in order to better understand health behavior and how the personal characteristics of the parents play a role in the process of seeking and obtaining care for children with disabilities. I will discuss how families and health workers in Kazungula manage childhood disability and which challenges the families meet when they experience illness in their child. The discussion will also incorporate other relevant literature in an effort to increase the understanding of the findings of the current study. The role of the rural health center will receive more focus than other providers within the health care system as a result of interviews being carried out only with health workers being the only providers of health care interviewed.

5.1. Structural barriers

The situation of poverty in rural Zambia is critical and creates obstacles difficult to overcome for families with disabled children. Poverty plays a major role in determining their access to health care, and can be viewed as an overarching phenomenon in exploring barriers and facilitating factors in the health-seeking process. The informants in this study described

numerous barriers in their encounters with ill health, and how they respond to episodes of illness will be strongly influenced by the poverty dimension affecting every aspect of their lives. They have few options to initiate and expedite change, and depend upon forces outside of their own sphere of control that have ramifications in all aspects of life. Overcoming the barriers consumes a lot of resources from those already living on the margins of what is possible. In the following discussion I will investigate the barriers as described by the parents and the health workers, and how these barriers create structural violence by prohibiting disabled children and their families from reaching their potential.

In order to better understand the situation of poverty in Zambia, I believe it is of importance to shortly address global inequity, which has structural violence incorporated as an establishment to sustain a state of inequality. This will be a very brief encounter with a very comprehensive debate. Theorists of structural violence characterize the world as unequal, with a growing disparity between rich and poor segments of the world's population, both between regions and countries of the world, and within countries (Pogge, 2002). Distribution of resources is uneven, created by people in power, and is consequently fundamental in producing and sustaining structural violence.

Zambia depends highly on development aid (GRZ, 2011) and, as such, global institutions interact with internal processes. One can argue that development aid contributes to social inequality by favoring a pattern of spending that benefits the already well-catered-for parts of the society (Uvin, 2010). The Zambian Government highlights the importance of strengthening transparency and accountability in the management of aid (GRZ, 2011), but mechanisms of exclusion are still supported. This illustrates how larger international orders substantially influence the dimension of poverty within the Zambian society and, therefore, is important to recognize when looking into the use of health care services on the ground.

Another important aspect to have in mind is the extensive corruption found within the Zambian society. According to transparency international, public money adding up to 65 billion euro every year is either misused, stolen or largely mismanaged (Hussmann & Chicalanga, 2007). This prohibits improvements in quality of life for those who are supposed to benefit from public spending, and illustrates a significant malpractice that is sustaining inequality and unfair power distribution. Consequently, the health condition of disabled children is at risk as a result of hunger, poverty, inequality and exclusion upheld by the existing structures.

5.1.1. Policies and legislation

In Zambia, the development of the Persons with Disabilities Act (1996), and the signing of the UN Convention on the Rights of Persons with Disabilities (2006) were undertaken with the aim to improve the situation for disabled people in Zambia, and eliminate all forms of discrimination on the grounds of disability. The development of a national policy on disability has been accomplished and would have served a purpose in addressing, among others, the situation of children with disabilities in Zambia. However, little has been done to implement these policies and legislation (Miller & Ziegler, 2006), and those intended to benefit on the ground say that they have not experienced any change in their everyday encounters with discrimination and challenging situations. This weakness of non-functional policies can serve as a structural barrier for persons with disabilities in accessing health care services, and influence the daily lives of disabled children and their families. As a result, inequality is maintained and those who could have benefited from implementation will not have their opportunities realized. Policies that are only active on paper will continue to uphold a system that contains a gap between the actual and potential resources utilized by people within that system. This disparity between actual and potential utilization of resources creates structural violence (Galtung, 1989). In Zambia, as a consequence, the caretaking of disabled children primarily takes place within the family. This established system can be seen to sustain an order where children with disabilities and their families suffer as a result of not being able to utilize their capacities.

5.1.2. Distance

In rural areas of Zambia, health care facilities are scattered and people have to walk long distances to reach basic health care. Long distances prohibited the families in this study from seeking help at a rural health center, and were described as a major barrier. This is supported by several other studies from Zambia (Diop, 1988; Hjortsberg, 2002; Van Dijk et al., 2009). In one such study (Van Dijk et al., 2009), it was reported that a large majority of children on Antiretroviral Therapy had to travel more than one hour to reach a government health facility and one quarter traveled for more than five hours. This illustrates how distance and travel time can challenge those rural Zambians in need of health care in their efforts to meet these needs. Ingstad's (2007) description of access to primary health care in Botswana, defined as being reachable by walking distance, illustrates the systemic barriers for those who do not

have the ability to walk. Differences between rural and urban areas of Zambia in relation to health behaviour and distance have been described (Diop, 1988), and Hjortsberg and Mwikisa (2002) points out that the differences in distance are particularly imbalanced when looking into inequalities between rural and urban areas. As such, people in rural Zambia have to pay more, relative to their income, to use health care services compared to more urban strains of the population.

The parents in this study described difficulties in carrying children (on their backs), which made distance an even more significant obstacle. As a consequence, parents or other family members often attended the RHC without bringing the disabled child with them. They would go to the RHC to collect the drugs they believed would benefit the child, and carry out the subsequent treatment at home. This illustrates how parents try to overcome one barrier, distance, by minimizing the burden on the family by leaving the child at home. This implies that the disabled child has already been assessed at home within the family, and the needs of the child, as seen from the perspective of the family, are presented at the RHC. Further management of the child is solely based on the information from relatives seeing as the health workers have not been able to examine the child themselves. The implications this has for quality of care is of great interest. Presumably, this situation leads to interventions that are strongly influenced by the perceptions of the disabled child's family. The level of education and sources of information available within these families influence their ability to give adequate care. At the same time, there might be situations where the understanding of the disability within the family is not in-line with the approach found to be beneficial from a biomedical perspective.

The health workers in this study reported that they are only partly able to meet this challenge by informing the relatives of disabled children about the importance of bringing the child to the RHC. They emphasized in their communication with family members that they did not have to bring the child every time, but once in a while so that the health workers could assess the child and (to some extent) get to know the child so that adequate services could be better applied in the further management of the disability. This illustrates how both parents and health workers try to find solutions within a system not adapted to their needs; the parents by sending a family member and, as such, trying to meet the challenging situation of distance, and the health workers by attending to the family members and encouraging them to bring the children to the RHC. Both of these strategies can be seen as actions that are of a more realistic nature within a system not adapted to the needs of those it is supposed to serve. If we take a

closer look at the practice of leaving a disabled child at home in the health-seeking process, the quality of care is highly threatened. At the same time, the alternatives these families have are limited and an even more disadvantageous situation is avoided by such a practice, namely that the families do not seek assistance from the RHC at all in response to episodes of illness in their disabled children.

5.1.3. Transportation and time

Another barrier mentioned by the parents was a lack of transportation, and in the event of transport being available, it was often not accessible due to financial constraints. Transport is limited, and the cost of transport high, particularly when compared to the resources available within their households. This is also reported by Evans and Young (1988), who described Zambian women who could not afford to become ill because getting themselves to the rural health center would mean they would have to stay away from productive activities. Rural households depend strongly on income from land through agricultural activities. When time that could have been used in the fields has to be reorganized to spend time reaching and using health facilities, this will influence the ability and motivation of families to use health services.

The infrastructure in the Kazungula District is of poor quality, and some areas are inaccessible as a consequence (Shankawaya, 2009). Walking is often the only way to move around, and was reported as a challenge in this study. This is in-line with Hjortsberg and Mwikisa (2002), who reported that residing in rural areas of Zambia has a negative impact on health-seeking behavior due to poor infrastructure. Van Dijk et al. (2009) reported a lack of transportation and poor road conditions as barriers to the use of health services for children on ARVs, and Birbeck and Munsat (2002) reported similar findings for people accessing neurologic services. The rainy season from November to April creates additional challenges and due to heavy rains, many places in Kazungula are cut off from health services and the main roads for months. The local communities have to survive without government health services until the rain stops and the roads are passable again. This situation clearly influences the use of health services in these areas.

Spending time taking the child to health care creates situations where one or more family members have to stay away from ordinary activities within the household and as such can

have a negative impact on the families. Consequently, time that could have been spent on income-generating or food-production activities must be sacrificed. If the family is already experiencing constraints, then it is even more difficult to overcome this barrier. For the parents in this study who depended on good harvests to generate income, the droughts in 2004 in the Kazungula District created a very challenging situation. Small-scale farmers were not able to produce enough food, which created hunger and further unpredictability among the affected families. In such situations, there are few alternatives available to improve living standards and to influence the overall distribution of resources within households. As a consequence, their ability to seek help is further deteriorated.

The barriers and impediments created as a result of long distances, lack of transport and use of time make it impossible for many of the families to reach the RHC when their children are sick and health care is needed. They are left to cater for their children's needs on their own, and a complex health status can make it very difficult for the families to actually provide adequate care themselves. This has the potential to worsen the conditions and increase the burden on the families as a result of an even more considerable need for care. Families having sole responsibility for the needs of disabled children can be seen as a result of the barriers prohibiting families from utilizing the services they need, and can compromise the health situation of these children (Ingstad & Grut 2007).

The Zambian Government has not been able to reach their missions in their health sector reforms to provide quality health care as close to the family as possible (GRZ 2011). The Declaration of Alma Ata in 1978 called for urgent attention to the importance of primary health care and the substantial need for immediate action throughout the world, with the primary aim to achieve "Health for all by year 2000". In Zambia, this has been addressed on a policy level, but still priorities are made which favor more urban and specialized sectors of the health care system. The central hospital facilities, which often have services operated by specialists and are better equipped, could have been of great benefit to children with disabilities, but these facilities are to a large extent far from reachable for the poor, rural families in the Kazungula District. This illustrates the essential role that rural health centers have in serving local communities and addressing their needs. The relocation of resources to facilitate more equity of access in health service delivery has not been realized (MoH, 2006). An increase in disability mainstreaming is planned for, which includes user-friendly infrastructure to intensify accessibility of public services (GRZ, 2011). If implemented, this could contribute to improvements in the lives of disabled children in rural Zambia.

There is a call for health services to become more operational where people are, and a decentralization process, which has taken place over the last two decades, was introduced to become more functional and accessible, and as such contribute to equity. It was noted in the current study, that such a decentralization process had not been developed far enough to reach the poor families in the Kazungula District. The rural health centers are the highest-level health facilities within the district, with a district hospital still in the planning process. This means that the rural health centers have an important role to play in catering for disabled children and their families. They provide primary health care to the rural population and are located closer to the families. This illustrates how important it is for the rural health center to be accessible and functional in meeting the needs of disabled children and their families, as they are often the only feasible option. Before I look further into the role of the rural health center, the situation within families will be addressed.

5.1.4. The disabled family

The economic situation of the parents interviewed in this study was marginal. They said that they had no formal income and had to base their financial opportunities on the sale of available fruit and vegetables, in addition to small-scale farming. Few resources were therefore available to improve the health situation of their disabled child. When families of disabled children were faced with illness, they described difficult situations where lack of money and other means created obstacles in the process of seeking assistance.

In Zambia, the abandonment of user fees for health services in 2006 was introduced in an effort to reach those who were not capable of paying for health services (MoH, 2006). This can be seen as a positive measure from the Zambian Government in reducing structural barriers, and the creation of a more inclusive health care system with equal access. Hence, by removing user fees, the aim to increase the use of health services among poor people could be achieved. Consequently, an environment can be created where access to health care is more evenly distributed.

The parents in this study described situations where economic factors other than user fees played a role in their ability to use the health care system, such as transportation, time and cost of upkeep. This is in-line with Hjortsberg and Mwikisa (2002), who found that user fees were not the main contributors to inequality, but the cost of travel and time spent to reach the

health facility were. These factors need to be taken into consideration to understand how the overall economic situation of a family will influence their access to health care, particularly within a health care system that does not have user fees. It also illustrates the importance of targeting multiple factors if the real barriers to health care utilization are to be overcome and structural violence reduced. Cost of access through travel expenses and time spent reaching a health facility can be seen as the crucial factors in the process of seeking health care (Hjortsberg & Mwikisa, 2002).

One common description parents and health workers shared was that the responsibility to take care of a disabled child falls primarily with the family. In many situations, the family becomes the only provider of care, and support has to be found within the structure of the family and household, as also reported by Ingstad and Grut (2007). How the family is constructed and functions will therefore play a vital role in the identification and management of the needs of disabled children. As such, the condition of a disabled child is experienced by the whole family through their involvement in caretaking and in having the child as an integrated part of the family (Ingstad, 2007).

Parents in this study had made minor and major adjustments in their daily lives and routines to better care for their children. The example of the mother who remarried after the father of her disabled child passed away, shows how important it is to have available options when disabled children are not looked after properly. She found herself in a difficult situation as a result of her new husband not supporting her disabled child from her first marriage. She described how her child was suffering and she was able to change her circumstances by going back to the village where she came from to stay with her parents. Consequently, this provided her with more support in taking care of her child on a daily basis, and exemplifies the importance of supportive family members within a household. It also says something about the significance in looking for sustainable alternatives, which might not always exist. Social support is important, some parents said they had opportunities to get help in looking after their children, others had a lot of responsibility shared by a few, both of which can affect the child in terms of what type of care can be provided in the home and how the utilization of health care services outside the domestic environment is carried out.

When a child is born with a disability or acquires a disability during childhood, this unexpected occurrence will influence the family in many ways. New adaptations have to be made to maneuver this extraordinary situation, and challenges arise, in particular within

marginal households where the struggle to meet basic needs is already present. This shift of balance will call for the reallocation of resources so that the family can attend to the basic needs of the child. As a consequence, fragile households in poverty will have even less to spend in upholding the elementary needs of the family. The parents in this study had scarce resources, and had made significant efforts to provide the basic commodities for their disabled child, who inevitably demanded more resources for care.

The parents can also approach the challenges of sustaining the capability of a fragile household by sending their children away (Ingstad 1997). Within this study, grandparents acted as primary caregivers in situations where the parents themselves lived in other places to look for better income-generating opportunities. Additionally, parents who were sick themselves had made arrangements so that the grandparents could take care of their child. This might be as a result of trying to restore balance within a household that has been influenced by the disability of the child (Ingstad, 1997). The parents in the current study described situations where their children had better opportunities for school and access to health care by being taken care of by other family members. This also opened up possibilities for the parents to be more able to contribute the necessary assistance for the care of the child. These different coping mechanisms can change the dynamics of a household so that it may be possible to provide better care for the disabled child within what is possible for the family. On the other hand, sending a child to stay with other family members might not be understood by the community and health workers in contact with the disabled child. This could explain the perceptions among health workers in this study who reported negligence as being present within some families with disabled children. Such perceived negligence might not mirror reality on the ground within these families, where parents struggle to overcome a multitude of barriers in an effort to provide what they perceive to be the best care for their children. If health workers express opinions about negligence without considering other possible explanations, this might serve as a further barrier for families bringing their children to the rural health center, where they may be met with prejudice before they even address the main issues of their child's illness.

When allocation of resources has to change as a result of increased health care needs within a family, fewer assets can be spent on other important activities such as the ability to access information and gain new knowledge. Under such circumstances, which were present for the parents in this study, the ability to know one's rights and to have an influential voice is threatened. Chiefs and village headmen regulate the local communities and through their key

positions they can be said to have a kind of monopoly on what information is available and how the community responds to and prioritizes such matters. This makes it very difficult for parents with disabled children to become literate in the disability of their children and utilize rights which they may not even be aware of.

From this, the interrelationship between disability and poverty can be approached. A vicious cycle of disability and poverty has been described by Yeo and Moore (2003) and illustrates how these two aspects influence each other reciprocally, and how disabilities affect the economic and social lives of people (Ingstad & Grut, 2007; Bonnel, 2004). It is not within the scope of this thesis to try to investigate such a potential relationship in childhood disability in rural Zambia. However, what has become apparent through the stories told by the parents and health workers in this study is that, as a result of poverty, these families are either not able to utilize health care because access is restricted or the services offered are inadequate. Such circumstances might facilitate a further deterioration of disabilities and consequent increased health needs. Furthermore, families will be more strongly influenced and will need even more resources to be able to take care of a disabled child and, as such, find themselves in situations where they have even fewer opportunities to use existing health care services. This could be one reason why people with disabilities in low-income countries are, to a large extent, among the poorest of the poor (Bonnel, 2004). Such an interrelationship between disability and poverty is also seen in connection with the Zambian health sector, which is not able to provide the services necessary to attend to disabled children. This will continuously reinforce situations where families are left to take care of their disabled children, a comprehensive task which is being strongly determined by poverty and threatens the sustainability of the household. For families to break out of this negative loop, they depend on powers outside of their control as described by Galtung (1989) and Farmer (2010), which are active in sustaining unevenly distributed resources in income, education and access to health care services.

5.1.5. The role of the rural health center

The rural health center is pivotal in addressing the health needs of its population and serves as a first line institution in identifying, assessing and managing children with disabilities. The health workers described challenging working conditions, which influenced their opportunities to provide adequate care, as well as circumstances where they were a long way

from being able to respond to the health needs of disabled children and their families. They pointed out heavy workloads and a lack of knowledge within the field of disability as some of the factors contributing to this situation. Consequently, the RHCs are not adequately staffed, equipped or empowered to handle the often very complex health situations of disabled children. This has to be addressed in connection with the health system within the Kazungula District, where there are no hospitals and the rural health centers do not just act as a first line government health institution, but as the only government health institution within the district.

The health condition of many of these children is difficult to assess because of the severity and unique manifestations of their conditions; this would be true even if enough resources had been available. The health workers in rural health centers face limitations in everyday practice, which can pose a great challenge and jeopardize opportunities to assist families with disabled children. Those limitations that affect knowledge, attitudes and practices among health workers within the field of childhood disabilities have to be viewed in a larger context rather than just addressing the individual health workers. Within their catchment areas they have priorities to follow and targets to reach set down by the Ministry of Health through the Kazungula District Medical Office. These circumstances will influence what type of training the health workers receive and, subsequently, how they divide their time and scarce resources to attend to the myriad health needs within their catchment areas. Simultaneously, the local communities have brought forward important issues in their areas, which have to be met by the health workers. As such, the lack of prioritization towards disabled children that is found within the Zambian health care system will prohibit mainstreaming into other more extensive and visible programs; a practice which is non-existent today. For the health workers who have a full calendar, new services might cause more worry for the staff, particularly if this extra workload comes on top of all the duties they already are trying to fulfill. This leaves a great gap in the provision of services to this group, which again might work as a further catalyst to even larger barriers in accessing health care services. At the same time, it serves as an obstruction on the move towards equity, a goal that will not be reached within the existing Zambian health care system.

A higher burden of disease among poor Zambians is reported (GRZ, 2011), as well as the fact that they are less likely to use health services than those who have better financial opportunities. This is supported in a study by Schellenberg et al. (2005) in rural Tanzania, where families with sick children did not seek health care to the same extent as families with more financial resources. In this study, the parents interviewed were from poor, rural

households and, as such, represent one homogenous group. I have not attempted to compare this group with more monetary strong families, and I will, therefore, not discuss potential differences. What I will address, however, is that the findings of this study indicate that the needs of disabled children and their families are not being met adequately as a result of their living in poverty.

In circumstances like this, the health workers have few options to choose from in their efforts to meet the needs of disabled children and their families. They are not able to provide help at the RHC, and have to request that families go for more specialized care at a more central-level health facility. Their limited experiences in seeing, diagnosing and treating children with disabilities leaves them with few options aside from referring, which is done extensively in the management of disabled children according to the informants in this study. It is then the family's responsibility to follow this up. As previously mentioned, within Kazungula, there is no district hospital, and disabled children are often referred to Livingstone General Hospital, which is in another district. In reality, this means longer distances, a greater need for the provision of transport and greater overall expenditure for the families, costs they are rarely able to bear. Such findings are in-line with Diop's research (1988), who found a tendency for people with higher incomes to live in urban areas and thus have better access to hospitals where they would find more specialized care capable of diagnosing and managing chronic illnesses. This again illustrates how the Zambian health care system lacks the competencies to meet the needs of disabled children and their families since the necessary treatment opportunities do not exist locally. Referring is the only option available, and in most cases just a formal option that these families have no possibility of utilizing. The situation of poverty that is very much present among the families and local communities of these disabled children is highly influential in restricting the actual choices these families have for seeking adequate health care services for their children.

Specialized care is often a necessity for disabled children and accessing this type of service was not possible for many of the parents in this study. In one regard, this implies that the structure of the health care system in Zambia creates obstacles that are impossible for families with disabled children to manage and is therefore active in sustaining a situation which is of no benefit to those in need. Specialized services are there, but they are out of reach for those who really need them. In other words, they are not able to make use of services which exist as a result of the structural barriers preventing them from reaching their potential (Galtung, 1989). The high burden of disease as a result of the HIV/AIDS epidemic, insufficient health

infrastructure and a critical shortage of health personnel within the Zambian health sector all play a role in the distribution of already limited resources, where childhood disability is not prioritized.

Another important aspect to address when looking into the role of the rural health center in managing childhood disability is what is actually being done locally for disabled children and their families. Health workers reported that they provide health education, which includes nutritional advice and information about the importance of integrating the child into the daily activities of the family. Prescriptions for medicines were also offered by the health workers and this was confirmed by the parents as the assistance they receive when they use the rural health center in relation to their children.

The health workers pointed out that good examples in the local communities can work as facilitating factors to get more disabled children into the RHC. In contrast, they are met with great challenges when they are not able to give adequate help to disabled children. The local communities have seen how professional health workers fail in providing sufficient assistance to some children with disabilities, and this can create situations where the communities that could have been a resource for families with disabled children, become passive and believe there is not much they can do either. This illustrates an important role the health workers have in signalling their attitudes and actions within the local communities in which they operate. They have an important role to play in providing these families with general health education to prevent further deterioration of a condition, also within a system where childhood disability is not prioritized.

As previously mentioned, the responsibility of the families themselves is extensive both in terms of knowledge about what could be wrong, the child's actual health needs and what can be done to help them. The families have knowledge about their children, about how they function and how they are taking part in activities on the social arena. But a consequence of poverty, amongst other things, may be that they have not been able to go to school and they may have responsibilities that prohibit them from having an overview and an understanding of the causal agents related to the disability of their child. These families with limited resources in terms of education, employment and financial means will have a difficult time acting as resources in the management of their children. The resources they have and the steps they are able to make in an effort to seek assistance to improve the condition of their children should

not be met by the structural obstacles that are currently present within the rural Zambian health sector. These obstacles will only serve to exclude disabled children further.

5.2. Explanatory models

Thus far, I have given an account of the structural barriers found in rural Zambia that are creating challenges in accessing health care services for disabled children and their families. The role of the family, the rural health center and the larger Zambian society have been discussed in an effort to understand how the needs of disabled children, as seen from the perspectives of the parents and health workers, are met through the actions taken. In the following section, I will look more closely at explanatory models and the rationale found within individuals in the process of transforming health beliefs into health behavior.

In order to understand how disabled children and their families use health care services, the health behavior of the parents in this study will be addressed. Explanatory models as presented by Kleinman (1981) give important answers to questions about the cause of the disease, symptoms, severity, treatment opportunities and prognosis, and can be said to be used by the parents in order to clarify, organize and administer particular episodes of impaired wellbeing found in their disabled children. How parents perceive the character and origin of the disability will play a major role in finding acceptable solutions, and will consequently inspire their health behavior.

5.2.1. In need of an explanation

Several studies report that the explanatory models of primary caregivers determine what actions are taken in the process of seeking assistance (Danescu, 1997; Diken, 2006; Maloni et al. 2010). These studies point to a multitude of treatment options being utilized, and illustrate how explanatory models play a powerful role within a health care system and act as the catalyst for when parents are seeking sustainable solutions for their disabled children. At the same time, they act as facilitating factors and barriers in the health and illness process.

Both the parents themselves and the health workers in this study underpinned plausible explanations as essential to the understanding of childhood disability and, consequently, health behavior. The need to understand what has happened to one's child and why it has

happened is an underlying factor that influences not only the health behavior of the parents but also the health workers and the communities, through their perceptions of disability.

The parents in this study mentioned that they had not had the condition of their child explained to them at a rural health center and among those parents who had been able to go to a higher-level hospital the experiences were largely the same. One exception within this study was the mother and grandmother of a young boy with hydrocephalus. They had been informed about his condition in relation to an assessment at a hospital and gave an account of how they understood the explanations they were given there. The large size of his head was caused by extra water that would not come out and continued to enlarge his head. This mother and grandmother accepted the explanation, but at the same time they described other rationalizations for the growing head, related to more traditional beliefs which I will come back to. In addition, individuals within the network of the family played a role when explanations are sought and provided. This illustrates how social and cultural factors can influence the explanatory models of the parents and contribute to the complex process of accepting various explanations. This can be understood through the characteristics of explanatory models as outlined by Kleinman (1981). He described explanatory models as being vague, with a multiplicity of meanings, and characterized by frequent change. This can result in the occurrence of different explanatory models as described by the mother and grandmother. Support for this is found in Diken (2006), who found that mothers had both biomedical and traditional beliefs when trying to make sense of their child's disability.

It is interesting to look into the role of the health worker at a rural health center when addressing the need for explanations among parents. In particular, because the parents did not believe they had been given explanations at the rural health center. Language barriers between parents and health workers could be one influential factor that complicates the process of giving understandable and acceptable explanations, as described by Diken (2006) and were reported by some health workers. The differences in cultures when health workers meet poor, rural individuals with little formal education could also increase communication barriers, and could affect the explanations being provided and how they are interpreted. To complicate this matter further, some health workers interviewed in this study described challenges in transforming medical explanations into local understandings. This distinction between scientifically-based explanations of disease given by health workers and illnesses as perceived by the parents will often create a discrepancy (Helman, 2007). Such discrepancy is a challenge to both providers and recipients of explanations, and makes it difficult to find a

common platform for understanding. This could explain why parents say they have not been given explanations, and why health workers believe they have met such needs. Under such circumstances, the health workers might very well have made an effort to have the parents understand the biomedical perspectives without succeeding. For traditional providers, on the other hand, sharing the cultural values of the parent might be an advantage for the development of a common platform. In one study regarding epilepsy in Zambia (Baskind & Birbeck, 2005), traditional healers reported providing explanations to the patients about seizures as being very important, and their efforts to potentially provide more acceptable explanations could influence on where the parents in this study go for assistance.

The health workers in this study also mentioned that, in some cases, they had little experience with childhood disability, and so explaining a condition that was new to them was a significant challenge. Moreover, when the disabled child is not brought to the rural health center because the parent would have to carry them on their back for long distances, it is even harder for the health workers to come up with an explanation seeing as they have not been able to assess the child themselves. What parents describe as signs and symptoms may not match diagnostic criteria as understood by the health workers and produce inconsistency (Helman, 2007).

Childhood disability can often be of a complex character and requires a comprehensive approach. Explanations are often far from straightforward, and causation does not follow a well-defined path. It would require some time to involve the parents fully in the explanations, and with a heavy workload and restrictions in available time, health workers might not have the opportunity to explain fully. When viewed in connection with the unfamiliarity with disabilities among health workers, this might create situations where parents stop coming to the health center because they are not provided with the tools to better understand their child's disability. The mother who delivered a daughter with a malformation of the feet did not have her needs met with regards to having her child's condition explained. The attendance of a doctor assessing her newborn baby could have been a resource to the understanding of the disability, but consequently acted as a barrier when this doctor hid the baby from the mother so that she was not able to see her daughter until after some days had passed. It is difficult to interpret the actions of this doctor, but it is possible the doctor did not know how best to present such an extraordinary child to the mother. This is a challenge that health personnel report to meet and are often not capable of managing, and can serve to influence further management of children with disabilities both within the family, community and the health

care system. For this mother, she reports that she is not comfortable with the situations of not knowing the cause of the disability. This might have influenced her when attending to the needs of her daughter.

When health workers are not able to provide explanations that compete with alternative explanations, a situation could arise where the disability of a child is no longer considered an illness. It is reasonable to believe that explanations not linked to ill health will not be brought to the rural health center, and parents might feel that they cannot seek help at the clinic, thus becoming a possible further barrier. This was described by Grut and Ingstad (2005) in a study about living conditions in Kenya. They reported that access to information and the gaining of knowledge about disability among parents is limited and will have consequences in the form of them not knowing where to seek help and how they can best manage the condition of their children. This shows the importance of understanding causation not just in influencing health behavior but also in empowering the parents themselves in the condition of their child so that they are better equipped to make their own independent choices. In Hill et al. (2003) the mothers' abilities to recognize signs and symptoms was found to be an important factor influencing health behavior, as also reported by Schellenburg et al. (2003). The mothers, therefore, need the basic tools to be able to assess their children and make adequate choices. Such competencies need to be developed among others through good explanations.

Religious beliefs were prominent in the lives of the parents in this study and need to be integrated into a discussion on the need for an explanation. Different providers within a health care system provide various explanations that are implemented and rationalized by parents Kleinman (1981). How God fits in will depend on numerous factors, but for parents in this study, the strong presence of God provided the families with an effective tool in giving hope for the future, by creating an opportunity for their children to get well at some unknown point. The strong presence of God also provided the families with an explanation as to the disability, and the will of God was often described as a natural understanding. This is described by Devlieger (1995), who found that in situations where no other explanations were found to fit, God became the cause of the disability. In this way, God has absolute powers and can be seen as the final element in understanding the causes of disability. The parents in this study also described the role of God as being responsible for the disability, which makes Him the primary power in handling challenges in the future. These views describing the overall importance of God are not static, but will change according to other reasonable explanations. At the same time, God can be seen as a much stronger force than other available explanations

and, as such, serves the vital purpose of always having a justifiable explanation for the disability found in their children.

5.2.2. Traditional beliefs

The majority of the parents in this study had traditional explanations for their child's condition. In the management of their children, the parents therefore often used some form of traditional medicine. The traditional providers described by the parents and health workers are referred to as a ng'anga, and have various backgrounds and competencies, such as those described by Sugishita (2009): herbalists, faith healers and spiritualists.

Bewitchment is often described as the cause of the disability. As also described by Sugishita (2009), bewitchment is not seen as something the family is responsible for themselves, but as brought onto them by other people, often explained to be someone in the community who is jealous. In this study, bewitchment was often described as occurring through the parents, brought on purposefully from other people. The mother of the young boy with hydrocephalus stepped on medicines someone had used to trap her with by leaving it somewhere she was likely to walk. She was not aware of such an action taking place, and believed that she, as a consequence of her own actions, had brought the hydrocephalus on to her son through the intentions of someone else. Something was brought into play on purpose, with the intention to harm the individual who is seen as the object of punishment. This explanation was accepted within the family and will therefore be influential when the child's needs are assessed and assistance is asked for. Another parents, the father with a blind son, explained his son's blindness as a consequence of a community member bringing his soul to their home and sleeping with the mother while she was pregnant, causing the child to be born with a disability. These problems perceived to be caused by witchcraft can only be managed by a ng'anga (traditional doctor) (Sugshita, 2009), and illustrates how explanatory models involving witchcraft will facilitate parents to consult a ng'anga when attending to the needs of their children.

The mother of a 15-year old epileptic girl was also using such explanatory models when she described the soul of her daughter as being taken away by someone in the village, and her body remaining alone. For the soul of the daughter to reenter to the body, it requires the identification of the person behind the bewitchment, a situation also described by Sugishita

(2009). The mother explained that if it was just a normal disease, her daughter would have been cured already. She had seen how her daughter suffers and attributes this to the power of other people who have removed her daughter's soul. Under these circumstances, the assistance of a traditional provider is again preferred. Through consultations with traditional providers, identification of the inflicting forces and possible solutions will be discussed. The parents will have the opportunity to meet the needs of their disabled children by asking for assistance in removing the force seen to be responsible for the child's condition. These stories show the essential role traditional providers play in giving assistance to parents with disabled children. It also shows how strong the traditional beliefs are and how they can guide families in their efforts to seek help from available resources. This could explain why traditional providers play such an essential role in providing health care in Zambia (Baskind & Birbeck, 2005).

When traditional beliefs make sense to the parents, they will look for help where they believe the chances of healing are best, and such circumstances may serve as a barrier to the use of other health care services. When causes of illness are described and understood through traditional beliefs as seen with these parents, some treatment opportunities stand out as being more relevant than others. Help from the rural health center is not considered, as it is not equipped to handle such cases. The belief in witchcraft can in this way be an important regulator in the health seeking process. The traditional beliefs found to be present among the parents in this study serve an important role in explaining disability, in particular when such explanations are complicated and difficult to provide for the rural health centers where they are not able to come up with acceptable alternatives. This case illustrates the strong powers found within traditional healing practices and their perceived capabilities for offering a cure (Ingstad & Grut, 2007). The prospect of complete healing, as found with traditional healers, influences health behaviors, and could explain why parents prefer this type of assistance when managing their children's disabilities.

5.2.3. Different providers serve different needs

The findings of this study suggest that the parents of disabled children use rural health centers when their children have a fever, headache, diarrhea or vomiting, but rarely for an assessment of their disability, as previously discussed within the framework of structural violence. I will

now return to this issue in relation to explanatory models and try to address potential explanations and the implications this has in meeting the health needs of disabled children.

The use of rural health centers is common for conditions such as fever, headache, diarrhea or vomiting. These conditions can be viewed in relation to the perceived acuteness of the symptoms and, as such, can be understood as acute manifestations with a quick change in the health situation of the child. If parents perceive such conditions of a more ordinary character as acute, then they consult the rural health center. As described by Ingstad (2007), conditions that are acute in nature are often dealt with through the use of professional health care, which might explain why they prefer to use the rural health center for these types of illness episodes. Chronic conditions, on the other hand, are often managed through consultations with traditional providers. In this study, the disability was described as something the parents had become accustomed to, and was perceived as a natural situation within the families. The condition of these children had persisted over time, often for years and could, therefore, be interpreted as a chronic condition. This is one possible explanation for the preferred use of traditional providers in managing disability. This could also be explained by the type of health education which the health workers reported to provide at the rural health center. The more common conditions might, to a larger extent, be addressed, and the parents could have been told to take action when the children presented with these more ordinary signs and symptoms. At this stage, it is important to highlight the fact that such a distinction between acute and chronic illnesses, as perceived by the informants, is of a flexible nature and cannot be seen as a fixed dichotomy, but was a potential explanation for their health behavior.

The parents in this study did not have a fixed chronology of where to seek help at each stage of the illness process. Some had been to traditional providers before they decided to seek help at the RHC and others initially went to the RHC before they consulted other providers. The responses from the parents do not coincide with responses from the health workers who, for the most part, believed that childhood disability was initially taken to a traditional provider and when this failed, they came to the RHC. These differences among the two groups of informants are supported by Sugishita's (2009) and Maloni et al.'s (2010) findings, who described similar opinions among health workers. At the same time, Sugishita (2009) reported that the views of the health workers were not in accordance with people in need of health care. Very few parents reported that they had consulted a ng'anga (traditional doctor) before they went for biomedical treatment. This lack of congruency between health workers and those making use of health services may say something about the diverse understanding of

health beliefs and their consequences. Moreover, it might also stem from the described situation where health workers rarely see disabled children and as such perceive them to be attended to by other providers. It could also be that the health workers generalize to a large extent, and that those variations which are described by parents might be there, but are not very visible within local cultures where the use of traditional providers is quite common. It is also important to consider the often-transitory nature of a disability, which might bring about different needs at different times, and can be an additional reason for varying explanatory models and altering health behavior. These changes will bring with them various responses from parents, and shows how their perceived need for certain types of health care in responding to episodes of illness is changeable, and a fixed dichotomy between acute and chronic manifestations as described above should therefore be interpreted cautiously.

Through the interview with the two parents with a daughter with epilepsy already mentioned, their descriptions of how they sat down to discuss their child's situation, how they viewed their options differently and how they negotiated with each other is essential. Their opinions fluctuated, changed and adapted to the present situation, and were not of a constant nature. This shows how a family changes their health behavior in an effort to find adequate treatment; they are influenced by their surroundings in choosing a provider. This family tried different options in an effort to reduce the fits; they experienced setbacks which made them change strategies as they proceeded. It is also of value to understand how they transformed and developed through various processes and how the experiences they had, the people they met and the advice they received produced new and different knowledge and actions with the aim of finding a solution to their daughter's epilepsy.

5.2.4. To find a cure

One strong rationale reported by parents for choosing traditional providers was the prospect of finding a cure. The parents had a strong wish for their disabled children to get well and many of them expressed the importance of complete healing as the only acceptable outcome. This has also been described by Ingstad and Grut (2007). Naturally, this view will influence their health behavior. This can be best understood with regards to the parents with an epileptic daughter who shared their differences in opinion about their daughter's condition. The parents sat down to discuss and plan, and they said that they usually came up with a common solution. The mother emphasized the importance of taking the daughter to traditional

providers, while the father expressed concerns about this potentially worsening his daughter's condition. He said he had experienced his daughter's confusion by the treatment prescribed by the traditional providers, and he said he preferred to take her to the RHC. He accepted that epilepsy was a difficult condition to treat, he had seen it in other people and he knew that it would never go away. The mother, on the other hand, believed in different solutions and wanted to continue with traditional treatment. Her experience so far equipped her with the opinion that the rural health center was an institution only able to treat the symptoms of the epilepsy. She had seen that her daughter's fits had reduced and this had decreased the burden of epilepsy experienced by her daughter and the family, but she knew that this was just a temporary state and that the fits were likely to return if her daughter ceases to take the medicines. This practice will not cure her daughter, and the mother therefore preferred to consult traditional providers in an effort to find a better, more sustainable solution for her daughter. People in the local community told the families that they were just wasting their time, the daughter was not improving and they recommended the family take her to a traditional provider. The parents stopped giving their daughter medicine provided from the clinic and started giving her herbal medicine from the traditional providers. Her condition worsened and the parents decided to go back to the clinic for further management. In this case, it is interesting to see that being able to reduce the severity of a condition was not good enough; complete healing is seen as the final and all-encompassing aim.

The parents in this study described a strong wish for their children to get well, as already discussed in earlier sections. Some said they were happy when they saw improvements, but the overall hope of finding a cure was very much present in their histories. Their health behavior was strongly influenced by a practice where the goal to find a cure stands out and health behavior will therefore change according to where parents believe the best chance of obtaining such improvements can be found. High expectations served the purpose of driving the parents to seek help. At the same time it could become a barrier if they experience that the services offered will not help their children; the parents may not see the improvements they had been hoping for and could therefore change their behavior. This can be seen in connection with Helman (2007) who stated that the explanations given, discussed earlier, are not as important as their efficacy in reducing suffering. This shows how actors within a pluralistic medical system are given various explanations to digest, but how parents behave in their efforts to prevent sickness and treat illness in their children will be even more driven by what is efficient in alleviating suffering, or what will at least make improvements in the condition

of their children. Furthermore, the treatment families with disabled children seek has to show some kind of effect for them to believe in it and for them to return to it (Stekelburg et al. 2005).

In this study, herbal medicine, in addition to the identification of inflicting forces, were frequently described, and used as treatment options for a large variety of conditions. Health workers reported to have had positive experiences with herbal medicines themselves, and accepted this type of assistance. What they described as problematic were those situations where herbal medicine was mixed with medication given from the rural health center, which can potentially influence the efficiency of other substances. It also made it difficult for parents to determine which of the treatments was effective. We have seen how the parents use a combination of various treatments in an effort to change the situation of the child, which makes it difficult to pinpoint exactly what is causing change.

The parents also expressed levels of skepticism at the potential effects of traditional medicine, and they do not attribute changes to their child's condition as something that came from traditional medicine alone. The parents had often been to several providers of traditional medicine in an effort to find the best treatment options, and they said that they believed that the disability could be dealt with if they could find a good enough traditional provider. They did also point out that people in their family and community were active in recommending traditional alternatives. This can be viewed as a different level of tolerance compared to the management at the rural health center. Such a development can be explained through traditional providers having more familiarity with local norms and traditions, as described by Helman (2007). They are, therefore, better equipped to understand the cultural and social circumstances of the families and are better able to tailor the management of disabled children more precisely to the perceived needs of the parents. The traditional providers might be better skilled at grasping the parents' perspectives of illness since they belong to the same local community. The potential gap between what parents are looking for through their health behavior and what different providers can contribute will diminish if the traditional providers have more knowledge about the perceptions of illness in the community in which they operate (Ingstad, 2007).

The parents noted that some of the signs and symptoms disappeared when they took their children to the rural health center. The importance of such experiences is emphasized by the health workers who argued that providing help for smaller problems will create an

understanding among the families that the clinic is actually capable of providing some kind of assistance. Medicines are reported to be good treatment options, and have helped many children with minor conditions. Medicines are also efficient when treating children with epilepsy; the families see changes for the better and come back to the rural health center with expectations about getting more medication next time the child is sick. This creates an understanding of the importance of medicines and creates expectations from families about the potential benefits for other, more severe conditions.

Parents reported that many of the improvements they had seen in their children came as a result of the will of God, and that they met challenging situations through believing in the strengths of God. The presence of God was not just important in direct relation to the disability, but also in being someone they can turn to for help with creating needed resources for the families; for example, the power of God in having a good harvest, or to keep other family members healthy. This can be seen as an indirect contribution from God for the family to be able to provide well for their children and have money for transport and upkeep while their child is being assessed and treated.

The strong belief in God and his abilities to interfere was not only present among the parents, but can also be seen as part of the treatment provided by the health workers. Some said that they use faith in God as an instrument when they do not know what can be done for the children. They have no way of providing assistance themselves and so will ask the families to turn to God in an effort to find answers to their questions. As such, God is not just an important power in explaining disability to the parents but also serves a purpose for health workers when they do not have a solution for the disability (Devlieger, 1995). As a product of this, the presence of God in the lives of these families is essential, and many of the uncertainties experienced as a result of having a disabled child will be explained through God and His superiority in preserving the ultimate truth.

There are several aspects to consider in understanding the actions taken by the parents, and usually there is an overlap in the use of available treatment options when different providers are consulted. However, and for different reasons, when the outcome of treatment in one sector is unsuccessful in treating ill health, another sector is usually preferred, a phenomenon that has been reported by Hjortsberg (2003) and Stekelenburg et al. (2005). For the parents in the current study, the endeavor to find positive solutions for the condition of their disabled children acted as strong health behavior mechanisms. This illustrates how different models for

explaining illness coexist or alter for each other, either in the society or in people's perceptions of their own health (Helman, 2007). People who get sick are often driven by the search for meaning using their experiences, knowledge and possibilities in an attempt to master their own situations. They are able to use and make sense of the differences, and at the same time combine strategies in the creation of a sensible whole. Moreover, when parents are given a range of options in trying to meet the needs of their disabled children, they are equipped with a range of therapeutic options to consider and make use of (Ingstad, 2007), and as such are given a comprehensive kit in the management of their own situation.

The parents in this study had often been to different providers of traditional medicine, and if one was not providing sufficient care as perceived by the parents, then another traditional provider was tested. One factor of interest looking into the use of health care providers in Zambia is the number of traditional providers operating in the local communities. Numbers from Zambia indicate that approximately 17 000 health workers are employed in the formal health sector, which is low compared both to World Health Organization recommendations (GRZ, 2011) and when compared with the 40 000 traditional practitioners operating within Zambia (Sugishita, 2009). In this study, it was reported a range of traditional providers to choose from, and they were more evenly distributed compared to government health services. As such, traditional providers may have to make an extra effort within this competitive environment in order to attract customers, which means they could potentially meet the needs of parents in a more accommodating manner than would be possible at a busy rural health center. The rural health center, on the other hand, is the only representative of biomedical health care and if parents are not satisfied with the services, they do not have another rural health center as an alternative within the catchment area. This could explain the more extensive use of traditional providers where the alternatives are many.

Another interesting point in that regard is raised by Ingstad (2007) when she describes the disadvantage biomedicine has in that it must be of some effect for people to see the benefit of using it. She argues that traditional medicine, in contrast, exists as an integrated part of a culture and does not have to legitimize its practices to the same extent. This could explain why parents rarely used the rural health center in addressing the disability of their children. Many of the parents had children with complex conditions who needed extensive management for improvements to be realistic, and such extensive management was not feasible at a rural health center. They were not able to provide sufficient assistance to disabled children there, and when parents do not see a benefit, they use other options. Parents

expressed dissatisfaction with treatment outcomes and therefore lacked incentives to continue such a practice. As previously discussed, traditional providers might be in a better position because they gain higher levels of tolerance from the parents. Many parents within this study had been promised complete healing as a result of interventions stemming from traditional providers. This will naturally make traditional providers more lucrative, not in meeting these high expectations of complete curing, but as supporters of such a view and they are therefore perceived to be more supportive in the process.

The majority of these children have disabilities that will not go away; they will always be present and part of them. The challenging part for health workers and communities is to provide the parents with realistic solutions in an effort to sustain present functioning and at the same time maintain the parents' hopes for their children. The RHCs are equipped with few resources to provide adequate treatment options to these children and their families. They are often faced with complicated conditions where improvements are not realistic and where maintenance and prevention from worsening the condition are much more reasonable focuses. This might not be understandable or explained well enough to these families and may prohibit them from seeking help at the rural health center in the future.

The challenges in dealing with high expectations are not just present on an individual level, but also in the community. The health workers shared a belief in creating sustainable solutions for the people within their catchment areas so that the local communities could see that the work being done at the rural health center was of effect. If the rural health center is able to provide some assistance to disabled children, then other families in similar situations might see this as something potentially achievable for their child and thus facilitates the use of the rural health center. The importance of good examples in the local communities was mentioned as a potential facilitating factor for families to seek help at the rural health center. However, the health workers described this as difficult to achieve when dealing with disabled children. More often, the health workers were not able to help disabled children because of a lack of skills and resources. Such situations can create negative experiences and send signals to the local communities about the lack of help available.

At the same time, when looking into the actions of parents in this study, what Kleinman (1981) defines as the popular sector of a health care system plays a central role in shaping the explanatory models. The families discussed with each other and got advice from the local community as part of the process of initiating health care activities. Kleinman (1981) points

out that illness is first recognized and defined within this sector. The exchange of opinions and ideas take place within a familiar location where people know or are associated with each other through being part of the same environment (Helman, 2007). As such, the parents, in coming up with strategies to address the needs of their child, will use other members of their community and each other to find ways to enter and exit the various sectors. As seen here, they try the professional and folk sectors as described by Kleinman (1981) through their encounters with the rural health center and several traditional providers. They brought these various experiences from the other two sectors back to their home environment for evaluation, and from that, made decisions about further management. This shows how the household and local community can be seen as the point of convergence within a health care system operated by various providers, and where elements of other sectors are rooted within the popular sector. Consequently, what takes place within the home of disabled children will be a decisive factor in the formation of explanatory models and, consequently, in the expedition of health behavior.

5.2.5. The ordinary disability

The parents in this study said that having a child with a disability was a natural situation for their family; ordinary, everyday life for them includes taking care of a child with extra needs. It is possible that, given the families see the condition of their child as a normal feature of life, they may not consider it to be an illness, as such, and this will be influential in the further management of their child. Hill et al. (2003) found in their study from rural Ghana that some illnesses were described by parents as not suitable for the hospital, and therefore they did not perceive biomedicine as a treatment option. This could, to some extent, explain why disabled children in the current study were rarely seen by the health workers at the rural health center. If the parents in this study did not perceive the condition of their child to be of a character that can be assessed at the rural health center, then they would not attend. This was reported by new parents who came to the information meetings. They didn't realize they could bring their disabled child to the rural health center; they had not known that was an alternative open to them.

Additionally, parents described situations where they did not perceive the disability to be something the rural health center could assist with. In cases where the families choose to seek help from the health care system, they are given few, if any, explanations. They are often

asked to come back later for a review, and they find that the health worker has little knowledge or information to offer within the field of disability. As such, their familiarity with not just the disability, but also the habitually notion that might develop about not getting adequate care might serve as strong barriers to seeking help from the rural health center.

This natural situation as described by the parents may contrast with the often unexpected situation of giving birth to a child with a disability or having a child who acquires a disability during childhood. The challenges they are faced with by experiencing something that is seen to be out of the ordinary makes it difficult to follow a “to-do-list” and know how to act. They might be the only family in their village with a disabled child and it could be very difficult to know how to approach such a new situation. When this is looked at in connection with the challenges described among the health workers in identifying, assessing and treating disabled children, the role of the popular sector of health care as described by Kleinman (1981) comes to be even more important. The family and local community will play a vital role not just in defining the newly acquired situation for the families, but also in providing the only care.

The health workers in this study did not have the treatment opportunities to provide adequate care locally for disabled children and therefore to a large extent, the care had to take place within the household. The parents used a variety of providers without experiencing improvements in their child’s condition and this will likely create situations for parents where they consequently give up (Ingstad, 1997). The care they provide at home might also be affected when parents do not see any improvements in their own efforts. The father with a blind son had sought provision at the rural health center on many occasions with a repeated message there to come back again and again for new reviews without perceiving to be assisted. And as such, his motivation for continuing this practice might diminish.

An important aspect to consider in understanding inactivity as a result of resignation is related to the difficult situations these families face on a daily basis from poverty (Ingstad & Grut, 2007). The families live marginal lives and have to relate to hunger, inequality and exclusion which are adding to the extra responsibility of taking care of a disabled child. This makes the situation of having a disabled child within the family only one of many components to respond to and a vital aspect to take into account in the facilitation of resignation (Ingstad, 1997).

At the community level, such practices may send signals that could be interpreted as the responsibility of taking care of disabled children falls on the families alone. This may explain

why parents reported a lack of support from other community members, with the exception of members of the same congregation who reported visiting and performing prayers with the families. A mentality can develop where the local community believes there is nothing that can be done for disabled children; they may have seen or heard that the rural health center cannot do much to contribute to any improvement, which then opens up for a culture that takes as “fact” that these children cannot get help. Moreover, when parents subsequently give up their efforts to be provided with assistance, the disabled children might become less visible in the communities.

6.0. CONCLUSIONS AND FUTURE RECOMMENDATIONS

In this thesis it has been argued that there is a complex set of explanatory models, personal characteristics and structural factors that influence the health behavior and the use of health care services. This multifaceted environment, viewed within a local health care system in rural Zambia, is continuously in transition, with personal beliefs, attitudes and practices constantly influencing and shaping health behavior. Additionally, poverty, as a major determinant of health, plays a substantial role in regulating access and utilization, thus illustrating how powerful structures outside of the control of individuals function, and how construct barriers will also profoundly influence health behavior. This study has shown that parents make use of the rural health center in responding to particular episodes of illness in their disabled children, but they do not perceive the rural health center to be the natural place to go for assessment of the disability. As such, it is important to look at health behavior not just in a use versus non-use perspective, but also explore how different providers are used and for what purposes. The rural health centers are not able to provide adequate health care to this heterogeneous group of children with often intricate conditions. This can be seen as both a consequence of the marginalized state of primary health care in Zambia in providing assistance for disabled children, and as an outcome of vulnerable families not generating enough resources to be able to seek help for their disabled children. Both these aspects are linked closely to poverty and contribute to situations where such health behaviors are persistently being normalized and upheld within the existing structures. Consequently, the management of disabled children has to be carried out within the family, and demands a reallocation of already scarce resources.

From this line of reasoning it was discussed how families manage in their daily encounters with illness, and how the composition of a household will be influential in understanding the behavior of the parents. This becomes apparent in situations where disabled children do not accompany family members when treatment is sought at the rural health center. Hence, families adjust their capabilities in meeting the needs of their children by applying solutions within the range of what is achievable for them. This puts a lot of responsibility on single families to identify, evaluate and manage childhood disability. Signs and symptoms, as perceived by the parents, become key elements in assessing disabled children when health workers do not have direct contact with the child. They must base their interpretations on statements from the parents, and this can have serious implications for the health status of the child. Further management is entirely based on the symptoms presented by the family

members in their meetings at the rural health center. The parents then return home with the available treatment options and advice to evaluate, adjust and carry out within the space of the household, often with resignation as a result when they are not able to facilitate improvements.

Considering the large responsibility brought upon the families, they consult a number of providers within their local health care system in an effort to respond to childhood disability. Their health behavioral patterns are characterized by being dynamic and in continuous transition. These important attributes have to be considered when making efforts to understand the functionality of a health care system. By using a multitude of providers, often simultaneously, different explanations and treatment options become available. This manifold information is evaluated and cultivated into one understanding which guides decision making about which providers to use. One driving force in that regard is the prospect of finding a cure for the condition of the child. Under such circumstances, expectations play a role and can be challenging to meet due to the complex manifestations of disability which often require a specialized care that is not necessarily available within their local health care system. Primary health care is more accessible to disabled children, but resources are not being distributed to strengthen the quality of these services and, as such, they are not able to meet the health needs found within childhood disability. The Alma Ata Declaration was a starting point in focusing attention on the importance of primary health care. The aim of health for all by year 2000 was not achieved, and the recent Millennium Development Goals, set for 2015, will not be met either. Universal access to health care is still far from within reach, and this strongly affects the management of childhood disabilities in poor, rural areas. The presence or absence of acceptable, accessible, appropriate and affordable health care alternatives will dictate abilities to choose and will also, therefore, influence health behavior.

When looking at these challenges, the identification of barriers to the use of health care must be included. There are many aspects to consider which have to be evaluated in relation to each other. Removing one barrier at a time might not serve the intended purpose, and a comprehensive approach taking several barriers into consideration could be more feasible in an effort to facilitate change. The MDGs have faced a considerable amount of critique for not incorporating equity into their proposed targets. This might facilitate the awareness of the existing issues of inequity and the marginal situation of those living in extreme poverty when new strategies are implemented in the aftermath of 2015.

6.1. Further recommendations

As for further research, the magnitude, severity of childhood disabilities, and how disabled children are integrated into ordinary child health programs should be addressed. More research is also needed to understand the local perceptions of disability, and the role of traditional providers and local communities in identifying, referring and managing childhood disabilities.

From the findings of this study, it is suggested that primary health care becomes more accessible for families with disabled children, referral systems strengthened and parents empowered to handle the disability of their children.

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Appendix 1- 8.

Appendix 1, Information letter primary caregiver, English version

Request to participate in the study: “Childhood disability in rural Zambia, a qualitative study on the use of health services among disabled children and their families”.

Background and purpose of the study

You are now asked to participate in a study where the aim is to better understand how children with disabilities and their families in Kazungula District use health care services. In this study I will interview health workers and primary caregivers of disabled children in an effort to find out more about the situations of disabled children. I wish to interview you since you have personal knowledge about the topic. Hopefully, the contributions from this study will provide information that can benefit disabled children and their families in the future. This study is done as part of the Master Programme in International Community Health at the University of Oslo, Norway. The study has been approved by The Regional Committee for Medical Research Ethics Sør- Øst, Norway and by Tropical Diseases Research Centre Ethics Review Committee, Zambia. The study will be conducted according to international ethical principles and guidelines. Participating in the study will be autonomous; your decision to participate as well as to give consent freely are on a voluntarily and open basis.

Information about your participation in the project

The interview will be held with you, me and an interpreter, and will last for approximately one hour. If it is not problematic for you, a tape recorder will be used during the interviews. You have the opportunity to end the interview at any time and you do not have to answer questions if you don't want to. If you chose to withdraw from the interview or decide you do not want to participate in the study, this will not influence your possibilities of receiving health care. Meeting time and place will be decided by you. If you want to do the interview in your own home, that is okay and a neutral place will be found if you prefer this.

What happens to the information you share?

The information you give and your confidentiality will be handled with care. Information that could make people recognize you, like your name and age will be kept anonymous and you will be given a new name when the interviews are transformed from the tape recorder to paper. The information you give in the interviews will only be handled by me and the interpreter, and only used in this project. Findings from the project will be published through the University of Oslo and information that could lead to your identification will be changed.

Contact information

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Appendix 2, Information letter primary caregiver, Tonga version

Mwalombwa kutola lubazu mumulimo wakuvwuntauzya

“Bulema kubana mutusi tunshyonto twa Zambia, mulimo wakuvwuntauzya kubona zya bilo zya nseba mbozibelesegwa kubana balema amikwasyi yabo”.

Matalikilo a muzeezo wabuvwuntauzi

Mwalombwa kuti mutole lubazu mumulimo wakuvwuntauzya kuli amuzeezo wakuyandaula kuziba kuti ino bana balaa buyumu yumu naakuti balema antoomwe amikwasyi yabo muno mu Kazungula babelesya buti zya bilo zyakubalanganya zya nseba akuti ino twaambo nzi tubakulwaizya kusala zyaabilo eezyo. Mukuvwuntauzya ooku, ndiyakuba amubandi wacigaminina abalanganya bana balema alimwi ababeleshi muzibbadela zyamunsi-munsi mucilawo. Kulombozya nkwa kuti kuyungizya kwiinda mumulimo ooyu kukape kukulwaizya kumbele amazuba mukuyandaula kupa lugwasyo kubana bala buyumu-yumu naa balema antoomwe amikwasyi yabo. OObu bukuntauzi bula citwa a bweendelezi naa amccililano mapati amasi mubunyina anseba acikolo cipati ca Oslo naa kuti master programme in international community health at the University of Oslo mucikuwa. Oyu mulimo wakuvwuntauzya waka pegwa nguzu zya kutola lubazu a ziiminino zipati Zya Medical Research amalayilile a kucisi ca Norway a amalayilile a Tropical Diseases Research centre omuno mu Zambia.

Muzeezo wabuvwuntauzi oobu ngwakuyanda kutondezya ciimino cabana bala buyumu-yumu naa balema alimwi amikwasyi yabo. Mukucita boobu, ndiyanda kuba amubandi wacigaminino andinwe mbokuli ndinywe muli aluzibo luntokomene mukaambo aaka. Okukuvwuntauzya kuya kweendelezegwa kweendelena a ziiminino a amalayilile a masi. kutola lubazu mukuvwuntauzya ooku nkwa kulyaaba; muzeezo wanu wakutola lubazu a kwiingula ciya mbuli mukulimvwa kwanu akwaanguluka kwenu.

Mulumbe ujakizya kutola lubazu kwanu mumulimo wakuvwuntauzya

Mubandi uyakutola busena andinywe, ambebo alimwi a sikusandulula, kwaciindi cisika ku woola lyomwe. Kutu kalitali penzi kulindinywe, inga twabelesya kawalesi naa tape recorder kubweza mulumbe oonse mucuindi camubandi. Mulipedwe nguzu zyakukosola mubandi kufumbwa ciindi alimwi tamusungilizigwi kwiingula mibuzyo njomwatayanda kwiingula. Kutu mwayanda kucileka mubandi wacigaminina, olo mwalimvwa kutayanda kutola lubazu mu mulimo ooyu, kunyina nocinga caba aabuyanabukizi mukutambula kwanu kwalugwasolwa nseba. Busena aciindi cakuswaangana muyakulisalila lwenu nobeni. Kutu muyanda kucitila mung'anda yanu mubandi kunyina bubu, naanka busena bwansini ingabwajanika kutimwacyanda oobo.

Ncini cicitika kumulumbe ngomwapa?

Mulumbe ngomwapa uyakweendelezegwa kabotu kabotu cakutaleta antangalala. Makani anga apakuti Bantu bamuziyibe, mbuli zina lyanu a myaka yakuzyalwa ayakusiswa, eelyo

mukupegwa nambala ciindi mubandi wakulembululwa kuzwa muwailesi naa tape recorder kubika a pepa. mulumbe ngomupa ciindi ca mubandi uyakweendelezegwa andime akubelesegwa buyo mumulimo ooyuwakuvwuntauzya. Buzubuluzi buya kujanwa a mulimo wabuvwuntauzi ooyu buya kutondezegwa kubana maleya a cikolo cipati ca University of Oslo, nkabela cakuti mulumbe ulangilwa kukwelelezya kuti muzyibwe inga wa cincwa.

Mulumbe wakukwabana

Hege Johanne Magnussen (sicikolo)/ Benedicte Ingstad (mwendelezi)

University of Oslo, Institute of Health and Society, Section for International Health, p.b 1130, Blindern, 0370, oslo.

Luwaile Zambia: 0977167337, Email: hjmagnus@student.uio.no

Diana Mannan Chanda (sikugwasilizya mukuvwuntauzya)

Luwaile: 0977 824235 , Email: dianamannan@yahoo.co.uk

The Chairman

TDRC Ethics Review Committee

Box 71769

Ndola

Luwaile: 0955914844, Fax: 02- 615444

Appendix 3, Information letter health worker

Request to participate in the study:

“Childhood disability in rural Zambia, a qualitative study on the use of health services among disabled children and their families”.

Background and purpose of the study

You are now asked to participate in a study where the aim is to better understand how children with disabilities and their families in Kazungula District use health care services. In this study I will interview health workers and primary caregivers of disabled children in an effort to find out more about the situations of disabled children. I wish to interview you since you have valuable insight into the topic being a health professional at a rural health clinic. Hopefully, the contributions from this study will provide information that can benefit disabled children and their families in the future. This study is done as part of the Master Programme in International Community Health at the University of Oslo, Norway. The study has been approved by The Regional Committee for Medical Research Ethics Sør- Øst, Norway and by Tropical Diseases Research Centre Ethics Review Committee, Zambia. The study will be conducted according to international ethical principles and guidelines. Participating in the study will be autonomous; your decision to participate as well as to give consent freely are on a voluntarily and open basis.

Information about your participation in the project

The interview will be held with you, me and an interpreter, and will last for approximately one hour. If it is not problematic for you, a tape recorder will be used during the interviews. You have the opportunity to end the interview at any time and you do not have to answer questions if you don't want to. If you chose to withdraw from the interview or decide you do not want to participate in the study you are free to do so. Meeting time and place will be decided by you. If you want to do the interview at the clinic, that is okay and a neutral place will be found if you prefer this.

What happens to the information you share?

The information you give and your confidentiality will be handled with care. Information that could make people recognize you, like your name and age will be kept anonymous and you will be given a new name when the interviews are transformed from the tape recorder to paper. The information you give in the interviews will only be handled by me and the interpreter, and only used in this project. Findings from the project will be published through the University of Oslo and information that could lead to your identification will be changed.

Contact information

A) Hege Johanne Magnussen (Student)/ Benedicte Ingstad (Supervisor)

University of Oslo, Institute of Health and Society, Section for International Health, Pb 1130 Blindern, 0370Oslo

Phone Zambia: 0977167337, Email: hjmagnus@student.uio.no

B) Diana Mannan (Research Assistant/ Interpreter)

Phone Zambia: 0977824235, Email: dianamannan@yahoo.co.uk

C) TDRC Ethics Review Committee, Box 71769, Ndola, Phone: 0955914844, Fax: 02- 615444

Appendix 4, Informed consent form, English version

Informed consent form

The information sheet has been read to me and I understand it / I have read and understood the information sheet.

I understand the purpose of the study.

I understand that the information regarding me that is collected within this study will remain confidential.

I understand that I am free to take part in the study or reject, and that I can withdraw from the study at any time, and without giving any reason. Deciding not to take part or to withdraw from the study will not affect the health care services that I am normally entitled to.

I understand that I have the right to stop the tape recorder during the interview or erase taped materials afterwards.

I have had the opportunity to ask questions and have them answered.

Signature or thumb-print of participant:

This form has been read to:
(Write name of participant)

in a language that he/she understands. I believe that he/she has understood what I explained and that he/she has freely agreed to take part in the study.

Signature of research assistant:

Signature of witness:

.....

.....

Name of research assistant:

Name of witness:

Diana Mannan

Appendix 5, Informed consent form, Tonga version

Pepa Lyabumboni

I pepa lyamulumbe lyabalwa kulindime alimwi ndateelela/ ndabala alimwi ndateelela pepa lyamulumbe.

Ndateelela muzeezo wabuvwuntauzi

Ndateelela kuti makani aajatikizya ndime mubuvwuntauzi oobu taakaletwi antangalala ayakuyobolwa mukaziye.

Ndateelela kuti ndilalaangulukide kutola lubazu, naa kutazumina kutola lubazu mubuvwuntauzi oobu, nkabela inga ndacileka kufwumbwa ciindi kakunyina akupa bupanduluzi.. Kulisalila kutola lubazu naa kucileka kuba mubuvwuntauzi kwiina nociya kuyambukizya zyabilo zyabukwabilizi bwa nseba nzendeede kutambula.

Ndalipedwe ciindi cakubuzya mibuzyo akwiinngulwa.

Kusimba olo cidinto casikutola lubazu:.....

Eeli pepa lyabalwa kuli:

(Lemba zina lya sikutola lubazu)

Ndasyoma kuti wateelela cindapandulula alimwi akuti walizumina kutola lubazu mukuvwuntauzya.

Kusimba kwabasikugwasilizya mukuvwuntauzya:.....

Zina lyabasikugwasilizya:.....

Kusimba kwabasikwiiminina:.....

Zina lyabasikwiiminina:

Diana Mannan

Appendix 6, Interview guide, primary caregiver

Interview guide primary caregivers

Theme: The disability of your child

Example of possible questions:

- How would you describe the health of your child?
- How would you describe the reasons for your child's disability?/ What types of explanations do you have?/ What types of explanations do others have?
- Can you think of reasons why this happened to your child?
- Could you describe his/ her participation in daily activities?
- How does it influence the family to have a disabled child?

Theme: Health needs

Example of questions:

- Can you tell me about a situation where your child was sick or had any symptoms?
- Last time your child was sick, what did you do? Who did you talk to about it?
- How did you make a decision to ask for the opinion of others?
- What solutions did you find?
- Last time you took your child to the clinic, what were your reasons for going there?

Theme: Access to health care facilities

Example of possible questions:

- What types of treatment has your child received?
- Do you have regular contact with the health clinic or other providers?
- Does the clinic know that there is a disabled child in your family?

Theme: Contact with special services for disabled children

Example of possible questions:

- Have you met any people from special health institutions in your village? If yes; what did you think about that?

Theme: Health Communication

Example of possible questions:

- Do you discuss your child's health situation with friends and neighbors? If yes; how do you find that? If not; could you think about reasons for not doing so?
- What types of advice have you gotten from others about your disabled child?
- How would you describe the communication with the staff at the health clinic?
- How would you describe the communication with other health care providers?
- What do the health workers ask you about and what do you ask the health workers about?

Appendix 7, Interview guide, health worker

Interview guide health workers

Theme: Challenges

Example of question:

- What are in your opinion the main challenges in having a disabled child in this community?

Theme: Health needs

Example of questions:

- What are your thoughts on the health needs of disabled children?

Theme: Access to health care

Example of questions:

- Do you have regular contact with children with disabilities and their families at the health clinic? If yes, how do you find that?
- What are in your opinion their reasons for coming to the clinic?
- What in your opinion prohibits them from accessing health care?
- Do you know about disabled children who are not coming to the health clinic? If yes; can you think of reasons for this?
- Can you think about any interventions to make it easier for them to access health care?
- In what ways are disabled children included in regular health activities within this community?

Theme: Special services for disabled children

Example of possible questions:

- Have you ever been in contact with a hospital or other special services regarding disabled children? If yes; how did you hear about it? how did you experience that?
- Have you met people from these institutions in the village? If yes; what did you think about that?

Theme: Contact with other health care providers:

- Have you heard about other ways of seeking help for the disabled child? If yes; what types of help?
- What is your opinion about the help they get at other providers?
- Where do they in your experience first come for assistance?
- Do you communicate with other providers like the traditional healers, churches, support groups about childhood disability?
- What could be the reasons for parents bringing their children to those different types of providers?

Theme: Role of the health worker

Example of possible questions:

- How would you describe the communication between the clinic and parents of children with disabilities?
- What types of questions do the parents have when they come to the clinic?
- What understandings to parents in your opinion have about the condition of their disabled child?
- What types of explanations do they use for the condition of their child?
- Do you think the work you do will have an impact on the health situation of disabled children? If yes; how?



UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Professor dr. philos Benedicte Ingstad
Institutt for samfunnsmedisin, avdeling for
medisinsk antropologi og medisinsk historie
Pb 1130 Blindern
Internpost

**Regional komité for medisinsk og helsefaglig
forskningsetikk Sør-Øst C (REK Sør-Øst C)**
Postboks 1130 Blindern
NO-0318 Oslo

Telefon: 22 84 46 67

Dato: 15.06.2010

Deres ref.:

Vår ref.: 2010/1378 (oppgis ved henvendelse)

E-post: post@helseforskning.etikkom.no

Nettadresse: <http://helseforskning.etikkom.no>

**Childhood disability in rural Zambia: A qualitative study on the use of health services
among disabled children and their families**

Vi viser til søknad mottatt til frist 29.04.2010 om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden er blitt vurdert av Regional komité for medisinsk og helsefaglig forskningsetikk i henhold til lov av 20. juni 2008 nr. 44, om medisinsk og helsefaglig forskning (helseforskningsloven) kapittel 3, med tilhørende forskrift om organisering av medisinsk og helsefaglig forskning av 1. juli 2009 nr 0955.

Formålet med studien er å undersøke tilgang og barrierer for helsehjelp for barn med funksjonsnedsettelse i Zambia. I studien vil man forsøke å skaffe en bredere forståelse av behovet for helsehjelp for disse barna. Videre vil man identifisere formelle og uformelle helsetilbud, og se hvilke valg som ligger bak de enkelte familienes valg. Studien har et kvalitativt design, hvor det skal gjennomføres intervjuer, observasjon og fokusgruppeintervjuer med pårørende og helsepersonell.

Prosjektleder: Dr. philos Benedicte Ingstad
Forskningsansvarlig: Universitetet i Oslo

Komiteen mener dette er en godt forberedt og interessant studie, og har ingen forskningsetiske innvendinger.

Vedtak:

Prosjektet godkjennes.

Tillatelsen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Tillatelsen gjelder til 31.12.2011. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato. Prosjektet skal sende sluttmelding på eget skjema, jf. helseforskningsloven § 12, senest et halvt år etter prosjektslutt.

Komiteens avgjørelse var enstemmig.


Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for *Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren*:

http://www.helsedirektoratet.no/samspill/informasjonsikkerhet/norm_for_informasjonsikkerhet_i_helsesektoren_232354

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. Forvaltningslovens § 28 flg. Eventuell klage sendes til REK Sør-Øst. Klagefristen er tre uker fra mottak av dette brevet.

Med vennlig hilsen

Arvid Heiberg (sign.)
professor dr. med.
leder



Tor Even Svanes
seniorrådgiver

Kopi: Universitetsdirektøren, universitetsdirektørens kontor, Pb 1072 Blindern, internpost

Vi ber om at alle henvendelser sendes inn via vår saksportal:
<http://helseforskning.etikkom.no> eller på e-post til: post@helseforskning.etikkom.no. Vennligst oppgi vårt saksnummer/referansennummer i korrespondansen.

All Communications to be addressed to the
District Medical Officer and not individuals
Tel: 213 -322971
Tel/Fax: 213 - 322645



In reply please quote

No.

MINISTRY OF HEALTH

OFFICE OF THE DISTRICT MEDICAL OFFICER
KAZUNGULA DISTRICT MEDICAL OFFICE
SOUTHERN PROVINCE
P.O. BOX 60596
LIVINGSTONE

26th August, 2010

The Provincial Medical Officer,
Provincial Medical Office,
P.O. Box
LIVINGSTONE

**RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH: MS. HEGE
JOHANNE MAGNUSSEN**

The above subject refers.

I wish to introduce to you the above named, a former Nord Kapp participant and Physiotherapist who is now a Masters Student at University of Oslo and seeking authority to conduct her research in Kazungula District under our office.

Her research topic is "**Childhood Disabilities in Rural Zambia, a qualitative study on the use of health services among disabled children and their families**". The methodology of the study will be qualitative were the officer will be conducting interviews with the selected samples.

I would be grateful if my request could be supported.

A handwritten signature in black ink, appearing to read 'Hadunka', is written above the typed name.

Dr. Hadunka, F.
Ag. District Medical Officer

TROPICAL DISEASES

Tel/Fax +260212615444
tdrc-ethics@tdrc.org.zm



RESEARCH CENTRE

P O Box 71769
NDOLA, ZAMBIA

TDR ETHICS REVIEW COMMITTEE
IRB REGISTRATION NUMBER: 00002911
FWA NUMBER: 00003729

TRC/ERC/C4/10/2010

29th October 2010

Hege Johanne Magnussen
Institute of Health and Society
Faculty of Medicine
University of Oslo
Norway

Dear Ms Magnussen

RE: Review of Protocol

Reference is made to your protocol entitled **Childhood disability in rural Zambia, a qualitative study on the use of health services among disabled children and their families** version dated 27th May 2010.

The following are our comments

1. In section 4.5.2 we take note that you plan to do some observations. Please take note that you are obliged to debrief the participants at the end of your observations about your study especially if the participants are not aware that you are observing them.
2. Consent form and information letter
 - a. Please ensure that you provide the ethics committee with a copy of the translated Tonga version of the consent form as soon as possible.
 - b. Please add the following contact information to the information letter in addition to your contact details:

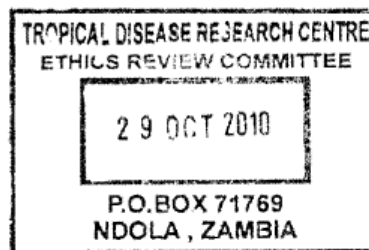
The Chairman
TDR Ethics Review Committee
Box 71769
Ndola
Tel: 0955914844, Fax 02-615444
 - c. As a matter of policy, we do not encourage verbal consent. As much as possible consent to participate in a study has to be written. If a person is illiterate then an impartial witness has to sign the consent form.

Kindly submit a response to the each of the above concerns and make the necessary revisions to the consent forms as soon as possible.

Yours faithfully

TROPICAL DISEASES RESEARCH CENTRE

Dr Gershom Chongwe B Sc, MB ChB, MPH
SECRETARY- TDR ETHICS REVIEW COMMITTEE



cc: Secretary, STC



TDRS ETHICS REVIEW COMMITTEE
IRB REGISTRATION NUMBER: 00002911
FWA NUMBER: 00003729

TRC/ERC/C4/11/2010

3rd November 2010

Hege Johanne Magnussen
Institute of Health and Society
Faculty of Medicine
University of Oslo
Norway

Dear Ms Magnussen

RE: Review of Protocol

Reference is made to your protocol entitled **Childhood disability in rural Zambia, a qualitative study on the use of health services among disabled children and their families** dated 27th May 2010 and your email dated 29th October 2010 in response to our comments.

On behalf of the Chairman of the TDRS Ethics Review Committee, I am pleased to inform you that we are satisfied with your response and this letter signifies approval of your protocol.

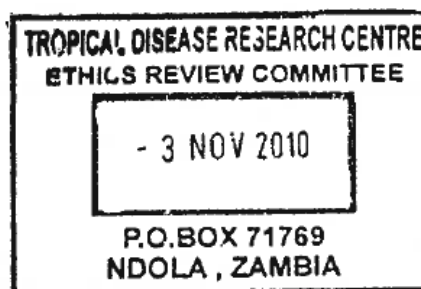
You are required to provide the Committee with a status report on the progress of the study at least twice in a year after which the study will be reviewed for the annual re-approval. You must submit a final report at the end of the study. You should seek approval from the TDRS Ethics Review Committee for any amendments to the protocol or informed consent.

Your study number is **TDRS/ERC/0310/0710**. This approval is valid up to 2nd November 2011. The Committee wishes you and your team every success in the execution of the study.

Yours faithfully

TROPICAL DISEASES RESEARCH CENTRE

Dr Gershom Chongwe B Sc, MB ChB, MPH
SECRETARY- TDRS ETHICS REVIEW COMMITTEE



cc: Secretary, STC