PROFILING CHILDREN WITH NEURAL TUBE DEFECTS AND EXPLORING EXPERIENCES OF MOTHERS

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KEY WORDS

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ABSTRACT

Neural tube defects (NTDs) are the world's second most common birth defects after cardiovascular defects. In developing countries, poor access to health care services among children with NTDs contributes to early infant deaths, while those who survive live with severe disabilities. In Zambia, all children with NTDs in need of surgery are referred to Lusaka and physiotherapy services are not available in health facilities below the first level hospitals. The aim of the current study was to determine the profile of children with NTDs and to explore the experiences of mothers with accessing health care services for these children.

The study which was conducted at the University Teaching Hospital (UTH) in Lusaka consisted of both quantitative and qualitative methods. The quantitative phase consisted of a retrospective record review of children with NTDs, who were admitted to UTH from January to December, 2010. A sample of 50 medical records was used based on available records, and data collection was done using a data extraction sheet which was specifically designed for the study. Analysis of quantitative data was done using Statistical Package for Social Science (SPSS) version 20.0. The qualitative phase had two parts, with the first part involving in-depth interviews with a purposefully selected sample of 20 mothers of children who were admitted to UTH. The second part used a sample of convenience of four mothers who had brought their children for follow up visits. All interviews were audio-taped, transcribed verbatim and translated, and recurring ideas were coded and collapsed into categories and themes. Permission to conduct the study was obtained from the UWC Research Grant and Study Leave Committee, University of Zambia Research Ethics Committee, and University Teaching Hospital management. Informed written consent was obtained from the mothers who accepted to take part in the study. Results from the record review revealed that the majority of children were from Lusaka province, with ages ranging from one day to 48 months and a male predominance of 58%. Myelomeningocele was the most common type of NTD (44%) with the lumbar region being the common site (52%). Hydrocephalus was present in 74% of children, 30% of children had both paraplegia and incontinence and 22% (n=11) of the files had no information on the neurological impairments. Wound infection was present in 40% (n=20) of the children. The majority (66%) of children were lost to follow up. Mothers of children who were admitted in UTH cited transport to UTH and back home as the main challenge. Other challenges included the lack of a prenatal diagnosis, the need for information, uncertainty about future of their children, and concerns about their family. Interviews with mothers on experiences with accessing physiotherapy services found that the lack of knowledge among mothers was the main reason children were not accessing physiotherapy services. Findings on access to health care were related to the "Four A's" access theory which consists of four dimensions of access namely geographical accessibility, availability, affordability and acceptability. It is recommended that health care providers and policy makers ensure that all children with NTDs are provided with free transport to and from referral hospitals. Policy makers need to consider involving physiotherapists in out-reach programmes and mobile clinics to ensure access to physiotherapy services for all children in need of the service. Health care providers must also ensure that they give adequate information to mothers of children born with birth defects as this enhances their access to appropriate health care services.

DECLARATION

I hereby declare that **“Profiling children with neural tube defects and exploring experiences of mothers”** is my own work, that it has not been submitted, or part of it, for any degree or examination in any other University, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Signature: ………………………….

Micah M Simpamba November, 2012

Witness: …………………………….

Professor P Struthers

DEDICATION

I dedicate this thesis to my husband for his love, support and understanding during the time I was away, and to my three sons and nephew Chiwanza, Chiputwa, Chikonde and Njavwa.

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ABREVIATIONS

CNS	Central nervous system
CSF	Cerebral spinal fluid
DC	District Commissioner
CT	Computed Tomographic scan
ETV	Endoscopic third ventriculostomy
FCC	Family centred care
ICF	International Classification of Function, Health and Disability
NTD	Neural tube defect
VPS	Ventriculo peritoneal shunt
UTH	University Teaching Hospital

CHAPTER 1

INTRODUCTION

1.1 BACKGROUND

Global estimates of birth defects indicate that 7.9 million children are born with birth defects each year and of these, 90% are born in developing countries (Christianson, Howson, & Modell, 2006). Most children who survive infancy after they are born with major birth defects are at greater risk for morbidity from physical, mental and social health disorders (Correa-Villasenor, et al., 2003). In developing countries, the lack of comprehensive services for care and prevention results in early deaths for infants born with birth defects and those who survive live with disabilities arising from primary or secondary effects (Howse, Howson & Katz, 2005). Among the five most common birth defects in the world, central nervous system (CNS) defects come second to cardiovascular defects in frequency (Christianson et al., 2006).

Neural tube defects (NTDs) are a group of congenital defects of the CNS resulting from failure of the neural tube to close during the first few weeks of foetal development (Padmanabhan, 2006). NTDs are classified according to those affecting the cranial structures, namely anencephaly and encephalocele, and those affecting the spinal structures known as meningocele and myelomeningocele (Bassuk & Kibar, 2009; Frey & Hauser, 2003). The spinal NTDs are commonly referred to as spina bifida. NTDs can also be classified as open if the neural tissue is exposed or closed when the neural tissue is skin covered (Mitchel, 2005). The most common NTDs are anencephaly and myelomeningocele which are both open NTDs (Mitchel, 2005). Anencephaly has been reported to be a lethal condition and incompatible with life while children with myelomeningocele are able to survive but with lifelong disabilities depending on the size and location of the defect (Bassuk & Kibar, 2009; Northrup & Volcik, 2000).

Spina bifida and occipital encephalocele may range from mild to severe forms with or without accompanying cognitive and physical disabilities (Biu, et al., 2007). Children with myelomeningocele may present with various types of impairments which include paralysis of the lower limbs, hydrocephalus, deformities of the limbs and spine, urine and bowel incontinence, motor and sensory impairments of the lower limbs and hip dysplasia (Lumley et al., 2009; Nili and Jahangiri, 2006; Northrup & Volcik, 2000; Botto et al., 1999). Severe occipital encephalocele may also be associated with hydrocephalus, microcephalus or seizures (Biu et al., 2007).

In developed countries, approximately 14% of children with spina bifida do not survive past the age of five years, with 35% increase in mortality rate among those with symptoms of Arnold Chiari malformation (Walsh & Adzick, 2003). However, current advances in management of these complications have led to more children surviving into adulthood (Bowman & McLone, 2010). While advances in prenatal diagnosis and health care services have led to increased rates of survival among children with NTDs in developed countries, the situation in African countries is different as children born with NTDs are faced with high mortality rates and severe impairments for those who survive (Miles, 2006). Causes of mortality depend on age, with complications of wound infection and hydrocephalus being main causes in early childhood while renal complications are major causes of death in adulthood (Lazareff, 2011).

Variations in the prevalence of NTDs exist between and within countries (Lumley, Watson, Watson, Bower, 2009). It is estimated that each year, about 300,000 new-born babies are affected by NTDs globally (Berry et al., 1999). The past three decades has seen a decline in the incidence of NTDs in most developed countries (Olney & Mulinare, 2002).

In Sub-Saharan African countries, the incidence rate of NTDs has remained between 0.16 to7/1000 births (Shehu & Ameh, 2004).

Besides genetic and environmental factors, the main cause of NTDs has been reported to be folic acid deficiency, which is crucial for the development of the foetal nervous system (Oakley, 2002). The decline in the prevalence of NTDs in developed countries has been attributed to advancement in prenatal diagnosis, serum alpha-fetoprotein tests, termination of affected pregnancies and folic acid supplementation among women of childbearing age (Fletcher & Brei, 2010; Kondo, Kamihira, & Ozawa, 2009; Botto et al., 2005). Despite overwhelming evidence from developed countries on prevention of NTDs, most countries in Sub-Saharan Africa do not have policies on prevention of NTDs (Adeleye, Dairo & Olowookere, 2010; Lumley et al., 2009; Djientcheu et al., 2008). South Africa is the only country in Africa which has reported the implementation of food fortification and the subsequent reduction in the prevalence of NTDs after fortification of the staple food (Sayed, Bourne, Pattinson, Nixon, & Henderson, 2008). In Zambia, sugar and maize meal (staple food) are fortified with vitamin A but most people from rural areas grow their own maize and may not afford the cost of sugar. These people may therefore not benefit from fortified food unless fortification is taken to the community. This is evidenced by results of a pilot study which was carried out in Western province of Zambia by World Food Programme (WFP) and its partners (van den Briel, Cheung, Zewari, & Khan, 2006). In this pilot study, WFP imported and installed containerised milling and fortifying units in a refugee camp and this led to a reduction in iron and vitamin A deficiency among the people in the camp (van den Briel, et al., 2006). This method could also be used to fortify maize meal with folic acid and could benefit the rural community who grow their own maize.

The reasons for the lack of implementation of policies in African countries has been attributed to the under-estimation of the burden of birth defects as well as the lack of awareness on the part of health care personnel and ignorance of the target population (Adeleye & Olowookere 2009; Djientcheu et al., 2008). The limited diagnostic capabilities, poor health statistics and reliance on hospital based studies as opposed to population based studies has contributed to the lack of awareness and underestimation of the burden of NTDs in developing countries (MOD, 2008; Penchaszadeh, 2002).

According to Olutoye and Adzick (1999), infants born with open NTDs must undergo surgery within 72 hours of birth in order to prevent infection of the wound with subsequent cerebral spinal fluid (CSF) infection. However, access to surgical management for many children with NTDs in African countries may not be easy because specialised services such as paediatric neurosurgery are only available in larger hospitals (Ameh, 2003; Miles, 2006). This means the affected children and their mothers have to be transported over long distances to the cities where the surgical services are available. This presents challenges for parents with children with NTDs who are usually from low socio-economic background and living in rural areas (Ameh, Dongo & Nmadu, 2001). The consequence is late presentation for surgery as well as infected wounds for those with open NTDs (Ameh et al., 2001).

Management of children with myelomeningocele requires a coordinated multidisciplinary team approach because of the multiple impairments associated with this type of NTD (Mitchel et al., 2004). After surgery, the children are supposed to be followed up by this multidisciplinary team but once they are discharged, many of the children in African countries do not make it for follow up visits (Djientcheu et al., 2008). Furthermore, rehabilitation services such as physiotherapy are not easily accessible or available for the majority of children with disabilities (Djientcheu et al., 2008; Saloojee, Phohole, Saloojee,

& Ijsselmuiden, 2007). Lack of access to rehabilitation services for children with NTDs contributes to preventable secondary complications and most of the children who survive end up being totally dependent for their activities of daily living (Lazareff, 2011).

1.2 STATEMENT OF THE PROBLEM

According to the records obtained from the paediatric surgical ward at the University Teaching Hospital (UTH), there were more than 100 children admitted with NTDs from January to December, 2010. These children came from different provinces in Zambia because surgical repair and shunting for children with NTDs is only done at UTH or Beit Cure Hospital, both of which are in Lusaka. The lack of specialised surgical services in hospitals located in peri-urban and rural areas contributes to premature deaths and lifelong disabilities among the children with NTDs due to late presentation for surgery (Bickler & Rode, 2002; Ameh et al., 2001).

In order to understand the extent of this problem in Zambia, it is important to determine the profile of children with NTDs admitted at UTH and to explore the mothers' views of their experiences with accessing specialised health care from referral hospitals. Profiling the children with NTDs will provide data on the prevalence of children with different types of NTD, their clinical profile and the demographic factors that may be relevant. Furthermore, exploring the experiences of mothers who have children with NTDs admitted to these referral hospitals will enable both health care providers and policy makers understand the challenges mothers experience and the support they need in transporting their children to the referral hospitals. Health care providers and policy makers can use this information to develop strategies to improve health care delivery for these children and for formulating policies on preventive measures.

The researcher was also prompted to explore the experiences of mothers accessing physiotherapy services. Despite the large number of children with NTDs admitted to the paediatric surgical ward at UTH within a period of one year, the researcher's found that physiotherapists from other provinces treat and manage very few children with spina bifida. This had been reported to the researcher during paediatric scientific meetings.

The physiotherapy records at UTH also revealed that there were more children with spina bifida from within Lusaka who were being attended to as in-patients and very few seen as out-patients. Furthermore, some children who require physiotherapy services will not be able to access the services easily if they live in peri-urban or rural areas because there are no physiotherapists in health facilities below the level of district hospitals in other parts of Zambia apart from in Lusaka. There was a need to ascertain the physiotherapy needs of these children. This highlights the problem that children with are not getting access to surgery or physiotherapy as required to survive and live a quality life. Profiling children with NTDs would provide useful information related to the physiotherapy needs of these children while exploring experiences of mothers regarding accessing physiotherapy services would provide information on the challenges mothers face getting access to surgery. This information will be helpful in formulating appropriate strategies aimed at providing equal access to physiotherapy services for children with NTDs.

1.3 RESEARCH QUESTIONS

1. What is the profile of children with NTDs admitted to the University Teaching Hospital in Zambia?
2. What are the experiences of mothers with accessing health care services for children with NTDs in Zambia?

1.4 AIM

To determine the profile of children with NTDs admitted to the University Teaching Hospital and explore experiences of mothers with accessing health care services.

1.5 SPECIFIC OBJECTIVES

1. To describe the profile of children with NTDs admitted to the University Teaching Hospital in Zambia.
2. To explore challenges and support experienced by the mothers of children with NTDs in relation to accessing health care services from the University Teaching Hospital (UTH).
3. To explore mothers' perception of the feasibility of accessing physiotherapy and returning for follow up visits when the child is discharged.
4. To explore experiences of mothers with accessing physiotherapy services for children with NTDs with associated motor impairments.

1.6 DEFINITION OF TERMS

Anencephaly: Type of NTD resulting from failure of closure in the cranial region and is characterised by partial or complete absence of the cranial bone and cerebral hemispheres (Bassuk & Kibar, 2009).

Arnold Chiari type II malformation: Downward herniation of the hindbrain, a common complication in myelomeningocele (Stevenson, 2004).

Arthrogryposis: This is a congenital birth defect which is characterised by multiple joint contractures with muscle weakness and limitation of joint movements (Niveditha, Singhal, Keshav, Rajesh, & Baliga, 2011).

Barriers to access: Barriers are factors that contribute to an individuals' failure to access health care services when they are needed (Iezzoni, Killeen, & O'Day, 2006).

Birth defects: Congenital malformations resulting from abnormal structural development before birth (Burton, 2008).

Encephalocele: An NTD caused by failure of closure of the cranium and characterised by protrusion of meninges and/or brain tissue which is covered by normal or atrophic skin (Lumley et al., 2009).

Frontoethmoidal encephalocele: Herniation of intracranial contents through a defect of the skull at the junction between ethmoidal and frontal bones (Holmes, Meara, Kolker, Rosenfeld & Klug, 2001).

Endoscopic third ventriculostomy (ETV): This is the endoscopic perforation of the floor of the third ventricle to treat obstructive hydrocephalus (Koch & Wagner, 2004).

Iniencephaly: This is a lithal and rare type of NTD which is characterised by defective occipital bones, partial or complete absence of cervical and thoracic vertebrae and hyper-extension of the malformed cervical-thoracic spine with significant shortening of the spinal column (Pungavkar, et al., 2007)

Rehabilitation: A set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments (WHO, 2011).

Spina bifida: The term spina bifida refers to all types of spinal NTDs which include meningocele, a closed NTD and myelomeningocele, an open NTD. Some literature refers to spina bifida as myelomeningocele, but in the current study, the term will be used to refer to both meningocele and myelomeningocele (Mitchel, 2005; Botto et al., 1999).

Tethered spinal cord: This is the traction or tension exerted on the spinal cord and nerve roots, leading to ischaemic injury and secondary neurological deterioration in affected individuals (Thomson, 2009).

1.8 CHAPTER SUMMARY

Chapter One presented the introduction and background of the research topic in relation to definitions, impairments, mortality and morbidity, prevalence, causes and management.

Comparisons on management, outcome and preventive measures are made between developing and developed countries. Lack of good health systems and policies on implementation of preventive measures in developing countries are also highlighted. The chapter also highlights the poor accessibility of children with NTDs to primary health care in Zambia and the need for research in this area in order to inform policy makers and health care providers on the extent of this problem.

1.9 OUTLINE OF OTHER CHAPTERS

This thesis consists of five more chapters which follow Chapter One. Chapter Two presents the literature review in relation to the research topic. The chapter starts with literature on the profile of NTDs which includes the prevalence, types of NTDs, associated impairments and surgical management. More emphasis is given to countries in the sub-Saharan African region. This is followed by the challenges faced with paediatric surgery in developing countries. Support for parents of children with disabilities, challenges faced by mothers of children with disabilities as well as rehabilitation services for children with disabilities in developing countries are reviewed and finally some theories on access to health care are presented.

Chapter Three presents the methodology used in this study. The study consisted of one quantitative part and two qualitative parts. The study design and setting for both the quantitative and qualitative parts are presented. Furthermore, the population and sampling methods used for the three parts of the study are presented as well as procedures used in data collection. The instruments used for quantitative data collection are described as well as interview guides used to collect qualitative data. Methods used to analyse both qualitative and quantitative data are described and ethical procedures followed before and during the study. The chapter ends with the researcher’s personal reflection.

Chapter Four presents the results for both quantitative and qualitative parts of the study. The chapter begins with presenting results of the quantitative part which was a record review. Descriptive data are presented using percentages and frequencies by means of graphs, tables and text. Associations between certain variables were tested by means of chi-square. Secondly, results from the interviews with mothers on experiences with accessing health care from University Teaching Hospital are presented including their demographic characteristics. The chapter ends with the presentation of results from interviews with mothers on experiences with accessing physiotherapy services for children with spina bifida.

Chapter Five discusses the findings from all the three parts of the study. The findings of the study are discussed based on the research objectives and how they compare with the literature reviewed. The chapter discusses the profile of children with NTDs and experiences of mothers with accessing health care services. The experiences of mothers with accessing health care services are also discussed in relation to access theories.

Chapter Six, the final chapter summarises the whole study and includes the conclusion, limitations of the study, significance of the study as well as recommendations and suggestions for future research.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The aim of this chapter is to give an overview of current literature in relation to this study. The chapter begins by presenting literature on NTDs in relation to its prevalence, types, associated impairments and surgical management. The literature review did not find articles specifically related to experiences of mothers of children with NTDs. However, the literature review focused on challenges of paediatric surgery in African countries; rehabilitation services for children with disabilities in developing countries, challenges faced by parents of children with disabilities in developing countries as well as support for parents of children with disabilities. In addition, literature on theories on access to health care was reviewed as well as its relevance to the current study.

The literature review was conducted using the electronic databases available through the University of the Western Cape which included Medline via PubMed, Google scholar and EBSCOhost. Other sources of information included books, journal articles and secondary references from selected articles. Key words used for searching were neural tube defects, spina bifida, myelomeningocele, access to health care, caregiver experiences, childhood disabilities, developing countries, paediatric surgery, paediatric rehabilitation and Zambia.

2.2 PROFILE OF NEURAL TUBE DEFECTS

This section reviews literature on profile of NTDs in relation to its prevalence, types, associated impairments and management with special emphasis on studies done in African countries.

2.2.1 PREVALENCE OF NEURAL TUBE DEFECTS

The worldwide incidence of NTD is estimated to range between 1.0 and 10.0 per 1000 births (Au, Ashley-Koch, & Northrup, 2010). It is estimated that NTDs affect about 3000 pregnancies in the United States each year (Williams, et al., 2005). Incidence of NTDs for developed countries (G 8 countries) during the period between 2000 and 2004 were estimated to range between 0.3 and 0.4 per 1000 live and still births including terminations (Kondo et al., 2009). Reports also show that the highest incidence of NTDs were reported in China at 19.94 per 1000 births during the period of 2002 to 2004 and 13.87 per 1000 births in 2003 (Gu et al., 2007; Li et al., 2005). Studies done in both developed and developing countries have shown a common trend regarding the educational and social economic status of the affected families. This trend shows that the majority of these families have a low educational background and low socioeconomic status (Bulbul, Can, Bulbul, Comert & Nuhogul, 2010).

The incidence of NTDs in most African countries has been reported to range between 0.16-7/1000 births (Shehu & Ameh, 2004). In South Africa where fortification of staple food with folic acid has been implemented, the incidence rates of NTDs were reported to decline from 1.41 per 1000 births pre-fortification to 0.98 per 1000 births after fortification giving a reduction of 30.5% (Sayed et al., 2008). Other studies which reported the incidence of NTDs in African countries includes a 10 year retrospective study which was done from 1997 to 2006 in Cameroon and reported 98 cases of NTDs with an incidence of 1.99/1000 births (Njamnshi et al., 2008). In Algeria, a three year hospital based retrospective study done between 2004 and 2006 reported a higher incidence of 7.5 per 1000 births (Houcher, Bourouba, Djabi, & Houcher, 2008). Another hospital based retrospective case control study which was done in Sudan between February 2003 and January 2004 reported 63 cases of NTDs among the hospital deliveries with an incidence of 3.48/1000 births (Elsheikh & Ibrahim, 2009). It is important to note that all the studies done in Africa are hospital based and hence do not reflect the actual prevalence of NTDs in these countries. In Zambia, there is no published report on specific types of disabilities including that of NTDs. However, the prevalence of disability according to the 2000 Zambia census of population and housing was 2.7% (256,690) out of a total population of 9.3 million people (Central Statistical Office (CSO), 2000). According to this report, the main causes of disability in Zambia are disease (39%), congenital or prenatal (13.7%), injury (17.2%), other (9%) and 20% are unknown (CSO, 2000). The age groups for the people with disabilities in the report showed that 13,343 people were aged between 0-4 years, 18,386 were aged between 5-9 years, 19,848 were aged between 10-14 years and the rest were aged above 15 years. This report based the prevalence on four types of impairments namely physical, visual, mental and hearing impairments (CSO, 2000). This method of determining prevalence is common in most African countries and results in under-reporting which are far below those of developed countries (Eide & Loeb, 2006). According to Loeb, Eide and Mont, (2008), a more sensitive and socially acceptable method of determining disability is to base it on functional ability as this allows for the reporting of prevalence based on the threshold of difficulties in performing activities of daily living. Results from a survey which was carried out in Zambia on the living conditions of people with disabilities showed that using the screening methods proposed by the Washington Disability Statistics resulted in a larger proportion (13.3%) of people with disabilities compared to the 2.7% reported by the 2000 census (Eide & Loeb, 2006). The implication of this discrepancy is that policy will be based on providing services for a small population of 2.7 % of disabled people when actually there are 13.3% of people who need the services (Loeb et al., 2008).

2.2.2 TYPES OF NEURAL TUBE DEFECTS

The most commonly occurring NTDs are anencephaly and myelomeningocele which are both open NTDs resulting from failure of closure of the cranial and spinal neural tube respectively (Bassuk & Kibar, 2009). A review of literature on studies done on NTDs confirmed that the two types are most common although most of the studies in Africa show myelomeningocele to be the most common (Taye and Bedru, 2009; Djientcheu et al., 2008; Njamnshi et al., 2008). One of the reasons why there are few reports of cases of anencephaly in Africa could be attributed to the high mortality associated with anencephaly and many children who are born at home with anencephaly may not be recorded. However, even in non-African countries, there are reports of more cases of myelomeningocele. For example, a study which was done in the USA reported spina bifida to be more prevalent (66.9%) compared to cranial defects 17.7% (Deak et al., 2008). On the contrary, there are studies which have reported anencephaly cases to be more common than spina bifida. One of these reports was from a study which was done in China with 41.4% of the cases with anencephaly followed by spina bifida (19.5%) and then encephalocele (13.3%) (Gu et al., 2007). Because of the high incidence of anencephaly in this study, only 13 of the affected pregnancies resulted in live births while 103 ended in abortions and the other 12 were still births.

Among the studies done in African countries that reported more cases of myelomeningocele and meningocele were those done in Ethiopia, Nigeria and Algeria. The study done in Ethiopia reported a predominance of myelomeningocele (64%) followed by meningocele (18%) and lastly encephalocele with 13% (Taye and Bedru, 2009). In Nigeria, a study which was done on CNS anomalies reported that out of 32 cases of NTDs, 23 were spinal lesions while the other nine were cranial lesions (Adeleye et al., 2010). Another study which was done in Algeria reported that out of 215 cases of NTDs, 122

(56.7%) had spina bifida, 69 (32.1%) had anencephaly, 23 (10.7%) had both anencephaly and spina bifida and 1 (0.5%) had encephalocele (Houcher et al., 2008). This study was also associated with a high mortality rate due to the large number of anencephaly cases.

Contrary to reports of more cases of myelomeningocele in these African countries, a study which was done in Sudan reported a higher incidence of cranial malformations with 23 cases of anencephaly, 9 cases of encephalocele, 30 cases of myelomeningocele and one unusual case of iniencephaly (Elsheikh & Ibrahim, 2009). As might be expected, this study reported a high mortality rate of 52 out of the 63 cases of NTDs due to the high number of severe and lethal cases.

The literature review also considered the site of the lesion because it is important in determining the neurological outcome and health related quality of life especially in spinal lesions where lower lesions have better outcome compared to upper lesion (Flanagan, Gorzkowski, Altiok, Hassani, Woo, 2011). The most common sites for spinal cord lesions are lumbar or lumbosacral regions while the less common sites are cervical, thoracic and sacral regions (Burton, 2008). Deak et al. (2008), in a study done in the USA, reported more cases of spina bifida to be on the lumbosacral region, with 602 out of a total of 784 patients with myelomeningocele. In another study which was done in Malaysia, it was reported that 79% of the lesions were on the lumbar and sacral regions (Idris, 2011). This study reported that out of a total of 42 children with myelomeningocele, 1 (2.4%) had thoracic lesion, 3 (7.1%) had thoracolumbar, 5 (11.9%) had lumbar lesions, 18 (42.9%) had lumbosacral lesions and 15 (35.7%) had sacral lesions (Idris, 2011). Most studies done in sub-Saharan African countries have reported the lumbosacral region to be the most common site for spinal NTDs (Adeleye & Olowookere., 2009; Idowu & Apemiye, 2008; Audu et al., 2004). A study which investigated factors affecting survival of infants with myelomeningocele in Uganda reported that of the 140 children that participated in the study, 60 had myelomeningocele on the lumbosacral region, 47 on the lumbar region, 10 on the thoracolumbar and eight on the sacral region (Warf, Wright & Kulkarni, 2011c). The high frequency of lumbosacral NTDs in new-borns reported in many African studies may not be an indication that most NTDs are located in this area. This is because most lumbosacral NTDs are mild and do not usually result in spontaneous abortions as is the case with more severe forms such as severe cervical myeloschisis and holoprosencephaly (Idowu et al., 2008). The accurate facts about the common sites can only be known if data for those affected pregnancies which end up in spontaneous abortions are also captured.

For encephalocele, it is reported that the most common site is the occipital region with approximately 75% of encephalocele cases (Burton, 2008). This is consistent with findings from studies done both in Africa and outside Africa which includes studies done in Uganda (Warf, Stagno, & Mugamba, 2011a), Atlanta (Siffel, Wong, Olney & Correa, 2003) and in Tehran (Dadmehr, et al., 2009). According to Thompson (2009), occipital encephaloceles are more common in Western countries while frontal encephalocele are more predominant in Asia. It is important to note that occipital encephaloceles have a higher rate of hydrochephalus and carries a worse prognosis compared to others types (Thompson, 2009; Bui et al., 2007). The researcher is of the view that this may have greater implications on management especially in developing countries where resources are scarce.

2.2.3 ASSOCIATED IMPAIRMENTS

Most of the studies done on NTDs have focused on myelomeningocele because of its high prevalence, the increased survival rate of affected individuals as well as the degree of lifelong developmental and physical disabilities children who survive experience (Mitchel, 2005). The damage to the spinal cord in patients with myelomeningocele may result in varying degrees of motor paralysis, bowel and bladder dysfunction and orthopaedic deformities of the lower limbs (Mayer, Weisser, Till, Grafe & Geyer, 2010). Other associated impairments include hydrocephalus and Chiari type II malformation, a characteristic hindbrain herniation into the upper cervical canal which is common in individuals with myelomeningocele and intellectual impairment, (Mitchel et al., 2004). Hydrocephalus has been reported to be the most common impairment associated with NTDs in studies done in African countries (Adeleye & Olowookere, 2009; Djientcheu et al., 2008; Houcher et al., 2008). In a study done in Cameroon, associated impairments consisted of hydrocephalus in 42% of children, club feet in 26%, and omphalocele in 2% of the cases (Djientcheu et al., 2008). In the same study other associated anomalies found were paraplegia and sphincter disorders in 52% of the children, sphincter disorder without paraplegia in 24% and no paralysis in 12% of the children. Another study by Idowu, Disu, Anga and Fabanwo (2008) reported that out of 47 patients with NTDs, 16 had club feet, two had arthrogryposis, one had an imperforate anus and another had a congenital hip dislocation. Other associated anomalies observed include undescended testis and different types of hernia as was the case in a study that was done in Ethiopia (Taye & Bedru, 2009). In another study which was done in Germany to determine the outcome of myelomeningocele management, it was reported that 85.5% of the participants required shunt insertion by the first year of life, 57.1% had Arnold Chiari II malformation and 41.9% had tethered cord syndrome (Mayer et al., 2010). In developing countries such as the sub-Saharan African countries, children born with associated impairments such as hydrocephalus and other congenital malformations that require surgery may pose a greater challenge to the family. This is because management of such complications would require expensive surgery which may not be readily available or affordable for the families as they usually come from low social economic backgrounds.

Other closed NTDs such as meningocele and encephalocele are less disabling although the outcome for encephalocele is dependent on the site of the defect and amount of brain tissue in the sac (Thomson, 2009). The impairments associated with encephalocele include hydrocephalus, seizures, microcephaly and intracranial abnormalities (Lo, et al., 2008; Bui et al., 2007). Findings from a retrospective hospital based review of encephaloceles which was done in Alabama showed that 60% of those with occipital encephaloceles had hydrocephalus and 17% had epilepsy while hydrocephalus was present in 14% of those with frontal encephaloceles and epilepsy was present in only 7% of this group (Bui et al., 2007). Another study which was done on encephaloceles in Uganda, reported that out of 110 patients with encephalocele, 35 (32%) had hydrocephalus. According to Lo et al. (2008), the presence of hydrocephalus, seizure disorders, microcephaly, intracranial abnormalities and the presence of brain tissue in the defect was significantly associated with poor outcome (Lo, et al., 2008). However, most of the studies done on encephaloceles have reported positive outcomes with mild or no neurological impairments among participants (Alexiou, Sfakianos & Prodromou, 2010; Shilpakar & Sharma, 2004). In a study which was done in Turkey, 16 out of 27 children with encephaloceles presented with hydrocephalus which was treated with ventriculo-peritoneal shunt (VPS) and none among the 27 had neurological deficits (Alexiou et al., 2010). However, it can be argued that the positive outcomes in some of these studies could be attributed to selection bias such as referral bias where severe and very ill neonates may not be referred in time. Other contributing factors may be high termination of foetuses with encephalocele and population bias where only those that can easily be reached are included in the analysis, a view also echoed by Lo et al., (2008).

2.2.4 SURGICAL MANAGEMENT OF NEURAL TUBE DEFECTS

The surgical management of children with NTDs is mainly focused on myelomeningocele but it should be noted that methods of management also involve other types of NTDs (Bowman & McLone, 2010). The main objectives of management for encephalocele include removal of the sac, preservation of the neural tissue, closure of wound and shunting in cases where hydrocephalus is present (Thompson, 2009).

It is believed that while still in utero, the foetus with an open NTD is exposed to secondary damage to the neural tissue by the amniotic fluid, direct trauma, hydro-dynamic pressure or the combination of the two (Walsh & Adzick, 2003). This hypothesis has led to in-utero surgical closure of open NTDs in developing countries (Walsh & Adzick, 2003). Studies done on this procedure have reported that in-utero repair of myelomeningocele have led to improved neurological function and reduced morbidity which results from complications of hydrocephalus and Arnold Chiari malformation (Bruner, et al., 1999). Despite reported advantages of in-utero management of myelomeningocele, Mayer et al. (2010) observed that the risks involved with in-utero surgery outweigh the advantages that go with it. Some of the reported risks associated with fetal surgery were chorioamnionitis, placenta abruption and premature delivery (Mayer et al., 2010). Another report that noted disadvantages of in-utero surgery for myelomeningocele was a study that compared the urodynamics of children who underwent prenatal closure of myelomeningocele to those with postnatal closure (Koh, DeFilippo, Borer, Khoshbin, & Bauer, 2006). This study reported that all five children who had prenatal closure of the defect had complete denervation of the sphincter muscles compared to 34 out of the 88 (32%) who underwent postnatal closure (Koh et al., 2006). However, findings from this study may not be statistically significant because of limitations such as the small sample size in the prenatal group which could have exagerated the results. With regard to postnatal surgery, there is controversy in relation to management of NTDs associated with hydrocephalus in the sense that some schools of thought advocate for simultaneous surgery while others advocate for staged surgery where repair is first done followed by shunting (Sinha et al., 2012; Idris, 2011). Simultaneous surgery is one where closure of the NTD and shunt for hydrocephalus is done at the same time during one surgical session. However, Thompson (2009) noted that simultaneous management should only be done in patients who have evident hydrocephalus at birth while shunting can be deferred in those with moderate ventricular enlargement. According to Mochado and Oliveira (2004), simultaneous shunt insertion and correction of the open NTD has the advantage of allowing healing of the defect without CSF leakage as well as preventing the brain ventricular dilatation caused by increased intracranial pressure. This is supported by their findings from a study which was done in Brazil to compare the outcome in patients who underwent simultaneous surgery and those who had delayed shunting. The study found that among the patients who had undergone simultaneous surgery, only one developed shunt infection (Mochado & Oliveira, 2004). It can be argued that the findings from this study may have been influenced by the fact that the study was done in a developed country where there are advanced medical technologies and resources. This may not hold true in developing countries where most children may have developed CNS infections by the time they are presented for surgery. The primary modality in the management of hydrocephalus in children with open NTDs in most countries in the sub-Saharan African region is ventriculo-peritoneal shunt (VPS) (Margaron, Poenaru, Bransford, & Albright, 2010). Contrary to the assertions that simultaneous management of both hydrocephalus and surgery of the lesion have more advantages, the findings from a study which was done in Kenya to evaluate if the timing of shunting and repair of myelomeningocele has an effect on shunt related complications did not support this (Margaron, et al., 2010). In this study, it was reported that out of a total of 276 children with spina bifida, 18 patients had ventriculo-peritoneal shunt (VPS) before closure of defect, 13 had simultaneous VPS and closure and the rest had closure followed by VPS at less than five days and between 5-10 days (Margaron et al., 2010). The findings from this study showed that there was a higher rate of shunt infection among children who were shunted prior to spina bifida closure, those who had simultaneous shunt and closure as well as those who were shunted in less than 5 days after closure of lesion. Margaron et al. (2010) further recommended that children with open NTDs who present late for surgery in developing countries should be managed first by closure of the defect followed by VPS within 5-10 days as long as they have sterile CSF.

The next section presents literature on challenges of paediatric surgery in developing countries in relation to access. This links to the second research question for the current study on mothers' experiences with accessing health care services for children with NTDs.

2.3 CHALLENGES FOR PAEDIATRIC SURGERY IN DEVELOPING COUNTRIES

Developing countries have not taken surgical care as a public health priority despite most surgical conditions adding to the burden of health conditions (Debas, Gosselin, McCord and Thind, 2006). This is partly because more attention is placed on diseases which cause great morbidity and mortality such as communicable diseases, maternal and perinatal conditions and nutrition deficiencies (Mshelbwala & Nwomeh, 2002). According to Farmer and Kim (2008), the other reasons could be lack of advocacy from the surgeons on need to rebuild surgical care and the common belief that surgery is often a highly complex and expensive intervention. However, the lack of attention to surgery in most developing countries has resulted in lifelong disabilities and premature deaths due to untreated surgical conditions such as congenital anomalies and injuries (Bickler & Rode, 2002).

There are many challenges faced by paediatric surgery in developing countries. Ameh (2003) pointed out lack of support from governments and non-governmental organisations as being the major challenge of paediatric surgery in sub-Saharan African countries. Ameh also highlighted other challenges such as limited number of trained surgeons at tertiary hospitals, lack of skilled surgical personnel at primary and secondary level hospitals as well as lack of relevant facilities and support personnel leading to increased burden on the already overworked paediatric surgeons. Besides poor health care facilities and shortage of skilled health workers, Mshelbwala and Nwomeh (2002) added socio-economic and cultural factors, poor referral systems and lack of transport as barriers to paediatric surgery in developing countries.

2.3.1 LACK OF SUPPORT FROM GOVERNMENTS AND INTERNATIONAL COMMUNITY

The scarcity of resources in developing countries have led health policy makers to focus on programmes which are aimed at providing immunisation, control HIV and malaria, and prevention of childhood nutritional deficiencies (Mshelbwala & Nwomeh, 2002). According to Bickler, Kyambi and Rode (2001), the lack of political support by governments and the international community towards paediatric surgery is a major reason why paediatric surgery has not progressed in these countries. Bickler et al. (2001) observed that regardless of the availability of resources, it is the responsibility of the governments to ensure that essential health services are available for the disadvantaged populations. However, the belief by many that surgery is too expensive and non-essential has led to neglecting paediatric surgical care by most health care policy makers and donor communities (Bickler & Rode, 2002).

Despite these beliefs, Bickler and Spiegel (2010), have noted that there is increased evidence showing that most surgical conditions are equally public health problems and that some surgical procedures that can prevent disability and death have been found to be as cost effective as other health interventions. The authors noted that these two factors together with the fact that there is a huge gap between access to essential surgical services in rural and poor urban populations in low and middle-income countries, have contributed to increased attention towards surgery and anaesthesia. Surgery has also been found to contribute to the millennium development goals in many ways. These include reduction of maternal mortality rate, care and prevention of HIV and AIDS through provision of circumcision at population level as well as surgical intervention for complications of HIV and AIDS (Luboga, Galukande, Mabweijano, Ozgediz & Jayaraman, 2010). Surgery is also said to have an impact on reducing poverty through care of patients who may otherwise be rendered unemployed by disability or injuries (Luboga et al., 2010).

2.3.2 SHORTAGE OF TRAINED SPECIALISED SURGEONS IN RURAL AND PERI-URBAN AREAS

The shortage of trained specialised surgeons in developing countries is one of the major challenges of surgical care. According to Ozgediz et al. (2008), the shortage of workforce in anaesthesia and surgery is partly caused by a lack of interest by health workers who are attracted to other areas of health care which have international support in terms of research and training collaboration focusing on infectious diseases. Other reasons for lack of interest are the length of training for surgery and anaesthesia, limited training opportunities for those interested in the field, poor infrastructure and heavy workload which demotivate care providers in addition to poor remuneration for government workers (Mshelbwala & Nwomeh, 2002).

Despite the shortfalls observed in surgery, there are proposed suggestions that have been found to reduce the reported challenges of surgery in developing countries. Gosselin, Gyamfi and Contini (2011) proposed extending local training programmes not only to surgeons and anaesthesiologists, but also to the general local medical and paramedical personnel so that they could provide appropriate and sustainable surgical services. In Niger, an initiative to train general practitioners with skills in general surgery for 12 months and then post them in rural areas yielded successful results. Sani et al. (2009) in a study to describe the impact of launching surgery at district level in Niger during the period of January 2007 to December 2007 observed that there were no deaths reported on cases of elective surgeries. It was also reported that there was a large reduction in transfers to the regional hospital with only 115 patients transferred during the study period compared to 635 transfers in 2005 and 240 transfers in 2006. To motivate trained specialists to stay where they are posted, it has also been suggested that they are given some form of incentive for the extra work they put in (Gosselin et al., 2011).

2.3.3 LACK OF APPROPRIATE FACILITIES AND SKILLED SUPPORT PERSONNEL

According to Farmer and Kim (2008, p. 534), "it is a simple fact that surgery is most often a highly and complex intervention which requires a significant investment in infrastructure, training and a steady supply of consumables". This has contributed to developing countries having surgical services only in big cities, a situation which makes it difficult for the poor rural communities to access the services (Farmer & Kim, 2008). However, this does not prevent these bigger hospitals from experiencing challenges in relation to surgical care. A study which was done in one of the major teaching hospitals in Tanzania where the objective was to outline the scope of emergency paediatric operations reported a number of challenges (Mhando, Young & Lakhoo, 2006). These challenges included a shortage of trained specialists, equipment for operation, post-operative care and monitoring as well as a shortage of essential drugs (Mhando et al., 2006; Bickler & Rode, 2002). The result of such challenges in developing countries is that only a small percentage of people who require surgery can have access while the majority poor and vulnerable population in both urban and rural areas have limited access to essential surgical care (Gosselin et al., 2011). Most developing countries which have the surgical facilities at district level have also reported major shortfalls. In a study to provide a baseline overview of essential surgical and anaesthetic capacity at district level health facilities in developing countries, it was observed that there were major shortfalls in basic infrastructure such as water, electricity and oxygen in most of the facilities (Kushner, Cherian, Noel, Spiegel, Groth & Etienne, 2010). This study observed that only 48% out of 73% of the facilities that were reported to be performing incision and drainage of abscesses were able to perform an appendectomy. Regarding difficulties encountered in meeting the millennium development goals Four (reduce child mortality), Five (improve maternal health) and Six (combat human immunodeficiency virus-HIV), the study reported that only a few facilities were able to perform basic procedures such as repair of congenital hernias (32%) and caesarean sections (44%) and most of them did not have goggles and aprons to protect staff from HIV (Kushner et al., 2010). Despite this study being carried out in only in a few developing countries, other countries with similar economic conditions could make use of these findings to identify deficiencies in delivery of surgical care as well as formulating strategies to integrate surgical services in primary health care.

2.3.4 SOCIO-ECONOMIC AND CULTURAL FACTORS

Access to surgery in most developing countries is restricted by the shortage of human resources and capacity, inadequate logistics, inability to pay, obsolete infrastructure, lack of transportation and late presentation at the health facility (Gosselin et.al, 2011). According to Brickler et al. (2001) timely access to the hospital is hampered by long distances and high transport costs leading to patients presenting with deteriorated conditions with high operative and mortality risks. The effects of these factors are experienced by both urban and rural areas and in particular by poor and vulnerable populations. Generally, in poor countries patients experience more problems accessing health facilities than in rich countries, and within countries poorer people experience greater problems with accessing health care (Peters et al., 2008). Poverty and difficulty with access to health are not only related in terms of limited resources to finance health care costs but the lack of access can also worsen the health condition leading to loss of income and higher health costs (Peters et al., 2008).

Access to surgical care can also be hampered by factors such as the lack of information about efficacy of health care options, poverty and public perception of the quality of care (McQueen et al., 2010). McQueen et al. (2010) cited examples from maternal literature where women are restrained by cultural norms from seeking care outside their homes. There is also a common public perception that having an operation is a matter of life or death (Luboga et.al, 2010). For children with congenital anomalies, cultural beliefs that supernatural forces or a curse by someone causes the baby to be born with an anomaly may hinder some parents from seeking medical attention (Djientcheu et al., 2008).

2.3.5 SURGERY FOR CHILDREN WITH NEURAL TUBE DEFECTS IN SUB-SAHARAN AFRICA

The lack of government attention to paediatric surgery in developing countries has a negative effect on children with open NTDs who are supposed to have surgery as soon as possible after birth. According to Idowu and Apemiye (2008), management of children with myelomeningocele is characterised by challenges such as harsh social economic conditions, harmful taboos, religious beliefs, and inadequate medical personnel as well as facilities all leading to late presentation of patients. As noted by Shehu (2009), closure of the open NTD should be done within the first 24 to 36 hours after birth in order to reduce the rate of infection and allow for a better surgical scar. However, many children in developing countries do not have the opportunity to access surgical care within 24 to 36 hours after birth. Shehu and Ameh (2004) outlined a number of challenges such as lack of pre-natal diagnosis, home deliveries, delays in reaching the hospital, shortage of specialised personnel, and lack of awareness by some families. Other factors contributing to challenges faced in management of children with disabilities in Sub-Saharan Africa include poverty, ignorance and cultural beliefs (Djientcheu et al. (2008).

A number of studies done in Africa have reported challenges faced in management of children with NTDs. In a study done in Nigeria on patterns and factors affecting the management outcome of spina bifida cystica, the mortality (22.7%) and infection rates were high among children who were presented after the fourth week of birth (Alatise et al., 2006). Another study by Ameh et al. (2001) on emergency neonatal surgery in a developing country, reported a mortality rate of 31% which was also attributed to late referral and presentation as well as inadequate resuscitation during transportation. The majority of babies who underwent surgery were presented late because they came from rural areas and had been transported over long distances. Adeloye (1995) also observed that management of NTDs in Africa is characterised by cyst infection, meningitis, late convulsions and intellectual impairment due to late presentation of children at the hospitals. Late presentation was also associated with intracranial sepsis and malnutrition in a study done by Idowu and Apemiye (2008). The authors of this study noted that intracranial sepsis was the main cause of death in patients who were not operated on time.

There is need to improve paediatric surgical care in developing countries because available data shows that surgical conditions such as congenital anomalies, injuries and surgical infections have a significant effect on child mortality and morbidity (Mhando et al., 2008).

The next part of the literature review will give an overview of access to rehabilitation services for children with NTDs as well as challenges faced by mothers in relation to accessing health care services. The section will end with a review of literature on types of support that is needed by parents of children with NTDs.

2.4 REHABILITATION SERVICES FOR CHILDREN WITH DISABILITIES IN DEVELOPING COUNTRIES

Children presenting with spina bifida will usually require physiotherapy services whose role is mainly to improve muscle power, muscle tone and prevent contractures in order to optimise the development and functioning of the child (Schoenmaker, Uiterwaal, Gulmans, Gooskens, Helders, 2005).

The World Report on Disability (WHO, 2011, p. 96) defines rehabilitation as a "set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments". Physiotherapy is one of the services that provide rehabilitation. It is important to note that early identification and access to rehabilitation services greatly helps the child achieve maximum functional capacity and prevent further disability (Grilli, Feldman, Swaine, Gosselin, Champagne & Pineault, 2007). On the other hand, it is also important to acknowledge the fact that limited access to rehabilitation services could hinder the child's functional development. As observed by Maloni et al. (2010), rehabilitation also plays a critical role in helping mothers of children with disabilities understand their children's disabilities and how they can manage them.

However, rehabilitation services in developing countries have not been given the attention it deserves. This is partly because health facilities are overwhelmed by acute medical conditions which are considered priority and consequently motor impairments which require rehabilitation services are neglected (Penny et al., 2007). A study to assess the quality of rehabilitation services for disabled in a rural community of India found that of the 17 participants who had motor impairments, only eight accessed medical or surgical services (Kumar, Das, & Soans, 2008). In the same study, of the 11 who required physiotherapy services, only two were able to access it and none of the participants was able to access occupational therapy.

The situation in developing countries is similar to that in East Africa where it was reported that the few trained specialists, inadequate rehabilitation, and poor social support systems were clear evidence that the majority of patients with neurological problems do not have access to medical attention or rehabilitation services (Idro, Newton, Kiguli, Mwesige, 2010). In a study by Saloojee et.al (2007) on unmet health, welfare and educational needs of disabled children in an impoverished peri-urban township in South Africa, a situation similar to other African countries was also observed. This study reported that out of the 143 children who could have benefited from rehabilitation services, only 37 (26%) were able to access physiotherapy, occupational therapy and/or speech therapy. Some of the reasons found in this study as hindering accessibility to rehabilitation services included inadequate and inaccessible transport, lack of visible progress in the child's ability following therapy and poor administration of services offered (Saloojee et al., 2007). In Zambia, a survey on the living conditions of people with disabilities showed that out of 1762 people with disabilities who needed rehabilitation services, only 679 (38%) were able to access the services (Eide & Loeb, 2006).

In another study to evaluate the management of NTDs in Cameroon, a resource limited developing country, it was noted that there was no social organisation in place for the re-education, rehabilitation or social integration of children with spina bifida (Djientcheu et al., 2008). Even after surgery the majority of children with NTDs were abandoned to their families, who were usually from low income backgrounds, leading to the children being lost to follow up (Djientcheu et al., 2008). Generally, it can be stated that the majority of children with disabilities in poor resourced countries fail to reach optimum functional recovery while others have relapses because services are not available for them (Penny et al. (2007).

2.5 CHALLENGES FACED BY PARENTS OF CHILDREN WITH DISABILITIES IN DEVELOPING COUNTRIES

The impact of the child’s disability on the family include an increased burden of financial costs, physical and emotional demands as well as the extra care required by the child (Reichman, Corman, & Noonan, 2008; Sen & Yurtsever, 2007; Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2004). These effects of childhood disability depend on the type and severity of the child’s disability as well as on the physical, emotional and financial well-being of the family (Reichman et al., 2008). People with disabilities have more complex and on-going health care needs which require them to utilise special types of health care services (Drainoni, Lee-Hood, Tobias, Bachman, Andrew & Maisels, 2006). All people, including those with disabilities, have the right of access to interventions such as promotive, preventive and curative health care services (Stein, Stein, Weiss and Lang, 2009). Anderson and Davidson (2001) noted that access to health is not only about visiting medical personnel, but it also involves getting to the right services at the right time. In developed countries, parents have been reported to experience challenges such as health problems, restrictions with access, financial difficulties, lack of support as well as lack of coordination among different service providers (Heiman, 2002).

In developing countries, the challenges of parents/caregivers of children with disabilities are exacerbated by scarcity of medical and rehabilitation services, poverty, lack of access to information, cultural beliefs and the negative attitudes towards disability by the general public (Hartley et al., 2004; Gona, Mung’ala-Odera, Newton, & Hartley, 2010). These challenges play a major role in accessibility of health care services among children with disabilities. The majority of children with disabilities in developing countries live in rural areas and because of poverty and absence of services in rural areas, parents of these children are not able to pay for transport costs to take the children to hospitals which are located in urban areas (Penny et al., 2007). Furthermore, the lack of information among caregivers coupled with the attitudes of health care providers prevents these caregivers from taking their children to the health facilities. A study which was done in Kenya reported that experiences of caregivers with health care personnel led to frustration among caregivers with some leaving the hospital without being properly discharged, while others opted to seek traditional medicine (Gona et al., 2010). Even for children who manage to undergo surgery, follow up management for them is not usually possible because parents cannot afford to make return visits (McElroy, Konde-Lule, Neema, & Gitta, 2007). The result is that a large percentage of children end up with preventable disabilities or secondary complications which could have been alleviated had they accessed appropriate medical and rehabilitation services at the right time (Penny et al., 2007).

2.6 SUPPORT FOR PARENTS OF CHILDREN WITH DISABILITIES

When parents receive a diagnosis of their child as disabled, their hopes are dashed and they have a variety of emotional reactions including shock, denial, hopelessness, uncertainty and depression (Sen & Yurtsever, 2007; Graungaard & Skov, 2006). Woolfson (2004) in his theoretical study on integration of a social model of disability with psychological research observed that parents of children diagnosed with a disability are likely to feel great sadness, sorrow and helplessness. Children with disabilities place high demands on their parents because of their health care needs which include the treatment and care, frequent visitations to the hospitals and rehabilitation needs (Taanila, Syrjala, Kokkonen, & Jarvelin, 2002). This contributes to stress which parents experience because of their child’s disability. A study on parenting stress for children with disabilities showed that mothers of children with spina bifida had higher parenting stress compared to those of children with other developmental disabilities (Vermaes, Janssens, Mullaart, Vinck, Gerris, 2005). Pountney (2007) further noted that parents, especially mothers, have a great impact on the development of the child with NTD because they provide the day-to-day care of the child.

Support services for parents of children with disabilities have been found to help parents cope with the stress that results from having a child with a disability (Resch, et al., 2010; Taanila et al., 2002; Sen & Yurtsever, 2007). Support for the families can be offered with the help of professionals in early intervention programmes. Professionals should be able to help families by building formal and informal support networks as well as empowering parents with information which can enable them become advocates for their children (Bailey et al., 2005).

2.6.1 SOURCES OF SUPPORT FOR PARENTS

According to Johnson and Kastner (2005), support for families of children with disabilities consists of natural support, informal support as well as formal support. Natural support refers to support from extended family, friends and neighbours while informal support refers to support from parent groups, community organisations, specialty clinics and the internet. On the other hand, formal support refers to government services such as financial, legal, insurance benefits, respite waiver vouchers as well as early intervention and special education programmes (Johnson & Kastner, 2005).

However, formal support services for children with disabilities in developing countries are not usually available for the majority of children (Saloojee et al. 2007). Most of the support reported in studies done in countries in the sub-Saharan Africa is informal, often coming from extended families, friends, well-wishers as well as the church (McElroy et al., 2007; Hartley et al., 2004). In a study that was done in Kenya on challenges encountered by caregivers, it was reported that caregivers of children with disabilities received support services from non-governmental organisations, charitable organisations as well as friends in the form of food and assistive devices such as wheelchairs (Gona et al., 2010). Another study which was done in Uganda reported that caregivers received informal support from family members such as siblings, aunts and friends in the form of caregiving for the child as well as helping with house chores (Hartley et al., 2004). This kind of support was found to ease the burden on the mothers who usually do most of the caregiving as well as attend to other household chores. Financial support has also been reported to facilitate access to health care and rehabilitation for children with disabilities in some developing countries. This is evidenced by reports from a study that was done in Uganda where parents of children with clubfoot who did not have problems with paying fees, reported being assisted by the church and foreigners (McElroy et al., 2007).

2.6.2 SUPPORT FROM HEALTH CARE PROVIDERS

In the absence of formal support services for mothers/caregivers of children with disabilities in developing countries, health care providers can provide support in the form of giving information to parents on the nature of the child's condition as well as the types of services required. Parents' abilities to cope with a child who has been diagnosed with a disability is said to be highly dependent on their initial experience with health care professionals (Graungaard & Skov, 2006). An exploratory study on the experiences of parents of children with developmental disabilities found that most parents who had feelings of hopelessness did so because of the remarks made by professionals and people who view disability in a negative way (Kearney & Griffin, 2001). It is therefore important to ensure that when disclosing the diagnosis of the child to parents, professionals should also give positive information that will give hope to parents so that they are able to cope with the child's condition.

Adequate information about the child’s disability helps parents to cope with the situation and adopt a realistic attitude towards their child’s life (Resch et al., 2010; Taanila et al., 2002). In a study by Resch et al. (2010), parents of children with disabilities narrated that there is a feeling of urgency to access information and services for the child when they are informed about the diagnosis. On the other hand, parents who are not given information may adopt negative attitudes towards their children. In an African cultural context, Djientcheu et al, (2008) observed that babies with NTDs are believed to result from witchcraft and this causes some families to neglect their children. Parents of children with NTDs are supposed to be informed as early as possible and in detail about the problems their children might be faced with in future, possible functional outcomes as well as possible therapies and resources that will be available (Tsai, Yang, Chan, Huang & Wong, 2002).

The fact that children do not seek treatment for themselves means that their problems will be defined by the people who are involved with these children (Brett, 2002). For this reason, Rosenbaum and Stewart (2004) urges health care professionals to use the International Classification of Function, Health and Disability (ICF) model when planning treatment for children with disabilities and consider the impact of environmental factors such as the family on the children’s wellbeing. It is important that professionals working with children with disabilities support and work with families so that together they can come up with goals that will help the child achieve optimum functional abilities (Rosenbaum & Stewart, 2004).

The next section presents a literature review on some of the theories available on access to care and among them, the “Four A’s” access theory which will be discussed in detail.

2.7 ACCESS TO HEALTH CARE: DEFINITIONS AND THEORIES

Despite the Alma Alta declaration of access to basic health care as a fundamental human right in 1978 (WHO, cited in Hall & Tailor, 2003), many people in poor resource settings still do not have access to even the most basic health care services (Hall & Tailor, 2003). In most developing countries, access to health care which is an important component of the overall health care system has a direct effect on the burden of disease (Simon, 2008). The phenomenon of access is one of the concepts that have been difficult for many health care users, providers and policy makers to understand (Racher & Vollman, 2002). Authors have defined access in a variety of ways based on personal or individual characteristics as well as characteristics of the health care system (Peters et al., 2008; Ricketts & Goldsmith, 2005; Thiede, 2005; Gulliford et al., 2002). Goddard and Smith (2001) observed that the notion of access depends on the context in which it is being used. For example, in America, access may refer to an individual's ability to pay for health care through public or private insurance cover. On the other hand, in Europe where every citizen is insured, access may be referred to as the ability to obtain a specific range of health care services at minimum personal inconvenience and cost while in possession of information (Goddard & Smith, 2001).

Gulzar (1999, p. 17) defined access to health as "the fit among personal, socio-cultural, economic, and system-related factors that enable individuals, families, and communities to have timely, needed, necessary, continuous, and satisfactory health services". Shi and Singh (2008), defines access to care as the ability to obtain needed, affordable, convenient, acceptable and effective health services in a timely manner. These definitions indicate that access to health care is influenced by both the supply and demand factors. Demand factors are those that operate at the individual level while supply factors refer to the production of health care services (Ensor & Cooper, 2004).

The next section gives an outline of some common theories and frameworks on access to health care.

2.7.1 ANDERSEN AND DAVIDSON'S ACCESS TO CARE FRAMEWORK

The most commonly used access to care framework is the one by Andersen and Davidson (2001) which is based on Andersen's (1995) 'Behavioural Model of Health Services Use'. This framework proposes that access to care is determined by contextual as well as individual factors. Contextual factors refers to health organisation factors, provider related factors and community characteristics while individual factors refers to the person's demographic, social and health beliefs. This framework states that both contextual and individual characteristics are influenced by predisposing factors, enabling resources and the need for services. Predisposing factors are those conditions which predispose people to using or not using services, enabling factors are those which facilitate or impede the use of services and need factors are those which laypersons and health care professionals consider as requiring health care services (Andersen & Davidson, 2001). Examples of individual predisposing factors include a person's gender, race/ethnicity, age, and educational status while individual enabling factors can be insurance, family income, marital status and employment status (Litaker, Koroukian & Love, 2005). The framework also recognises the importance of health behaviours of individuals and their health outcomes including satisfaction. Health behaviour refers to health care use and personal health practices (Ricketts & Goldman, 2005).

2.7.2 PENCHANSKY AND THOMAS ACCESS FRAMEWORK

The other commonly used theoretical framework on access is that of Penchansky and Thomas (1981), where access is described as the 'fit' between the client and the health delivery system and hence has two sides namely the supply and demand side. This model states that access can be measured using five dimensions namely accessibility, availability, affordability, accommodation and acceptability. Availability refers to the existence of health care personnel and resources, accessibility refers to the geographical relationship between the health facility and user, affordability relates to costs involved and acceptability to attitudes of users towards providers and vice versa (Ricketts & Goldsmith, 2005). Accommodation refers to the relationship between the manner in which supply resources are organised and the clients' perception of their appropriateness (Penchansky & Thomas, 1981).

2.7.3 KHAN AND BHARDWAJ'S ACCESS FRAMEWORK

Khan and Bhardwaj proposed a conceptual framework of access which recognises access as the outcome of processes between the characteristics of the health care system and those of potential users in a specified area, and influenced by health care related policy and planning efforts (Khan & Bhardwaj, 1994). The framework has four dimensions namely potential, realised, spatial and aspatial. According to Guagliardo (2004), potential refers to coexistence in space and time of a needy population with a willing and able health care delivery system, while realized care refers to the actual use of care which occurs when all barriers to access are overcome. Aspatial access refers to socio-psychological aspects of the system and user such as system organisation, human and material resource as well as user demographics attitude and behaviour (Gulzar, 1999). Spatial refers to geographical or physical access. Khan and Bhardwaj (1994) also identified opportunity and cost as additional dimensions of access. According to Khan and Bhardwaj (1994), this type of framework can be used at national or regional level and it can be used to identify specific access to care problems which will assist with formulation of specific outcome measures of health care performance for purposes of evaluation.

There are many theories on access to care and most of them are variations of the above mentioned frameworks. An example is the “Four A’s” which was derived from the Penchansky and Thomas framework (Hausmann-Muela, Ribera and Nyamongo, 2003).

2.7.4 THE “FOUR A’s” ACCESS TO CARE FRAMEWORK

The results of the current study will be discussed with reference to the access to care framework, commonly known as the “Four A’s” (Jacobs, Bigdeli, Annear & Van Damme, 2011; Peters et al., 2008; Hausmann-Muela et al., 2003). This framework was derived from the Penchansky and Thomas access framework and only four dimensions namely availability, accessibility, affordability and acceptability are used. Availability refers to the existence of health care personnel and resources, accessibility refers to the geographical relationship between the health facility and location of the user, affordability relates to costs involved and acceptability to attitudes of users towards providers and vice versa (Ricketts & Goldsmith, 2005).

These dimensions represent access in terms of patients’ ability to get to the health facility, patients’ knowledge about health care services, financial costs, patients’ ability to pay for services and patients’ satisfaction with services as well as service location in relation to patients’ location (Rutherford et al., 2010). The framework therefore recognises that access is influenced by the characteristics of the population (demand side) and that of the health care providers (supply side) (Peters et al., 2008). The researcher found this framework suitable for the current study because the literature review on access to health care for children with NTDs in developing countries was consistent with the four dimensions of the “Four A’s” framework.

i) AVAILABILITY

Access to health care services stipulates that services are adequately available when wanted or needed (Gulliford, et al., 2002). According to Thiede and McIntyre (2008), availability refers to factors related to actual existence of specific health care services within reach of the patients and user friendly services such as appointment systems and convenient working hours. Indicators of service availability include a number of health personnel in relation to population, ratio of hospital beds to the population, service delivery system, adequate resources (diagnostic and drugs), outreach and education programmes, appropriate service hours and waiting times (Peters et al, 2008). O'Donnell (2007) observed that insufficient resources, inappropriate allocation of resources and inadequate quality are major barriers to delivery of effective health care to the poor in developing nations. Availability can be enhanced by increasing investment in health services, improving infrastructure and increasing number of health institutions and health care providers (Thiede, 2005). Gulliford et al. (2002) suggests that financial incentives to health care providers can also affect availability of services and types of services available.

Perry and Gesler (2000) in their study identified access barriers to be associated with understaffed and poorly supervised health personnel, poorly equipped centres and unmotivated staff. Respondents in another study which was done in Uganda reported limited working hours, lack of drugs, rude personnel, and poor referral system as barriers experienced with accessing health care services (Bakeera, Wamala, Galea, State, Peterson & Pariyo, 2009).

ii) GEOGRAPHICAL ACCESSIBILITY

Geographical accessibility to health care which refers to the distance and time travelled in order to access health care services has been reported in many studies as one of the barriers to health care access (Iezzoni et al., 2006; O'Meara, Noor, Gatakaa, Tsofa, McKenzie &

Marsh, 2009). Apart from distance, this dimension also includes road networks, topography and communication systems which have been found to affect access to health care facilities (Peters et al, 2008; Perry & Gesler, 2000). Poor road networks affect the availability of public transport while difficult geographical environments makes construction of road networks more costly and difficult. Extreme topographic relief can make development of an area in terms of road networks and communication systems, very difficult and costly. According to Brems, Johnson, Warner and Roberts (2006), geographical isolation does not only relate to users, but it can also be burdensome to health care providers who have to travel long distances to reach small and isolated rural communities.

A study by Perry and Gesler (2000) in a remote and impoverished region of Andean Bolivia reported physical barriers such as extreme topographic relief, sparsely settled communities, long distances to travel to the health centre, lack of public transport and poor road networks which make it difficult to travel. This is similar to another report on access in remote rural areas which identified some of the barriers to be geographical isolation in terms of distance, hostile terrain, lack of good roads and limited choice of transportation (Bull, Krout, Rathbone-McCuan & Shreffler, 2001).

In most developing countries in sub-Saharan Africa, there is uneven distribution of health care facilities within the country, whereby more services are allocated in urban areas than in undeveloped and rural neighbourhoods (Whitehead, 2001). This leads to problems of access especially for children with disabilities because the majority of them come from rural areas where essential health care services are not available (McElroy et al., 2007; Bickler et al., 2001). The long traveling distances has also been found to be associated with increased mortality and morbidity among children from rural areas (Rutherford, et al., 2009). In a study to assess factors related to mortality among children below the age of five years in Uganda, it was reported that a greater distance to travel to the health facility was significantly associated with the death of the child (Rutherford et al., 2009).

iii) AFFORDABILITY

According to Peters et al. (2008), affordability which is also referred to as financial accessibility is one of the most important dimensions that determines access to care and it is directly associated with poverty. The cost of health care services can be divided into direct and indirect costs, where direct costs refer to cost of treatment and informal payments. On the other hand, indirect costs include cost of time spent on reaching the health facility, opportunity cost of time of the patient and those accompanying him, transport costs, food and lodging fees (Peters et al., 2008; Hjortsberg & Mwikisa, 2002). In developed countries, barriers to accessing health care services are more commonly associated with lack of medical insurance cover (Newacheck, Mcmanus, Fox, Hung & Halfon, 2000). In a study done in the United States of America (USA), aimed at exploring rural Hispanics' perceived barriers to accessing health care, lack of and limitations with health insurance cover as well as high cost of health services were reported to be among the most common perceived barriers (Cistancho, Garces, Peters & Mueller, 2008). However, in most developing countries, even when some health care services are free, users still spend to access these services because of the indirect costs that are involved. In a study done in Zambia on cost of access to health care, it was reported that distance from the health care facility increased the cost of travel and time and this makes it difficult for the affected individuals who are usually poor to access services (Hjortsberg & Mwikisa, 2002). In another study which was done in Uganda to understand the barriers affecting adherence to clubfoot management, it was reported that poverty was a major barrier to treatment adherence (McElroy et al., 2007)

iv) ACCEPTABILITY

Health care acceptability is simply the willingness to use health care services (Simon, 2008). Beliefs of health care users refer to their attitudes, values and knowledge about health as well as their perception of health care needs (Andersen & Davidson, 2001). According to Peters et al. (2008), acceptability is the relationship between health care providers' responsiveness to the social and cultural expectations of individual users and communities. The individual's behaviour such as motivation to seek care based on their perceived need, lack of accepting diagnosis, negative experiences with the health system and their perception of the effectiveness of treatment to cure their illness, have been identified as barriers to accessing appropriate health services (Goudge, Gilson, Russell, Gumede, Mills, 2009). Therefore any deficiencies in the quality of health care services such as irregular opening and closing times, absenteeism of health care providers, hostility towards patients and a shortage of drugs can affect utilisation of services by consumers (O'Donnell, 2007). Such poor quality services can also lead to patients seeking health care services from other sources such as private or traditional doctors who seem to satisfy their needs whenever they require the services (Peters, et al., 2008). A study carried out in the USA on minority groups regarding their perceived disrespectful encounter with the health care providers, observed that those who reported negative encounters with their physicians were less likely to seek subsequent health care services when needed (Blanchard & Lurie, 2004).

Attitudes and beliefs of people towards receiving health care, their knowledge of diseases and available health care services can also affect an individual's ability to use health care services (Simon, 2008; Gulliford et al., 2002). Spiegel et al. (2010) noted that inadequate or delayed presentation to the medical services in some patients may be due to cultural and personal factors such as opting to visit the traditional practitioners before going to the medical facilities. This contributes to complications in the disease process which when presented to the medical facility requires more complex and costly treatment with desired outcomes almost unachievable.

2.8 CHAPTER SUMMARY

The literature review looked at the profile of NTDs in relation to prevalence, types, associated impairments and management with more emphasis on developing countries. The outcome for children with NTDs is better in developed countries due to advanced medical technologies which have led to early prenatal diagnosis and includes foetal surgical intervention. Management of children with NTDs in developing countries is characterised by poor access to surgical services, late presentation of children for surgery as well as CNS and wound infections leading to high mortality among affected children. Rehabilitation services for the majority of children with disabilities in developing countries are not available. The literature has also shown that parents of children with disabilities in developing countries face many challenges including difficulties with access to health care services, poverty, lack of access to information, cultural beliefs as well as society's negative attitudes towards disability. Furthermore, parents of children with disabilities need to be supported in order for them to cope with the situation as well as manage their children in a way that will improve their wellbeing. The challenges of access to health care for children with disabilities in developing countries are related to the "Four A's" access theories which includes barriers such as geographical access, availability, affordability and acceptability.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

This chapter gives an overview of the methods used in this study. The study consisted of three parts, one quantitative and two qualitative parts. The first part was used to answer the first objective which was to describe the profile of children with NTDs admitted at the University Teaching Hospital. Part Two addressed the second and third objectives. The second objective was to explore challenges and support experienced by the mothers of children with NTDs in relation to accessing health care services from the University Teaching Hospital. The third objective was to explore mothers' perception of the feasibility of accessing physiotherapy services and return for follow up visits when the child is discharged. Part Three addressed the fourth objective which explored mothers' experiences with accessing physiotherapy services for children with NTDs associated with motor impairments. Data collection began with Part One which was a record review, and, after its completion, Part Two and Three followed and were done simultaneously.

The chapter describes the methodology for both qualitative and quantitative parts under the following headings: study setting, study design, population and study sample, data collection tools and procedure for data collection. In addition the chapter discusses how validity and trustworthiness were ensured and ends with a description of data analysis and ethical considerations.

3.2 STUDY DESIGN

The study design will be presented in three parts according to the parts of the study.

3.2.1 PART ONE: RECORD REVIEW ON PROFILE OF CHILDREN WITH NEURAL TUBE DEFECTS

Part One was a medical records review which used quantitative methods to describe the profile of children with neural tube defects who were admitted at the University Teaching Hospital (UTH) between 1st January and 31st December, 2010. A descriptive retrospective design was used. According to Domholdt (2000), the purpose of a descriptive retrospective research is to document the past in order to make decisions in the present based on past information. Worster and Haines (2004, p. 187) defined a medical records review as "a study that uses pre-recorded patient-focused data as the primary source of information to answer a research question". The use of patients' medical records from the clinical files was appropriate to answer the first research objective in the current study.

3.2.2 PART TWO: EXPERIENCES OF MOTHERS WITH ACCESSING HEALTH CARE SERVICES FROM UNIVERSITY TEACHING HOSPITAL

Part Two used qualitative methods to explore the experiences of mothers of children with NTDs who were admitted at the University Teaching Hospital. The experience of people is best explored using qualitative methods because the main purpose of qualitative research is to describe and clarify experience as it is lived by the individual (Polkinghorne, 2005). Furthermore, using qualitative methods allows participants to express themselves in their own words as well as allowing the researcher to get detailed information about these experiences from the participant's own perspectives (Howitt, 2010).

3.2.3 PART THREE: EXPERIENCES OF MOTHERS WITH ACCESSING PHYSIOTHERAPY SERVICES

Part Three also used qualitative methods with in-depth interviews to explore experiences of mothers with accessing physiotherapy services in their home districts. These were mothers who had come from different parts of the country and brought children with NTDs to the University Teaching Hospital for follow up visits.

3.3 STUDY SETTING

The study setting for all the three parts of the study was the national referral hospital, known as the University Teaching Hospital (UTH). This is the country's biggest hospital, situated approximately four kilometres east of the city centre of the capital city Lusaka. Besides being the national referral hospital, UTH also provides second and third (explained in next paragraph) level health care services. This hospital receives referrals from all parts of the country and being the country's specialist centre, it also acts as the principal training institution for all health and allied disciplines. Until August, 2011, when the new Lusaka district hospital was opened, UTH served as a district hospital for Lusaka district in addition to being the provincial hospital for Lusaka province. The name Lusaka is used to refer to either the province or district, depending on the context in which it is being used. UTH has a number of specialists with the back-up of modern medical technology for both diagnostic and treatment purposes. The total bed capacity of UTH is about 2000 and, of these, 352 are in the paediatrics wing. The paediatrics department is divided into two blocks namely the "A- block" and "D-block". The "A-block" is the main wing and includes the out-patient unit, admission ward, intensive care unit and in-patient wards. The "D-block" has two sections, the neonatal wards (D11 & D12) and the paediatric surgical wards (D01 & D02).

According to the Zambia National Health Strategic Plan (Ministry of Health, 2011), the health care service delivery system in Zambia falls into five categories as presented in Table 3.1.

Table 3.1 Zambian Health Facilities

Health Facility	Level where service is Provided
Level Three (Tertiary)	At national level
Level Two Hospital	At provincial level
Level One Hospitals	At district level
Rural and Urban Health Centres	At community level
Health Posts	At community level

Surgical management of children with NTDs in Zambia is only done at UTH and Beit Cure Hospital which are both situated in Lusaka. Beit Cure Hospital is an international hospital which was opened in Zambia in 2004 with funding from Beit Trust, a UK based charitable organisation. Beit Cure Hospital was opened to provide specialised care of children living with disabilities and since its inception, this hospital has been complementing the efforts of UTH in surgical management of children with NTD and hydrocephalus referred from all parts of the country.

Most hospitals will refer the children to UTH while others refer patients directly to Beit Cure Hospital. Some children from Beit Cure Hospital are referred to UTH for specialised management of other complications or for advanced diagnostic procedures. Such diagnostic procedures include Computed Tomography (CT) scan and Magnetic Resonance Imaging (MRI) which are only found at UTH. Occasionally, the neurosurgeon from Beit Cure Hospital would consult with UTH neurosurgeons and identify some children who require endoscopic third ventriculostomy (ETV), a procedure which is only done at Beit Cure Hospital. When these children are identified, they are then transferred to Beit Cure Hospital where ETV is done.

3.3.1 STUDY SETTING FOR PART ONE AND PART TWO

Part One and Part Two of this study were conducted in the paediatric surgical ward (D01) at UTH. Part One consisted of a records review while Part Two consisted of interviews with mothers of children admitted in this ward. The paediatric surgical ward (D01) is the admission ward for paediatric general surgical conditions and neurosurgical conditions. Some of the common neurological conditions seen include hydrocephalus, spina bifida, encephaloceles and space occupying lesions of the brain. Non-neurological conditions include congenital malformations such as cleft lip and palate, intestinal obstruction, splenomegaly, fistulas, hernia, phymosis as well as scared contractures caused by burns. The ward has a total of 41 beds for both neurological and non-neurological conditions, and of these, 17 single beds and 20 baby coats are located in the main ward. The other four are single beds and are located in the fee-paying section of this ward. The neurological section of this ward is usually full and children share the beds when there is no space available for new admissions.

All the children admitted in this ward and any paediatric ward, except the neonatal unit and ICU, are supposed to have a relative at their bedside who takes care of their daily needs. These needs include feeding, bathing, changing nappies and dressing. The nurses cannot take care of the basic needs of every child as the wards are usually full.

3.3.2 STUDY SETTING FOR PART THREE

The third part of the study involved interviews with mothers of children returning for follow up visits. Follow-up visits to monitor children who had been operated on are conducted in Clinic Four, which is an out-patient clinic located within University Teaching Hospital. Mothers or caregivers are advised to bring the children to Clinic Four for follow up visits or whenever they notice any unusual change in the child’s condition. The clinic manages patients coming from different parts of the country. The clinic for neurological conditions takes place on Tuesday and Thursday mornings and includes both adults and children. The patients attending this clinic come from all parts of the country and patients have to be at the clinic as early as 06h00 in the morning although the doctors start at 07h30. Patients who arrive late are usually given another appointment. This means those patients coming from outside Lusaka have to be in Lusaka the day before, and, depending on where they come from, they may go back home on the same review day or only the following day.

3.4 STUDY POPULATION AND SAMPLING METHODS

The population and sampling are presented separately for the three parts of the study.

3.4.1 PART ONE: RECORD REVIEW ON PROFILE OF CHILDREN WITH NEURAL TUBE DEFECTS

The study population for the record review included all children with NTDs, who were admitted into the paediatric surgical ward (Ward D01) from 1st January to 31st December, 2010. Worster and Haines (2004) stated that the common method of sampling in medical record reviews is convenience sampling where all consecutive cases within a given time frame are selected, provided the period is long enough to include seasonal variations. Ward D01 admission register indicated that there were a total of 101 children with NTDs admitted during this period.

Inclusion criteria: All children with NTDs who were admitted or readmitted during the stated period. **Exclusion:** All children with NTDs who had previously been admitted (i.e. before the stated period).

Only 50 of the patients' medical records could be located in ward D01 at the time of data collection. According to the records Clerk, when they are discharged, some mothers and caregivers take their children's hospital files to enable them book for follow up visits at the neurology Clinic Four at the University Teaching Hospital. However, after making the booking, some mothers take the files home with them instead of returning them to ward D01.

The only information available on the 51 patients whose medical records could not be located was that which was in the admission register. This information included the file number, province of origin, date of admission, name of child or mother and provisional diagnosis.

The sample size for the data obtained from the admission register represented the study population of 101 children who were admitted in 2010. The sample size for the medical records available was 50. Polit and Beck (2008) noted that when the records available are not the entire set of all possible records, it is a source of bias and the researcher is advised to address the question of representativeness of the existing records. The researcher attempted to do this by including the information that was available from the admission register for all the children including those whose files could not be located. According to Worster and Hanes (2004), and Babbie and Mouton (2001), the sample is said to be representative of the population if certain aggregate characteristics or variables are approximately similar to that of the population. In this case, when the findings from the sample size of 50 whose medical records were located were compared with the missing files, the results indicating province of residence and type of NTDs were similar. This suggests that by using only the 50 files available for the sample, the results would not have been substantially different from using the full study population if all the medical records were located. These findings are presented in Chapter Four.

3.4.2 PART TWO: EXPERIENCES OF MOTHERS WITH ACCESSING HEALTH CARE SERVICES FROM UNIVERSITY TEACHING HOSPITAL

The study population for part two consisted of mothers of children with NTDs who were admitted to ward D01 during the study period. A total of 35 children were admitted with NTDs during the study period. Table 3.2 presents the distribution of children and mothers according to province of origin. A purposeful sample of 20 mothers was selected from this population. According to De Vos (2002), purposeful sampling allows the researcher to make a judgement by selecting a sample consisting of participants with characteristics representative or with typical attributes of the population. The characteristics of this sample were that the participant should be the mother of the baby admitted with a NTDs, should be referred from any of the nine provinces of Zambia and that the mother should be willing to share her experiences. Interviewing only mothers was important because they all had an experience which was typical and were therefore able to provide rich information that was relevant to the research question (Denver & Frankel, 2000). This typical experience involved giving birth to a child who had a NTDs and being referred to the University Teaching hospital for specialist management. In order to ensure that all the nine provinces are represented in the sample, the researcher planned to interview two participants from each province and if they give diverse experiences, a third participant would be interviewed until reaching data saturation in that particular province.

There were nine provinces in Zambia until in October 2011, when the newly elected government named a tenth province. However, since this study was only based on nine provinces, the newly added province was not considered in this study. The nine provinces involved in this study were Northern, Southern, Eastern, Western, North Western, Lusaka, Luapula, Copperbelt and Central provinces.

A total of 20 mothers were interviewed, with five provinces having two participants each while the diversity in the experiences of mothers from Lusaka, Central and North Western provinces prompted the researcher to go for the third participant. This was in order to get a more detailed understanding of the experiences. This is in line with Polkinghorne (2005) who observed that qualitative inquiry requires that the researcher collects a series of intense, full and saturated descriptions of the experience under investigation. The researcher only managed to interview one participant from Luapula province as she was the only mother available at UTH during the study period, who met the selection criteria from that province.

Table 3.2 Number of children admitted during study period and mothers interviewed

Province of origin	**Children admitted (n)**	**Mothers interviewed (n)**
Lusaka	10	3
Southern	6	2
Northern	4	2
Central	4	3
Eastern	3	2
North Western	3	3
Copperbelt	2	2
Western	2	2
Luapula	1	1
Total	**35**	**20**

Inclusion criteria consisted of mothers of children with meningocele, myelomeningocele and encephalocele admitted in ward D01 during the study period. The mothers should have been referred from any of the nine provinces and willing to share their experiences.

Figure 3.1. Map of Zambia showing provinces.

3.4.3 PART THREE: EXPERIENCES OF MOTHERS WITH ACCESSING PHYSIOTHERAPY SERVICES

The study population for the third part of the study involved all mothers or caregivers of children with NTDs who came for follow up visits during the study period which was from

September 2011 to December 2011. A purposeful sample of convenience was planned for this part and the researcher’s initial intention was to continue sampling until data saturation. Guest, Bruce and Johnson (2006, p. 65) operationalized the definition of data saturation as “the point during data collection and analysis when new information produces little or no change to the code book”. In the current study, the researcher intended to continue collecting data until no new information was obtained from subsequent interviews.

However, in the study a convenient sample was identified as the researcher only managed to find a sample size of four mothers. They were the only mothers who attended Clinic Four and fitted the inclusion criteria during the whole study period. This situation together with the reduced number of patients’ files in Part One prompted the researcher to include an additional question in Part Two during interviews with mothers of children who were admitted in ward D01 on their possibility of returning to the hospital for follow up visits.

Inclusion criteria consisted of mothers/caregivers of children with NTDs above the age of six months who presented with motor impairments and required the services of a physiotherapist.

3.5 DATA COLLECTION TOOLS

Data collection started with Part One and was done using a data extraction sheet which was specifically developed for the study. Part Two and Three used face-to-face in-depth interviews with two separate interview guides which were developed for each part. Open ended questions were asked which were followed by prompts aimed at addressing the research objectives.

3.5.1 PART ONE: DATA EXTRACTION SHEET FOR RECORD REVIEW

The record review involved collection of information from patients' files using the data extraction sheet (Appendix 1). This tool was developed based on the research objectives, the researcher's experience as well as information from the literature review on similar studies done on NTDs (Djientcheu et al., 2008; Idowu et al., 2008; Igun, Sule, Dakum & Opaluwa, 2000). From this background, a list of variables to be included on the data extraction sheet was drawn from these studies and an initial data extraction sheet was developed. A pilot study (described in Section 3.5.3) was conducted and information such as radiological investigation, results and treatment follow up were subsequently included on the data extraction sheet. After the pilot study, the final data extraction sheet consisted of the following information: demographic data, diagnosis, management and follow-up.

i. DEMOGRAPHIC DATA

This section included information on the child's age on admission, gender and province of origin. Age on admission is important in this study as it will show how long it takes for most children to access specialised medical services. Studies have shown variations in age at presentation, ranging from one day old to more than a month old (Adeleye & Olowookere, 2009; Djientcheu et al., 2008). This study included gender in order to determine which gender was more prevalent as well as to compare with other countries in the region. Most studies done in African countries found the incidence of NTDs to be higher in male babies than females (Idowu et al., 2008; Djientcheu et al., 2008). Some studies have found that certain regions within a country have higher incidence of NTDs than other regions. This study hoped to compare the numbers of children presenting with NTDs from the nine provinces during the study period.

ii. DIAGNOSIS

This section of the data extraction sheet consisted of information on type of NTD, site of NTD, neurological status, associated impairments, radiological investigations and radiological findings. The type of NTD is important as it will assist with identifying the most prevalent type presenting at the hospital and comparison with other studies. The level of the NTDs will also be important for making comparisons within the country as well as with other studies in the region. Generally, studies done in the region have found spinal NTDs to be more prevalent than cranial NTDs, and myelomeningocele of the lumbar region to be more prevalent than other types of NTDs (Adeleye & Olowookere, 2009; Njamnshi et al., 2008). Cranial ultrasound has been found to provide the most reliable and valuable information on children with NTDs and other related conditions (Krugar & Naman 2010). Radiological investigation and the results assisted with identifying how many children had hydrocephalus as an associated anomaly.

iii. MANAGEMENT AND FOLLOW UP

The information in this section consisted of surgical management, complications experienced and the number of follow up visits. Surgical management was included on the data extraction sheet because it is the main reason why children with NTDs were referred to University Teaching Hospital. Studies have shown that delayed surgery has resulted in complications such as infection of the wound (Alatise et al., 2006; Djientcheu et al., 2008). There is also evidence from studies done in developing countries that most children are lost to follow up after surgery (Djientcheu et al., 2008).

3.5.2 VALIDITY

According to Babbie (2007), validity is the ability of an instrument to measure the concept it is intended for. Face and content validity of the data extraction sheet was achieved by asking two experts to go through the data extraction sheet. One of the experts has been working as a physiotherapist in paediatrics for more than 10 years, while the other has been working as a physiotherapist and doing part time teaching at the University of Zambia for more than five years. This was in order to ensure that all the appropriate variables to address the first objective were identified (Parahoo, 1997). The researcher gave the first draft of the data extraction sheet to the experts who went through it and proposed some changes. These included combining the question in section B on level of NTDs for cranial and spinal defects under one question i.e. question ‘2’ and included all the possible sites for NTDs with options including lumbosacral, lumbar, sacral, thoracic, cervical, frontal, occipital, nasal and others for those who had multiple NTDs. Other suggestions were to include multiple congenital anomalies on associated impairments as some babies with NTDs are born with multiple congenital anomalies. On management, the initial draft did not specify the type of management and a suggestion was made to put surgical management as most of the children are referred to UTH for surgical management. Lastly it was suggested that follow up management and outcome be included but this was adjusted to number of follow visits after a pilot study was done.

3.5.3 PILOT STUDY

A pilot study for the data extraction sheet was conducted on 10 hospital files for children with NTDs and only included those for 2011 because they were not part of the study population. The purpose of a pilot study includes among other things to develop and test adequacy of research instruments and to assess the feasibility of the full study (van Teijlingen, Rennie, Hundley & Graham, 2001). The pilot was done in order to determine whether the instrument covered all the relevant information as well as to ensure that all the data required was available in the hospital files. Changes were made on the data extraction sheet and these included addition of information on radiological investigations and results, as well as the number of follow up visits. Radiological information provides reliable information on the presence of hydrocephalus other than just relying on clinical notes which may be unreliable if the hydrocephalus is not visible to the naked eye. The addition of the number of follow up visits was also important as it shows the possibility of continued care for these children who come from all parts of the country.

3.5.4 PART TWO: INTERVIEW GUIDE ON EXPERIENCES OF MOTHERS WITH ACCESSING HEALTH CARE SERVICES FROM UNIVERSITY TEACHING HOSPITAL

Data collection on experiences of mothers of children admitted at University Teaching Hospital with NTDs was done through in-depth face-to-face interviews using a semi-structured interview guide (Appendix 2). This interview guide was developed based on the research objectives (Ryan, Coughlan & Cronin, 2009). The use of open ended questions in in-depth interviews allows the researcher to deeply explore the respondent's feelings and perspectives on a subject thereby resulting in rich information which can elicit further questions on the topic (Guion, Diehl & McDonald, 2011). In the same vein, the use of semi-structured interviews allows the researcher to pursue a series of less structured questions as well as allowing for exploration of new issues raised by participants (Ryan et. al., 2009). The initial interview guide consisted of two broad open ended questions as well as prompts aimed at ensuring that the research objectives were addressed. The first question involved asking the mother to narrate in the form of a story what she went through after the baby was born up to the time the baby was admitted to University Teaching Hospital. The prompts consisted of questions on problems faced, support and her suggestions on how government could assist mothers faced with this problem. The second question was finding out from the mother about access to health care services back home when the child was discharged from the hospital. Prompts involved asking about any barriers to or facilitators to accessing health care, a description of facilities and services at the nearest health centre and suggestions on how access could be made easier for children with NTDs and other related problems.

This interview guide was later amended to include questions on experiences which were reported by participants during the initial interviews as well as observations made from the data collection for Parts One and Three of this study. Making these amendments was in line with DiCicco-Bloom and Crabtree (2006) who note that the iterative nature of qualitative research process often leads to alteration of some questions as the researcher learns about the subject. The changes on the initial interview guide were also prompted by some participants who had problems expressing themselves when the first broad questions were asked to them. For example, one mother's response to the first broad question was "*I had no problems with delivering and everything was fine*". When the researcher followed up with prompts so that the mother could expand on what she went through, the response was "*I was carried on a bicycle from home to the hospital*". The reluctance to talk freely by some of the mothers made it difficult for the researcher to collect information from such participants. However, the subsequent inclusion on the interview guide of additional prompts linked to concerns raised by other participants and information from other parts of the study made it easier for the researcher to get information from these participants. Additional questions and prompts in the interview guide included factors related to birth experiences, means of survival while in Lusaka, shelter for the accompanying spouse or relative, care for the children that remained home, possibility of coming for follow up visits and the means of returning home when the child was discharged.

3.5.5 PART THREE: INTERVIEW GUIDE ON EXPERIENCES OF MOTHERS WITH ACCESSING PHYSIOTHERAPY SERVICES

The interview guide (Appendix 3) for Part Three consisted of one broad question which sought to find out about the challenges faced by the caregiver regarding taking the child for physiotherapy. The prompts included finding out about any support from the family, community or health centre in relation to the child getting physiotherapy services; frequency of physiotherapy sessions; costs involved and the mothers' perception of the services offered. However, only two out of the four participants interviewed had been informed about the need for physiotherapy for their children. The other two had not been told about physiotherapy so they were asked questions concerning the availability of physiotherapy services where they lived as well as questions on some issues raised by the other mothers who had information on physiotherapy. All the four children had myelomeningocele and were all presenting with paraplegia and hence they all required physiotherapy.

3.6 PROCEDURE FOR DATA COLLECTION

Data collection commenced as soon as written permission was granted by the Research Ethics Committee in Zambia and the University Teaching Hospital management (See Ethical Considerations). Data collection started with Part One and took two weeks to be completed. After completing Part One, data collection for both Part Two and Three commenced and was done simultaneously.

3.6.1 PART ONE: RECORD REVIEW ON PROFILE OF CHILDREN WITH NEURAL TUBE DEFECTS

Before commencing with the data collection, the researcher introduced herself and the purpose of the study to the nursing officer in charge of the ward. The approval letter from the University of Zambia Research Ethics Committee as well a letter of permission from the University Teaching Hospital management was also presented. The nursing officer in turn introduced the researcher to the two records clerks for that ward who explained the arrangement of the patients' files and where to find the 2010 files. The admission register was availed to the researcher in order to assist her with a record of all patients with NTDs who were admitted in 2010.

Before starting data extraction from files, a list of names and file numbers for all patients with NTDs who were admitted in the year 2010 were recorded from the admission register. This was followed by retrieving the actual files in batches of tens and then appropriate data from each file was recorded on the data extraction sheet. This was done in August 2011 and took two weeks to complete.

3.6.2 PART TWO: EXPERIENCES OF MOTHERS WITH ACCESSING HEALTH CARE SERVICES FROM UNIVERSITY TEACHING HOSPITAL

Data collection for this part of the study was dependant on availability of new admissions of children with NTDs. Data collection was conducted over a period of four months, starting from 8th September, 2011 when the first interview was conducted and ending 29th December, 2011 when the last interview was done. Recruitment of participants was on-going during this period and depended on new admissions. The researcher had already taken approval and permission letters to the nursing officer in charge of the ward during the data collection for Part One. The purpose of Part Two of the study was explained to the nursing officer and a request was made to her to inform the researcher whenever participants were available. This was important because as noted by Devers and Frankel (2000), the qualitative researcher is required to develop and maintain good relationships with the research subjects and the sites in order to have an effective sampling and a credible research. The researcher was allowed to conduct interviews in the nursing officer’s office and the fee-paying room which was quiet and suitable for recording interviews. The nursing officer also allowed the researcher to check for new admissions in the admission register which was kept at the front desk. To recruit participants, the nursing officer was approached or the admission register was checked on Monday, Wednesday and

Friday. Monday was particularly important as most of the children referred from other provinces were admitted over the weekend while Wednesday and Friday were chosen because of admissions from the out-patient neurology clinic (Clinic Four) which was conducted on Tuesdays and Thursdays.

When a new participant was identified, the researcher would introduce herself to her and explain the purpose of the study using the information sheet (Appendix 9 A-E) that had been translated into the mothers' home language. Any mother who met the inclusion criteria was then asked if she would take part in the study which included audio recording. For those who accepted, an appointment to conduct the interview was made and the interview would be conducted at the time suitable for the mother. Before conducting the interview, the purpose of the study was again explained to the mother and if she still accepted that she could be interviewed by audio tape, then she was asked to sign the translated informed consent form (Appendix 11 A-E). The face-to-face interview was then conducted in a quiet private room (nursing officer's office or fee paying room) within the ward. The interviews were conducted in four local Zambian languages namely Chi Bemba, Chi Tonga, Chi Nyanja and Si Lozi, except for one which was done in English. In cases where the researcher was not able to speak the mother's language, a research assistant, usually a physiotherapist, who was able to speak the mother's language fluently, would conduct the interview in the presence of the researcher.

3.6.3 PART THREE: EXPERIENCES OF MOTHERS WITH ACCESSING PHYSIOTHERAPY SERVICES

After obtaining permission to conduct the study, the researcher went to Clinic Four and introduced herself to the nursing officer in-charge of the clinic. The purpose of the study was also explained to the nursing officer as well as the medical consultant for the neurology clinic (Clinic Four). The researcher was advised to work with the two registry clerks responsible for giving appointments to patients. Every Tuesday and Thursday morning during the study period, the researcher went to Clinic Four at 06h30 in the morning to identify participants who met the inclusion criteria. On each clinic day, the researcher went through the files for patients who were booked on that day to identify any that had meningocele or myelomeningocele (spina bifida). Most of the children with spina bifida who came to this clinic were below the age of six months and hence their mothers did not meet the inclusion criteria for this study. Once those who met the inclusion criteria were identified, the mother was invited in a separate private room. The researcher explained the effects of Meningocele or myelomeningocele on the functional ability of the child to the mother. The mother was then asked if the child had any problems with legs or with sitting, crawling, standing and walking. Regardless of what the she said, the researcher also examined the child’s legs to confirm if there was a problem or not. If a problem with movement was identified, the researcher would then explain the purpose of the study using the translated information sheet (Appendix 10). If the mother agreed to be interviewed using audio tape, she would then be requested to sign the translated consent form (Appendix 11 A-E) and the interview was conducted immediately, or after the doctor’s review.

3.6.4 TRANSLATION OF THE INFORMATION SHEET AND THE CONSENT FORM

The information sheet and the consent form were taken to a registered company which offers linguistic services so that they could be translated into the local language languages (Appendix 9 and 11). Since the participants were coming from different parts of the country, the translation was done in four different languages which are commonly spoken in different parts of the country. These languages were Chi Bemba which is a common language spoken in Luapula, Copperbelt, Northern provinces and some parts of North

Western province; and Chi Tonga spoken in Southern and parts of Central province. The others were Chi Nyanja commonly spoken in Lusaka, Central and Eastern provinces and Si Lozi which is spoken in Western province.

3.7 DATA ANALYSIS

This section describes the methods that were used to analyse both quantitative and qualitative data.

3.7.1 QUANTITATIVE DATA ANALYSIS: PART ONE

Raw data from the data capturing sheet was entered in SPSS (version 20.0) software for analysis. This being a descriptive study, data analysis consisted of descriptive statistics in form of frequency tables and percentages. Associations between variables were tested by chi-square. These associations included the following variables: province of residence and type of NTD, type of NTDs and neurological status; and type of NTDs versus associated impairments. The level of significance was set at $p < 0.05$.

3.7.2 QUALITATIVE DATA ANALYSIS: PART TWO AND PART THREE

Recorded audiotaped data from in-depth interviews were transcribed verbatim. Interviews done in English were transcribed by the researcher while cassettes for interviews done in local languages were given to the professional translator who translated from local language to English. One of the limitations of this study was the fact that the interviews done in local language where only transcribed and translated without back translating. This was because of the limited time and additional costs involved in asking the translator to do the back translation (Squires, 2008). However, to ensure accuracy of the translated scripts, the researcher together with physiotherapists who assisted with interviews verified the scripts by listening to the audio tapes and comparing with the transcribed scripts. The researcher then compared the scripts which were in local language to those that were translated in English in order to ensure that the content and meaning of the two documents were the same.

Analysis of the translated interview scripts was done by the researcher using thematic content analysis. According to Green and Thorogood (2009) thematic content analysis involves analysis of content of the data and categorising recurrent or common themes.

All the interview transcripts were numbered by page and script lines to make referencing easy (Green & Brown, 2005). The researcher read and re-read the transcribed data several times in order to familiarise herself and get a general understanding of the scope and contexts of key experiences under study (Bradley, Curry, & Devers, 2006). As the researcher was reading through the scripts, she was taking note of the interesting contents from the data and from these data codes were formulated (Braun & Clarke, 2006). The sentences or paragraphs from the texts which had similar content or context were grouped together into meaning units (Graneheim & Lundman, 2004). The codes were then compared based on similarities and differences so that those with same meaning were grouped together under one common heading called categories (Elo & Kyngas, 2007; Graneheim & Lundman, 2004). In cases where no similar unit was identified, a new category was formed (Shenton, 2004). These categories and meaning units were then discussed and revised with the research supervisor, and, from this discussion, themes were generated (Bradley et.al, 2006; Graneheim & Lundman, 2004). The generated themes were compared with existing theory, other studies as well as the research objectives (Shenton, 2004). Unexpected findings that did not fit within the framework and the research objectives are reported on in Chapter 4 and discussed in Chapter 5.

3.7 TRUSTWORTHINESS FOR PART TWO AND THREE

In qualitative research, trustworthiness refers to credibility, dependability and transferability of study results (Graneheim & Lundman, 2004). According to Graneheim and Lundman (2004), credibility corresponds to internal validity, dependability to reliability and transferability to external validity. Methods of ensuring credibility includes prolonged engagement with participants, persistent observation in the field, triangulation, checking interpretations against raw data, use of peer debriefing, researcher reflexivity, member checking and thick description of the study methodology (Morrow, 2005; Zhang & Wildemuth, 2009). To ensure credibility, member checking was done by going back to the interviewed mothers whose children were still admitted after transcribing their interviews, and to clarify with them some of the themes that came out during interviews so that they could verify whether the interpretations accurately represents their views (Green & Thorogood, 2009; Creswell & Miller, 2000). According to Creswell and Miller (2000), member checking enables participants to have a chance to react to both the data and final narrative thereby adding to the credibility of the study. Credibility is further strengthened with a description of the researcher's position in the study which is given at the end of this chapter.

Transferability of research findings entails that the readers should be able to determine whether the findings of the research can be applied to other contexts (Curtin & Fossey, 2008). Shenton (2003) added that researchers should be able to give a thick detailed description of the phenomenon under investigation in order to allow the readers have a better understanding of it and make comparisons with those they have seen in their situations. Transferability in this study was ensured by detailed descriptions of the context, characteristics of participants and their selection, data collection methods and analysis (Graneheim & Lundman, 2004). The characteristics of the selected participants included mothers of children from all nine provinces in the country; having a child with an NTD admitted in the paediatric surgical ward or a mother of a child with spina bifida who brought the child for follow up visits.

3.8 ETHICAL CONSIDERATION

Ethical clearance was obtained through written permission from the Senate Research Ethics Committee of the University of the Western Cape. In Zambia ethical clearance was obtained from the University of Zambia Research Ethics Committee (Appendix 5) and written permission was granted by the University Teaching Hospital management to carry out the study at the institution (Appendix 7). Using the translated participant information sheet (Appendix 9 A-E), the objectives of the study were explained to the mothers in their native language. They were informed that they may not directly benefit from the study but results might help health care providers and policy makers come up with strategies which would improve access to health care services in future. The mothers were also assured of confidentiality and they were informed that they would only be identified by codes and that the information they provided would only be accessed by the researcher. They were also informed that there were no risks involved in participating in the study. They were told that their participation was voluntary and should they feel like withdrawing from the study, they were free to do so at any time and their action would not prevent their child from receiving medical attention from the hospital. Permission was also obtained from mothers to allow the interview to be audiotaped. They were assured that the information from audiotapes would only be used for this study and that all audiotapes would be destroyed after finalisation of the study. Mothers who agreed to take part in the study were asked to sign an informed consent form which they read or that was read to them in the language they understood. Out of all the mothers approached by the researcher during the study period, only two declined to take part in the study and both were not asked for reasons why they refused.

3.9 THE RESEARCHER'S REFLECTION

Reflexivity refers to the ways in which the researcher can influence and shape the research process through prior assumptions and experiences (May & Pope, 2000). Creswell and Miller (2000) observed that it is important for the researchers to acknowledge and describe their entry beliefs and biases in the research as this helps readers to understand how the researcher might have influenced the process.

In the current study, my position as a researcher is that of a novice qualitative researcher in the sense that this was the first qualitative study that I had undertaken. I am a physiotherapist by profession and I have been working in the paediatrics section at University Teaching Hospital (study site) since 1998. My professional qualifications include a diploma in physiotherapy, Bachelor of Science in physiotherapy and two certificates in Bobath neuro-developmental therapy in the management of children with cerebral palsy. I have also been working as a part-time clinical tutor with the University of Zambia were I have supervised Bachelor of Science undergraduate physiotherapy students during their paediatrics rotation. During my practice, I have mainly been attending to children presenting with developmental disabilities and other motor impairments of which cerebral palsy was the commonest. I used to attend to children with spina bifida as out-patients as well as in-patients. There were very few children with spina bifida seen as out-patients, but as in-patients I used to attend to a lot of children with spina bifida because they were referred to the hospital from all parts of the country.

My experience with mothers of children admitted to the paediatric surgical ward especially those referred from other parts of the country prompted the conception of the current study. With these experiences as well as being an employee at University Teaching Hospital, I was familiar with the study site and gaining entry to the site was easy because I was a known person. I was also aware that most of the children in the paediatrics surgical ward were referred from different parts of the country and that some came by hospital transport while for others, their parents had to source transport. However, I was not aware of the different challenges mothers went through in securing transport to Lusaka as well as other challenges mothers faced while in Lusaka. That I would learn about in the course of the study.

Despite being familiar with the study site, there was no prior relationship between myself and the mothers who took part in this study. I was meeting these mothers in my capacity as a researcher and not as a physiotherapist. Therefore, despite informing the mothers that I was a physiotherapist at University Teaching Hospital, I made it clear that I was currently on sabbatical and was not involved in treating the children who required physiotherapy. I was able to continue to interact with the mothers whose children were admitted after I had already interviewed them because some of them stayed for some time. During interviews with mothers who brought their children for follow up visits (Part Three of study), I learnt that children were not attending physiotherapy. Despite telling the mothers that I was on sabbatical, I therefore made a decision that after an interview, I would refer children who required physiotherapy to their nearest physiotherapy centre.

3.10 SUMMARY OF THE CHAPTER

The study had three parts, with one quantitative and two qualitative parts. The chapter discussed the methodology used by describing the study design, research setting, sampling methods and the procedure for data collection and analysis for each of the three parts. The chapter also discussed methods used to ensure validity and trustworthiness as well as translation of the information sheet and consent forms. The ethical procedures followed before and during the study were also explained and lastly the researcher’s reflection was included.

The next chapter presents results of the record review, experiences of mothers of children who were admitted to UTH and experiences of mothers who brought their children for follow up visits regarding accessing physiotherapy services.

CHAPTER 4

RESULTS

4.1 INTRODUCTION

Chapter Four presents results for the quantitative and two qualitative parts of the study and is therefore divided into three parts. In Part One results for the record review are presented. In Part Two results from interviews with mothers on experiences with accessing health care from University Teaching Hospital are presented. In Part Three the results from interviews with mothers on experiences with accessing physiotherapy services are presented. This chapter ends with a summary of findings from all the three parts of the study.

4.2 PART ONE: PROFILE OF CHILDREN WITH NEURAL TUBE DEFECTS

This section presents results of the record review on the profile of children with NTDs at the University Teaching Hospital. Firstly, data on the study population (N = 101) will be presented to show the distribution of children with NTDs in different provinces during the period of January to December, 2010. Results from the study sample (n = 50) will then be presented according to demographic data on children's age on admission, gender, and province of origin. In addition, data on type of NTDs, site of lesion, neurological impairments, associated impairments, radiological investigations, surgical management and number of follow up visits will be presented.

4.2.1 DISTRIBUTION OF CHILDREN WITH NEURAL TUBE DEFECTS ACCORDING TO PROVINCE OF RESIDENCE

The study population consisted of 101 children with NTDs, but there was limited data for 51 children whose files could not be located. The only data available for all 101 children were the province of residence and diagnosis. The diagnosis for the study population will be presented as spinal or cranial because detailed information on type of spinal defects was not available for some children. This data is presented in Table 4.1 and included the 101 children who were admitted in 2010 between January and December. The data show that the majority of the children were from Lusaka province and most of the children had spinal defects.

Table 4.1 Study population according to type of neural tube defect and province of origin (N = 101)

Province	Type of Neural Tube Defect Spinal NTD N (%)	 Cranial NTD N (%)	Total N (%))
Lusaka	23 (22.8)	9 (8.9)	32 (31.7)
Southern	10 (9.9)	4 (4.0)	14 (13.9)
Central	6 (5.9)	2 (2.0)	8 (7.9)
Eastern	11 (10.9)	3 (3.0)	14 (13.9)
Western	9 (8.9)	6 (5.9)	15 (14.8)
North Western	2 (2.0)	1 (0.9)	3 (3.0)
Northern	3 (3.0)	5 (4.9)	8 (7.9)
Luapula	3 (3.0)	0 (0.0)	3 (3.0)
Copperbelt	1(0.9)	3 (3.0)	4 (4.0)
Total	68 (67.3)	33 (32.7)	101 (100)

Table 4.2 present the distribution of children in the sample according to province of residence. The majority of the children were from Lusaka province while the provinces with the least number of children were North Western and Copperbelt provinces which had one child each.

Table 4.2 Distribution of children in the sample according to province of origin (n=50)

Province	Frequency (n)	Percentage (%)
Lusaka	14	28.0
Southern	6	12.0
Central	7	14.0
Eastern	5	10.0
Western	8	16.0
North -Western	1	2.0
Northern	5	10.0
Luapula	3	6.0
Copperbelt	1	2.0
Total	**50**	**100.0**

4.2.2 DEMOGRAPHIC PROFILE OF THE CHILDREN

The sex of the children in the study sample is presented in Figure 4.1. From the 50 children whose files were located, 29 (58%) were male and 21 (42%) were female.

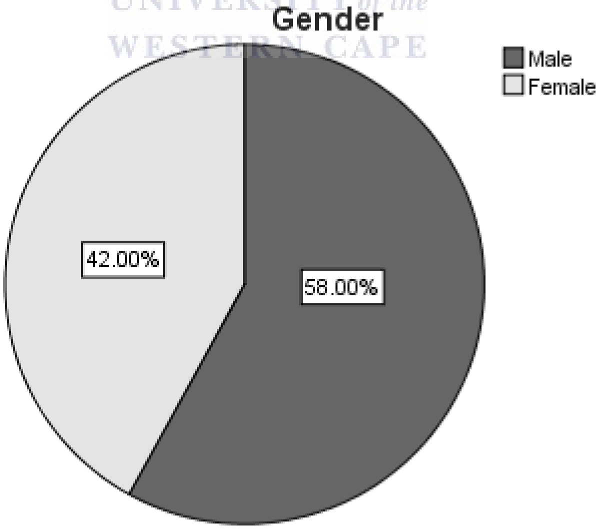

Figure 4.1 Sex of children with Neural Tube Defect (n=50)

The age distribution of the children on admission ranged from one day old to 48 months with the majority (n =40, 80%) of the children aged from one day to one month. There was one child who was aged 14 years at the time she was admitted for the first time. However, she was excluded from the sample and subsequent analysis because of her age which could have distorted the findings. Table 4.3 shows the age of the children in relation to their province of origin. All children coming from Lusaka, Southern and Central provinces were admitted between one day old to one month. A total of 13 (%) children were admitted within the first three days after birth while a total of 25 (%) children were admitted within the first week of birth. Among those who were admitted within the first three days of birth, eight children were from Lusaka province, three from Central province and one each from Southern and Eastern provinces. Chi-square test shows a significant relationship between province of residence and age of child on admission (p = 0.0001).

Table 4.3 Age of children in relation to province of origin (n = 50)

	Age of children in months							
Province of residence	**0-1**	**2-3**	**4-5**	**6-7**	**8-9**	**10-11**	**12-13**	**Above 14**
Lusaka	14	0	0	0	0	0	0	0
Southern	6	0	0	0	0	0	0	0
Central	7	0	0	0	0	0	0	0
Eastern	3	1	0	0	0	0	1	0
Western	6	0	1	0	1	0	0	0
North Western	0	0	0	0	0	0	0	1
Northern	3	0	0	1	0	0	1	0
Luapula	1	1	1	0	0	0	0	0
Copperbelt	0	0	0	0	0	0	0	1
Total	**40**	**2**	**2**	**1**	**1**	**0**	**2**	**2**

4.2.3 TYPE OF NEURAL TUBE DEFECTS

The frequency distribution of the types of NTDs is given in Table 4.4. The results show that the most common type of NTD was myelomeningocele affecting 22 (44%) children followed by 16 (32%) with meningocele.

Table 4.4 Distribution of children according to type of Neural Tube Defect (n=50)

Type of NTD	Frequency (n)	Percentage (%)
Encephalocele	11	22.0
Meningocele	16	32.0
Myelomeningocele	22	44.0
Meningocele/encephalocele	1	2.0
Total	**50**	**100.0**

The sex distribution of children in relation to type of NTDs is given in Figure 4.2. There were nine males and two females with encephalocele (n=11), eight males and eight females had meningocele (n=16), 11 males and 11 females with myelomeningocele (n=22) and one male child who had both encephalocele and meningocele. Chi-square test shows no association between type of NTD and sex of the child (p = 0.232).

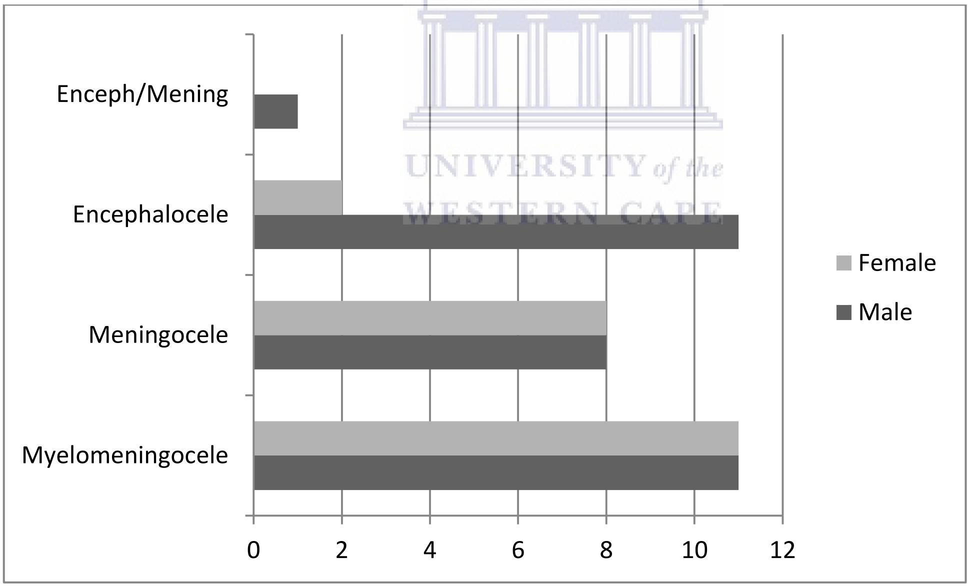

Figure 4.2 Distribution of children according to sex and type of NTD (n=50)

The distribution of type of NTDs according to the province from where the children came from is presented in Figure 4.3. The chi-square test shows no significant association between type of NTD and province of residence (p = 0.172).

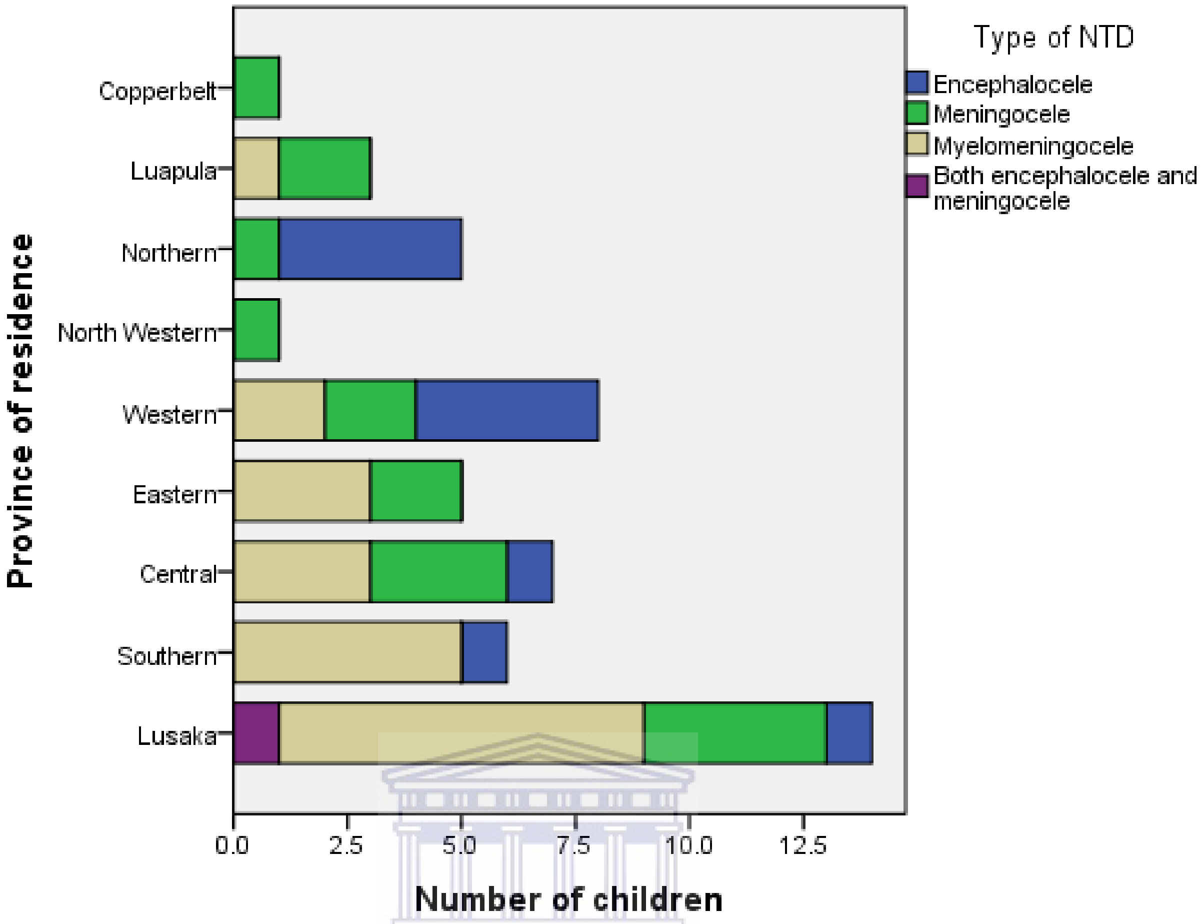

Figure 4.3 Distribution of children according to type of Neural Tube Defect and province of origin (n=50)

4.2.4 SITE OF NEURAL TUBE DEFECTS

Table 4.5 presents the distribution of children with NTDs according to the site of the spinal defects as well as cranial defects. The most common site for spinal NTD was on the lumbar region with 52% (n=26) followed by the lumbosacral region (n=10, 20%). As for cranial NTDs, the occipital region was the most common site accounting for six out of the total (n=11) number of encephaloceles.

Table 4.5 Distribution of Neural Tube Defect according to site (n=50)

Site of NTD	Frequency (n)	Percentage (%)
Spina bifida		
Lumbosacral	10	20.0
Lumbar	26	52.00
Sacral	1	2.0
Thoracolumbar	1	2.0
Cervical	1	2.0
Encephalocele		
Occipital	6	12.0
Nasal	3	6.0
Frontal	1	2.0
Occipital/Lumbar	1	2.0
Total	**50**	**100.0**

4.2.5 NEUROLOGICAL STATUS AND ASSOCIATED IMPAIRMENTS

The neurological status of the children is presented in Table 4.6. According to the information obtained from the files, the results show that 15 children had no neurological impairments. The neurological status for 11 (22%) children was not recorded in the files and therefore their status was unknown.

Table 4.6 Neurological impairments (n=50)

Neurological status	Frequency (n)	Percentage (%)
Paraplegia and incontinence	15	30.0
Paraplegia	8	16.0
Incontinence only	1	2.0
No neurological impairment	15	30.0
Unknown status	11	22.0
Total	50	100.0

Table 4.7 shows the distribution of the neurological impairments in relation to type of NTD. The chi-square test shows a significant association between type of NTD and neurological impairment (p= 0.0001).

Table 4.7 Neurological impairments and type of Neural tube defects (n=50)

	TYPE OF NEURAL TUBE DEFECTS			
NEUROLOGICAL STATUS	**Encephalocele**	**Meningocele**	**Myelomeningocele**	**Encephalocele/Meningocele**
	n (%)	n (%)	n (%)	n (%)
Paraplegia only	0	4 (8.0)	4 (8.0)	0
Paraplegia & incontinence	0	1 (2.0)	14 (28.0)	0
Incontinence only	0	1 (2.0)	0	0
No impairment	10 (20.0)	5 (10.0)	0	0
Unknown:	1 (2.0)	5 (10.0)	4 (8.0)	1 (2.0)
Total	11 (22.0)	16 (32.0)	22 (44.0)	1(2.0)

Figure 4.4 shows that the most common associated impairment was hydrocephalus (n=28, 56%), followed by hydrocephalus with clubfeet (n=9, 18%), giving a total of 37 (74%) children who had hydrocephalus. One child had multiple congenital impairments which included deformity of legs, chromosomal disorders, hydrocephalus and clubfeet and another child had microcephalus with chromosomal disorders. There was no information on associated impairments for two children and nine children had no associated impairments.

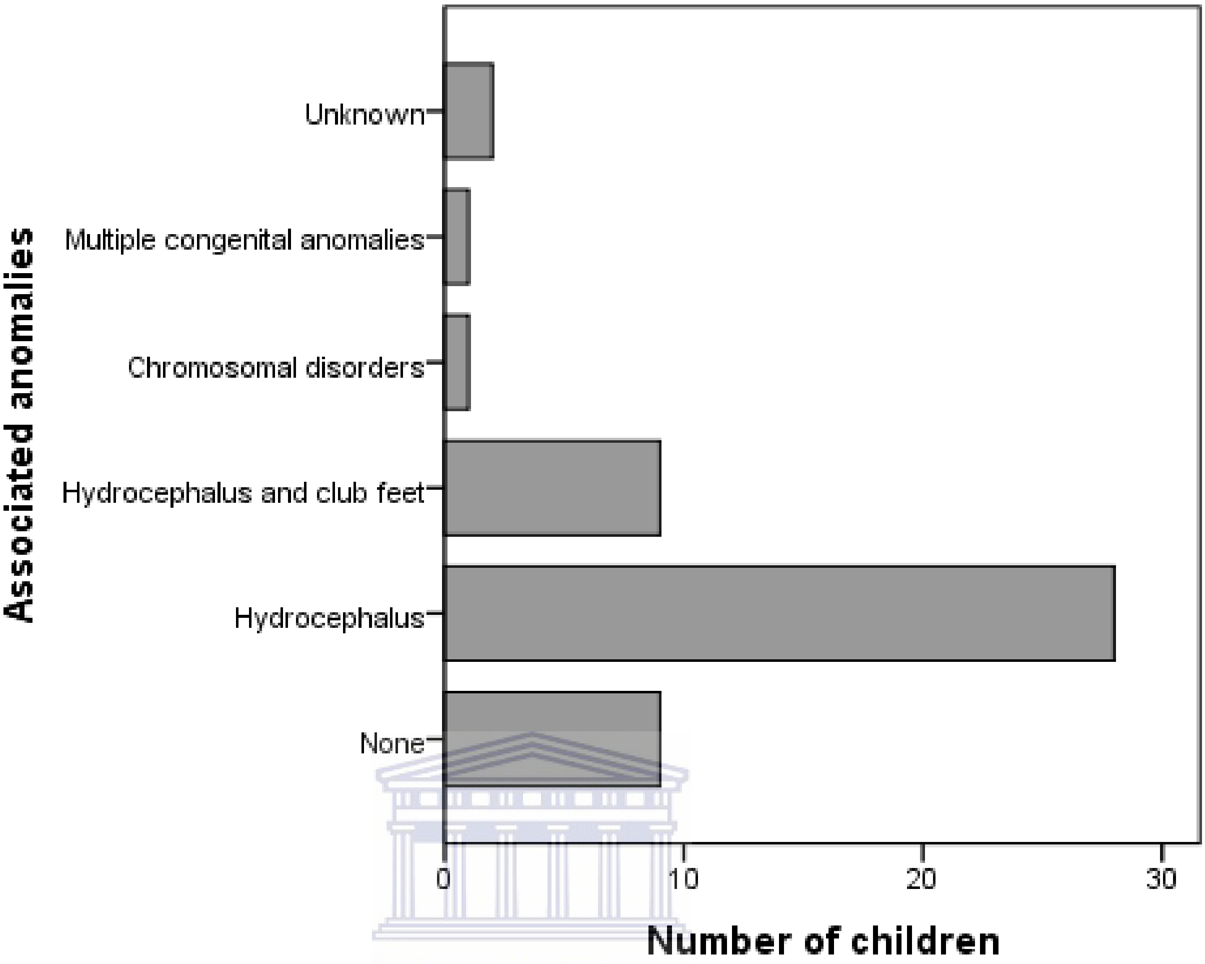

Figure 4.4 Associated impairments (n=50)

Figure 4.5 shows the distribution of associated impairments according to type of NTDs. Apart from one child, whose status was unknown, all children with myelomeningocele had either hydrocephalus or a combination of hydrocephalus and clubfeet. As for the children who did not have any associated impairments, four had meningocele and five had encephalocele. The chi-square test did not show any significant relationship between type of NTD and associated impairment (p = 0.086).

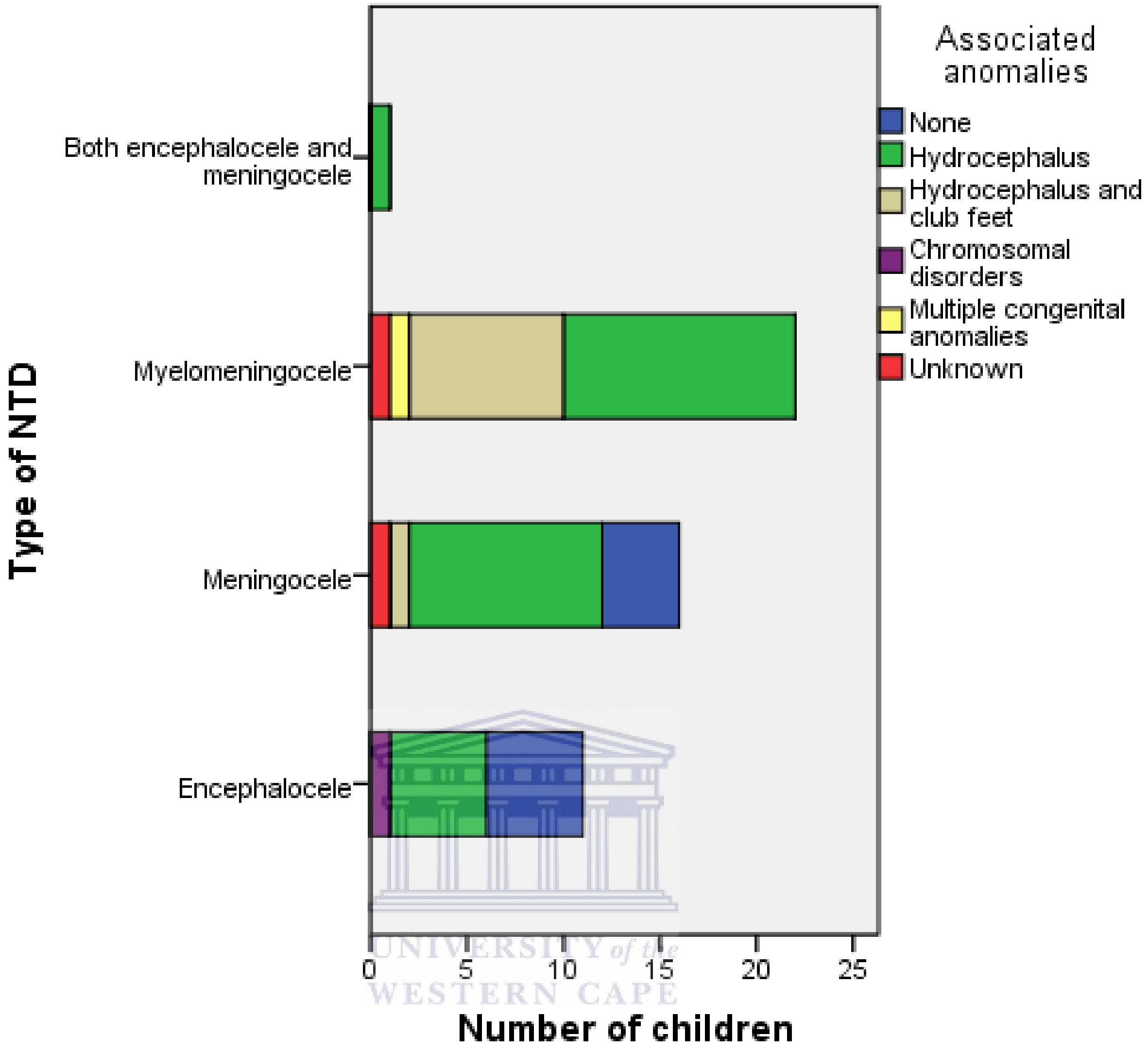

Figure 4.5 Associated impairments according to type of NTD (n=50)

4.2.6 RADIOLOGICAL INVESTIGATIONS

Table 4.8 shows that ultrasound was the most common radiological investigation done. The medical records for seven children had no results or notes on radiological investigations and were therefore recorded as not done.

Table 4.8 Radiological investigations (n=50)

Radiological investigation	Frequency (n)	Percentage (%)
Ultrasound	40	80.0
CT Scan	4	8.0
MRI	1	2.0
No radiological investigation	5	10.0
Total	50	100.0

4.2.7 SURGICAL MANAGEMENT

Surgical management involved either the repair of the defect, insertion of a shunt or both the repair of the defect and the insertion of a shunt. The type of shunt for all the children whose surgery was done at University Teaching Hospital was the ventriculo peritoneal shunt (VPS). Repair of defect alone was done in 20% (n=10) of the children, shunt only was done in 28% (n=14) of the children and 22% (n= 11) of the children had both repair of the defect and shunting for hydrocephalus. Thirty percent (n=15) of the children did not undergo any surgical management.

4.2.8 COMPLICATIONS

Table 4.9 presents the complications of NTDs which were recorded in the medical files and shows that wound infection was the most common complication (n=20, 40%). The information on presence of complications was not available for two children, and 48% (n= 24) of the children had no complications.

Table 4.9 Complications associated with Neural Tube Defects (n=50)

Complications	Frequency (n)	Percentage (%)
No complication	24	48.0
Meningitis	1	2.0
Wound infection	20	40.0
Blocked shunt	1	2.0
Wound infection and blocked shunt	3	6.0
Unknown	1	2.0
Total	50	100.0

4.2.9 FOLLOW UP VISITS

The number of follow up visits that children had attended at the hospital was also recorded. Table 4.10 shows that the majority (n=33, 66%) of the children had no follow up notes in their files while one follow up visit was recorded in four patients. Seven (14%) files had at least between two and three follow up visits and only four had more than three follow up notes. Two of the children were referred to Beit Cure hospital according to the notes but no follow up notes were recorded to show the outcome from Beit Cure hospital.

Table 4.10 Number of follow up visits for children with Neural Tube Defects (n=50)

Follow up visits	Frequency (n)	Percentage (%)
No follow up notes	33	66.0
1 follow up visit	4	8.0
2-3 follow up visits	7	14.0
Above 3 follow up visits	4	8.0
Referred to Beit Cure Hospital	2	4.0
Total	**50**	**100.0**

4.3 PART TWO: EXPERIENCES OF MOTHERS WITH ACCESSING HEALTH CARE SERVICES AT THE UNIVERSITY TEACHING HOSPITAL

4.3.1 DEMOGRAPHIC CHARACTERISTICS OF MOTHERS

Part Two of this study used qualitative methods to address the second and third objectives. Data collection for this part was done through in-depth interviews with 20 mothers of children with neural tube defects who were admitted in the paediatric surgical ward (ward D01). Detailed descriptions for each mother are given in Appendix 12. The age of the mothers ranged from 19 years to 36 years. Most of the mothers were dependent on cultivation as a means of living because the majority (n= 15) came from rural areas.

The age of their children when they were admitted ranged from one day to nine months, with a male predominance of 14 compared to 6 female children. The most common type of NTD was myelomeningocele (n=10), followed by meningocele (n=6) and four children had encephaloceles.

4.3.2 THEMES

The second objective was to explore challenges experienced by mothers of children with NTDs in relation to accessing health services from the University Teaching Hospital and the third objective explored their perception on the feasibility of accessing physiotherapy and to return for follow up visits after discharge. Five themes emerged during in-depth interviews which were related to both the second and third objectives and are presented in table 4.11.

Table 4.11 Themes and sub-themes that emerged from in-depth interviews with mothers

	Theme	Sub-themes
1.	Access to health care	Birth experiences Referral system Being sent back home Access to health care back home
2.	Transport	Transport from referring hospital to UTH Transport to go back home Transport to come back for follow up visits
3.	Being a mother to a baby with a NTD	Finding out that the baby had a NTD Need for information Uncertainty
4.	Family concerns	Care for children who remained home Spouse’s living conditions at UTH Family’s cultural beliefs
5.	Support	Family support Government support

Each of these themes has sub-themes which are presented under each theme, and to make them clearer, actual quotes from mothers are also included. The experiences of the mothers included both the challenges and support they experienced from the time the baby was born to the time of admission at UTH. For purposes of anonymity and confidentiality, transcribed quotations from interviews will be cited in the cryptogram M 01 to M 20, where M refers to mother and the number indicates a number allocated to that mother.

4.3.2.1. THEME 1: ACCESS TO HEALTH CARE

When mothers were asked to describe what they went through from the time the baby was born to the time the baby was admitted to University Teaching Hospital, there were a number of issues raised that fell under the theme access to health care. Sub-themes under access to health care included the birth experiences, the referral system, being sent back home and access to health care when child goes back home.

i. BIRTH EXPERIENCES

The first broad question required mothers to explain what they went through from the time the baby was born up to the time of admission at University Teaching Hospital. Mothers were able to describe their experiences which included labour and place of delivery. Out of the 20 mothers interviewed, five mothers delivered at home, four delivered at the clinic, two delivered on the way to the clinic and nine delivered at the hospital. The mothers who delivered at home had to go to the nearest clinic or hospital after finding out that the baby was born with a problem. Of the two who gave birth on the way to the health facility, one gave birth in the bush while the other had to ask for help from a nearby house in which she delivered. After giving birth, both mothers and their accompanying relatives proceeded walking to the health facility when they discovered that the baby was born with a defect. The following were quotes from mothers who did not deliver from a health facility:

> *I delivered from home…Just a neighbour assisted me…* (M 14)
>
> *We were coming from home (*walking) *on our way to the hospital, then I felt that I could not manage to reach the hospital…We asked from one of the houses on the way for assistance and I delivered there…* (M 13)

ii. REFERRAL SYSTEM

Mothers narrated different experiences regarding what they went through to have the child referred from the health facilities within the provinces until the time they were referred to University Teaching Hospital. Some of the mothers took their babies to the local clinic which later referred them to the first level hospitals or directly to the second level hospitals. Other mothers went straight to the first level hospitals where they were either referred to the second level hospitals or directly to UTH. Some mothers who did not pass through the clinics were charged by-pass fees. This is a fee a patient must pay if they go directly to the hospital without being referred by the clinic. With regard to transport, some mothers were assisted by the hospitals and others were not assisted.

Among the mothers who first went to the clinic, only four mothers delivered at the clinics. Those who did not deliver at the clinics had to go through the local clinics, because the clinics were near to their homes or because of their fear of paying by-pass fees if they went directly to the first or second level hospitals. Going directly to the first level or second level hospital would result in a by-pass fee which was introduced by Ministry of Health as part of the health sector reforms during 1993 to 1997 (Blas & Limbambala, 2001). This was done in order to encourage utilisation of primary health care facilities and prevent congestion at higher level referral hospitals. However, its implementation was not well defined as decisions were mainly left to the individual hospitals and health centres (Blas & Limbambala, 2001). Experiences of some mothers in the current study revealed that some health facilities are still charging by-pass fees while others are not. One of the mothers who delivered at a first level hospital had her husband go by bicycle to a local health centre to collect a referral letter when she started her labour. This clinic was far from home while the hospital was nearer. Her reason for going through that procedure, as expressed in the following quote, was to avoid being charged by-pass fee at the hospital:

> *If that is the case (going straight to the hospital), then you pay K3, 000.* (M 01**)**

Another mother who delivered at home and then went straight to the first level hospital after finding that the baby had a problem was charged *K50, 000. [1]This by-pass fee did not only apply to referring health facilities because one of the mothers who came with a referral letter from the first level hospital to UTH was asked to pay K80, 000 at UTH. The

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* The exchange of Zambian currency to rand was R1 to K00, 700 during the study period.

reason, as stated in the following quote, was that the letter had no date stamp from the referring hospital:

> *Even that side, at the reception I paid K80, 000… They said date stamp, there was no date stamp …. Yes, but I paid K80, 000, the only money I kept for transport to go back.* (M 18)

While some mothers who went through local clinics were just given referral letters and asked to find their way to the referral facilities, some mothers were assisted with transport by clinic staff who called for an ambulance from the referral hospital which went and picked the mother and the child.

> *But the person at the clinic sent a radio message to* (hospital) *and the ambulance came to pick us. I asked if I could go home to pick clothes for the baby but they said no.* (M 11)

Decisions from first level hospitals to refer the patient either directly to Lusaka or through a second level hospital seemed to be dependent on individual referring hospitals. It was found that most of the children who were referred from first level to second level hospitals and then to UTH were relatively quicker in reaching UTH because they were assisted with transport. On the other hand, most of the children who were referred directly from first level hospitals to UTH delayed mainly because of transport problems. Others reported that they were asked to go home and return at a later date by doctors at first level hospitals, as discussed below.

iii. BEING SENT BACK HOME

Although all the children who were presented at the clinics were immediately referred to the hospitals, eight mothers who reported to the first level hospitals were sent home by doctors despite the babies presenting with NTDs. Sending the children back home instead of referring them to higher level hospitals contributed to their late presentation for surgery for those who required surgery. According to the mothers, five were sent back home to look for transport money to take their children to Lusaka and three were discharged and asked to go back to the hospital at a later date. Some of the mothers said the doctors told them that the babies were too young to travel over the long distance from their provinces of residence to Lusaka.

> *I only stayed in the hospital for 3 days and went home…so that is how I kept the baby until one month…they said at the moment, the baby is still too small to travel that far.* (M 19)

Another mother who was asked to look for transport money to take the child to Lusaka reported that she could not find transport money and she just decided to stay home until after three months when some people who visited the village gave her some money.

One of the mothers was sent back home from a second level hospital after she had found transport money to get to that hospital. This mother was told by someone in her village that there was a white man at the second level hospital who helps patients with transport when they are referred to tertiary hospitals. However, when she reached the second level hospital, she was told that the white man was out of town and she was asked to go back home and look for transport money to take the baby to Lusaka.

> *I was admitted and after 2 days, I was given a letter to take to Lusaka…So we had to go back* (to the village) *to look for transport money to go to Lusaka.* **(**M 12)

The medical personnel who were sending the mothers back home were not taking into consideration the condition of the babies before sending the mothers home. This was according to reports by some mothers who said the condition of their babies got worse while at home and they had to go back to the hospital as expressed in the quotes below:

> *So one day this wound on the back broke. I think that was on 6th June, at night. So the yellowish fluid started coming out and the baby started crying a lot and he*

> *cried the whole night. The fluid in the head increased and the eyes were up. So I took him to the hospital.* (M 19**)**
>
> *So we went back home and we stayed. Then we just noticed that the head of the baby is getting bigger. So we went back to the hospital….so when I went back, they told me that we advised you to go to Lusaka.* (M 04)

iv. ACCESS TO HEALTH CARE BACK HOME

Children admitted at University Teaching Hospital with NTDs are required to be followed up either at this hospital or at hospitals within their provinces of residence after surgery. Children who present with paraplegia are supposed to be accessing physiotherapy services within their home provinces. For this reason, mothers were asked about availability of health care services at home. The majority of mothers (n=14) indicated that they would not have problems with accessing physiotherapy services or follow up visits back home while others stated that they would not be able to. Those who said they would not have problems said they lived near hospitals such as first or second level hospitals.

> *If they operate on the wound and they say we can go for review at the general hospital (*first level hospital)*, then there will be no problem.* (M 01)

The mothers who lived far from these hospitals expressed concern about taking their children to the hospitals and cited long distance from home to the facility and lack of transport money as reasons.

> *Ya!! That place is very far. Ha!!....Going K10, 000 and coming back K10, 000…. No I can't afford.* (M 14)

4.3.2.2. THEME 2: TRANSPORT

In explaining their experiences with accessing health care services for their children, the issue of transportation from one health facility to the other was one of the barriers mentioned by most of the mothers. Even those who were assisted with transport to get to

UTH expressed concern about transport for when they would be going back home. When asked about how they wanted government to assist them, most of them talked about transport. The theme transport had three subthemes namely: transport from the referring hospital; transport to return home when the baby is discharged; and transport to come for follow up visits.

1. TRANSPORT FROM THE REFERRING HOSPITALS

With regard to travelling from the referring hospitals up to University Teaching Hospital (UTH), mothers talked about challenges with transport from home to first health facility, from the first level hospital to either second level hospital or UTH and getting from second level hospital to UTH. Of the 20 mothers interviewed, 10 mothers were referred directly from the first level hospital to UTH while the other 10 were referred from the first level to the second level hospital and then to UTH.

Under this sub-theme, mothers talked about their experiences regarding transport from home to first health facilities, transport from first level hospitals to UTH and transport from first to second level hospitals and finally to UTH.

a) Transport from home to the first health facility

The means of getting from home to first health facilities among mothers consisted of walking, going by bicycle or by either private or public transport for those who could afford it. Some mothers went to health facilities after giving birth at home, while others when they were in labour. While getting to health facilities was not a problem for those who lived near clinics or hospitals, some mothers who lived far from health facilities reported that they had to walk for many hours to get to the nearest health facility. One of the mothers (M 11) who delivered on the way to the clinic reported that walking to the nearest clinic takes about three and half hours. For some mothers who said they stayed far from the health facilities, this challenge was eased by using bicycles or vehicles as expressed in the following quotes:

I was carried on a bicycle from home to the hospital. (M 20)

They went to tell my uncle that the baby has a wound and they asked him to help us with his car to take the baby to hospital. (M 02)

b) Transport from the first level hospital to University Teaching Hospital

Among the 10 mothers who were referred directly from first level hospitals to UTH, four mothers were assisted with transport by the first level hospitals while six had to find their own means of transport. Among those who were assisted with transport at first level hospitals, two mothers, both from Lusaka were taken by ambulance, while one mother from Southern province was asked to contribute money to put fuel in the hospital vehicle.

The hospital staff said that they didn't have money for fuel… They told us to put fuel in the vehicle…the hospital vehicle so that we could come with it to Lusaka. So we gave them some money. (M 02)

Another mother reported that the staff from the first level hospital gave her and her husband money and paid for their bus fares from the province to Lusaka.

No, they gave us money from their pockets. It was not money for the hospital (individual staff gave them)*….They gave us money and they paid for the bus to bring us here.* (M 20)

Among the mothers who did not get assistance with transport from first level hospitals to UTH, some mothers said that they went through problems finding transport money. One of the mothers said that after she was told by the hospital to go home and look for transport money to take the baby to Lusaka, she decided to go to the social worker's office hoping that she would be assisted.

So I went to the Boma and when I got in the social worker's office, I was told that the social worker is in Lusaka….Then I thought to myself that what should I do, I just said let me just go back home. They also said just go home. (M 04)

When this mother went back home, she realised that the baby's head was growing, she could not stand the situation so she had to think of other means. She decided to go back to the social worker's office but she was told that the person was still out of office. She decided to go to the office of the District Commissioner (DC) where she was assigned a driver who took her to Lusaka:

After three days, the condition was just getting worse; I said this head is becoming worse, so I went back. I asked them if the person is back (social worker)*, they said we told you that this person is not around. So I left and I said to myself that let me just go to the DC. (*M 04)

Another mother who did not have transport money to go to Lusaka decided to stay home until some unknown people who visited the village gave her some money.

We did not have money to go to Lusaka so we went back home and stayed for three months. Later some white people came to our area and they gave us some money to take the child to Lusaka. (M 17)

Among others who had to find their own means to get to Lusaka, one of the mothers reported that she had to sell maize to raise transport money while another one said she borrowed some money.

c) Transport from first to second level hospitals and then to University Teaching Hospital

Most of the mothers who were referred from first to second level hospitals and later to UTH were provided with transport by the referring hospitals. Assistance with transport from first to second level hospitals consisted of transporting the mother and child using the vehicle from the first level hospital or calling for an ambulance from the second level hospital to pick up the mother and child.

So they said this problem we can't do anything here so you will go with other patients to Ndola (second level hospital) *using the hospital vehicle.* (M 13)

While some first level hospitals went out of their way in order to assist, others could neither provide transport nor call for assistance with transport from the second level hospitals. One mother narrated how she was given some money by the hospital staff at a first level hospital and even taken to a second level hospital by a hospital vehicle. At the second level hospital, this mother later travelled to Lusaka using the money she was given by staff from the first level hospital:

The doctor said that where you are going, you will need some money. So the staff at the hospital contributed some money… According to what they told me, they contributed. I even saw the paper which they used for collecting contributions….They contributed K420, 000 (R 560)…So I just used the money which they contributed for me from Mkushi hospital. **(**M 19)

Another mother who was referred to a second level hospital by a first level hospital without being given any assistance with transport decided it would be better to go to Malawi for help. She went across the Malawian boarder to the nearest hospital. This mother didn't have enough money to go to the second level hospital in Zambia because it was far and so a friend advised her to go to a hospital in Malawi which was nearer to their village. She went with her husband using the bicycle and when they reached that hospital in Malawi, they were referred to another bigger hospital within Malawi which was far. They could not afford the transport cost so they decided to return to their village and started looking for money to go to the second level hospital in Zambia, where they had been referred to. The mother only managed to raise this transport money when the baby was about five months old. She went to the second level hospital which referred and transported her to Lusaka. The following quote was what she went through in trying to access health services for her baby.

We had already been to the hospital (first level) *but they told us to look for money to go to Chipata* (second level hospital)*.....Someone advised us to go to Malawi. So we went to Malawi with a bicycle… and there they told us to go to Lilongwe* (another city in Malawi)*.....We had to come back because we didn't have money to go there***.** (M7)

2. TRANSPORT TO RETURN HOME WHEN THE BABY IS DISCHARGED

Almost all mothers expressed concern when asked about how they would go home when the baby was discharged. The mothers who were assisted with transport to get to Lusaka were even more worried than those who were not assisted, about getting back home because they were not sure if the referring hospitals would come back for them. Two of the mothers said that it was because the referring hospitals were not able to come back and pick those patients whom they took to UTH. One of the mothers whose baby was re-admitted during the study period reported that during the previous admission, she was transported to Lusaka by the referring hospital but after the baby was discharged, she was not assisted with transport.

From this mother's experience, it became clear that once the referring hospital takes the patient to UTH, there was no guarantee that they would return to UTH and take their patient back to the home province once they were discharged. Even the mother who was assisted by the District Commissioner's office was worried because the cell phone number which she was given by the driver who took her to Lusaka could not be reached whenever she tried to call.

> *So they said you should call but each time we call they are outside coverage area…. So now we are worried because we don't know where we will find money to go back when the baby gets better*. (M 04)

Most of the mothers had no money and they were worried about where to find transport money. One mother had her husband lose his job because he had to accompany her to Lusaka when the hospital decided to refer the baby to Lusaka as soon as the wife delivered. She was very worried because the husband's job was their only source of income. This mother was assisted with transport by the second level hospital and the husband accompanied her.

> *So here we don't even know where we will find transport money….The issue of going back even me it is giving me a headache.* (M 01)

One of the mothers who was assisted with transport from both the first and second level hospitals was even making plans to look for some piece work at the hospital to raise funds to go back home when the baby was discharged.

After each interview, the mothers were asked if they had any questions and some of them asked the researcher if she knew of any way they could be assisted with transport or of any possibility of UTH providing transport for them to go back as stated in the following quotes:

> *Yes, I was thinking about the issue of going back?* (M 01)
>
> *What I wanted to find out is whether this hospital can assist us with transport to go back?* **(**M 05)

3. TRANSPORT FOR FOLLOW UP VISITS AT UTH

Management of children with NTDs requires continued care for the affected children who are supposed to be followed up and monitored by specialists. When asked if they would be able to bring the child back to UTH for follow up visits, mothers cited transport as one of the most challenging barriers to bringing the baby. The response from the majority of mothers to the question of whether they would make it for follow up visits showed that most children would not be able to be reviewed after surgery at UTH because of transport difficulties.

> *…but if they operate and say we should come back to Lusaka for review, then there will be a problem with transport.* (M 01)
>
> *To move from Mansa to this place I cannot afford. It is just too much (she laughs).* (M 05)

4.3.2.3 THEME 3: BEING A MOTHER TO A BABY WITH A NEURAL TUBE DEFECT

During their narration of their experiences, mothers talked about a number of issues related to the way they got to know about the diagnosis of the child's condition as well as their perception. These will be presented as sub-themes of being a mother and included finding out that the baby had a NTD as well as their need for information and uncertainty about the future.

I. FINDING OUT THAT THE BABY HAS A NEURAL TUBE DEFECT

Finding out about the baby's condition for most mothers came as a surprise because none of the mothers interviewed was aware that the child would be born with a NTD. All mothers were told about it after the baby was born. One of the mothers who had a baby with a large encephalocele was told after a scan that she was going to have twins, but she was surprised to see the baby with a large lump on the head.

> *The time I was pregnant they thought I had twins, but when I delivered that is when they discovered the problem….I delivered well without any problems but when the child came out, I noticed this thing on the head.* (M 20)

Others had no idea until the baby was born and they had to find out in different ways. One of the mothers who delivered at a first referral hospital was not even told when she delivered and only came to know at the time when her friends who went to see her wanted to bath the baby. When she went to the nurses to tell them about what the baby had, she found that the nurses already knew about it even though they never told her.

> *I didn't even know about the wound but when my friends wanted to bath the baby, they saw it and asked me what it was. I didn't know so we took the baby to the nurses who already knew about it and they said it is called spina bifida. So that is how I knew about it.* (M 19)

Other mothers who delivered at home and those who delivered on the way to the health facilities were also surprised to see the babies with wounds on either the back or heads. They had to take the babies to the health facilities immediately after giving birth.

II. NEED FOR INFORMATION

During the interviews some mothers made some statements related to the need for information about the child's condition. Mothers talked about the need to have information about NTDs during pregnancy, others wanted to know about the cause of this condition and others wanted to know about the surgery which was done on their children. Some mothers also talked about the need for skills and information on how to take care of the children.

One of the mothers complained that she was not told when she was pregnant that there was such a condition and she blamed the medical staff for not talking about this during antenatal clinics. She also mentioned that it was very distressing for mothers to give birth and only to find that the baby had this problem and was required to be admitted in the hospital.

> *Even me I didn't know that there is such a problem. I used to go for antenatal but they never mentioned about it… So I had little knowledge about this and it is very difficult, very distressing when you are going through this.* (M 09)

This mother also mentioned that there was a need for medical staff to teach mothers about preventive measures during antenatal clinics. She also stated that medical staff should teach mothers who had children with NTDs about how to take care of these children once they are discharged.

Some mothers wanted to know what caused this problem and one of them wondered why her baby was continuously passing loose stool which she thought was diarrhoea. This was a mother who had a six month old baby with meningocele who had incontinence of both urine and bowel.

> *Ah…I want to know, what causes diarrhoea?....She has diarrhoea like continuously….Just from time to time…..but what worries me is that it is always loose.* (M 07)

Other mothers wanted to know about the surgery which their children were going through. For example one mother wanted to know more about how the shunt works and was worried about its complications. This mother said that while in the ward (D01), she had heard people talking about shunts and so she wanted to know if it could be removed after some time and also whether it would not interfere with the fontanel.

> *Because when it bulges up* (the fontanel), *the baby gets very sick, is it not so?...Now I want to know what will happen if they put a shunt and this thing* (fontanel) *sinks down, what can they do?* (M 07)

Another mother who had a baby with myelomeningocele wondered why her baby's wound was not operated on like the other babies and thought that even her child should be operated on.

> *I have noticed that all of my friend's babies with this problem are being operated on and I thought that even my baby will be okay if they operate.* (M 06)

In relation to acquiring skills, two mothers narrated how they had been advised by the medical personnel to take care of the wound. One mother said she was given something to apply on the baby's wound at the first level hospital and she said the wound closed after sometime. Another mother narrated how she was shown how to position the baby and take care of the wound to prevent friction which could lead to rupturing of the wound.

> *So they said you should be very careful with this thing because it may break…You should be putting him on the side and then put a piece of cloth to support so that he does not lie on the back. If it breaks, it will cause problems.* (M 19)

III. UNCERTAINTY

Most mothers expressed uncertainty about the future of their babies as most of them wanted to know whether the baby would be able to sit or walk. Others were worried about the deformed legs of their babies and wondered whether they would ever be able to straighten.

> *I just want to find out if the baby will be able to sit because the wound is somewhere here where he's supposed to sit from so I'm wondering how he can sit.* (M 13)
>
> *What about the legs which are bent?* (M 01)

4.3.2.4 THEME 4: FAMILY CONCERNS

During interviews, mothers expressed concerns related to family which included being worried about children left home, concerns about their spouse's living conditions while they were in Lusaka as well as family beliefs about the baby's condition. These will be presented as subthemes under the theme family concerns.

1. CONCERNS ABOUT CHILDREN LEFT HOME

Some of the mothers who were referred from other provinces were worried about the care of other children who remained home. This was because they were not aware when they went to the hospital that the condition of the baby would require them to immediately go to Lusaka. As a result, they had no time to arrange for the care of the remaining children as presented in the quotes below:

> *I just left the other children with no one to take care of them.* (M 11)

Worrying about the children left home seemed to increase the mother's anxiety as was observed with one mother who wanted the doctors to attend to the baby as soon as possible so that she could go back home.

> *…but can they operate on her as soon as possible because I'm worried about my children who have remained alone back home…I am just asking for assistance so that they can operate on the baby soon so that I can go back to the village.* (M 16)

However, other mothers had no worries about the children they left at home because some family members such as grandparents or fathers, in case of those whose spouses did not accompany them to Lusaka, were able to take care of the children.

2. CONCERNS ABOUT ACCOMPANYING SPOUSE

Six mothers who were referred from provinces other than Lusaka were accompanied by their husbands while one was accompanied by her sister. The others were not accompanied by any relatives while those from within Lusaka were just visited by their families during visiting hours. Among those who were accompanied by their husbands, some of the mothers expressed concern about the living conditions for their spouses especially where they used to spend the nights and what they were eating. These mothers stated that there was no provision at UTH for a sleeping place for the accompanying male spouse. There is only one room in this ward which is used as feeding and waiting room and only females are allowed to sleep in there. The mothers also stated that the hospital security staff used to chase their husbands away from the ward whenever they found them sleeping along the corridors of the ward. Some mothers were worried because they did not know where their husbands were spending the nights when they were chased from the ward.

> *My husband is suffering a lot and sometimes he sleeps outside and sometimes they chase him, he has nowhere to stay…Yesterday I don't know where he slept, the watchman took him… Yes, they just took him outside, so he went and slept there.* (M 04)
>
> *He sleeps by the corridors of this ward but last night they were chased and I don't know where he slept.* (M 17)

To avoid being accosted by security guards at night, one mother stated that the husband used to spend the nights at the intercity bus terminus (station) which is located about 30 minutes' walk from UTH.

> *He just comes to see me, then he goes to inter-city bus station to sleep then he comes back in the morning.* (M 20)

One of the mothers also complained about her husband not having food and said that the hospital was only giving her one portion which she used to share with her husband. However, other mothers who were accompanied by spouses or relatives said they were allowed to get two portions so that they could give one to the spouse.

3. FAMILY BELIEFS

There was only one mother who spoke of the challenge of having to convince the husband and her in-laws that the baby should be taken to the hospital instead of relying on the herbs which they started applying on the sore of the baby. The baby was born at home and the father of the baby and his parents refused to take the baby to the clinic. Instead, they started applying some traditional herbs on the meningocele but the mother of the baby insisted on taking the baby to the clinic. After a week, they realised that the herbs were not working and the husband agreed to take the baby to the clinic.

The mother of this child was an Apostolic Faith member and she believed in praying for the sick. Despite believing in prayers, this mother also believed in modern medicine because of her past experience. She narrated how previously her other child had died when she went in the bush with church members to pray for the sick baby. While in the bush, she had woken up the following morning and found her baby dead. Because of that experience, this time she did not want to take chances and she said she would only go for prayers after the baby has been operated on.

> *After they do the operation, then I will come back for prayers instead of these traditional herbs which our church does not believe in.* (M 07)

4.3.2.5 THEME 5: SUPPORT

The theme of support consisted of two sub-themes namely family support and government support.

1. FAMILY SUPPORT

Some mothers talked about family support which they received from extended family before admission at UTH and during their stay at UTH. Before being referred to UTH, some mothers received support from their families in the form of being escorted to the hospital when the baby was referred to a higher hospital level as well as assistance with transport money to the referral hospitals.

> *So my relatives said that since this baby is supposed to go to Lusaka, we are going back to the village to look for money so that we can travel well to Lusaka.* (M 02)

Other support within their home provinces consisted of caring for the other children while the parents were taking care of the baby in the hospital or when they travelled to Lusaka after the baby was referred to UTH.

> *They* (children) *remained with their grandparents.* (M 04)

While in Lusaka, some of the mothers who had relatives in Lusaka talked about getting support from these relatives. Family support while the baby was admitted at UTH included being visited by family members within Lusaka who brought them food as well as bathing soap and detergent for washing napkins for the babies.

> *They have visited me on three occasions …Yes, they bring nshima* (local food from maize meal). (M 18)

Some mothers who did not have relatives in Lusaka complained about food which was provided by the hospital while others said the food was fine. The hospital only provides lunch and supper for caregivers and so mothers reported that they had to find breakfast by themselves and those who did not have the means had to wait until lunch time. Some of the mothers who had relatives taking food to them shared the food with others who did not have relatives in Lusaka.

> *They* (hospital) *bring nshima for us here but I don't enjoy it…The nshima is not well cooked ….I usually eat from friends who have relatives who bring food for them from home.* (M 20)

Other mothers who had relatives within Lusaka stated that they were not able to be visited by their relatives for various reasons such as long distance from where they lived to UTH and others said their relatives were not healthy enough to visit them.

> *The relatives who are here stay very far from this place.* (M 18)
>
> *There is my mother (aunt) who stays in Mtendere but she is elderly so she cannot manage because she has problems with legs.* (M 16)

Some mothers who had relatives in Lusaka talked about staying with those relatives while they waited to be admitted at UTH or after being discharged. One mother who had travelled from another province with her older child as well as the baby who had a NTD said she was met at the station by her relatives who took her to their home. After staying there for two days, they took her and the baby to UTH where she was admitted. Her other child remained home with relatives in Lusaka where they looked after her while the mother was in hospital nursing the baby.

Some mothers whose babies were readmitted said that although they stayed with their relatives in Lusaka after the baby was first discharged, they were not happy with the way they were treated by the relatives. One of these mothers said while she stayed with her sister for a week, her sister had the habit of shouting at her own children and this mother used to get offended by this behaviour. In Zambian culture, it is believed that when one has visitors in a home, your own children are not supposed to be beaten or shouted at because it would imply that you do not want those relatives if you do that. So this mother vowed never to go to her sister again because she thought her sister did not want her in the house.

> *You know I was so heart-broken because this is the person I thought was going to keep me…So I can't stay with her.* (M 19)

Three mothers who were from within Lusaka had a lot of support from their immediate family. One of the mothers who had a caesarean section was assisted by a relative who cared for the baby at UTH while the mother was still admitted at another hospital where the baby was delivered. When this mother was discharged from the hospital, she went to UTH where the baby was and her sister in-law continued caring for the baby at night at UTH to allow the mother go home every evening to rest and clean her wound.

> *My sister in-law is helping me. At night I go home and wash the wound* (had C-section)*, then I come back early in the morning.* (M 09)

2. GOVERNMENT SUPPORT

Mothers were also asked about their perceptions about how government should assist those who find themselves in their situation and the most common assistance which mothers asked for was that of transport. Although some mothers did not want to talk about this topic, those who were able to talk about it expressed concerns with transport to the referral hospitals as well as transport back home. Mothers wanted government to find ways of ensuring that children who were born with NTDs were transported to the referral hospitals as quickly as possible. One of the mothers suggested that in case the hospital fails to provide transport, the office of the social workers should be responsible for providing transport in form of money. This mother however stated that whenever people went to these offices for assistance, they were usually told that there was no money.

> *This is difficult, but there must be social welfare to assist with transport money so that the baby is quickly taken to the hospital .....But you know in our areas, such services they say they don't have enough money.* (M 19)

This difficulty with getting support from social workers was also reported by another mother who was told that the social worker was out of office on the two occasions that she went to the social worker's office.

Other mothers also stated that government hospitals should be providing free services to the people who cannot afford the services and this included providing free transport when a patient is referred to another hospital. Mothers suggested that hospitals which could not transport patients using hospital vehicles should be providing transport money to those patients if they request for help from them.

> *The hospital is supposed to assist especially if a person cries for their help, they should assist.....They should even give money to that person so that she can travel.... I would like them to give me money to go back.* (M 18)

One of the mothers who was asked to contribute some money to buy fuel for the hospital vehicle which took her to Lusaka said that government hospitals should not be asking patients to pay for transport. She stated that if the hospital was using their vehicle to transport a patient to the next hospital, the government should ensure that those patients were transported for free.

Mothers also talked about the need to be assisted with transport to go back home when their children were discharged from UTH. This was because most of the mothers had no money to pay for transport to go back home. Some of those who were readmitted mentioned that despite being assisted with transport when they were first referred, they were not assisted with transport to go back home when the children were discharged.

> *Yes, I really appreciate the way they assisted me because I was worried about how I would travel and where I could find transport money….But when going back, that is where there is a problem because we don't have transport money….Yes, they are supposed to be assisting even with going back.* (M 06)

Apart from assisting with transport, one of the mothers whose child had myelomeningocele stated that the government should be able to provide wheelchairs for their children if they find that they needed to use wheelchairs.

4.4 PART THREE: EXPERIENCES OF MOTHERS WITH ACCESSING PHYSIOTHERAPY SERVICES

4.4.1 PARTICIPANTS

This part of the study had initially been planned to include any caregiver who brought the child for follow up visits if they met the inclusion criteria, i.e. if the child they brought was aged six months and above and presented with meningocele or myelomeningocele (spina bifida) and motor impairments of the lower limbs. However, all the participants who took part in the study were mothers of to these children. Among these mothers, only one participant had been taking the child for physiotherapy regularly. The demographic characteristics of the mothers and their children are presented in table 4.12.

Table 4.12 Demographic characteristics of mothers and their children

Mothers	Age	Marital status	Number of Children	Province of residence	Employment status	Age of child	Current motor level of child
Mother A	23	Single	1	Lusaka	Pupil	7 months	Sitting unsupported
Mother B	28	Married	1	Lusaka	Employed	6 months	Sitting with support
Mother C	39	Married	5	Southern	Unemployed	1 year and 5 months	Crawling
Mother D	42	Divorced	6	Northern	Unemployed	10 years	Crawling

4.4.2 THEMES

The objective of this part was to explore experiences of mothers with accessing physiotherapy services and three themes were identified. These were information about physiotherapy; access to physiotherapy services and support.

4.4.2.1 THEME 1: KNOWLEDGE ABOUT PHYSIOTHERAPY SERVICES

Lack of information and knowledge by the mothers about the children's conditions and services required was found to be a barrier to accessing physiotherapy services. Two mothers said they knew about the children's need for physiotherapy and the other two did not know.

Despite knowing that the child needed to be attending physiotherapy, one of these two mothers (mother B) said she only took the child once for physiotherapy. Mother B also knew that UTH, which was near to her home was providing physiotherapy services for children but she never took the child. According to this mother, she was told by the physiotherapist at the hospital where she took the child that she could be doing exercises by herself at home.

The other mother (mother D) who knew about physiotherapy said that nobody mentioned to her the need for physiotherapy for her child when the child was first admitted at UTH. This mother said that she requested for exercises for her child when she saw physiotherapists doing exercises with other children who were admitted. This was when her child was re-admitted at UTH at the age of one year and eight months. The physiotherapists at UTH later started exercises with the child and when she was discharged, the mother was given a letter to take to the physiotherapists in her province where the child continued going for physiotherapy.

> *They had not told me by then and even the time I started I just asked them when they* (physiotherapists) *were passing in the ward…that is when they said they will come and take me so that they could show me where they do exercises. So that is how I started taking her for exercises here in Lusaka.* (Mother D)

The other two mothers (mother A and mother C) who did not know about the need for physiotherapy said they were not told that the children required physiotherapy despite having been going for follow up visits at UTH. Their children were both presenting with motor impairments of the lower limbs and they said they did not know that their children could benefit from physiotherapy.

4.4.2.2 THEME 2: ACCESS TO PHYSIOTHERAPY SERVICES

When the mothers were asked if the children had, at any time had any form of exercises for the lower limbs, all four mothers indicated that they had, including those who denied knowing about the need for physiotherapy for the child. Mother D who reported that she only requested physiotherapists to start exercises with her child at UTH when the child was re-admitted said that she continued taking the child for exercises in her home province after she was discharged from UTH. She said she had been taking the child for physiotherapy at least once every three weeks until recently when the child developed pressure sores and was admitted at a district hospital within the province.

> *Yes, when I went back* (home town) *I continued taking her for exercises. I was given a letter from here which I took to* (first level hospital) *I used to go after 3 weeks…but when she developed sores, I stopped taking her.* (Mother D)

This mother also stated that she was taught by physiotherapists how to do exercises and take care of the child at home.

The other mother (mother B) who also knew that the child needed physiotherapy said that she took the child to a private hospital for physiotherapy when she was four months old. She stated that during that session, which lasted about 10 minutes, she was shown how to stretch the baby's legs and she was told to continue doing exercises at home. She was however not given another appointment because she was told that she was the best physiotherapist for the child.

> *And from what I was told at* (private hospital) *was that I can do the physiotherapy myself and that the best physiotherapist is the mother…So I would, like, try to do*

physiotherapy myself at home... hoping that I would be the best physiotherapist she can access. (Mother B)

The two mothers who said they did not know that their children required physiotherapy agreed that during the first admission, just after the babies were born, some medical staff did exercises for their babies' legs. This was after the interviewer asked them if anyone had done any form of stretching or exercises for the baby's legs while in the hospital. When asked if they were shown how to do those exercises, the two mothers agreed but said they had since stopped. When asked when and why they stopped, one mother said she could not remember when but all she knew was that the legs were deformed at first.

I can't remember, but they (legs) *were deformed now they are straight.* (Mother C)

Despite this encounter with physiotherapists, the mothers however said that they were not told that they were supposed to be taking the children for physiotherapy when they were discharged.

4.4.2.3 THEME 3: SUPPORT

Mothers talked about getting support from family members as well as from other well-wishers such as the church and non-government organisations. Taking the child for physiotherapy can be challenging for parents as this is something done over a prolonged period of time. Mothers were asked if they had any form of support in relation to taking the child for physiotherapy. One mother (mother B) said that both she and her husband were in formal employment and taking the child for physiotherapy was a challenge. She said she could not manage to take the child for physiotherapy on a regular basis because of her commitments with her job. She, however, stated that either she or the husband could get permission from their employers in order for them to take the child for physiotherapy.

> *Yes, I can ask my husband… but obviously we can't be busy at the same time, if I am tied up at work maybe he can ask for permission from his place of work.* (Mother B)

Mother B also said that her own mother could also assist at times where both she and her husband were busy. However, when the interviewer asked if she could allow the child's home caregiver who looks after the baby at home while she goes for work to take her for physiotherapy, she did not agree with that idea. She said that she did not trust the caregiver and she would rather do it herself because of the nature of the baby's condition.

Another mother (mother A) who was still a pupil at school and being supported by her parents stated that her father gives her transport money. She said that even when she starts taking the child for physiotherapy, the father would be giving her transport money.

I stay with my parents… Dad gives me money for transport (Mother A)

The mother (mother D) who was able to take the child for physiotherapy regularly cited a number of organisations that had been assisting her with transport money from home and travelling to Lusaka for follow up visits. These included organisations such as the church, the social welfare and a non-governmental organisation. She said she used to take the child for physiotherapy at a first level hospital within the province and was required to travel by public transport. She said she had been getting support in form of transport money to take the child for physiotherapy as well as being provided with assistive devices such as callipers and a wheelchair. This mother also said she was able to travel to Lusaka for follow up visits because these organisations had been helping her with transport money or even take her to Lusaka using their vehicles.

> *Just to say the truth, there are many people who have helped me since 2001. Number 1, the church people who helped me are the Catholics where I belong…Yes, after I moved from where I was staying* (divorced) *and went to my*

> *home place, the social welfare started assisting me with transport… From there, I took her (the child) to World Vision which is still helping me up to this time.* (Mother D)

4.5 SUMMARY OF RESULTS

In this chapter, the results were presented in three parts according to the three parts of the study. Results for the record review shows that the majority of the children were from Lusaka province. Most of the children were admitted during the first month after birth. Only 13 children were admitted during the first three days after birth. The most common type of NTD was myelomeningocele and the common associated impairment was hydrocephalus. Wound infection was the most common complication. There was no follow up on the majority of the children.

Results for Part Two consisted of findings from interviews with mothers of children with NTDs who were admitted at UTH and five themes were identified. The themes were access to health care, transport, being a mother of a child with an NTD, family concerns and support. Mothers reported passing through a chain of referral systems which included the clinics, the first level hospitals and the second level hospitals before getting to UTH. Most mothers who were not referred through the second level hospitals experienced more problems with transport to get to Lusaka. All mothers who were not from Lusaka province were concerned about transport to return home as well as transport to attend follow up visits at UTH. None of the mothers were aware that they would have a child with a NTD during pregnancy and most of them wanted to know the cause of this condition. There were also feelings of uncertainty about the future of the children. Some mothers, who were accompanied by spouses, complained about the living conditions for their spouses while in Lusaka. Others were worried about their children who remained at home. Some mothers who had relatives in Lusaka talked about getting support from those relatives while others did not get any family support. All mothers wanted the government to assist them with transport, both for travelling to Lusaka as well as going back home.

In Part Three, the results of experiences of mothers with accessing physiotherapy services for children with NTDs were presented. Three themes emerged which included knowledge about physiotherapy services, access to physiotherapy services and support. All four participants were mothers of children with spina bifida and their children presented with motor impairments of the lower limbs. Two mothers had knowledge about the need for physiotherapy for their children while the other two did not. However, only one mother had been able to take the child consistently for physiotherapy. Mothers also talked about getting support from families as well as from the community.

The next chapter discusses the findings from the three parts of the study and relates to current literature.

CHAPTER 5

DISCUSSION

5.1 INTRODUCTION

Chapter Five discusses findings from all three parts of the study. The results are discussed in relation to the objectives of the study as well as how they relate to relevant literature reported from other studies. The results are also discussed with reference to the “Four A’s” access theory which includes the four dimensions of access to health care namely geographic accessibility, availability, affordability and acceptability. This study had four objectives: to describe the profile of children with NTDs admitted to University Teaching Hospital in Zambia; to explore challenges and support experienced by the mothers of children with NTDs in relation to accessing surgical services from UTH; to explore mothers’ perceptions of the feasibility of getting access to physiotherapy after discharge and of returning for follow up visits; and to explore the experiences of mothers regarding access to physiotherapy services for children with NTDs who are brought for follow up visits.

5.2 PROFILE OF CHILDREN WITH NEURAL TUBE DEFECTS ADMITTED TO UNIVERSITY TEACHING HOSPITAL

While there is a lot of literature on prevalence of NTDs in developing countries, data on prevalence of NTDs in Africa is scanty and where available, it is restricted to hospital based studies. While UTH is one of the two hospitals, both located in the capital city Lusaka, providing surgical services for children with NTDs in Zambia, other countries may have more hospitals providing such services, making comparison difficult. Despite these limitations, findings on the profile of children with NTDs admitted to a hospital can be a source of useful information to physiotherapists and other health care providers involved in management of these children. This information can be used to instigate the understanding of the scope of the problem, design and implement programmes of service delivery to the affected children as well as to assess the impact of the disability on the children and their families (Loeb et al., 2008). Children with NTDs are at higher risk of morbidity and mortality than those without this condition. It is therefore important that health care planners and providers, including parents and patients have an understanding of the extent of the problem in the country.

5.2.1 PREVALENCE OF CHILDREN WITH NEURAL TUBE DEFECTS

There is no published data in Zambia on the prevalence of children with NTDs. This is consistent with an observation by Adeleye and Olowookere (2009) who noted that NTDs in African countries are under reported or not reported at all. The study population for the record review consisted of 101 children with NTDs who were newly admitted to UTH during the year 2010. Lusaka province had the highest number (32%) of children. Literature has shown that the prevalence of NTDs could have geographical trends with certain areas having higher incidences than others (Frey & Hauser, 2003; Gu et al., 2007). However, it would not be appropriate to conclude that Lusaka has the highest incidence rate of NTDs among new born babies in Zambia. UTH is located in Lusaka province and the high proportion of children from this province may be attributed to easy geographical accessibility. This finding is similar to another study which was done in Yaounde, Cameroon, where 66% of the children came from within the city of Yaounde where the hospital was based (Djientcheu et al., 2008). Geographical accessibility is one of the dimensions of access that has been reported to favour people living in urban areas compared to those living in rural areas (Feikin et al., 2008; Hjortsberg & Mwikisa, 2002; Perry & Gesler, 2000). This problem is common in developing countries where tertiary hospitals which have surgical services are only located in larger cities (Harris, et al., 2011).

Equal accessibility in terms of distance could be made more realistic by providing free transport to all mothers with children who are referred to Lusaka for surgery regardless of where they are coming from.

5.2.2 DEMOGRAPHIC CHARACTERISTICS OF CHILDREN

Age on admission for children with NTDs is an important factor in determining the outcome of the management. Various authors indicate that surgical closure for open NTDs should be done within 36 to 72 hours after birth to minimise the risk of CNS infection and improve the neurological outcome (Bowman & McLone, 2010; Thomson, 2009; Mitchel et al., 2004). Complications associated with late presentation for both open and closed NTDs include massive macrocephaly, severely raised intracranial pressure, visual impairment, rupture of the lesion and septicaemia (Komolafe et al., 2008).

Age on admission for children with NTDs who were admitted at UTH in 2010 ranged from one day old for those based in Lusaka to 48 months for those coming from other provinces. The majority of children (80%) presented within the first month after birth, but only 26% (n = 13) presented within 72 hours after birth. The child aged 48 months presented with lumbar meningocele which required surgery, and paraplegia. This child had no hydrocephalus. One of the children was aged 14 years when she was first admitted at UTH. She presented with cervical encephalocele which was later repaired. This child was not included in the analysis because her age presented as an outlier in the analysis.

Similar findings of the age at presentation for children with NTDs have been reported from studies done in African countries (Adeleye et al., 2010; Warf et al., 2011c; Djientcheu et al., 2008). However, a report from a study done in Cameroon showed that 44% of the children presented to the hospital on the first day after birth (Djientcheu et al., 2008). This was probably because the majority (66%) of the babies admitted at that particular hospital were born from within the city of Yaounde were the study site was located. The easy access for those close to health care facilities is also consistent with the access theories which show that geographical accessibility influences service utilisation (Peters et al., 2008). Similarly, a study which was done in Kenya to explore the impact of distance on utilisation of peripheral health facilities showed that utilisation decreased with increase in distance from the health facility (Feikin et al., 2009).

Among the reasons for the late presentation of children with NTDs in developing countries is lack of prenatal diagnosis and many children are delivered at home (Shehu & Ameh, 2004). Other reasons for late presentation among some of the children in this part of the study are related to geographical accessibility and non-availability of surgical services in other provinces. These will be discussed in detail in Section 5.4 which discusses the experiences of mothers of children with NTD with travelling to UTH. Reports from studies done in developed countries show that repair of the lesions are usually done within the first week after birth (Ulsenheimer et al., 2004; Rintoul et al., 2002). This is partly due to availability of advanced diagnostic services where prenatal diagnosis is done in most cases leading to planned deliveries in hospitals which have adequate neonatal and surgical facilities (Pasquier et al., 2006; Garne, et al., 2005).

With regards to sex of the children, there were more male children with NTDs in both the record review and among the children of mothers who were interviewed. There were 29 male children compared to 21 female children in the record review. However, the chi-square test did not show any significant association between sex and type of NTD. Male predominance among children with NTDs has been reported in other studies done in African countries such as Nigeria (Adeleye and Olowookere, 2009; Idowu et al., 2008; Alatise et al., 2006), Cameroon (Djientcheu et al, 2008), and South Africa (Buccimazza, Molteno, & Dunne, 1999). A retrospective study done at a University Teaching Hospital in Nigeria on the trend and outcome of NTDs reported a male predominance with 25 male and 12 female out of a total of 37 children with NTDs (Ugwu et al., 2007). Similar findings of male predominance have also been reported in other countries outside Africa such as USA (Luben, Messer, Mendola, Carozza, Horel, Langlois, 2009) and Taiwan (Chang, Wong, Huang, Chan and Yang, 2008).

Contrary to studies reporting male predominance, female predominance among children with NTDs have been reported in other studies both in Africa countries (Elsheikh & Ibrahim, 2008; Houcher et al., 2008) as well as non-African countries (Vinck, Nijhuis-van der Sanden, Roeleveld, Mullaart, Rotteveel, Maassen, 2010; Au et al., 2008; Mahadevan & Vishnu, 2005). In a study by Houcher et al. (2008) which was done in Algeria, 58.6% (n = 126) of the children were female while 40% (n = 88) were males out of a total of 215 children with NTDS. According to Brown and Susser (1997) and Deak et al. (2008), studies which are done in developed countries report more females among individuals with NTDs while developing countries have more reports of male predominance. There are many theories used to explain variations in sex among children with NTDs. Brown and Susser (1997) investigated the sex distribution of deaths caused by spina bifida among children exposed and unexposed to severe peri-conceptional famine and found that there was an increase in the occurrence of spina bifida among live born males. One of the reasons they suggested for this finding was that severe peri-conceptional malnutrition may have a greater effect on occurrence of spina bifida in live born males compared to live born females. Brown & Susser (1997) also suggested that this could be the reason why there are more male children with spina bifida in developing countries where prenatal malnutrion plays a part in the etiology. Furthermore, Seller (1995) noted that female children are more often likely to have cranial and upper spinal NTDs while males are more likely to have lower spinal NTDs. In support of this assertion, Deark et al (2008) also noted that cranial NTDs are more common among females than males. This is supported by an observation from the review of literature on studies done in Africa which showed that studies which had a higher frequency of cranial defects reported more females than males (Elsheikh & Ibrahim, 2008; Houcher et al., 2008). Similarly, studies by Warf et al., (2011a) and Kotil, Kilinc and Bilge (2008) reported more females than males among children with encephalocele. However, the record review of the current study found more males (n = 9) than females (n = 2) among children who had encephalocele. Findings similar to the current study were reported in a study done in Pakistan where out of 25 children with encephalocele, 19 were males and 6 were females (Raja, Qureshi, Memon, Ali, & Dev, 2008).

5.2.3 TYPE OF NEURAL TUBE DEFECTS

The most common type of NTD identified among children in the record review was myelomeningocele (44%), followed by meningocele (32%). There were 11 (22%) children who had encephalocele and one child had both meningocele and encephalocele. There were more children with spinal NTDs (76%) than those with cranial defects (22%). This is similar to an observation by Idowu et al. (2008) who stated that many studies have reported higher frequency of spinal defects than cranial defects. The current study did not report any case of anencephaly.

Studies done in both African and non-African countries have reported myelomeningocele as the most common type of NTD (Taye & Bedru, 2009; Deak et al., 2008; Djientcheu et al, 2008; Njamnshi et al. 2008; Audu et al., 2004; Mahadevan & Vishnu, 2005; Luben, et al., 2009). According to Northrup & Volcik (2000), myelomeningocele and anencephaly which are both open NTDs, are common compared to meningocele and encephaloceles which are closed NTDs. However, because anencephaly is said to be incompatible with life, the most common NTDs among live births is myelomeningocele (Padmanabhan, 2006; Mitchel, 2005). Although myelomeningocele is compatible with life, those who survive suffer life-long morbidity and as stated by Mayer et al. (2010), this has motivated health care providers around the world to continue finding better therapeutic methods of alleviating the problems.

Contrary to findings from the current study which did not report any case of anencephaly, there are studies which reported more cases of anencephaly than those of encephalocele. These include studies done in Iran (Golalipour, Najafi & Keshtkar, 2010), Texas (Luben et al., 2009), Sudan (Elsheikh & Ibrahim, 2009) and India (Mahadevan & Vishnu, 2005). The highest incidence of anencephaly was reported in Iran where out of 78 cases of NTDs, 39 children had spina bifida, 35 had anencephaly and four had encephaloceles (Golalipour et al., 2010). China reported 41.1% of anencephaly compared to 19.5% of spina bifida and 13.3% of encephalocele (Gu et al., 2007). All these studies which reported high incidences of anencephaly were characterised by high mortality rates among live births, foetal deaths and abortion rates. This supports the assertion of Botto et al. (1999, p. 1511) that "all infants with anencephaly are still born or die shortly after birth, whereas many infants with spina bifida now survive, usually as a result of extensive medical and surgical care".

For this reason, it can be argued that the absence of children with anencephaly in the record review does not imply the complete absence of cases of anencephaly in Zambia. Even if there were children born with anencephaly, they might not reach the tertiary hospitals because of the incompatibility with life. For those who may have been referred without any assistance with transport, problems to do with geographical accessibility and affordability could lead to delayed access and children dying before their parents could find transport money to travel. Policy makers should therefore note that the incidence of NTDs reported in most developing countries does not necessarily reflect the actual number of children born with NTDs because most of those with anencephaly are unlikely to reach the tertiary hospitals as they usually end up being aborted or die within a few days after birth.

5.2.4 SITE OF THE LESION

In the record review, assigning the level of the lesion for children with spinal NTDs was not based on motor or functional level because there was no information in the medical records regarding neurological assessment. The medical records only included information based on the general anatomical level of the spinal column such as cervical, thoracic, lumbar, lumbosacral and sacral regions. This therefore makes it difficult to compare with studies which used clinical classification methods described in literature (Bartonek, Saraste & Knutson, 1999). Bartonek et al. (1999) also noted that the differences in classification methods for describing motor function and lesion levels for persons with myelomeningocele makes it difficult to make comparisons among studies done on treatment outcomes. Despite these variations in classification, Burton (2008) observed that the most common sites for spinal defects are the lumbar and lumbosacral which accounts for 70% of persons with myelomeningocele.

The majority of children in the current study who had spinal NTDs had the defect in the lumbar region while the occipital region was the most common site for encephaloceles. Similar findings in which the lumbar region was the common site have been reported in studies done in Cameroon (Djientcheu et al., 2008), Jordan (Khasawneh & Al-Akayleh, 2002), Philadelphia (Rintoul et al., 2002) and Turkey (Ersahin, Mutluer and Kayahan, 1998). However, there are other studies that have reported the lumbosacral region as the most common site for spinal defects (Idris, 2011; Warf et al., 2011c; Adeleye et al., 2009; Idowu & Apemiye, 2008; Khan, Khan, & Ahmed, 2006; Audu et al., 2004; Ulsenheimer et al., 2004).

The level of the spinal NTDs has been found to be an important factor in determining functional independence and self-care among patients with spina bifida (Hetherington, Dennis, Barnes, Drake, Gentili, 2006; Schoenmakers, Uiterwaal, Gulmans, Gooskens & Helders, 2005). According to Fujisawa et al. (2011), the level of the lesion for spinal defects also determines the neurological status which in turn determines the functional ability of the affected individual.

With regard to site for encephaloceles, findings from the current study that the occipital region was the most common site are consistent with findings from other studies done on encephaloceles by Warf et al. (2011a), Adeleye and Olowookere (2009), Idowu et al. (2008) and Bui et al. (2007). According to Burton (2008), approximately 75% of encephaloceles are said to be located in the occipital region. On the contrary, a study which reported cases of encephaloceles in Thailand found that out of 21 patients with encephalocele, 20 were located on the fronto-ethmoidal region while only one was located in the occipital region (Agthong & Wiwanitkit, 2002). Another study by Lo et al. (2007) reported that of 83 cases of encephaloceles, 40 had frontal, 33 occipital and 12 had parietal lesions.

5.2.5 NEUROLOGICAL STATUS AND ASSOCIATED IMPAIRMENTS

The neurological information was only available in 11 (22%) medical records and therefore the findings on neurological impairments do not reflect the true proportion of the study population. However, based on information available, the most common neurological deficit was a combination of paraplegia and incontinence (bowel and urine) found in 30% of the children and 16% of the children had paraplegia only. No children with encephalocele in the current study were reported to have neurological impairments. The chi-square tests indicated a significant association between the type of NTD and neurological impairments. Of the 22 children with myelomeningocele, 18 children had neurological impairments and information for the other four children was not available. As for the eleven children who had encephalocele, ten children had no neurological impairments and information for one child was not available. Similar findings in which paraplegia and incontinence were the most common neurological impairments have been reported in other studies by Idris (2011), Djientcheu et al. (2008), Idowu and Apemiye (2008) and Ong, Lim and Sofiah (2002). In these studies, myelomeningocele was the most common type of NTD. A prospective study on the outcome of myelomeningocele in Nigeria reported that all 35 of the 36 patients with myelomeningocele had urinary incontinence and 32 of these also had paraplegia (Idowu & Apemiye, 2008).

With regards to encephalocele, the severity depends on the site of the lesion, amount of neural tissue in the sac and other associated malformations (Thompson, 2009). Although literature shows that occipital encephaloceles have a poorer prognosis compared to those located in other sites (Thompson, 2009; Bui et al., 2007), the current study did not report any neurological impairments among the children who had occipital encephalocele. The absence of neurological impairments among patients with encephalocele in the current study is consistent with reports from other studies (Alexiou et al., 2010; Shilpakar & Sharma, 2004). In a study that was done in Nepal, all the 16 children with encephalocele were reported to have normal neurological and mental function (Shilpakar & Sharma, 2004).

The most common associated impairment reported in the current study was hydrocephalus which was present in 74% of the children, the majority of whom had myelomeningocele. This supports the findings of Sinha et al. (2012) who noted that about 80-90% of children with myelomeningocele had hydrocephalus. These findings are consistent with findings from other studies (Adeleye & Olowookere, 2009; Djientcheu et al., 2008; Houcher et al., 2008; Bui et al., 2007). According to Warf (2011b), about half to two thirds of children with myelomeningocele require treatment for hydrocephalus and about one third of those with encephalocele will require management for hydrocephalus. Five out of the eleven children who had encephalocele in the current study had hydrocephalus. Studies which reported hydrocephalus to be present in about a third of children with encephalocele include those by Warf et al. (2011a) who reported hydrocephalus in 32% of children, Kotil et al. (2008) reported 25% of children and Lo et al. (2008) who reported that 23 out of 85 children with encephalocele had hydrocephalus. On the contrary, studies by Alexiou et al. (2010) and Bui et al. (2007) reported hydrocephalus to be present in about 60% of the children with encephalocele.

5.2.6 MANAGEMENT AND OUTCOME

Most of the children identified in the record review were referred to Lusaka for surgical management of the defect as well as shunting for hydrocephalus. Radiological investigations done on the children included Ultrasound, CT scan and MRI. Radiological investigations were usually done routinely to ascertain the presence of hydrocephalus and other abnormalities of the brain. According to Burton (2008), the use of a CT scan for children with encephalocele is recommended as it helps with defining the contents of the extra cranial sac as well as assessing intracranial contents for any abnormalities. The most common radiological investigation done among children in the current study was cranial ultrasound which was done in 80% (n= 40) of the children while CT scan was done in four children and one child had an MRI. This is consistent with findings from other studies which used radiological investigations to determine the presence of hydrocephalus and to assign the level of spinal defect (Audu et al., 2004; Rintoul et al., 2002). The routine use of ultrasound on most of the neonates admitted to UTH with NTD made it possible to determine the presence of hydrocephalus in children who did not have this information in the clinical notes. Use of radiological results to ascertain presence of hydrocephalus is also supported by Burton (2008) who noted that 90% of children with myelomeningocele have hydrocephalus which in most cases is present even before the actual increase in the head circumference is observed. Ultrasound has been found to be the most convenient and affordable method for detection of foetal NTDs as well as early diagnosis of hydrocephalus in infants born with NTD and it has been recommended for use in developing countries (Adeleye et al., 2010).

At UTH, surgical management involved closure of the lesion only, shunt only, or both shunt and closure of the lesion. A total of 35 (70%) children had surgery. Surgical closure of the lesion without shunt was done for 10 (20%) children, shunting only for 14 (28%) children and 11 (22%) children had both shunt and closure of the lesion done. The other 15 children did not undergo any surgical management as most of them who had infected lesions were sent home and their mothers advised to return on given dates. Among the 11 children who had both repair and shunting, four children had no information on which procedure was done first. Six children had VPS done during the first procedure and repair was done later. One child who presented with infected CSF had an external shunt done in the first operation and after the infection cleared, both shunting by VPS and closure of the lesion were done during one operation.

Literature on surgical management of children with NTDs indicates that there are variations in the surgical management with some authors supporting simultaneous surgery while others go for staged surgery. There are some studies which reported having more cases of staged surgery than simultaneous (Idris, 2011; Idowu & Apemiye, 2008; Ulsenheimer et al., 2004; Buccimazza et al., 1999), while others had more cases of simultaneous surgery (Djientcheu et al., 2008; Machado & Oliveira, 2004; Khasawneh & Al-Akayleh, 2002). According to Margaron et al. (2010), simultaneous surgery may not be possible for most children in African countries because of the late presentation which is characterised by infected wounds and therefore poses a high risk of shunt malformation. These are some of the adverse effects of geographical accessibility on children with NTDs in developing countries who have to travel long distances to reach the tertiary hospitals.

Wound infection, shunt malformation and CSF infection which could result in meningitis are common complications associated with NTDs (Ulsenheimer et al., 2004; Khasawneh & Al-Akayleh, 2002). At UTH, it was found that 40% of the children admitted presented with wound infection and one child was reported to have meningitis. Some children who had wound infections were discharged to allow the infection to clear before surgery could be done. However, the proportion of complications may be an under estimation because over 66% (n = 33) of the medical records had no follow up notes after the initial discharge despite the records indicating the need for follow up. This lack of follow up could be associated with all the dimensions of the “Four A’s” access theory which will be discussed later under this section.

Wound infection in children with myelomeningocele has been reported in many studies (Warf et al., 2011c; Idowu & Apemiye, 2008; Khasawneh & Al-Akayleh, 2002; Igun et al., 2000). Wound infection, which is a common observation in most studies done in Africa, is associated with delayed closure of the defect which is a consequence of the late presentation of children (Rabiu 2008). Despite the late presentation of children with open NTDs, Igun et al. (2000) advise that closure should be done as this has been found to reduce the mortality and morbidity rate in these children. A study which was done in Nigeria to evaluate the results of management by non-operative closure and delayed operative closure found that delayed operative closure had the benefits of reducing mortality and morbidity (Igun et al., 2000). However, the children who were lost to follow up in the current study may not have the chance to have delayed surgery.

The low incidence of children presenting with meningitis in the current study has also been reported in other studies (Djientcheu et al., 2008; Talamonti, D'Aliberti, & Collice, 2007). On the contrary, there are studies that have reported higher rates of meningitis. One such study was done in Brazil which reported cases of meningitis to be four times greater in patients who underwent VPS than those who did not (Ulsenheimer et al., 2004). Of the 27 patients who had shunts inserted, 14 patients where reported to have acquired meningitis and required shunt revision (Ulsenheimer et al., 2004). The authors of this study attributed the high rate of CNS infection to delayed closure of the defect which was done after 72 hours.

Another complication common among children with NTDs is shunt malfunction. The current study reported a low incidence of shunt malfunction (n= 3). This could be attributed to the fact that most children who presented with wound infection were discharged for wound cleaning without any surgical intervention. This is in line with the recommendation to delay shunting for children with infected wounds by first putting them on antibiotics and wound cleaning for at least a week before surgery (Margaron et al., 2010).

There was abscence of follow up notes in files of children from both Lusaka province and other provinces. The lack of follow up on children with NTDs has been reported in studies done both in Africa and non-African countries (Djientcheu et al., 2008; Talamonti et al., 2007; Ulsenheimer et al., 2004). The only difference between studies done in Africa and non-African countries is that the proportion lost to follow up in Africa is higher than those from developed countries. The location of tertiary hospitals in large urban cities where mothers are expected to take their children for follow up visits contributes to access barriers in terms of both geographical accessibility and affordability because most of them cannot afford transport costs due to the long distance. Distance from the health facility was also cited by Ulsenheimer et al. (2004) in a study that was done in Brazil where it was found that 30% of the children with myelomeningocele lived in towns that were outside the town were the study site was located. Apart from transport costs, other costs involved when mothers travel to the tertiary hospitals include food and lodging which could also be unaffordable for most of them due to poverty (Peters et al., 2008). The other barriers to follow up could be explained in terms of acceptability which refers to the willingness to use health care services. Factors that may influence willingness to use health care services for children with NTDs in developing countries include harmful taboos, cultural beliefs, poverty and ignorance (Djientcheu et al., 2008; Idowu & Apemiye, 2008). These factors may partially explain the lack of follow up among Lusaka based children who had no follow up notes in the record review. According to O'Donnell (2007), acknowledging the presence of illness and potential benefits of treatment are essential prerequisites to utilisation of health care services.

According to a report presented by one of the Zambian neurosurgeons during a conference for the International Federation of Spina Bifida and Hydrocephalus (IF) which was held in Kampala in 2011 (Sichizya, 2011), the lack of follow up on children with NTDs who undergo surgery in Zambia poses a challenge to neurosurgeons managing these children. Follow up visits for children with NTDs have been reported to have a bearing on survival rates of these children. According to Warf et al. (2011c), it is important to note that despite providing competent and evidence based initial management of children with NTDs, their survival largely depends on adequate follow up management.

5.3 EXPERIENCES OF MOTHERS WITH ACCESSING HEALTH CARE SERVICES FROM THE UNIVERSITY TEACHING HOSPITAL

One of the key principles of health care service delivery in Zambia is to ensure equitable access and affordable health for all (MOH, 2011). This equitable access includes all citizens regardless of their geographical origin, gender, age, race, and social, economic, cultural and political status. However, equal access in most developing countries is unlikely because most of the health facilities are located in urban areas and the poor who are mostly in rural areas have to travel long distances to the facility and pay greater transport costs than those living in the city to access the health care facilities (Hjortsberg & Mwikisa, 2002). The second part of the study involved interviews with mothers of children with NTDs who were admitted in UTH and explored their experiences with accessing health care services from this hospital.

5.3.1 ACCESS TO HEALTH CARE SERVICES

Among the mothers who were interviewed, nine delivered at a hospital and four delivered at a local health clinic. Of the seven (35%) mothers who did not deliver at the health facilities, two mothers delivered on the way as they walked to the health facilities. The remaining five delivered at home. Home deliveries are common in developing countries especially among women from poor socio-economic backgrounds (Kunst & Houweling, 2001). One of the main reasons for home deliveries in most developing countries has been attributed to having sparsely located health facilities especially in rural areas resulting in a long distance to walk and/or time to travel (de Groot, 2008). Geographical accessibility which refers to the actual distance travelled in order to access health care has been identified as an important barrier in developing countries (Al-Taiar, Clark, Longenecker, & Whitty, 2010).

Other barriers associated with home deliveries in developing countries are related to availability and acceptability. A study by Stekelenburg, Kyanamina, Mukelabai, Wolffers and van Roosmalen, (2004) which was done in a rural district of Zambia found that besides long distance, other reasons given for home deliveries included inadequate health education during antenatal clinics, inadequate health personnel and poorly equipped health facilities. The lack of health education relates to acceptability of health care services by the mothers while lack of health personnel and poorly equipped health facilities relates to availability. Another factor which relates to acceptability and affordability is an observation by O'Donnel (2007) who stated that health care utilisation is least among the poor. This is supported by Kiwanuka et al.(2008) in a study done in Uganda on access and utilisation of health services for the poor which reported that most of the poor women used traditional and untrained health personnel for delivery. Findings from the current study about mothers who delivered at home could be attributed to geographical accessibility of health care services as well as lack of health education among the mothers.

Home deliveries have been reported to have a higher risk of neonatal mortality compared to institutional deliveries (Walraven, Mkanje, Roosmalen, van Dongen, & Dolmans, 1995). According to Shehu and Ameh (2004), most babies with NTDs in sub-Saharan African countries are delivered at home and are exposed to high risks of infection, rupture of the myelomeningocele and those with hydrocephalus may suffer from asphyxia due to obstructed labour. Bowman and McLone (2010) noted that delivery of a child with spina bifida should be done at a hospital with personnel experienced in the management of such cases. This observation is supported by Pasquier et al. (2006) in a study which examined the effects of distance between maternal residency and hospitals with neonatal surgery on outcome of pregnancies with severe foetal malformations. Findings from this study showed that there was a reduced risk of neonatal death when delivery was done in maternal hospitals that were equipped with neonatal surgical care (Pasquier et al., 2006). These findings indicate that availability of essential health care services for delivery and management of children with NTDs could have better outcomes for these children. This is consistent with an observation by Audu et al. (2004) who noted that the importance of planned and cautious delivery for children with open NTDs can reduce the risk of trauma to the lesion and contribute to better a neonatal outcome.

Planned deliveries can only be possible when there is early detection of congenital malformations during pregnancy. This is because prenatal diagnosis provides essential information on continued care of pregnancy, management at birth and prompt referral for specialist care, thereby minimising complications and mortality (Adeleye et al., 2008). However, early detection for mothers in the current study was not done and consequently none of them had prenatal diagnosis of their children's conditions. One of the mothers was told that she had twins when an ultrasound was done, but later, when she delivered, she realised that she had one baby with a very large occipital encephalocele. According to Gulliford et al. (2002), access to care requires that there is adequate supply of health services that are available. The findings from the current study indicates that mothers did not have adequate access to antenatal care and this contributed to unplanned deliveries which put the babies at risk of infections and delayed referrals. If the mothers had had prenatal diagnosis, some of the deliveries could have been planned to take place at a higher level facility and babies would have had more timely access to surgical management. This finding is consistent with reports from other African countries where prenatal diagnosis is said to be non-existent or when done, fails to identify NTDs or any other congenital anomalies (Adeleye et al., 2010; Djientcheu et al., 2008; Shehu & Ameh, 2004). A study by Adeleye et al. (2010) reported that only six out of the 43 participants who had an ultrasound done, had prenatal diagnosis of NTDs. The rest of the babies were reported as normal including those born with gross anomalies. Unlike reports from developing countries where there are poor prenatal diagnostic services, most studies from developed countries report that many affected pregnancies are diagnosed early by ultrasound (Talamomti et al., 2007; Garne et al., 2005; Ulsenheimer et al., 2004; Persad, Van den Hof, Dube, & Zimmer, 2002). In a study which was done in Italy on long-term management of myelomeningocele, it was reported that out of the total of 220 children who were part of the study, 198 were delivered by elective caesarean section (Talamonti et al., 2007). This was after prenatal diagnosis of the NTDs and therefore the deliveries were appropriately planned. Availability of prenatal diagnosis in developing countries also results in some mothers opting for termination of affected pregnancies (Luben et al., 2009; Mosley, et al., 2009; Busby, et al., 2005). According to Gulliford, et al. (2001) availability refers to the relationship between volume and type of services provided and the volume of patients and types of needs. Given this definition and the reports from these studies, it can be asserted that there is inadequate availability of antenal care services in most developing countries for most of the women who are in need of these services.

5.3.2 EXPERIENCES WITH THE REFERRAL SYSTEM

Mothers who participated in the current study shared their experiences with the health services referral system within their province of residence before they were finally admitted in UTH. Some mothers reported having problems while others did not have any problems. According to Macintyre and Hotchkiss (1999), referrals are an important aspect of primary health care and a well-functioning referral system ensures that treatment of patients is given at the appropriate level. Mothers who reported having problems cited lack of transport, delayed referrals and lack of assistance in form of transport from the referring health care providers. On the other hand, mothers who said they did not have problems were those who were referred immediately and were assisted with transport by the health care providers who referred them. Referrals consisted of babies being referred in the following manner: from the local health centre to the first level hospitals; from the first level to the second level hospitals; from the second level to UTH; and others who were referred directly from the first level hospitals to UTH.

Upon presenting at the health facility, access to the next referral level was dependant on distance of the health facility to the referral hospital, the attitude and experience of health care providers and the ability of the mothers to pay the cost of transport. In relation to the access theories, the distance relates to geographical accessibility, attitude and experience of health care providers are related to availability and acceptability while the ability of mothers to pay for transport costs are related to affordability (Peters et al., 2008; Jacobs et al., 2011). Some mothers who presented at the local clinics were just given referral letters and advised to find their way to the next referral hospital while others had the clinic staff call for an ambulace from the referral hospital who came and picked up the mother and the child and took them to the place they had been referred to. The use of communication in form of radios or cell phones by health workers at the local health centre to call for an ambulance from the referral hospital have also been reported in other studies (Samai & Sengeh, 1997). It was reported that using radio communication by health workers at the local health facility to call for transport from the referral hospital reduced delay in reaching the referral hospital by two hours for those patients coming from the furthest areas (Samai & Sengeh, 1997). Similarly, another study which explored the referral system for injured patients in Cambodia reported that 98% of the health centres used either cell phones or radios to communicate with the next referral facility before transferring the patient (Nakahara, et al., 2010). Use of radios could be useful in rural parts of Zambia where communication with cell phones is still a problem.

All the mothers who passed through the local clinics were immediately referred to the next level health facilities where there are more skilled health personnel. However, upon reaching the first level hospitals, some mothers were sent back home and advised to return at a later date. Reasons given for being sent back home included doctors saying the baby was too young to travel over a long distance to the next referral hospital while others had no transport money to travel to the hospital they had been refered to. Most of the children who were sent home required surgery and this contributed to the delayed presentation for surgery. Sending patients back home when they are supposed to be referred contributes to delayed presentations which results in deterioration of the patient’s condition leading to increased operation and mortality risks (Bickler et al., 2001). This is supported by Macintyre & Hotchkiss (1999) who noted that delayed referrals have the consequences of premature death or can lead to permanent disability. Delayed presentation was therefore a consequence of geographical accessibility, availability, affordability and acceptability. All children based in Lusaka presented to UTH within 24 hours after birth while children who presented later were from other provinces, implying that geographical accessibility played a part in delayed presentation. Delayed presentation was also the result of non-availability of specialised surgical services in other provinces and attitudes as well as inexperience among health personnel who sent children home instead of referring them. Some of the mothers who could not afford to pay transport costs had to go home until they managed to secure transport through other means, an indication that affordability was among the barriers to accessing referrals for these children. The problems experienced by mothers in relation to transport will be discussed in detail under Section 5.2.3.

The decisions by some medical personnel to send some children back home when they were supposed to refer them relates to non-availability of experienced health personnel at the referring hospitals. The actions of these health personnel can be said to be unacceptable because the consequences of delayed surgery on the children could be serious . The mothers who were sent back home may not be able to trust those health personnel and this would affect their utilisation of health care for these children in future. Similar reports of health personnel sending patients back home who require surgery have been reported in other studies (Al-Attas, Williams, Pitchforth, O’Callaghan, Lewallen, 2010; Bronsard, Geneau, Shirima, Courtright, & Mwende, 2008). A study done in Tanzania to explore factors contributing to delayed presentation for children with cataracts found that 13% of the respondents stated that they were sent back home with either eye drops or nothing when they first took their children to the health facilities (Bronsard et al., 2008). Another study which was done in Nigeria to determine factors contributing to late presentation for gross congenital anomalies of the CNS, reported that besides patients delay, some children who were born in health facilities were discharged and sent home without proper referal or counselling for the mothers (Komolafe et al., 2008).

5.3.3 TRANSPORT

Availability of transport is one of the most important factors in primary health care delivery in that it enhances a well-functioning referral system as well as a determinant of community trust in the health care providers in times of crisis (Macintyre & Hotchkiss, 1999). The problem with securing transport from the first level hospital to either second or third level was one of the challenges experienced by mothers in relation to accessing health care services in the current study. Mothers were also concerned about transport going back home when the child is discharged from hospital. While health care services for children are free in Zambian public health facilities, the cost of transport to and from health care facilities is a challenge, especially for people living in rural areas. Some mothers from rural areas reported having to walk long distance from home to get to the nearest health facility with two of them consequently delivering on the way.

Mothers who were referred from the first level hospitals directly to UTH without passing through the second level hospitals experienced more problems with transport than those who were referred through the second level hospitals. Most of the first level hospitals do not have the capacity to provide transport from their provinces to Lusaka due to the long distance. On the other hand, some first level hospitals were able to provide transport to the second level hospital due to shorter distance and most of the second level hospitals had the capacity to provide transport to Lusaka despite the long distance. According to the National Health Strategic Plan (MOH, 2011), lower level health facilities experience inequities in the distribution of health workers and essential physical infrastructure and equipment, leading to insufficient capacity in provision of health care services. This could be the reason why most of the first level hospitals were not able not provide transport for the mothers while the second level hospitals were able to.

Only three mothers had their children admitted within 24 hours after birth and all the three were from Lusaka province. The other mothers only presented their children at UTH after 72 hours and others were already two weeks old or older than that. Most of them cited problems with transport as the reasons for late presentation. The problem of transport has also been reported in other studies as one of the barriers to accessing health care services (Kiwanuka et al., 2008; Mwende, Bronsard, Mosha, Bowman, Geneau, & Courtright, 2005; Hjortsberg & Mwikisa, 2002). The lack of and high cost of transport associated with access to health care has been reported to have a significant bearing on health care utilisation and outcomes (Macintyre & Hotchkiss, 1999). Studies done in Zambia and other African countries have shown that the cost of travel and time spent to travel to a health facility contributes to limitations in access (Hjortsberg & Mwikisa, 2002; Feikin et al., 2009). In a systematic review of socio-economic differences in morbidity and access to health in Uganda, it was found that many studies identified distance from a health facility as one of the most common barriers to access (Kiwanuka et al., 2008). Another study which was done in Zambia on cost of access to health found that people living in rural areas paid more on transport in terms of accessing health care services compared to their urban counterparts (Hjortsberg & Mwikisa, 2002). The observation by Peters et al. (2008) that transport cost is directly associated with distance from a health facility both in terms of cost of transport and time spent to get to the facility indicates that transport relates to both geographical accessibility and affordability . Paying for transport to get to the health care facility is an indirect cost which prevents most of the poor people from accessing health care services (Peters et al., 2008).

Despite experiencing financial barriers to accessing health care services for their children, some of the mothers in the current study who were not assisted with transport reported having different sources of financing transport costs. Some of the sources included borrowing money, selling maize and being given money by other people. Kruk, Goldmann, and Galea (2009) referred to the concept of borrowing and selling to finance health care services as ‘hardship financing’ which is a common practice among the poor. A study to analyse the extent of hardship financing for health care services in low and middle-income countries found that the poor had higher rates of borrowing and selling to finance health care than the rich individuals in most countries (Kruk et al., 2009). Another study on caretakers’ experiences with paediatric referrals reported that some of the participants in a focus group interview stated that they sold coffee in order to raise money for transport and other hospital fees (Peterson et al., 2004). The experiences of the poor in relation to accessing health care services supports an observation by Peters et al (2008) who noted that affordability which is one of the most important determinants of access is directly associated with poverty.

Mothers also expressed concern over transport to go back home when their babies were discharged from UTH. This was because the hospitals which assisted mothers with transport to UTH were not able to come and take them back. This also corresponds to geographical accessibility and affordability because the mothers who complained were those coming from other provinces outside Lusaka.

5.3.4 OTHER CHALLENGES FACED BY MOTHERS

Giving adequate information to parents whose children have just been diagnosed with a disability has been reported to be an important factor in ensuring parent satisfaction (Hasnat & Graves, 2000). In the current study, most of the mothers expressed the lack of knowledge about the conditions which their children presented with and they wanted to find out more about their children's condition from the interviewers. Mothers also wondered why they were not told about congenital malformations during antenatal clinics and they wanted to know what causes NTDs. They also wanted to be shown how to take care of their children when they go back home. The need for adequate information by parents of children diagnosed with disabilities has been reported in many studies done on needs of parents (Resch et al., 2010; Graungaard & Skov 2006; Hopia, Tomlinson, Paavilainen, & Astedt-Kurki, 2005; Rahi, Manaras, Tuomainen and Gillian & Hundt, 2004). According to Resch et al. (2010), giving information to parents on the type of disability and services available at the time of diagnosis helps to reduce parental stress. Rosenbaum (2005) also noted that the first information parents of children diagnosed with cerebral palsy would like to know is how bad the condition is and whether the child will ever walk. This is common to all parents of children with disabilities. However, Rosenbaum (2005) further noted that certain questions which parents ask may not be easy to answer especially for health professionals with limited knowledge on the child's condition. Information from literature that provides evidence based answers has been found to be useful in informing both parents and service providers (Rosenbaum, 2005). As observed by Ensor & Cooper (2004), providing information to individuals has an impact on treatment options and health seeking behaviours. This can therefore be used to influence acceptability of health care services among mothers of children with disabilities by helping them to seek appropriate health care services for their children.

Having a child hospitalised is stressful for both the child and the family and it is important to take into consideration the needs of parents as they reflect the needs of the child (Shields et al., 2003). Mothers in the current study talked about their concerns in relation to children who remained home and their spouse's living conditions, for those who were accompanied by them to Lusaka. Other studies have also reported parents' worries about the other children who remained home (Bronsard et al., 2008; Petersen et al., 2004). A longitudinal pilot study to explore parental stress and anxiety during the child's hospitalisation reported that one of the themes that emerged from the qualitative part of the study was separation from family (Wray, Lee, Dearmun, & Franck, 2011). The problem with finding someone to take care of the children who remained at home has been cited as one of the reasons for delayed access to cataract surgery among children in Tanzania (Bronsard et al., 2008). In another study done in Uganda on caretaker's ability to complete referrals, some parents cited taking care of other children at home as reasons for failing to complete referrals for sick children (Petersen et al., 2004). Caregivers' social responsibilities may be barriers to accessing health care services for children and this relates to acceptability which, according to Simon (2008) refers to the cultural and social distance between health care services and users.

The concept of allowing family members of hospitalised children to spend nights at the child's bedside or elsewhere in the hospital has become a standard practice in some hospitals (Meltzer, Davis, Mindell, 2012; Stremler, Wong, & Parshuram, 2008; Lam, Chang, & Morrisseye, 2006). In a meta-analysis of studies on psychological adjustment of families of children with spina bifida, it was reported that family support especially that of the partner had a positive effect on the psychological health of parents (Vermaes, Janssens, Bosman, & Gerris, 2005). In most studies done in developing countries, the lack of a person to escort the patient or mother to the referral hospital was reported as one of the barriers or factors leading to delay to accessing health care (Gyasi, Amoaku, & Asamany, 2007). This barrier relates to acceptability of health care services as it is a social-cultural aspect which is dependent on the patient to make a decision to utilise the health care services. Mothers in the current study were spending the nights by their children's bedside and were either sleeping on the floor or on plastic chairs which are at the bedside. Six mothers were accompanied by their spouses while one was accompanied by her elder sister and all were spending nights in the hospital. There is only one room for mothers/caregivers in ward D 01 and only female caregivers are allowed to sleep there. As a result, male caregivers were sometimes forced to sleep by the corridors of the ward and when security staff found them, they were usually chased out of the ward. As a result of the lack of sleeping facilities, one mother reported that her husband used to spend the nights at the inter-city bus station.

Most of the mothers who were accompanied by their spouses complained that the spouses did not have a place where to sleep at night while one mother was worried that her husband was not able to get food from the hospital. Similar findings of hospitals not providing accommodation or a place for parents of hospitalised children have been reported in other studies (Lam et al., 2006). According to Stremler et al. (2008), adequate sleep for parents taking care of hospitalised children is important because it maintains their psychological functioning as well as their ability to participate in their children's care. Other reports from literature have also shown that apart from worrying about the condition of the child, parents of hospitalised children in developed countries also have to worry about costs of food and accommodation during the child's hospitalisation (Peters et al., 2008; Furber, 2002; Atkinson et al., 1999). According to Peters et al. (2008), other indirect costs of health care which prevent the poor from seeking health care services include the opportunity cost of time for the patient and accompanying relative, transportation costs as well as food and lodging expenses.

Another challenge which relates to the dimension of acceptability was an experience by one of the mothers who had to deal with family beliefs where other members of the family opted to use traditional remedies as opposed to taking the child to the hospital. Similar reports of seeking traditional remedies have been reported in studies done in developing countries (Maslove, Mnyusiwalla, Mills, McGowan, Attaran & Wilson, 2009; Bari et al., 2006; Jacobs & Price, 2005). This mother, who delivered at home, could not take the baby to the hospital soon after birth because her husband refused to allow it. Studies done in developing countries have reported the dependence of women on other family members such as their husbands to make decisions on utilisation of health care services (Fantahun, Berhane, Wall, Byass and Hogberg, 2007; Kowalewski, Jahn, & Kimatta, 2000). The lack of power by women to make decisions about taking the child to the hospital has been reported to be a contributing factor to delayed access to health and high mortality rates among children in poverty stricken areas (Fantahun et al., 2007; Bronsard et al., 2008).

5.3.5 SUPPORT

Family support while the baby was admitted in UTH ranged from bringing food, bathing soap, washing powder and just visiting the mothers while they were in hospital from those family members who lived in Lusaka. Family support in form of providing food and others services was reported as being important especially in some of the hospitals in developing countries that do not provide meals for patients (Gyasi et al., 2007). In the same vein, lack of relatives in the urban referral hospitals was cited by participants in a study done in Tanzania as one of the reasons for not complying with referrals (Kowalewski et al., 2000). The findings by Gyasi et al. (2007) and Kowalewski et al. (200) indicates that family support is an important factor in access and could help overcome barriers related to geographical accessibility and affordability. Mothers in the current study reported that the hospital only provided lunch and supper and therefore mothers were required to provide their own breakfast. This meant that those who did not have family support within Lusaka had to find their own breakfast or wait for lunch to have something to eat. This challenge mainly affected mothers who came from other provinces and had no family support. This challenge is also noted in the Zambia National Health Strategic Plan where it is reported that poor people from rural areas face access barriers to referrals such as transport costs, time costs, food and accommodation for in-patients and relatives (MOH, 2011).

In relation to geographical accessibility and affordability, mothers expressed concern about the failure of some hospitals to provide transport despite being government institutions and they were even more concerned about lack of transport to go back home even after being taken to Lusaka by hospital vehicles. According to the mothers, government services should be provided to the people for free and not at a fee. This includes hospital services and transport costs. For hospitals which do not have the capacity to transport patients to the referral hospital, mothers suggested that money for transport should be given by the referring hospitals or the social welfare should be providing transport. According to the Zambia National Health Strategic Plan, one of the key strategies of the Ministry of Health is to ensure availability and equitable distribution of adequate and appropriate transport for supporting health service delivery at all levels (MOH, 2011, pg. 60). However, despite acknowledging the importance of transport towards providing quality health services, the Ministry of Health is aware of its inefficiency and inadequate transport system (MOH, 2011). This could explain why some second level hospitals were able to provide transport while first level hospitals were not. It is important to ensure that transport which has been cited as a major barrier to accessing health care is provided by government as part of the health care delivery package. As stated by McQueen et al. (2010), essential surgical care should be considered as a basic human right and as such, governments should ensure equal access for the affected individuals. Children with open neural tube defects are at great risk of having CNS infections which could subsequently lead to death or secondary neurological impairments. In order to prevent these complications, Bowman and McLone (2010) noted that closure of the defect should be done within 72 hours after birth. It is therefore important for all referral hospitals to take note of this time frame and provide transport so that the children are able to reach the appropriate referral hospitals on time. This is supported by Peters et al. (2008) who noted that access is the timely use of health services according to need.

5.4 MOTHERS' PERCEPTIONS OF THE FEASIBILITY OF ACCESSING HEALTH CARE AFTER DISCHARGE

Mothers of children with NTDs who were admitted in UTH were asked if they would be able to take their children who presented with neurological impairments for physiotherapy and to return for follow up visits. Those who said they would not manage cited problems related to geographical accessibility and affordability of transport cost to the first level hospitals where the services were available. Most of these mothers were from rural areas and lived far from the district hospitals where physiotherapy services are offered. The mothers stated that they would not be able to afford the transport costs because of the long distance from where they live to the hospitals. A study which was done in Uganda to understand barriers to clubfoot management reported similar difficulties among parents who lived in rural areas who cited transport costs to accessing the health facilities which offered rehabilitation services as one of the barriers (McElroy et al., 2007). Another study which was done in Uganda to determine factors preventing injured patients from attending rehabilitation services reported problems of distance and cost of transport among the barriers (Harms & Kobusingye, 2003). Studies done on effect of distance on access to health care have shown that there is a decline in health care utilisation as distance from health facility increases (Feikin et al., 2009; Kiwanuka et al., 2008; Khan et al., 2005). Acknowledging the relationship that exists among the dimensions of access, McLaughlin and Wyszewianski (2002), urged researchers to recognise the interdependency of these dimensions if their findings are to provide the foundation for effective policy changes.

The mothers were also asked if they would be able to bring their children for follow up visits to Lusaka. Those who came from other provinces indicated that they would not be able to and cited long the distance and problems with paying transport costs as reasons. This is consistent with findings from other studies done in developing countries where follow up visits are deterred by distance and transport costs (Pirani et al., 2009; Djientcheu et al., 2008; Eriksen, Bronsard, Mosha, Carmichael, Hall, & Courtright, 2006). Other reasons cited by Jones, Sherman and Varga (2005) for lack of compliance to follow up visits includes socio-economic factors such as poverty, geographical location and lack of paternal support.

5.5 EXPERIENCES OF MOTHERS WITH ACCESSING PHYSIOTHERAPY SERVICES

The fourth objective of the current study explored experiences of mothers with accessing physiotherapy services. Children with spina bifida will usually require long term rehabilitation programmes due to the disabling nature of the condition (Esenyel & Currie, 2002). However, rehabilitation services especially for many children with disabilities in poorly resourced areas of developing countries are not easily accessible (Saloojee et al., 2007).

Four mothers who brought their children for follow up visits to UTH were interviewed and all their children had physical impairments in the lower limbs. Only two mothers reported having knowledge about the need for physiotherapy for their children. Only one child was receiving physiotherapy services while the other three were not.

5.5.1 MOTHERS' KNOWLEDGE ABOUT PHYSIOTHERAPY SERVICES

An individual's knowledge about the disease and available health care services has been found to influence a person's ability to use health care services (Gulliford et al., 2002). This is true with findings from the current study where mothers reported lack of knowledge as a reason for not taking the children for physiotherapy. Among the four mothers who participated in this part of the study, two mothers (Mother B and Mother D) said they knew about physiotherapy services for their children while the other two (Mother A and Mother C) did not know anything about the service. According to the two mothers who had no knowledge, they were never told by anyone that their children required physiotherapy for their condition, suggesting that they were not given adequate information about the services their children needed. Similar findings about lack of knowledge regarding rehabilitation services among parents of children with disabilities have also been reported in other studies (Saloojee et al., 2007; VanLeit, Channa, & Rithy, 2007). A study that was done in Cambodia on the functional status of children with disabilities and its implications on service utilisation reported that despite the availability of rehabilitation services and free assistive devices, some children with movement disorders did not access these services (VanLeit et al., 2007). This was because their parents did not know about the services and even those who knew about the service were worried about the costs because they did not know that the assistive devices were free (VanLeit et al., 2007). Parents of children with disabilities, like any person with an illness, need to be informed about the children's conditions and services required because as stated by Thiede and McIntyre (2008), information empowers individuals and communities to make choices in health care and thus increase access. Thiede and McIntyre (2008) further noted that the type of information that determines an individuals choice on utilisation of health services is an essential aspect of access and relates to the dimensions of availability, affordability and acceptability.

5.5.2 ACCESSESSING PHYSIOTHERAPY SERVICES

Mother D, who was able to take the child for physiotherapy reported that she had requested physiotherapists to start treating her child when she was admitted in UTH the second time. Mother D also reported that when the child was discharged, she continued taking her for physiotherapy at the district hospital in her province.

Mothers B, who also knew about physiotherapy said she was referred for physiotherapy by doctors during follow up visits and she only took the child for physiotherapy once. According to this mother, she was shown how to do exercises in that one session and was advised to continue doing exercises at home and no appointment for the follow up visit was given. Mother B said that she was told that, as a mother, she was the best physiotherapist the child could access and so she should continue doing exercises at home. However, according to Campbell (1999), physiotherapy for children with spina bifida should start during the neonatal period and and as the child grows older, management will change depending on the level of lesion and age of the child. The type of exercises which Mother B was shown when she took the child for physiotherapy at the age of four months would not be the same at different stages of the child’s development. There was a need for Mother B to be given an appointment for a return visit so that the child would be reassessed and a treatment plan formulated according to the changing needs of the child and family (MacDonald & Callery, 2007). Furthermore, return visits would also be beneficial to the mother because as noted by Taanila et al. (2002), she would be able to get professional support and advice from the physiotherapists as well as meeting and sharing with other parents of children with disabilities. The interaction with other parents of children with disabilities helps parents to cope with the child’s disability.

The other two mothers (Mother A and Mother C) who said they had no knowledge about their children's need for physiotherapy also acknowledged having seen the physiotherapists doing passive movements when the babies were first admitted in the hospital just after birth. This suggests that the mothers might have been informed about their children's physical problems at an early age. However, the communication with these mothers at that time may not have been effective enough for them to realise that physiotherapy could help overcome their children's motor problems (Maloni et al., 2010). These mothers also stated that the hospitals which offered physiotherapy services were not far from where they lived, so geographical accessibility was not a problem. However, the lack of access to physiotherapy services among these mother could be attributed to availability and acceptability. The mothers' lack of knowledge about their children's disabilities and where to seek knowledge is an indication of inadequate health care services. This is because, despite being in contact with physiotherapists and accessing health care through follow up visits, these mothers were not advised to take their children for physiotherapy. On the other hand, lack of access could also be related to acceptability because all mothers were aware of their children's disabilities and they reported having physiotherapy at some point in the hospital, but they did not continue when they were discharged. According to Porterfield and McBride (2007), one of the reasons why some children with special health care needs fail to access health care services is because of their caregivers' failure to recognise the need for those services. Patients' failure to recognise the need for a health service is one of the factors that affects access and this can be addressed if health care providers can give adequate information to the patients concerning their illnesses and services available (Jacobs, Ir, Bigdeli, Annear, & Van Damme, 2011; Oliver & Mossialos, 2004).

5.5.3 SUPPORT REGARDING ACCESS TO PHYSIOTHERAPY

Caring for children with disabilities can cause stress for the families especially mothers who are the principle caregivers (Resch et al., 2010; Hartley et al 2004; Taanila, et al., 2002; Heiman, 2002). The challenge of caring for a child with spina bifida is exacerbated by the complex nature of the condition which requires multiple disciplines of care (Fletcher & Brei, 2010; Liptak & El Samra, 2010). There are many studies which have shown that support for families of children with disabilities helps parents cope with the stress that comes with these challenges (Sen & Yurtsever, 2007; Saloojee, 2006; Hartley et al., 2004; Taanila, et al., 2002).

Mothers of children in the current study talked about support which included family and community support. Mother B reported that when the child starts going for physiotherapy, she would be getting support from family members in assisting with taking the child for physiotherapy if she is busy at work. Mother A stated that she gets financial support to cover transport costs from family members. Similar reports about getting financial support from family members were also reported in a study which was done in Turkey to determine difficulties experienced by parents of children with disabilities (Sen & Yurtsever, 2007). In another study on coping strategies among parents of children with disabilities, it was reported that parents found family support helpful (Taanila et al., 2002),

The literature on childhood disabilities also shows that the cost of caring for a child with disabilities are high and usually unaffordable for the families who are mainly from low social economic backgrounds (Adeleye et al., 2010; Ouyang, Grosse, Armour, & Waitzman, 2007). Affordability or financial accessibility which is the relationship between cost of health care services (direct and indirect costs) and the willingness or ability of users to pay for services (Peters et al., 2008) are more challenging for the mothers especially those from low social economic status and living in rural areas. In Zambia, health care services for children are free but there are indirect costs such as transport to get to the health facilities which parents have to pay. Mobility aids for children with disabilities are not provided by government and therefore parents have to buy these, except for a few who are able to get them for free from non-governmental organisations. Mother D was able to take the child for physiotherapy because she had been getting financial assistance for transport to get from her home to the district hospital where physiotherapy services are available. She also reported that she was able to travel to Lusaka for follow up visits because of the financial support which she has been getting from the church, a non-governmental organisation and the social welfare. Mother D also reported that the child had been receiving support in form of assistive devices which included a free wheelchair and callipers.

Despite coming from a low socio-economic background, mother D was able to access the health care her child needed because of the support she was getting. A study which was done in South Africa on experiences of the poor households with accessing chronic health care in a rural area reported that patients who received social grants were among those who were able to seek health care regularly (Goudge et al., 2009). Similarly, findings from a report on the Community Based Rehabilitation and orthopaedic surgery for children with motor impairments in Uganda showed that many children from poverty stricken rural populations were able to access the services because of financial and transport support (Penny et al., 2007). It can be noted that support gives the poor the opportunity to access health care and, as observed by Thiede and McIntyre (2008), health care financing has a significant effect on the dimension of affordability. However, not all children in developing countries have this opportunity because, as noted by Djientcheu et al. (2008), the majority of children with NTDs who come from poor families do not access any rehabilitation services and are usually lost to follow up. This is partly because of problems with geographical accessibility and affordability as most of the poor live in remote areas which are far from health facilities. Accessing health care for these people would require them to spend more on travel time and transport costs (Peters et al., 2008).

5.6 SUMMARY OF DISCUSSION

The findings from the record review were discussed in respect to the first objective. This was based on the profile of children with NTDs who were admitted in UTH in 2010. The profile of children was discussed under the following headings; the prevalence; demographic characteristics; types of NTDs; site of the lesion; neurological impairments and; management and outcome. The findings were consistent with reports from other studies done in other countries, particularly the sub-Saharan African countries. Among the major findings discussed were that the children came from all parts of the country and the majority of children had no follow up notes despite the medical records indicating the need for follow up. Reasons for non-follow up were discussed in relation to the dimensions of access theories namely, geographical accessibility, affordability and acceptability.

The second and third objectives which were based on experiences of mothers of children admitted with NTDs were discussed in relation to access theories and compared with relevant literature. This included accessibility of health care within the provinces and to UTH as well as experiences while in UTH. Geographical accessibility was related to distance from home to the health facilities and referral hospitals and was cited as one of the reasons for delayed presentation as well as perceived feasibility of accessing follow up visits and physiotherapy services. Barriers related to availability included inadequate antenatal care, lack of surgical services in provincial hospitals and inadequate knowledge among some health care providers. The lack of adequate information on their children’s conditions among mothers was related to the dimension of availability of health care services because health care providers failed to provide the necessary information to the mothers. Problems to do with affordability included direct and indirect costs. Direct costs affecting affordability included by-pass fees for those who were charged while indirect costs included transport and living expenses while in Lusaka. Indirect costs constituted the main barrier to access and contributed to delayed presentation especially for mothers who came from other provinces. Family support while in UTH and government support in form of transport were found to reduce the problems related to affordability. Factors related to acceptability included mothers' unwillingness to use health facilities for delivery, attitudes of some health personnel who delayed referring children and one mother who had difficulty with family beliefs. Mothers expressed concerns about the care of children who remained at home and about the living conditions of their spouses while in Lusaka for those who were accompanied.

The fourth objective focused on experiences of mothers who brought their children for follow up visits regarding access to physiotherapy services. Mothers' experiences with accessing physiotherapy services were compared with findings from other studies and they related to the dimensions of availability, affordability and acceptability. The dimension of geographical accessibility was not linked to the lack of access to physiotherapy services amongst these mothers. Some mothers reported having no knowledge about physiotherapy for their children, suggesting that health care providers did not give them adequate information. Support in the form of finances, transport costs and assistive devices were found to have an effect on affordability and were associated with regular access to physiotherapy services. These findings are consistent with other studies done in developing countries.

CHAPTER SIX

SUMMARY, CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

6.1 INTRODUCTION

This chapter presents the summary, conclusion and the significance of the study. The summary is presented in three sections according to the three parts of the study. The chapter also describes the limitations of the study and makes recommendations based on findings of the study.

6.2 SUMMARY OF THE STUDY

The aim of this study was to determine the profile of children with NTDs admitted in University Teaching Hospital, Lusaka, Zambia, and to explore experiences of mothers with accessing health care services. The study consisted of three parts. Part One used a record review to determine the profile of children with NTDs, Part Two explored experiences of mothers of children with NTDs admitted to UTH in relation to accessing health care services and Part Three explored experiences of mothers with accessing physiotherapy services. The reason for this study was because there were many children with NTDs admitted to UTH within a period of one year and yet only a small number of children with spina bifida were being attended to by physiotherapists countrywide. Furthermore, all children born with NTDs anywhere in Zambia have to be transported to Lusaka for surgical management and when they return back home, those who live in peri-urban and rural areas may not have the opportunity to access physiotherapy services. This is because physiotherapy services in Zambia are only found at first level hospitals except in Lusaka where they are also found in urban health centres. The objectives of this study were, therefore, to describe the profile of children with NTDs admitted to UTH; to explore challenges and support experienced by the mothers of children with NTDs in relation to accessing health care from UTH; to explore mothers' perceptions of the feasibility of accessing physiotherapy services and returning for follow up visits when the child is discharged; and to explore experiences of mothers with accessing physiotherapy services for children with NTDs associated with motor impairments.

Part One of the study used a quantitative retrospective method with a data extraction sheet which was used to collect data from the medical records. A sample of 50 medical records was used out of a population of 101 children with NTDs, who were admitted to UTH between January and December, 2010. Part Two used in-depth interviews to explore the experiences of a purposefully selected sample of mothers of children who were admitted to UTH during the study period. Part Three involved a sample of convenience of four mothers who brought their children for follow up visits and used in-depth interviews to explore their experiences regarding accessing physiotherapy services for their children.

The literature review included studies done on prevalence of NTDs, types of NTDs, associated impairments and management. The review also highlighted challenges faced by paediatric surgery as well as surgery for of children with NTDs in developing countries. Experiences of parents in relation to accessing both surgical and rehabilitation services for these children were also reviewed as well as the support needed by these parents. To further understand the barriers to accessing health care services in developing countries, the access to care frameworks were reviewed with a focus on the "Four A's" framework.

The summaries of findings for each of the three parts of the study are presented separately.

6.2.1 PROFILE OF CHILDREN WITH NEURAL TUBE DEFECTS

Information obtained from the admission register indicated that there were 101 children with NTDs who were admitted from January to December 2010 but detailed analysis only involved the 50 medical records that were available. The results showed that the majority of children were from within Lusaka province, and the age ranged from one day to 48 months at the time of admission. There were more male children (58%) than females and the most common type of NTD was myelomeningocele with 44%. The lumbar region was the most common site with 52% and hydrocephalus was present in 74% of the children. Other significant findings included wound infection which was present in 40% of the children and 66% of the medical records had no follow up notes. These findings are consistent with other studies done in developing countries especially those from the sub-Saharan Africa.

6.2.2 EXPERIENCES OF MOTHERS WITH ACCESSING HEALTH CARE AT UNIVERSITY TEACHING HOSPITAL

The second part of the study used in-depth interviews to explore the experiences of mothers of children with NTD who were admitted to UTH in relation to accessing health care services to UTH. This part also explored mother's perceptions of the feasibility of accessing physiotherapy services and returning for follow up visits when the child returns home. The major challenge was transport to Lusaka and to return home. This was related to geographical accessibility and affordability. Other challenges included problems accessing health care within the provinces where they lived, the lack of appropriate prenatal diagnosis and the lack of information on the condition of child. The problems with accessing health care in their provinces were related to geographical accessibility and affordability as most of the mothers who lived far from the hospitals stated that they could not afford the cost of transport. The lack of prenatal diagnosis was related to availability and acceptability and the lack of information related to availability of health care services. Mothers were concerned about their children who remained at home and the living conditions for their spouses who accompanied them to Lusaka. Support from government and family was found to be helpful and reduced the barriers related to affordability. Experiences of mothers in the current study were consistent with findings from other studies done on access to surgical care in developing countries.

6.2.3 EXPERIENCES OF MOTHERS WITH ACCESSING PHYSIOTHERAPY SERVICES

Part Three of the study used in-depth interviews to explore experiences of mothers with accessing physiotherapy services for children with NTDs who presented with motor impairments. Four mothers who met the inclusion criteria were interviewed and findings revealed that their lack of knowledge about their children's need for physiotherapy contributed to some of them not having access to physiotherapy services for their children. This lack of knowledge could be related to availability of health care services as these mothers were not informed by health personnel when the children were first admitted to UTH and during follow up visits. Support in form of transport money from families and the community was found to increase the chances of the child's access to physiotherapy services. Lack of information and knowledge among parents of children with disabilities has been cited in literature to be among the barriers to accessing rehabilitation services for these children.

6.3 CONCLUSION

The aims and objectives of this study were successfully achieved. The findings from the record review suggest that management of children with NTDs in Zambia is faced with challenges such as late presentation, wound infection and loss to follow up management. This is consistent with literature which indicates that developing countries have higher incidences of children with NTDs and yet they are faced with many challenges related to prevention of NTDs and management of children who have NTDs. Mothers of children with NTDs experience challenges related to accessing health care for their children due to poverty and the very long distance to the tertiary hospitals where the surgery required is available. The findings also revealed the lack of adequate information mothers have about the condition of their children and services required. The lack of knowledge among mothers contributed to the lack of access to physiotherapy services for these children while availability of support from both government and family increased the chances of accessing health care among the children. In conclusion, it could be asserted that providing free transport to the tertiary hospitals and back home for all children with NTDs would increase access to surgical care and subsequently reduce the incidence of wound infection and other complications. It would also increase mothers' adherence to follow up management. Furthermore, providing adequate information as early as possible to mothers of children born with NTDs would increase the children's access to physiotherapy services.

6.4 SIGNIFICANCE

The mission statement for the Ministry of Health in Zambia is "To provide cost effective, quality health services as close to the family as possible" (Ministry of Health, 2011). This is in line with the Alma-Alta declaration which adopted primary health care as a means of providing comprehensive, universal, equitable and affordable health care services for all (WHO, cited in Hall & Taylor, 2003). However, attaining equity of access to health services is not yet possible for many children with NTDs in Zambia because health care services such as neurosurgery can only be found in Lusaka and physiotherapy services cannot be found at the primary health care level outside of Lusaka. This lack of access to essential health care services has been reported to be the major cause of early deaths and severe disabilities among children with NTDs in developing countries (Lazareff, 2011).

The results from the current study will be used to provide information to physiotherapists in Zambia regarding children with NTDs and the barriers faced by their parents in relation to accessing physiotherapy services. This will in turn enable physiotherapists to engage with the Ministry of Health to facilitate finding the means for these children to get access to rehabilitation through providing rehabilitation services as close to the children’s homes as possible.

The results will be used to inform health care providers and policy makers about the extent of the problem faced by mothers of children with NTDs and challenges faced by their mothers with accessing health care services. This could potentially lead to improved service delivery in terms of timely and coordinated referrals that ensure continued care after surgery for children with NTDs at primary health care level. In addition, this study may also enable policy makers to consider making physiotherapy services accessible to all patients in need of the service regardless of where they live.

The study will also add to the body of literature on the profile of NTDs in a developing country as well as challenges faced by families with accessing health related services for these children.

6.5 LIMITATIONS OF THE STUDY

This study had the following limitations:

1. Some of the medical records available had information missing.
2. Some mothers who participated in Part Two of the study were not able to express themselves easily and in detail when asked the first broad question. This made it difficult for the interviewer to draw information about their experiences from these mothers. This problem was addressed by including more prompts in the interview guide based on information gathered from those mothers who were able to express themselves more easily.

3. Part Three had only four participants who met the inclusion criteria during the study period and therefore it was not possible to reach data saturation.
4. The communication problems between the researcher and some of the mothers whose language the researcher could not speak fluently led to involving research assistants who interviewed these mothers. Information obtained from such interviews may not be as detailed or in as much depth as that obtained when the researcher conducted the interviews.
5. The researcher did not send back the translated interview scripts to the translator for back translation because of the limited time and extra costs involved in back translating. The researcher however had put in measures to ensure that the translated and transcribed documents were accurate and had same meaning.

6.6 RECOMMENDATIONS

The following are the proposed recommendations based on the findings of this study:

1. **Improving access to health care services**

- Routine ultrasound should be carried out in all pregnant women who are able to attend antenatal clinics in order to detect congenital abnormalities prenatally. This helps with planning for delivery and prevention of complications that may arise due to unplanned deliveries.
- The Ministry of Health should provide strategies of ensuring that free transport during first referrals and follow up visits is provided for all children whose parents cannot afford the cost of transport due to poverty or geographical accessibility.

- Health care providers from both first and second level hospitals should consider all children presenting with open NTDs as surgical emergencies, unless they present with already infected wounds.

- First level hospitals that do not have the capacity to transport patients to tertiary hospitals should be referring them to the second level hospitals and not directly to the tertiary hospitals. This is because second level hospitals have the capacity to provide transport to the tertiary hospitals.
- Neurosurgeons working with children with NTDs should ensure that all children presenting with motor impairments are referred for physiotherapy.
- Physiotherapists at UTH should be assessing the neurological status of all children admitted with NTDs and record the information in the child's clinical file. This will facilitate referrals of these children for physiotherapy services when they are discharged.
- The Ministry of Health should consider incorporating physiotherapists in out-reach programmes and mobile clinics in order to provide physiotherapy services to children living in areas were the services are not available.

2. **Providing information and support to parents of children with NTDs**

- Health care providers should provide adequate information to all mothers of children born with congenital defects on the nature of the condition, possible outcome and services required. This helps the mothers to cope with the situation and ensures that the child has access to the essential health care services.
- Referral hospitals should ensure that all parents who accompany their children to these hospitals should be provided with food and accommodation. This will help reduce stress on mothers and encourage parents to return for follow up visits when they are requested to do so.

3. **Further research**

- A vital question which is beyond the scope of this study is the whereabouts of those children who are lost to follow up. These children represent a greater proportion of children with NTDs and it is therefore important that a study is carried out to find out what happens to these children.

- The profile of children with NTDs was only done at UTH and involved only those children whose parents were able to make it to UTH. There is need for a countrywide database on congenital birth defects involving all district and provincial hospitals so that the incidence of NTDs in the country could be determined. This information will help policy makers come up with strategies that will enable equity of access to the needed health care services for all affected children. The information would also help policy makers revise food fortification measures so that they benefit the vulnerable population.

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APPENDICES

APPENDIX 1

DATA CAPTURING SHEET

SECTION A

DEMOGRAPHIC DATA OF CHILD

1. Serial number

2. Gender

Male	Female
1	2

3. Date of admission………………………………………………………..

4. Age on admission (in months)..

5. Date of discharge………………………………….

6. Province of residence…………………………………………

1. Lusaka	1
2. Southern	2
3. Central	3
4. Eastern	4
5. Western	5
6. North Western	6
7. Northern	7
8. Luapula	8
9. Copperbelt	9

SECTION B

1. Type of NTD

Anencephaly	1
Encephalocele	2
Meningocele	3
Myelomeningocele	4

2. Site of NTD

Lumbosacral	Lumbar	Sacral	Thoracolumbar	Cervical	Frontal	Occipital	Nasal	Other
1	2	3	4	5	6	7	8	9

3. Associated impairments

None	1
Hydrocephalus	2
Club foot	3
Hydrocephalus/club foot	4
Chromosomal disorders	5
Others	6
Multiple congenital anomalies	7

4. Neurological status

Paraplegia	1
Paraplegia/incontinence	2
Incontinence	3
Normal	4

Other	5

5. Radiological investigations done

Ultrasound	1
Magnetic Resonance Imaging (MRI)	2
Computed Tomographic Scan (CT)	3
None	4

6. Surgical management

Surgical repair of defect	1
Shunt for hydrocephalus	2
Both repair and shunt	3
None	4

7. Complications

None	1
Meningitis	2
Wound infection	3
Shunt malfunction	4
Other	5
Multiple complications	7

8. Follow-up management and out-come

No follow up notes	1
1 follow up visit	2

2 follow up visits	3
3 or more follow up visits	4
Referred to Beit Cure Hospital	5

APPENDIX 2

INTERVIEW GUIDE ON EXPERIENCES WITH ACCESSING HEALTH CARE FROM UNIVERSITY TEACHING HOSPITAL

QUESTION 1

Tell me in form of a story about the events which followed after the birth of your child. I am most interested in knowing what happened starting from labour, when the child was born up to the time the child got admitted in this hospital.

Prompts

- Where did you deliver from and what challenges did you encounter getting to the nearest health facility?
- What challenges did you face in relation to coming here?
- What kind of support did you get from the local health centre, the district hospital, the community and your family?
- What challenges are you facing here knowing that you are away from your home?
- If you have come with your spouse, where is he spending the night?
- Who is taking care of your other children at home while you are here?
- What suggestions do you have in terms of helping parents in your situation get to this hospital?
- How do you intend to go back home when the baby gets discharged?

Question 2

When you go back home, the child may need medical attention from the nearest health centre or hospital as well as coming back here.

- Will you be able to bring the baby back for follow up visits if you are asked to come back?

- Describe the things which you feel will make it easy or difficult for you to get to the nearest health centre or hospital.
- Describe to me the nearest health centre in terms of personnel, structure, equipment and services.
- What suggestions do you have about making access to health care easy in your area?
-

APPENDIX 3

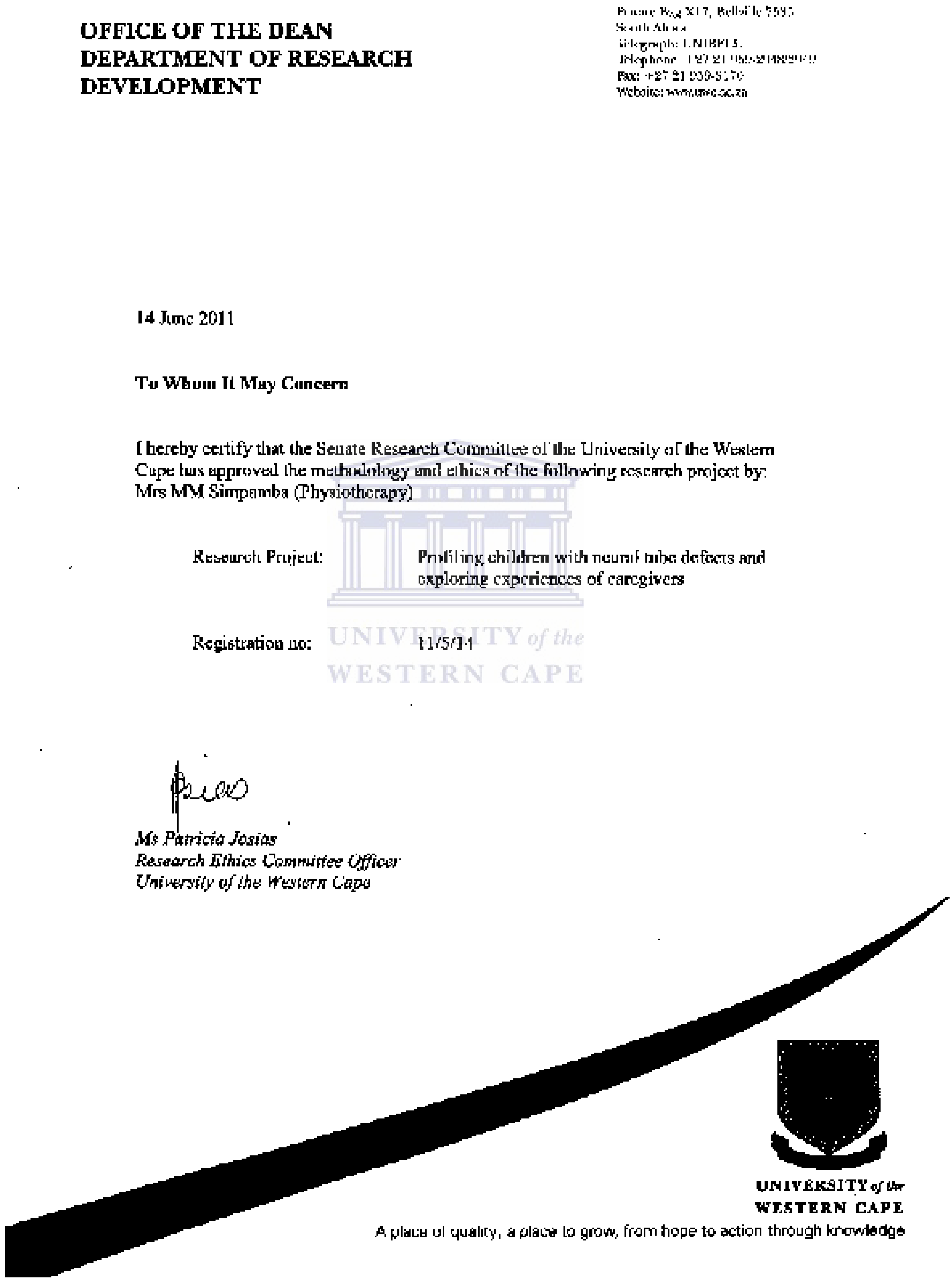
INTERVIEW GUIDE ON EXPERIENCES WITH ACCESSING PHYSIOTHERAPY SERVICES

Tell me in form of a story about your experiences with getting your child to have physiotherapy services. I would like know if there are any challenges you face or support in relation to ensuring that the child gets physiotherapy.

Prompts

- What challenges do you face with accessing physiotherapy services
- Do you get any support from family, community and health centre
- How often do you take the child for physiotherapy
- Are there any costs involved and do you have any problems with covering costs
- How can you describe the services at the facility including personnel?

APPENDIX 4



OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

Private Bag X17, Bellville 7535
South Africa
Telegraph: UNIBELL
Telephone: +27 21 959-2948/2949
Fax: +27 21 959-3170
Website: www.uwc.ac.za

14 June 2011

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by: Mrs MM Simpamba (Physiotherapy)

Research Project: Profiling children with neural tube defects and exploring experiences of caregivers

Registration no: 11/5/11

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

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WESTERN CAPE
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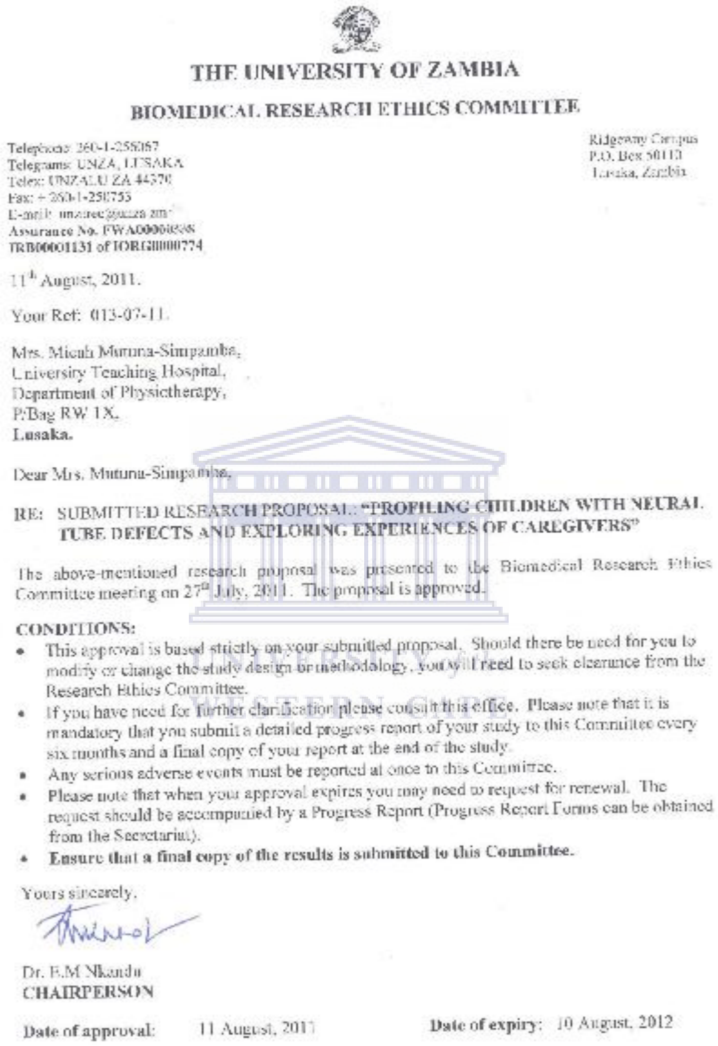
APPENDIX 5



THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza.zm
Assurance No. FWA00000338
IRB00001131 of IORG0000774

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

11th August, 2011.

Your Ref: 013-07-11.

Mrs. Micah Mutuna-Simpamba,
University Teaching Hospital,
Department of Physiotherapy,
P/Bag RW 1X,
Lusaka.

Dear Mrs. Mutuna-Simpamba,

RE: SUBMITTED RESEARCH PROPOSAL: **"PROFILING CHILDREN WITH NEURAL TUBE DEFECTS AND EXPLORING EXPERIENCES OF CAREGIVERS"**

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee meeting on 27th July, 2011. The proposal is approved.

CONDITIONS:

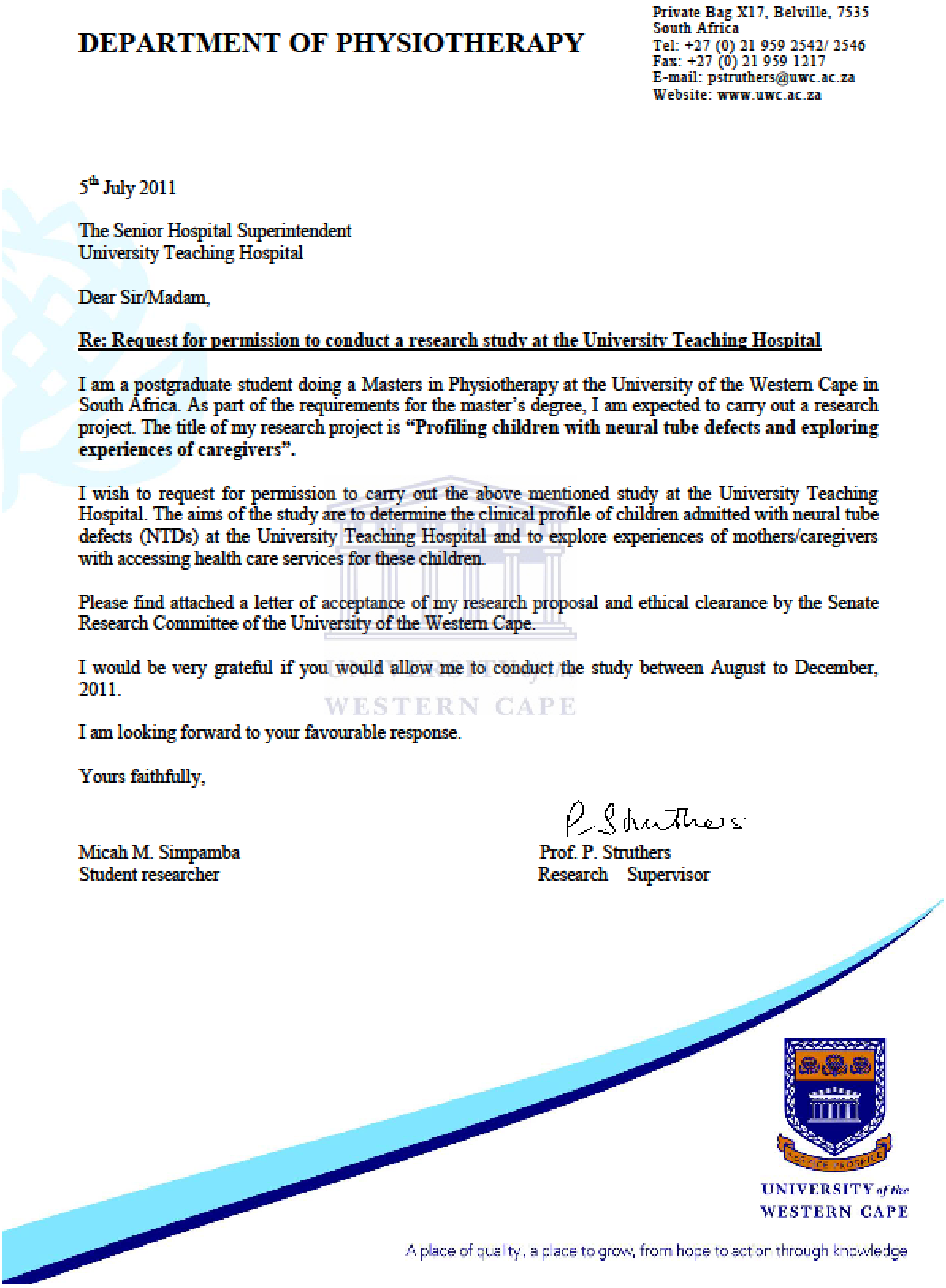
- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- **Ensure that a final copy of the results is submitted to this Committee.**

Yours sincerely,

Dr. E.M Nkandu
CHAIRPERSON

Date of approval: 11 August, 2011 **Date of expiry:** 10 August, 2012

APPENDIX 6



DEPARTMENT OF PHYSIOTHERAPY

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South Africa
Tel: +27 (0) 21 959 2542/ 2546
Fax: +27 (0) 21 959 1217
E-mail: pstruthers@uwc.ac.za
Website: www.uwc.ac.za

5th July 2011

The Senior Hospital Superintendent
University Teaching Hospital

Dear Sir/Madam,

Re: Request for permission to conduct a research study at the University Teaching Hospital

I am a postgraduate student doing a Masters in Physiotherapy at the University of the Western Cape in South Africa. As part of the requirements for the master's degree, I am expected to carry out a research project. The title of my research project is **"Profiling children with neural tube defects and exploring experiences of caregivers".**

I wish to request for permission to carry out the above mentioned study at the University Teaching Hospital. The aims of the study are to determine the clinical profile of children admitted with neural tube defects (NTDs) at the University Teaching Hospital and to explore experiences of mothers/caregivers with accessing health care services for these children.

Please find attached a letter of acceptance of my research proposal and ethical clearance by the Senate Research Committee of the University of the Western Cape.

I would be very grateful if you would allow me to conduct the study between August to December, 2011.

I am looking forward to your favourable response.

Yours faithfully,

P. Struthers

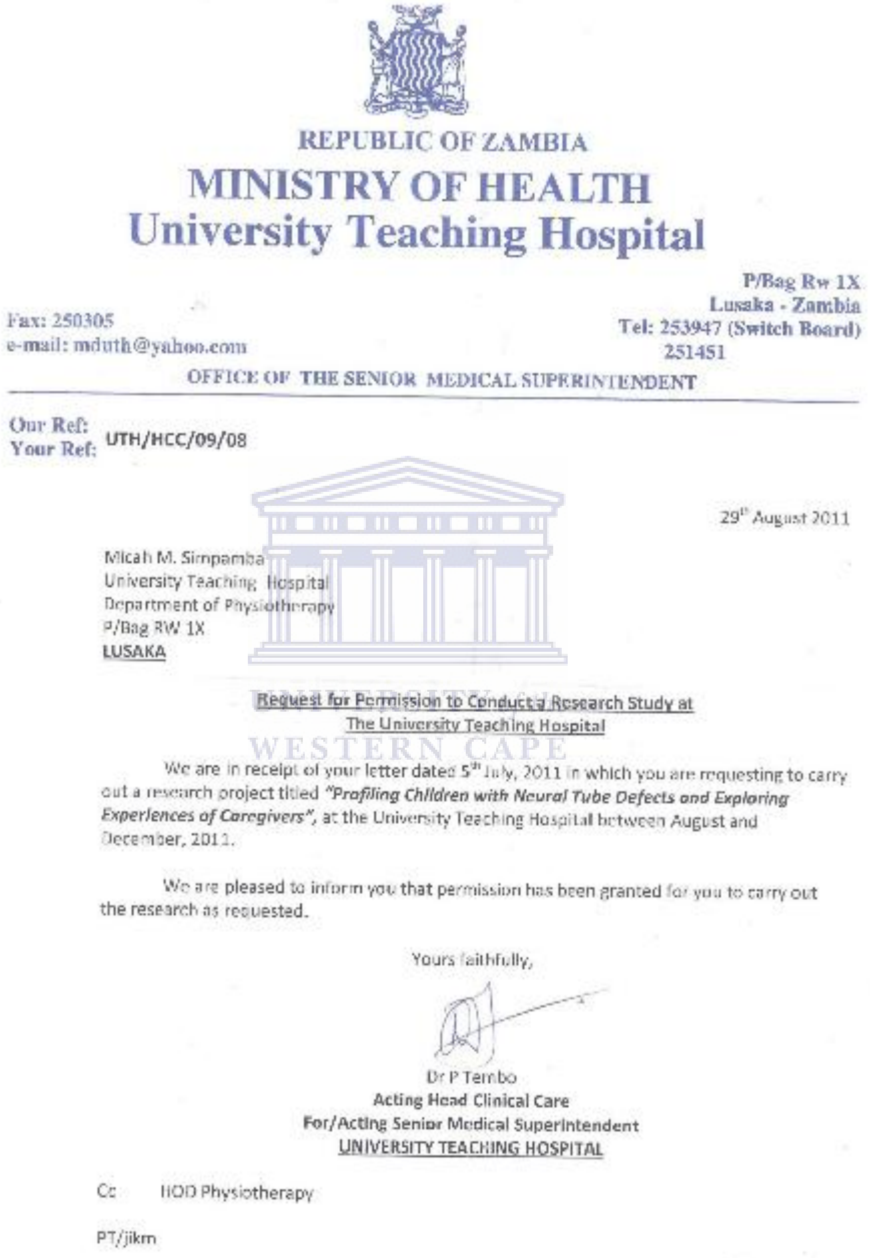
Micah M. Simpamba
Student researcher

Prof. P. Struthers
Research Supervisor

UNIVERSITY of the
WESTERN CAPE

A place of quality, a place to grow, from hope to action through knowledge

APPENDIX 7



REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
University Teaching Hospital

P/Bag Rw 1X
Lusaka - Zambia
Tel: 253947 (Switch Board)
251451

Fax: 250305
e-mail: mduth@yahoo.com

OFFICE OF THE SENIOR MEDICAL SUPERINTENDENT

Our Ref:
Your Ref: UTH/HCC/09/08

29th August 2011

Micah M. Simpamba
University Teaching Hospital
Department of Physiotherapy
P/Bag RW 1X
LUSAKA

Request for Permission to Conduct a Research Study at
The University Teaching Hospital

We are in receipt of your letter dated 5th July, 2011 in which you are requesting to carry out a research project titled ***"Profiling Children with Neural Tube Defects and Exploring Experiences of Caregivers"***, at the University Teaching Hospital between August and December, 2011.

We are pleased to inform you that permission has been granted for you to carry out the research as requested.

Yours faithfully,

Dr P Tembo
Acting Head Clinical Care
For/Acting Senior Medical Superintendent
UNIVERSITY TEACHING HOSPITAL

Cc HOD Physiotherapy

PT/jikm

APPENDIX 8

PerfectText
3rd Floor, Lotti House, Cairo Road P.O. Box 30248 Lusaka 10101
Phone: +26 096 682 1516; +26 095 582 1516
Email: perfecttext@quickedge.com

25 August, 2011

Mrs. Micah M. Simpemba
University of the Western Cape
Private Bag X17 Belleville 7535
South Africa

Dear Madam,

SUBJECT: TRANSLATED REASERCH FORMS INTO ZAMBIAN LOCAL LANGUAGES

We are glad to inform you that the translation of the materials as per above has completed. The translation has been don into four Zambian languages, ie, Bemba, Lozi, Nyanja and Tonga.

Should you have any questions regarding these translations, please donot hesitate to let us know.

We really appreciated your having given us the opportunity to translate the documents for you. We look forward to doing business with you again in the future.

Please find enclosed the invoice regarding the payments for the work done.

Regards,

PERFECTTEXT LIMITED
P.O. BOX 30248
LUSAKA
FAX: 021 1231314

Sikopo Ng'andwe (Mrs)
Chief Executive Officer

APPENDIX 9 A

UNIVERSITY OF THE WESTERN CAPE

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E-mail: micamutuna@yahoo.co.uk

INFORMATION SHEET FOR MOTHERS

Project Title: PROFILING CHILDREN WITH NEURAL TUBE DEFECTS AND EXPLORING EXPERIENCES OF MOTHERS

What is this study about?

This is a research project being conducted by Micah M. Simpamba, at the University of the Western Cape. We are inviting you to participate in this research project because you are a mother with a child who has a neural tube defect and is getting treatment at the University Teaching Hospital. The purpose of this research project is to explore experiences of mothers of children with neural tube defects with accessing health care services. This is in order to understand the problems faced with accessing health care services. The information may be used by the health care providers in your province and policy makers to improve accessibility to these services in future.

What will I be asked to do if I agree to participate?

You will be asked to tell me about yourself and where you are coming from. I will also ask you to explain to me in your own words the events from the time your child was born up to the time of admission. I would also like to know about any problems you faced or any assistance you received in ensuring that the child is brought to this hospital. I would also like you to tell me what you think would make it difficult for you to access health care services for the child when he/she gets out of hospital.

Would my participation in this study be kept confidential?

This study will involve making audiotapes of you. This is in order to help the researcher get every detail of the interview. We will do our best to keep your personal information confidential. The recorded information from the interview will only be kept by the researcher and she will keep it under lock where she alone will have access to the key. To help protect your confidentiality, you will not be identified by your name but only codes will be used for transcribing the information on computer. There will be an access password to this information which will only be known by the researcher. After the study is finalised, all the audiotapes used during the study will be destroyed to maintain confidentiality and ensure that they are not used for any other purpose.

If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There are no known risks associated with participating in this research project. However, should any emotional trauma be caused during the interviews, measures have been put in place for psychosocial counselling of those who will be affected.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about problems faced by mothers accessing health care services for children with neural tube defects. We hope that, in the future, other people might benefit from this study through improved health care delivery systems which will ensure timely and coordinated access to essential health care services for children with neural tube defects throughout the country.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, your child's medical attention at this hospital or anywhere else will not be compromised at all.

What if I have questions?

This research is being conducted by Mrs Micah Simpamba from the Physiotherapy Department, at the University of the Western Cape. If you have any questions about the research study itself, please contact the study supervisor Sr. Margaret Mweshi, Cheshire Homes in Kabulonga, Lusaka.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

The Chairperson,
University of Zambia Research Ethics Committee,
P.O Box 50110,
Lusaka, Zambia

This research has been approved by the University of the Western Cape's Senate Research Committee and the Research Ethics Committee and the University of Zambia Research Ethics Committee.

APPENDIX 9 B

UNIVERSITY OF THE WESTERN CAPE

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Tel: +27 21-959, Fax: 27 21-959
E-mail: micamutuna@yahoo.co.uk

AMASHIWI KU BAFYASHI

Umutwe: UKULONDOLOLA PA BANA ABAFYALWA NO BULWELE BWA KULI BONGOBONGO NA MU MONGOLOLO NO KWISHIBA IFIPITAMO ABABATENSHA

Bushe uku ukufwailisha kwa nshi?

Abalefwailisha pali uyu mulandu ni ba Mama Micah M. Simpamba aba pe sukulu likalamba ilya University of the Western Cape. Ico tulefwaila ukuti mulandepo pali uyu mulandu ni co mwalikwata umwana uwafyalwa no bulwele bwa kuli bongobongo na mu mongololo uo baleundapa ku cipatala cikalamba ica University Teaching Hospital. Tulefwaya ukwishiba ifipitamo abafyashi abakwata abana abakwata ubu bulwele ukumona nga cilabangukila ukusanga bashing'anga abaishiba ukucina no kukosha ifilundwa fya mubili. Ico tulecitila ifi ni co tulefwaya ukwishiba amafya ayo abatensha bakwata pa kuti basange bashing'anga ba musango uyu. Ifyo mwalalanda kuti bafibomfya aba fya cipatala mu citungu mwikala e lyo na bapanga amafunde na bo kuti bafibomfya pa kuti cikamyangukileko ukusanga aba kundapa.

Finshi bakalanjipusha nga nasumina ukulandapo?

Nkamipusha ukuti mukailondolole no kunjeba uko mwafuma. Nkamipusha no kuilondolwela mwe bene ifyacitika ukutula apo umwana wenu afyalilwe ukufika pa nshita bamutekele mu cipatala. Nkamipusha na pa mafya mwakwete nangu pa bwafwilisho ubuli bonse mwapokelele pa kuti mulete umwana ku cipatala. Ndefwaya mukanjebe ne fili no kumikosela sana pa kuti mukasange ababomfi ba fya cipatala aba kulayafwa umwana wenu ilyo akafuma mu cipatala.

Bushe bakansokolola nga nalandapo?

Tuli no kukopa ifyo mukalanda pali tepu pa kuti abalefwailisha bekalabapo nangu kamo pa fyo mukalanda. Tatwakasokolwele uuli onse ifyebo ifikumine imwe. Uulefwailisha ifi fyebo e uli no kufisunga eka fye kabili akafikomena e lyo eka fye e ukakwata amakii ya ku ncende bakafikomena. Pa kuti mwikeshibikwa, tatwakalemita ishina lyenu, lelo tukalabomfya inshila shimbi pa kubika ifyo mukalanda pali kompyuta. Takwakabe nangu umo uuli no kusanga ifyo mukalanda pali kompyuta kano fye uyu wine uulefwailisha. Ilyo tukapwisha ukubombela pali ifi tulefwailisha, tukonaula amatepu yonse ayo tukakopamo ifyo mukalanda pa kuti mwikeshibikwa na pa kuti bambi tabayabuulile no kwambulamo ifyo mukalanda.
Nga twalemba lipoti nangu fimo fimo pa fyo muli no kulanda, tatwakamisokolole nangu panono.

Bushe ifyo nkalanda fili no kundetelela?

Ifyo muli no kulanda ilyo bakalamipusha tafyakamiletelele nangu panono. Lelo nga ca kuti ilyo mulelondolola mwaumfwa ububi ku mutima ne cikonko camikata, kuti bamyafwa abaishibisha ifya matontonkanyo.

Busuma nshi ubwa uku kufwailisha?

Uku kufwailisha te kwa kwafwa imwe, lelo ifyo muli no kulanda fili no kwafwa abalefwailisha pa kuti beshibe amafya yapitamo abatensha pa kuti basange abengafwa abana abafyalwa no bu bulwele. Tulecetekela ukuti ku ntanshi, ifi fyebo fili no kwafwa bambi nga ca kuti kwaba ukuwamyako ifya cipatala ne myundapile pantu ifi fikalenga cikanguke ukusanga bashing'anga abaishiba ukucina no kukosha ifilundwa fya mubili aba kwafwa abana abafyalwa no bulwele bwa kuli bongobongo na mu mongololo mu calo cesu conse.

Bushe mfwile fye ukusumina ukulandapo pali uku kufwailisha kabili bushe kuti nafumamo apo ndefwaila?

Tatulemipatikisha ukulandapo muli uku kufwailisha iyo. Nga mulefwaya kuti mwalandapo, nga tamulefwaya teti mulandepo. Nga ca kuti mwasumina ukulandapo e lyo mulefwaya ukufumamo, kuti mwafumamo apo mulefwaila. Nga tamulefwaya ukulandapo nangu nga mwafumamo apo mulefwaila, te kweba ati ninshi bali no kuleka ukwafwa umwana uo muletensha pali cino cipatala nangu ukuli konse kumbi iyo.

Kuti nacita shani nga ninkwata amepusho?

Abalefwailisha pali uyu mulandu ni ba Mama Micah Simpamba aba mu cipani ca Physiotherapy Department, pe sukulu likalamba ilya University of Western Cape. Nga muli na mepusho ayali yonse pa fyo balefwailisha, kuti mwaipusha abalelolekesha pali uku kufwailisha ba Sr. Margaret Mweshi.

Nga namukwata amepusho pali uku kufwailisha na pa nsambu shenu mu kwampana no ku kufwailisha nangu nga mulefwaya ukuseba ubwafya ubuli bonse ubo muli no kusanga ukukuma kuli uku kufwailisha, mukwai lembeleni ku keyala kakonkapo:

The Chairperson,
University of Zambia Research Ethics Committee,
P.O. Box 50110,
Lusaka, Zambia

Ba University of the Western Cape's Senate Research Committee na ba Research Ethics Committee na ba University of Zambia Research Ethics Committee, e basuminishe ukuti kube uku kufwailisha.

APPENDIX 9 C

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959, Fax: 27 21-959
E-mail: micamutuna@yahoo.co.uk

MALANGIZO A ANAKUBALA

Mutu wa Nkhani: KULONGOSOLA ZA ANA AMENE AMABADWA NDI BVUTO LAKUSOKONEZEKA BONGO, KUPUNDUKA KWA MSANA NDI ZIWALO ZINA NDINSO ZOKUMANA NAZO ZA OTHANDIZILA ANAMWINO

Kodi kafukufuka aka nikaciani?

Iyi ndi nkhani ya kufufuza kapena kafukufuku kocitidwa ndi amai Micah M. Simpamba aku sukulu ya maphunzilo apamwamba a ku University of Wester Cape. Mukuitanidwa kukafukufuku aka cifukwa mwaleta mwana wamene abadwa ndi bvuto la kusokonezeka bongo, kupunduka msana, ndi zwalo zina kuti alandile thandizo kucipatala ca cikulu ca University Teaching Hospital. Cholinga ca kufufuza uku ndico kuona mabvuto ambili omwe anakubala a ana awa akukumana nawo mukuyesa kupeza thandizo lakuciritsa ana awo. Zotululukapo pakafukufuku kano kazathandiza kupeputsa bvuto pakati pa anyanchito aza umoyo kumadera akwanuko ndi kuti pakhale kukonza ndikuongolela mbali zina.

Nika bvomela kugawanamo, kodi ndizafunsidwa ciani?

Muzafunsidwa kundiuza zainu ndi kumene mucokela. Ndipo muzafunsidwanso kundiuza m’mau anu-anu kuti mulongotsole kungoyamba cabe panthawi yakubadwa kwa mwana kufikila nthawi imene anasungidwilapo mu cipatala. Ndingakondwenso kumva kwa inu za bvuto lililonse mukuyanganizana nalo la kulandila thandizo la kuciritsidwa pamene mwana acoka mcipatala.

Kodi padzakhala chinsinsi mukugawanamo kwanu?

Pazakhala kukujambulani pamakambitsilano. Chochitikaci chidzandithandiza kulondola bwino makambitsilanoyo. Ndipo ndizacita kuthekela kulikonse kusunga makambitsilano kukhala achinsinsi. Makambitsilano alionse ndi zojambula zidzatsimikizilidwa kuti zasungidwa ndi kuzikhomela ndi loko, ndipo makiyi adzakhala ndi ineyo basi. Kuti tisamale bwino chinsinsi chathu, dzina lanu silizachulidwa, koma m’malo mwake tizango gwilitsila ntchito maina ena ndi kuyaika pa makina a kompyuta basi. Zikaikidwa pa kompyuta, kompyuta izakhomiwa, ndikusimikiza kuti zizango belengedwa ndi ineyo basi. Titangotsiliza kafukufuku aka, zojambulidwa zonse zizafafanizidwa ndikutaidwa kutsimikizila kuti

dzina lanu ndi inuyo simuchulidwa mpang'ono pomwe naku simikidza kuti sidzigwilisidwa cintho zina.
Ngati lipoloti kapena zolemba zina za zolankhuzana zathu izi zifalitsidwa, tidzatsimikiza kuti dzina lanu silichulidwa mpang'ono.

Kodi ndi mabvuto otani ali mukufufuza kwa nkhaniyi?

Ife tikupeza kuti palibe bvuto lililonse mukafukufuku kulinga ku ntchito iyi. Koma ngati ofunsidwa achita mantha ndi nkhani iyi, pali makonzedwe ya alangizi azaumoyo amene adzathandiza okhudzidwawo.

Kodi ndi mapindu otani ali mukufufuza uku?

Mapindu kwenikweni salunjikitsidwa mwacindunji kwainu ai, koma ka ofufuza kuti adziwe mabvuto ya azimai amene ali ndi ana amene ubongo, msana ndizopweteka zina zamthupi mwao m'mene akubvutikila. Chikhulupilo tili nacho chakuti unyinji wa anthu ena adzapindula ndi kafukufuku aka ndikuti pazakhala thandizo labwino ku mbali zones zadziko lathu lino.

Kodi ndingapezekemo mukafukufuku aka kapena ndingasiye nthawi iliyonse?

Kupezekamo kwanu mukafukufuku aka ndikosabvuta. Ngati mwasankha kusapezekapo, icho ndicosankha chanu, ndipo chosankhaco sichizakhuza ana anu amene akulandila thandizo muzipatala ai.

Bwanji ngati muli ndi mafunso?

Kufufuza uku kukucitidwa ndi amai a Micah M. Simpamba aku Dipatimenti ya kuona pa anthu olemala pa sukulu ya maphunzilo yapamwamba ya University of Western Cape. Ngati pangakhale mafunso ali onse kulinga ku kafukufuku aka, chonde dzimveni anthu aufulu kufunsa oyanganila amai Margaret Mweshi. Kenaka, ngati mungakhale ndi bvuto lililonse lokhudzana ndi kafukufuku aka, chonde mungakambitsilane ndi:

The Chairperson
University of Zambia Research Ethics Committee,
P.O. Box 50110
Lusaka, Zambia

Chilolezo chakafukufuku aka chabvomelezedwa ndi a komiti ya akulu-akulu azofufuza ya ma University awili, Western Cape University Senate Research Committee ndi University of Zambia Research Ethics Committee.

APPENDIX 9 D

UNIVERSITY OF THE WESTERN CAPE

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LITABA ZA BOMAA BANA

Toho ya Taba ya Patisiso: KU ZIBA KAZA BANANA BABA PEPILWE NI BUANGA BWA MWA BOOKO NI MUKOKOTO NI KU ZIBA ZE BA IPUMANANGA KU ZONA BABALELI

Patisiso yei ama zañi?

Ye ki patisiso ye eziwa kibo Micah M. Simpamba ba kwa University of the Western Cape. Lu mi mema kuli mu abane mwa patisiso ye kakuli mu bababaleli baba tisize mwanana ya pepilwe ni buanga bwa mwa booko kappa bwa mukokoto kwa sipatela sesituna sa UTH kuli a to tatubiwa. Mulelo wa patisiso ye ki wa ku ziba ze ezahalanga ze ba bonanga bababaleli ba banana babali lianga mwa ku fumana likalafo za ku otolola mubili (physiotherapy). Lu eza cwalo kuli lu kone ku utwisisa matata ali teñi mwa ku fumana likalafo kwa sipatela. Litaba ze likana za itusiswa kiba kwa sipatela kwa sibaka ko mu pila ni batomi ba milao kuli ba kondolose litukiso za likalafo zaku otolola mubili kwapili.

Nika tokwiwa ku ezañi haiba ni lumela ku abana teñi?

Mu ka kupiwa kuni taluseza kuli ki mina bomañi ni komuzwa. Hape ni ka kupa kuli mu ni taluseze mwa manzwi a minaze ezahezi ku zwa fa pepezwi mwanaa mina kuto fita faa kenezi mwa sipatela. Hape nika tabela ku ziba za matata kaufela ene mu bile ni ona kappa tuso ye ne mu filwe mwa ku bona teñi kuli mwanaa mina wa tiswa kwa sipatela. Hape ni ka tokwa kuli mu ni taluseze ze mu nahana kuli li ka tisa butata kuli mu fumane likalafo za mwanana ha ka zwa mwa sipatela.

Kana ku abana kwaka mwa patisiso ye kukaba kunutu?

Patisiso ye ika ama ku mi lekoda. Mubatisisi u ka eza cwalo ilikuli abe ni litaba kaufela za patisiso. Lu ka eza kamolu konela kaufela kuli litaba za mina z aka butu libe kunutu. Litaba ze lekodilwe za puhisano li ka bulukiwa fela ki mubatisisi mi li ka beiwa moku kiilwe mi kii yateñi ika ba fela ni yena. Kuli kunutu I bukelezwe, libizo la mina halina ku pundiwa, ku ka itusiswa fela linombolo kwa ku beya litaba fa kompyuta. Litaba zeo li ka konwa fela ku balwa ka ku itusisa linzwi la kunutu lelika zibwa fela ki mubatisisi. Patisiso ye haika fela, matepu kaufela a itusisizwe

teñi a ka sinyiwa kuli litaba kaufela li be za kunutu ni ku ikolwisa kuli haa itusiswi kwa lika zeñwi.
Haiba lu ka ñola piho kapa taba kaza patisiso ye, lu ka lika kamolu konela kaufela kuli mu sike mwa pundiwa teñi.

Likozi ze mwa patisiso mo ki lifi?

Hakuna likozi ze zibahala za ku abana mwa patisiso ye. Kono haiba ku kana kw aba ni ku utwa butuku kwa pilu mwahalaa puisano, ku ezizwe litukiso za ku fa likelezo ku b aba ka amiwa.

Bunde bwa patisiso ye ki bufi?

Patisiso ye haisika lukisezwa ku tusa mina luli, kono ze ka fumaneha teñi li ka tusa mubatisisi ku ziba matata e ba fumananga bababaleli ba banana baba pepilwe ni buanga bwa mwa booko ni mukokoto mwa ku fumana likalafo za ku otolola mubili (physiotherapy). Lu sepa kuli kwapili, batu babañwi ba kana ba tusiwa ka patisiso ye kuli litukiso za likalafo li ka kondoloswa mi kacwalo mwa naha kaufela, banana baba pepilwe ni buanga bwa mwa booko ni mukokoto ba kone ku fumana ka bunolo likalafo zaku otolola mubili.

Kuli ni tokwa luli ku abana mwa patisiso ye mi kana na kona ku tuhela nako ifi kapa ifi?

Mu abana mwa patisiso ye ka ku itatela. Mwa kona ku keta ku asa abana teñi. Haiba mu itakaleza ku abana teñi, mwa kona ku tuhela nako ifi kapa ifi. Haiba mu keta ku sa abana teñi kapa haiba mu tuhelela fahali, likalafo za mwanaa mina mwa sipatela mo kapa ko kuñwi kaufela halina ku amiwa.

Hani kaba ni lipuzo bo?

Patisiso ye ieziwa ki bo Mufumahali Micah Simpamba baba mwa likolo la Physiotherapy kwa University of the Western Cape. Haiba munani lipuzo kaza patisiso ye, mu bonane ni muzamaisi wa patisiso ye, bo Sr. Magaret Mweshi. Haiba mukaba ni lipuzo ka za patisiso ye ni litukelo za mina ka ku ba muabani mwa patisiso, kapa haiba mu bata ku bilaela sesiñwi ka za teñi,mu ñolele ku bo:

The Chairperson,
University of Zambia Research Ethics Committee,
P.O. Box 50110,
Lusaka, Zambia

Patisiso ye ieziwa ka tumelezo yaba University of the Western Cape Senate Research Committee niba University of Zambia Research Ethics Committee.

APPENDIX 9 E

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IPEPA LYAMAKANI AABAMAMA

Mutwe Wabuvwuntauzi: KUPANDULULA TWAAMBO TUJATIKIZYA BANA BALEMA MUBONGO ALIMWI AMOONGOLO AKWIIYA NZYOBAJANA BABALANGANYA

Ino buvwuntauzi oobu bujatikizya nzi?

Oobu buvwuntauzi bulacitwa aba Micah M Simpamba, ku University of the Western Cape. Twamutamba kuti mutole lubazu mukuvwuntauzya ooku nkaambo muli baama bajisi mwana mulema mubongo amumoongolo (spine) alimwi mujana busilisi kuzwa kucibadela ca University Teaching Hospital. Ikaambo kakuvwuntauzya ooku nkakuyanda kuziba zintu nzyobaswaanganya bamamama bali abana balema mubongo amumoongolo ciindi nobayandaula busilisi. Ooku nkusola kuziba buyumuyumu buliko mukujana busilisi. Makani aaya alakonzya kuyoobelesyegwa abantu balanganya zyabusilisi mucooko canu kutegwa cikaube kusilika mumazuba aakumpela.

Ino ndiyooambilwa kucita nzi ndaakuzumina kutola lubazu?

Ndiyoomulomba kuti mukalipandulule alimwi akundaambila nkomuzwa. Alimwi njoomulomba kuti mukandaambile zyakacitika kuzwa ciindi mwanaanu naakazyalwa kusikila naanjila mucibbadela. Alimwi njooyanda kuziba mapenzi aali oonse ngomwaajana naba mbomwaagwasyigwa kutegwa mwana aletwe kucibbadela. Alimwi njoomulomba kundaambila ncomuyeeya kuti inga capa kuti cimuyumine kujana busilisi bwamwana ciindi aakuzwa mucibbadela.

Sena kutola lubazu kwangu takukazibisyigwi kuli bamwi?

\Kuvwuntauzya ooku kuyoojatikizya kulekkooda majwi aanu mumateepu. Ooku nkusola kupa kuti sikuvwuntauzya akatumvwe twaambo toonse ntomuyooamba. Tuyoosolekesya kusisa makani aanu. Mubandi uuyolekkoodwa uyooyobolwa buyo asikuvwuntauzya alikke alimwi uyoozikkiila zyakalekkoodwa akwaayobola makki. Ikugwasya kutamuzibya, tamukazibwi azina pe, pele manamba ayoobelesyegwa kubweza makani aanu kuzwa mukkompyuta. Kunooli mabala aayandika kulembwa kutegwa muntu ajane twaambo twanu mukkompyuta (password). Alo aayoozibwa buyo asikuvwuntauzya alikke. Kuvwuntauzya kwaakumana, mateepu

oonse aakalekkoodwa ayakunyonyoonwa kutegwa mutazibwi alimwi akuti atabelesyigwi munzila imwi.
Ikuti twaakulemba lipooti naa kapango kujatikizya kuvwuntauzya ooku, tuyoosolekesya kutamuzyibya.

Nintenda nzi zili mukuvwuntauzya ooku?

Kunyina ntenda zizibidwe zijanwa mukutola lubazu mukuvwuntauzya ooku. Pele kuti umwi waba akukopana mumizeezo ciindi nabuzigwa-buzigwa, kuli basyaazibwene mukutontozya bantu ibayoomugwasya

Nimpindu nzi zili mukuvwuntauzya ooku?

Kuvwuntauzya ooku takubambilidwe kujanya ndunwe mpindu, pele iziyooigwa kuzwa mumo inga zyaakugwasya sikuvwuntauzya kuziba mapenzi basikulanganya bana aaba ngobajana mukusola kujana busilisi bwakoolola-olola mubili wabana balema mubongo amumyoongolo (physiotherapy). Tulombozya kuti kumbele aamazuba bamwi bayoojana mpindu kuzwa kukuvwuntauzya ooku kwiinda mumapulogilamu aabusilisi aayoopa kuti mucisi coonse kabuliko busilisi bwakoolola-olola mubili bana balema mubongo amyoongolo.

Sena ndeelede kutola lubazu mukuvwuntauzya ooku alimwi sena inga ndaleka aciindi cili coonse?

Kutola lubazu mukuvwuntauzya ooku nkusala kwanu. Ikuti kamutayandi, tamukonzyi kutola lubazu, ikuti mwasala kutola lubazu, mulakonzya kuleka ciindi cili coonse. Ikuti mwasala kutatola lubazu naa kuleka kutola lubazu mukuvwuntauzya, kusilikwa kwamwanaanu aacibbadela eeci naa cimbi takukanyonganizigwi naaceya.

Ino kuti ndijisi mibuzyo?

Kuvwuntauzya ooku kucitwa aba Mrs Micah Simpamba baku Physiotherapy Department ku University of the Western Cape. Ikuti kamuli amibuzyo kujatikizya kuvwuntauzya ooku, amulembele beendelezi babuvwuntauzi oobu ba Sr Margaret Mweshi.
Ikuti kamuli amibuzyo kujatikizya buvwuntauzi oobu, naaba kujatikizya nguzu zyanu mbuli sikutola lubazu mubuvwuntauzi oobu naaba kuti kamuyanda kutuzyiba mapenzi ngomwajana aajatikizya mubuvwuntauzi, mwalombwa kuzibya ba:

The Chairperson,
University of Zambia Research Ethics Committee,
P.O. Box 50110,
Lusaka, Zambia

Kuvwuntauzya ooku kwazumizigwa a University of the Western Cape's Senate Research Ethics Committee alimwi a University of Zambia Research Ethics Committee.

APPENDIX 10

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INFORMATION SHEET ON EXPERIENCES WITH ACCESSING PHYSIOTHERAPY SERVICES

Project Title: PROFILING CHILDREN WITH NEURAL TUBE DEFECTS AND EXPLORING EXPERIENCES OF MOTHERS

What is this study about?

This is a research project being conducted by Micah M. Simpamba, at the University of the Western Cape. We are inviting you to participate in this research project because you are a mother or caregiver who has brought the child with a neural tube defect for review at the University Teaching Hospital. The purpose of this research project is to explore experiences of mothers/caregivers of children with neural tube defects with accessing physiotherapy services. This is in order to understand the problems faced with accessing health care services. The information may be used by the health care providers in your province and policy makers to improve accessibility to physiotherapy services in future.

What will I be asked to do if I agree to participate?

You will be asked to tell me about your experiences in relation to accessing physiotherapy services for the child in your district. I would like you to explain to me the challenges you face with accessing physiotherapy services and any support you get from the family, community and health centre in relation to physiotherapy services. I would also like to know how often the child goes for physiotherapy, any costs involved and how you perceive the services at the health facility as well as the personnel. The interview will be tape recorded and it will take about 45 to 60 minutes.

Would my participation in this study be kept confidential?

This study will involve making audiotapes of you. This is in order to help the researcher get every detail of the interview. We will do our best to keep your personal information confidential. The recorded information from the interview will only be kept by the researcher and she will keep it under lock where she alone will have access to the key. To help protect your confidentiality, you will not be identified by your name but only codes will be used for transcribing the information on computer. There will be an access password to this information which will only be known by the researcher. After the study is finalised, all the audiotapes used during the study will be destroyed to maintain confidentiality and ensure that they are not used for any other purpose.

If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There are no known risks associated with participating in this research project. However, should any emotional trauma be caused during the interviews, measures have been put in place for psychosocial counselling of those who will be affected.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about problems caregivers with accessing physiotherapy services for children with neural tube defects. We hope that, in the future, other people might benefit from this study through improved health care delivery systems which will ensure easy access to physiotherapy services for children with neural tube defects throughout the country.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, your child’s medical attention at this hospital or anywhere else will not be compromised at all.

What if I have questions?

This research is being conducted by Mrs Micah Simpamba from the Physiotherapy Department, at the University of the Western Cape. If you have any questions about the research study itself, please contact the study supervisor Sr. Margaret Mweshi, Cheshire Homes in Kabulonga, Lusaka.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

The Chairperson,
University of Zambia Research Ethics Committee,
P.O. Box 50110,
Lusaka, Zambia

This research has been approved by the University of the Western Cape’s Senate Research Committee and the Research Ethics Committee and the University of Zambia Research Ethics Committee.

APPENDIX 11 A

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E-mail: micamutuna@yahoo.co.uk

CONSENT FORM
Title of Research Project: PROFILING CHILDREN WITH NEURAL TUBE DEFECTS AND EXPLORING EXPERIENCES OF MOTHERS

The study has been described to me in the language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

I have also been informed that this study will involve making audiotapes of me.

………………I agree to be audiotaped during my participation in this study.
………………I do not agree to be audiotaped during my participation in this study.

Participant's name………………………..
Participant's signature……………………………….
Witness……………………………….
Date………………………
Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name:
Mrs. Micah M. Simpamba
University of the Western Cape
Private Bag X17, Belville 7535
Telephone: 027(21)7922444665
Fax: 027 (21)959-1217 Email: micamutuna@yahoo.co.uk or
3100108@uwc.ac.za

APPENDIX 11 B

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E-mail: micamutuna@yahoo.co.uk

IPEPALA LYA KULEMBA NGA MWASUMINA UKULANDAPO

Umutwe: UKULONDOLOLA PA BANA ABAFYALWA NO BULWELE BWA KULI BONGOBONGO NA MU MONGOLOLO NO KWISHIBA IFIPITAMO ABABATENSHA

Nabanjeba fyonse mu citundu ico ng'umfwikisha ifyo uku kufwailisha kuli no kuba kabili ning'umfwa e lyo ndeifwaila ne mwine ukwasukako ifyo bali no kunjipusha. Nabanjasuka fyonse ifyo ndefwaya ukwishiba pali uku kufwailisha. Nabanjeba ukuti tabakansokolole ukuli konse no kuti nga ndefwaya ukufumamo kuti nafumamo apo ndefwaila nangu nshibebele umulandu ndefuminamo kabili tabakancite icili conse ne fintu tafyakambipile.

Nabanjeba no kuti bali no kukopa ifyo nkalanda pali tepu.

__________ Nasumina ukuti ifyo nkalanda bakakope pali tepu.

__________ Nakaana nshilefwaya ukuti ifyo nkalanda bakakope pali tepu.

Ishina lyenu______________________________________

Saineni pano____________________________

Kamboni________________________________

Ubushiku________________________________

Nga namukwata amepusho pali uku kufwailisha nangu nga mulefwaya ukuseba ubwafya ubuli bonse ubo muli no kusanga ukukuma kuli uku kufwailisha, mukwai lembeleni abalekondenkanya uyu mulimo:

Ishina lya Balekondenkanya uyu mulimo:

Mrs. Micah M. Simpamba
University of Western Cape
Private Bag X17, Belville 7535
Telephone: 027(21)7922444665
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APPENDIX 11 C

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FOMU YA CHILOLEZO

Mutu wa Nkhani: KULONGOSOLA ZA ANA AMENE AMABADWA NDI BVUTO LAKUSOKONEZEKA BONGO, KUPUNDUKA KWA MSANA NDI ZIWALO ZINA NDINSO ZOKUMANA NAZO ZA OTHANDIZILA ANAMWINO

Nkhani iyi yalongosoledwa kwaine m'cinenelo chomwe ndi mamva ndipo ndikubvomela ndikudzipeleka inde mwini kuti ndigawanemo m'ntchito iyi. Mafunso anga ayankhidwa. Ndamvetsela kuti makambitsilano athu ndi achinsinsi chosanza wina aliyense, ndinso ngati ndifuna ndi ngacoke nthawi ili yonse popanda kupeleka zifukwa ndipo kuteleku sikuzakhudza kaimidwe kanga m'njila iliyonse
.

Chidziwitso chapelekedwa kale kwaine kuti makambitsilano athuwa azajambulidwa.

……………………………………Ndibvomela kujambulidwa pa phunzilo lathu ili.
……………………………………Sindikuvomela kujambulidwa pa phunzilo lathu ili.

Dzina lanu ………………………………………………………………………..
Sigineca yanu…………………………………………………………………
Kamboni………………………………………………………………………….
Tsiku……………………………………………………………………………….

Ngati mungakhale ndi mafunso, kapena pangakhale bvuto lililonse lokhudza ku nkhani ino, chonde mungathe kuonana ndi a kodineta athu:

Dzina la a Kodineta:
Amai Micah M. Simpamba
University of the Western Cape
Private Bag X17, Belville 7535
Telephone: 027 (21) 7922444665
Fax 027 (21)959-1217 Email: micamutuna@yahoo.co.uk olo 3100108@uwc.ac.za

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FOMU YA KU ITUMELELA

Toho ya Taba ya Patisiso: KU ZIBA KAZA BANANA BABA PEPILWE NI BUANGA BWA MWA BOOKO NI MUKOKOTO NI KU ZIBA ZE BA IPUMANANGA KU ZONA BABALELI

Ni taluselizwe kaza patisiso ye mwa puo ye ni utwisisa mi ni ya itatela ni ku bay a lukuluhile ku abana teñi. Lipuzo zaka ka za patisiso ye li alabilwe. Na utwisisa kuli hanina ku zibahazwa ni kuli na kona ku tuhela ku abana teni nako ifi kamba ifi ni sa fi mabaka mi kueza cwalo hakuna kun i tiseza butata nibobukana.

Hape ni zibisizwe kuli patisiso ye ika ama kuni lekoda.

………………………………….Na lumela ku lekodiwa haninze ni abana mwa patisiso ye.
………………………………….Hani bati ku lekodiwa haninze ni abana mwa patisiso ye.
Libizo la muabani………………………………………………………
Mu saine fa……………...……………………………………………….
Paki…………………..………………………………………………….
Lizazi…………………………………………………………………….

Haiba mu kaba ni lipuzo kaza patisiso ye kappa haiba mu bata ku biha matata e mu kopani ni ona a ama patisiso ye, mu zibise muonga-ongi wa yona fa:
Libizo la muonga-ongi:

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FOOMU YAKUZUMINA

Mutwe Wabuvwuntauzi: KUPANDULULA TWAAMBO TUJATIKIZYA BANA BALEMA MUBONGO ALIMWI AMOONGOLO AKWIIYA NZYOBAJANA BABALANGANYA

Ndapandulwidwa kuvwuntauzya ooku mumwaambo ngwemvwa alimwi cakuliyandila ndazumina kutola lubazu. Mibuzyo yangu iijatikizya buvwuntauzi yaingulwa. Ndilizi kuti nsekazibisyigwi kubuleya alimwi kuleka kutola lubazu mubuvwuntauzi kukunyina akwaamba nkaambo nzi, alimwi kunyina eeci nociyoondiletela penzi lili lyoonse.

Alimwi ndaambilwa kuti majwi aangu ayoolekkodwa amateepu.

………………Ndazumina kulekkoodwa ciindi netola lubazu mukuvwuntauzya ooku.
………………Nkakaka kulekkoodwa ciindi netola lubazu mukuvwuntauzya ooku.

Zina lyasikutola lubazu……………………………………………….………
Kusaina kwasikutola lubazu…………………………………………….………
Kamboni………………………………………………..
Buzuba…………………………………………….…..
Ikuti kamuli amibuzyo kujatikizya buvwuntauzi oobu, naaba kamuyanda kutuzyiba mapenzi ngomwajana aajatikizya mubuvwuntauzi, mwalombwa amwaambile beendelezi babuvwuntauzi ba:
Zina lyabeendelezi babuvwuntauzi:

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APPENDIX 12: DEMOGRAPHIC CHARACTERISTICS OF MOTHERS OF CHILDREN WHO WERE ADMITTED TO UNIVERSITY TEACHING HOSPITAL

Mothers ID and Demographic characteristics of mothers and the child
M 01 Aged 22 years, from Eastern province, married, unemployed and this was the third child. Husband was the only source of income but lost job as he accompanied wife to Lusaka when baby was referred. Child was male, had myelomeningocele and age on admission was one month. The baby was born at the first level hospital and was referred to second level which later referred to Lusaka. She was assisted with transport at both the first and second level hospitals.
M 02 Aged 19 years, from Southern province, single and was a pupil at secondary school before she became pregnant. This was her first child and she was being kept by her grandmother in the village and depends on cultivation. Child was aged two weeks on admission and presented with lumbosacral myelomeningocele. The baby was born at home and taken to first level hospital by her uncle’s car. Was referred by first level hospital directly to UTH and family contributed money for fuel in hospital vehicle which brought her to UTH.
M 03 Aged 29 years, from Western province, married and depended on cultivation as means of living. This was her fourth child and was male aged five months on admission and presented with a lumbar meningocele. Delivered at the first level hospital but doctor asked her to go back home and return after three weeks. Went back as advised and was taken to second level hospital by hospital vehicle where she was later transported to Lusaka after a week. At UTH baby was not admitted but asked to go back home and return after four months. Returned after four months at clinic four but was told to return after a week as she was late. Went and stayed with brother and returned after a week and baby was admitted awaiting surgery. Accompanied by husband.

M 04

Aged 25 years, from North Western province, married, unemployed, dependent on cultivation. This was her third child, female aged six months on admission and presented with lumbar meningocele. Delivered from the first level hospital which was walking distance from her home. Was told to find transport money and travel to Lusaka but did not have money. So went and stayed home until after about four to five months when she noticed baby's head getting bigger. Went back to hospital but still could not be assisted, went to social worker's office who was out of office and later went to district commissioner's office who assisted by sending driver to take her and the husband to Lusaka.

M 05

Aged 24 years, from Luapula province, married and dependent on cultivation as source of living. This was her third child, female aged nine months on admission and presented with nasal encephalocele. Delivered from home assisted by traditional birth attendants and took baby to the local clinic when they noticed the lump above the nose. Clinic staff asked them to go to the first level hospital and husband booked a cab and there, they were told that they need to find money to go to Lusaka. They went back home and stayed for seven months and then returned to the hospital. This time she was told to go back home and find money to travel to the second level hospital because it was nearer than going to Lusaka. She went back home and borrowed some money and went to the second level hospital accompanied by her elder sister. At the second level hospital, she was taken by hospital vehicle to Lusaka.

M 06

Aged 34 years, from Copperbelt, divorced, but had this child with another married man and she is unemployed. Being kept by relatives and the other three children were kept by their father. This was the second admission for the baby, and was aged five months, female with myelomeningocele of the lumbar. The baby was born at the first level hospital and she was transported to the second level hospital where she had wound dressing and shunt for hydrocephalus and discharged after three weeks. At home after a week, baby started crying continuously and was taken back to second level hospital where they diagnosed intestinal obstruction and immediately transported to UTH were abdominal surgery was done the following night. Baby was discharged and the mother had no transport money to go back so she went to her sister who gave her money and she left after a week. She stayed home but after four months baby developed problem with shunt and at second level hospital they said this time they could only refer her to UTH and the hospital transported her.

M 07

Aged 25 years, from Eastern province, married, husband makes metal basins and she makes table clothes as source of income. Child was aged six months on admission, female with lumbar meningocele. This was her fourth child, one was deceased and the other two had a different father so they were being kept by their grandparents. Baby was born at home and the father to baby, with his parents, refused to take child to the hospital but started applying traditional herbs on the lump. The mother to the baby pleaded with them and after a week they took the baby to the local clinic where they were advised to go to the first level hospital and since it was near, they walked. At the hospital, they were advised to go to the second level hospital but they did not have money for transport. A family friend advised them to go to Malawi since it was near and they went by bicycle, but the hospital in Malawi told them to go to Lilongwe (a City in Malawi) which was even further. They had to come back home and when she managed to raise enough money through selling table cloths, she started off to the second level hospital. There she was transported by hospital vehicle to UTH.

M 08

Aged 30 years, from Lusaka, single, unemployed, sells at the market and being kept by sister. This was her second child and was male, aged one day presenting with lumbosacral myelomeningocele. Delivered at the local clinic and a district ambulance was called which picked her and took her and the baby to UTH.

M 09

Aged 28 years from Lusaka, married to a taxi driver and she is in employment. This was her third child, female aged one day on admission. The baby presented with lumbosacral myelomeningocele. Child was born at a second level hospital in Lusaka by caesarean section and baby was transported to UTH by hospital ambulance while mother remained admitted at the second level hospital. Before mother was discharged, the baby was being cared for by her grandmother until after three days when the mother was discharged. The mother continued spending nights at home because of the caesarean section while the baby remained under the care of her mother's sister until morning when the mother returned.

M 10

Aged 19 year from Lusaka, married and the husband worked as a garden boy. This was her second child, was male aged one day on admission and presented with lumbosacral myelomeningocele. The baby was born at home and was taken to the local clinic were an ambulance was called but did not come until after four hours when nurses advised the mother to go by herself to UTH. The mother was given some money by the husband so she used it to book a cab to UTH.

M 11

Aged 23 years from Western province, married, and depended on cultivation for a living. This was the third child, male aged two weeks on admission and presented with occipital encephalocele. The baby was born in the bush as mother was being escorted to the clinic which was far from home and they had to walk. After the baby was born, they continued walking to the clinic. The clinic staff called for an ambulance from the second level hospital that picked up the baby and both mother and father. After a week, the hospital vehicle transported them to UTH. After the baby was operated on, they had to stay at UTH for some weeks because they did not have money to go back home.

M 12

Aged 24 years from Northern province, married and depended on cultivation for a living. This was her second child, male aged one month and a week on admission and presented with lumbar myelomeningocele. The baby was born at a local clinic and the clinic staff referred them directly to the second level hospital. The mother was told by the clinic staff that at the second level hospital there was a white man who pays for fuel for the hospital vehicle when there are patients who need to be transported to Lusaka. After two days, they travelled to the second level hospital and the baby was admitted and two days later she was given a referral letter to take to UTH. She was told to find money and use public transport because the white man who was providing money for fuel was out of town that time. So she had to go back to the village and the husband had to borrow some money while she also borrowed some from a local cooperative and she started off to Lusaka with her two children. She was received by her cousins and she spent the night at her uncle's place who took her to UTH were the baby was admitted.

M 13

Aged 28 years from Copperbelt, husband left her for another woman while she was pregnant. She used to sell local brew and sometimes fish for her living. This was her third child, male aged three weeks and presented with meningocele. The baby was born on the way as she was being escorted to the first level hospital. When she felt like the baby coming, they had to ask from one of the houses in the village and that was how she delivered in one of the houses. After delivery, they had to continue to the hospital when they noticed the wound on the back of the baby. At the hospital, she was transported to the second level hospital where she was later transported to Lusaka.

M 14

Aged 22 years from central province, married, husband went back to school to complete his secondary school. Unemployed and depended on cultivation. This was a third child, male aged one month on admission and presented with myelomeningocele. The baby was born at home and they took him to the first level hospital where the mother was charged K50,000 for delivering at home. After a week she was referred to UTH and went by public transport with money with her mother's sister who escorted her.

M 15

Aged 26 years from Central province, married, depended on cultivation for a living. This was a third child, male aged two weeks and presented with lumbar meningocele. The baby was born from home and upon seeing the lump, they took him to the nearest clinic. The clinic staff referred them to the first level hospital, where they were taken to the second level hospital by hospital vehicle. At second level hospital they stayed for a week and were transported to Lusaka by hospital vehicle.

M 16

Aged 33 years from Northern province, husband died when she was pregnant and depended on cultivation for a living. This was the sixth child, female aged three weeks on admission and presented with lumbar meningocele. The baby was born at the first level hospital by caesarean section and after three weeks, the mother was told to find transport money to take the baby to Lusaka because the hospital ambulance had broken down. She had to borrow money and she travelled to Lusaka by public transport.

M 17

Aged 21 years from Southern province, married and depended on cultivation. This was her second child, male aged four months on admission and presented with an occipital encephalocele. The baby was born from home and after seeing the lump on the head, they took him to the nearest local clinic where they were given a letter to go to the first level hospital. Next day they took the baby to the hospital and they were told to find transport money to take the baby to Lusaka. They did not have money so they went home and stayed. After three months, some white people, whom she described as dentists visited the village and gave her transport money to take the baby to Lusaka. She had to wait for the husband and they started off when the baby was four months old.

M 18

Aged 29 years from North Western province, married and depended on cultivation. This was her third child, male aged three months and presented with lumbosacral myelomeningocele. Delivered at the first level hospital and was asked by the doctor to go back home and return to the hospital after three weeks. When she went back, she was told to look for transport money to travel to Lusaka and she went home, sold the maize which she had and started off after three months. When she reached at UTH, she was charged K 80, 000 by pass fee because the referral letter has no hospital stamp and therefore they regarded her as a self-referral.

M 19

Aged 36 years from Central province, married and husband was a plumber and she used to sell at the market. This was the sixth child, male aged four months and presented with lumbar myelomeningocele. The baby was born at the first level hospital and after three days she was asked to go home because the baby was too small to be taken to Lusaka. She stayed home and after a month, the wound ruptured and the following morning she was taken back to hospital and was put on injections for one week after which she was given a letter to take to Beit Cure Hospital in Lusaka. The hospital staff at the hospital contributed some money for her and an ambulance took her to the second level hospital. At the second level hospital they told her to wait until transport was available but she told them that she would use public transport and so she was allowed to go to Lusaka after a week. She went to UTH and the baby was admitted in a medical ward because they said he had meningitis and after three weeks he was transferred to the paediatrics surgical ward for insertion of the shunt. She was however told to go back home and return after two weeks and she went and stayed with her sister in Lusaka and returned to UTH after two weeks. The shunt was inserted and she went back home and returned on 16th September, 2011, when she participated in this study.

M 20

Aged 20 years from North Western province, married and unemployed. This was her first child, male aged one month and presented with a large occipital encephalocele. The baby was born at the first level hospital and the hospital gave them money for transport so that they could take the baby to Lusaka. She travelled with the husband to Lusaka by public transport. When the baby was operated on, it was found that the encephalocele contained more brain tissue and the baby died three days after surgery.