

PHYSIOTHERAPY MANAGEMENT OF SPINA BIFIDA IN LUSAKA, ZAMBIA

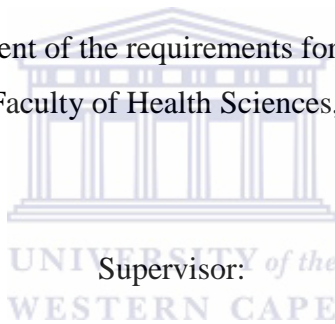
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Thesis submitted in partial fulfillment of the requirements for the Degree of Master of Science in
the Physiotherapy department, Faculty of Health Sciences, University of the Western Cape



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KEY WORDS

- Physiotherapy
- Management
- Spina Bifida
- Zambia
- Process of care
- Experiences
- Profile
- Role
- Rehabilitation
- Disability



ABSTRACT

Background: Spina Bifida (SB) is one of the leading causes of disability in children globally. Its management in Sub-Saharan countries is quite challenging and has shown to be an expensive public health problem. A recent study on SB has shown that physiotherapy is poorly utilised in Zambia. Although it is very cardinal in the rehabilitation of children right from birth, very little is known on the role of physiotherapy in the management of children with SB. **Aim:** To investigate the role of physiotherapy in the management of SB patients both at the University Teaching Hospital (UTH) and Beit Cure International Hospital (BCIH) during the period: January 2010 to December 2014. **Study design:** A sequential explanatory mixed study design was used for this study. An adapted validated data extraction form was used to capture quantitative data from hospital records, while an interview guide was used in in-depth interviews and Focus Group Discussion (FGDs) with specialist physiotherapists. **Data analysis:** Quantitative data was analysed using SPSS version 23 and descriptive statistics represented on graphs, charts and tables in form of percentages and frequency distributions. Qualitative data was audiotaped during the focus group discussion and in-depth interviews, transcribed verbatim and thematic analysis was used. **Results:** A total number of 207 children with SB were managed during the period under review at the two hospitals with the most prevalent type of SB being myelomeningocele and hydrocephalus at 69.4%, commonly located in the lumbar region 53.3%, prone in female patients 55.6%. A total of 38% had an increased tone while 2% had low tone indicating the need for physiotherapy. Through purposive sampling, a total of eight physiotherapists took part in the qualitative study. Results showed that there are poor referral systems for physiotherapy at the two hospitals making follow up quite difficult at times. Information on physiotherapy sessions was not included in patient files but only indicated in the physiotherapy departmental registers. Some physiotherapists felt that their role in the rehabilitation process was not known amongst team members such as surgeons. However, the availability of assistive devices at the hospitals helped provide better services which in turn promoted improvement in patients and also contributed to motivation. **Conclusion:** Having undergone some training as rehabilitation team members, all the physiotherapists noted that training helped to empower them, gain experience and changed attitudes of some rehabilitation team towards them. It is therefore recommended that the referral system and documentation be improved upon in order to effectively work together as a rehabilitation team with common goals.

DECLARATION

I declare that “**The Physiotherapy Management of Spina Bifida in Lusaka, Zambia**” is my own work, that it has not been submitted for any degree or examination in any other university, and that all sources used or quoted have been acknowledged by complete references.

F. Banda

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11th January, 2016

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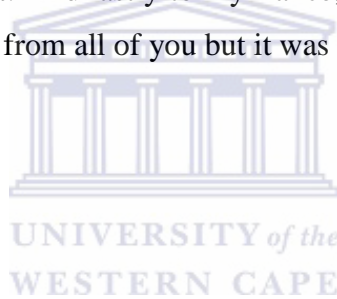
DEDICATION

“My son, hear the instruction of your father, and forsake not the law of your mother: For they shall be an ornament of grace unto your head, and chains about your neck.”

Proverbs 1 vs 8 – 9

Heavenly Father, I am grateful for being faithful to me and opening many opportunities for me for your plans are to prosper me. I am more grateful for the parents that you have given me, to guide me through life.

Alport and Florence Banda this is a dedication to you for being such wonderful parents, I am truly blessed. To Mwiinga and Gideon thank you for your support and love to the middle sibling. To my grandmother, Melania Chipungu, aunties, uncles and cousins for thank you for believing in me and being an encouragement. And lastly to my fiancé, Sydney, thank you for being there for me. It was not easy being away from all of you but it was worth it.



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A word of thanks to the University Teaching Hospital and Beit Cure International Hospital management, physiotherapy departments and the records departments for all the assistance rendered to me, they made my research experience easier and worthwhile.

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Mr. Chabinga, Mr. Sithole, Mr. Muchindu, Mr. Kachale, Mr. Makhalla, Ms. Sakala, my course mates and friends God placed you my way for a time and you have all been a blessing to me. This phase of my education was made lighter by your support, insight, counsel and prayers. You are blessed for life.

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ABBREVIATIONS

BCIH - Beit Cure International Hospital

CIC - Clean Intermittent Catheterization

CNS - Central Nervous System

CT - Computed Tomographic scan

ETV - Endoscopic Third Ventriculostomy

ICF - International Classification of Functioning, Disability and Health

MRI - Magnetic Resonance Imaging

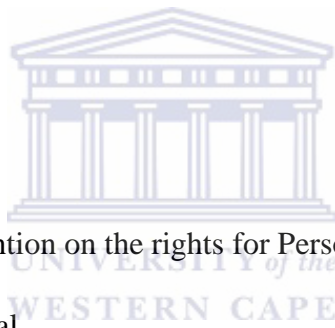
NTD - Neural Tube Defect

PWD - Persons with Disabilities

SB - Spina Bifida

UNCRPD - United Nations Convention on the rights for Persons with Disabilities

UTH - University Teaching Hospital



CHAPTER ONE

INTRODUCTION

INTRODUCTION

This chapter is an outline of background of Spina Bifida management worldwide and in the Zambian context. The problem statement, research question, aim, objectives, significance and definition of terminologies of this study are further outlined.

1.1 BACKGROUND

Spina Bifida (SB) is one of the most common types of neurological conditions affecting the developing fetus (Bid, 2006). SB is second in incidence to congenital cardiac disease (Fiegggen, 2014). It is a neural tube defect (NTD) "... that occurs due to failure in completion of the neural tube around 28 days after fertilization causing, a defect in the surrounding vertebrae" (Gupta and Gupta, 2004; Lundry-Ekman, 2007). Furthermore, SB is estimated to occur in at least 1- 2 cases in a total of 1000 births worldwide.

This failure in formation results in spinal elements being exposed in a meningeal sac called a meningocele. Myelomeningocele may have neuronal elements or not which is a meningocele and they both represent open lesions; in closed lesions where the skin is intact they are called lipomeningocele, lipomyelomeningocele and occulta (Bid, 2005; Burke and Liptak, 2011; Mitchell, 2005). The most severe and common type of SB that is associated with high sensory and motor defects is myelomeningocele. Hydrocephalus occurs in association in at least 90% of cases, these two are the most recurrent and disabling malformations in neonates in Sub-Sahara Africa (Burke and Liptak, 2011; Macaldowie and Hilder, 2011; Qureshi, 2010).

Common causes associated with SB include medically diagnosed obesity in mother, maternal insulin- dependent diabetes in mother, insufficient folic acid intake by mother before pregnancy,

history of NTD affected pregnancy, genetics, radiation and certain medications like valproate and carbamazepine (Bid, 2011). Studies reported that environmental (lower economic status) and racial/ethnicity (more common in white than black women and more among hispanic than non-hispanic women) contribute to the etiology of SB (Lungu, 2004; Spina Bifida Association of North Texas; 2010).

According to studies done over centuries, mortality in children with untreated myelomeningocele is approximately between 90 – 100%, in most cases in developed countries approximately 14% of children do not survive past five years, and many present with Arnold Chiari malformations which causes an increase of 35% (Adick and Walsh, 2003; Lungu, 2004). Advancements in technology and science (McDonnell and McCann, 2000; Shurtleff, 2000), have extended the life span of individuals with SB into adulthood by approximately 75-85% (Ouyang *et al.*, 2007), in African countries the story is different and challenging (Miles, 2006).

SB is one of the risk factors that causes disability in children and is a burden of disease (Institute for Health Metrics and Evaluation, 2010). The responsibility of the multi-disciplinary team is to provide comprehensive habilitation and rehabilitation services and programmes for all Persons with Disabilities (PWD) (United Nations, 2006). According to Ingstad and Grut (2007), disability affects all aspects of an individual's life; different implications at different stages of the lifecycle. This condition represents a multi-factorial neuromuscular developmental disorder that crosses multiple disciplines and requires a coordinated input from all the health care professionals (Fletcher and Brei, 2010). Children with SB need specialists who can address issues such as hydrocephalus, neurogenic bowel and bladder, mobility, paralysis of lower limbs, motor and sensory impairments, spina and limb deformities, hip dysplasia, and learning difficulties (Adzick *et al.*, 2011; Bid, 2011; Dicianno *et al.*, 2008; Liptak and Samra, 2010) which include Neurosurgeons, Urologists, Orthopaedicians, nurses, physiotherapists, special needs teachers.

According to the World Health Organisation (2001) in the International Classification of Functioning, Disability and Health (ICF) framework, they decided to move away from the “Consequence of Disease” classification to “Components of Health” classification which treats patients in a holistic manner covering all aspects of their life and wellbeing. This tool would help in collaboration amongst members of the multi-disciplinary team. It addresses issues such as

components of functioning and disability, and also contextual factors (WHO, 2001). Addressing all aspects of an individual's life is cardinal because characteristically SB predisposes many children to varying activity and participation restrictions (IFSB, 2014), barriers exist in the communities where persons with disabilities live (WHO, 2001). Conditions that come with Myelomeningocele such as epilepsy, shunt malfunctions, endocrine dysfunction and the circumstance repeated hospitalizations, causes deterioration in the individual's health even despite having made some progress in some areas (Barf *et al.*, 2003; Burke and Liptak, 2011; Fieggen *et al.*, 2014). Most individual with SB have an Intelligence Quotient (IQ) of between average and low and some have a high IQ, but having an episode of shunt malfunctions in children with hydrocephalus tends to worsen or regress them (Barf *et al.*, 2003). SB and hydrocephalus in developing countries like Zambia leads to conditions like cerebral palsy (CP) and physical, psychological and social disabilities (Taylor and Francis, 2005). Factors such as non-infrastructures at schools, landscaping in communities, toilets, public buildings, insufficient funds to buy wheelchairs or assistive devices, long distances to schools, physical exercise programmes in schools can be limiting for these individuals (Fieggen *et al.*, 2014).

According to the Ministry of Health 2011 and 2012, in Zambia referrals start from the health posts and health centres (rural and urban) which operate at community level, level one hospitals operate at district level, level two hospital operate at provincial level and level three hospitals, which are considered specialist or tertiary hospitals, operate at national level. In the case of SB, the patients may pass through all those referrals before arriving at the top. In other walk-in cases, the first in line of management are the neurosurgeons (Lungu, 2004; Maifwa, 2014).

The management of SB myelomeningocele starts immediately after birth, when the sac needs to be protected, therefore a closure must be done ideally within 24 hours but definitely within 72 hours after birth so as to prevent infections of the Central Nervous System (CNS), spinal cord injuries and neurological damage (Fieggen *et al.*, 2014; Gupta and Gupta, 2004). Late presentations are common in Sub- Sahara African countries and infected, open, leaking and dirty wounds in SB are common as many families have to travel long distances to get access to services. This poses as a challenge for those from a low socio-economic background and in rural areas. This places the child at risk and it is likely to influence the prognosis and also eventually lead to death (Miles, 2006; Mweshi *et al.*, 2011; Simpamba, 2012).

According to the Australian Physiotherapy Association (APA) (2015), physiotherapy supports disabled children aged 0 to 18 years through treatment, management to reduce participation restriction. Physiotherapy in SB rehabilitation plays a big role in improving the quality of life through physical function, mobility and independence (Verhoef *et al.*, 2005). According to Thompson (2009) early physiotherapy is essential for optimal motor function: before surgery, so as to have an idea of the patient's condition and post-operatively for proper planning of a rehabilitation programme. Kumar and Singh (2003) emphasise that accurate assessment in SB is crucial, bearing in mind that the skin level of the defect and spinal level may not tally, some children may exhibit both upper and lower motor neuron lesions, and that the level may be asymmetrical. Despite the rehabilitation programme, most children are lost in follow-up and in other cases discharged before being referred (Djientcheu *et al.*, 2008; Lazareff, 2011) to other physiotherapists in their communities, though it is not easily accessible for all children (Simpamba, 2011). This leads to more complications in children with SB.

Myelomeningocele patients are poorly managed and it is one of the few conditions that survival and quality of life depends on initial management or mismanagement (Fiegggen *et al.*, 2014). A study conducted in Zambia observed that physiotherapy was poorly utilised by team members of a multi-disciplinary team in the management of SB, and a higher priority was given to HIV counselling, delaying milestones and counselling even despite it being evident that physiotherapists spend more time with these children throughout their lives (Mweshi *et al.*, 2011). Although a fair number of SB cases are seen in Zambia, little is known about the experiences of physiotherapists in the management of these cases as well as co-ordination among the multiple disciplines.

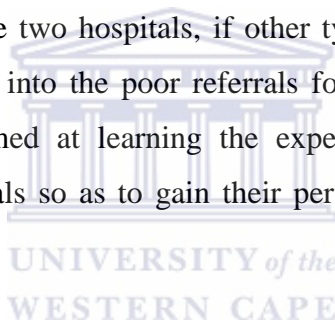
1.1 PROBLEM STATEMENT

According to Article 26 of the UNCRPD (UN, 2006) and the Persons with Disabilities Act No. 6 (2012) under habilitation and rehabilitation, it is emphasized that health service providers must ensure effective and appropriate measures to enable PWD to gain and maintain maximum independence - physically, mentally, socially and vocationally, and gain inclusion in all aspects pertaining to life. To attain this, many professionals are needed in the rehabilitation, as in the

case of SB where they bring different skills to help manage the patients comprehensively. Physiotherapy in the management of SB promotes ambulation, independence, postural maintenance (Burke and Liptak, 2011; Diccanno *et al.*, 2008).

Physiotherapy care in the management of SB at UTH and BCIIH in Lusaka, Zambia has been poorly utilized by members of the multi-disciplinary team. A study conducted between January 2001 and December 2010 found that 253 patients were managed with SB in Zambia and it showed that of the 188 children who underwent the CNS examination, 158 needed physiotherapy and only 36 had been referred (Mweshi *et al.*, 2011). These results reflect poor use of physiotherapy services.

To gain a clear understanding of the situation in Zambia, the researcher hopes to update the demographic profile of children with SB from January 2010 and December 2014, to follow-up on the management of SB at these two hospitals, if other types of management are still given priority over others. To also look into the poor referrals for physiotherapy that existed in the previous study. It was also aimed at learning the experiences of the physiotherapists in managing SB at these two hospitals so as to gain their perspective and to understand what is really on the ground.



1.2 RESEARCH QUESTION

What is the role of physiotherapy in the management of SB children at the University Teaching Hospital and Beit Cure International Hospital in Lusaka, Zambia?

1.3 AIM

To determine and explore the role of physiotherapy in the management of SB children at the University Teaching Hospital and Beit Cure International Hospital in Lusaka, Zambia.

1.4 OBJECTIVES

The objectives of this study are:

- To determine the demographic profile and the process care for children with SB at the University Teaching Hospital and Beit Cure International Hospital in Lusaka, Zambia.
- To explore the experiences of physiotherapists in the management of SB children at the University Teaching Hospital and Beit Cure International Hospital in Lusaka, Zambia.

1.5 SIGNIFICANCE

This research is expected to empower physiotherapists in Zambia and increase their involvement in the management of SB at these two hospitals and also to help them market their role to other health professionals through clinical presentations. The outcomes of this research will hopefully bring interventions by the Ministry of Health and Hospital systems in addressing the problem statement to the better lives of persons with SB and inclusive service delivery. This study will inform health professionals on the current profile in the SB in a developing country like Zambia and help improve collaboration amongst multiple disciplines in holistic management of SB. It will also give a deeper understanding of the experiences of physiotherapists in the management of SB.

1.6 DEFINITION OF TERMS

Activity - is the execution of a task or action by an individual (WHO, 2001).

Activity limitations - are difficulties an individual may have in executing activities (WHO, 2001).

Ancencephaly - “Absence of brain calvaria totally or partially” (Narasinga Rao and Pramila Padmini, 2011 pg. 1).

Arnold Chiari malformations – The downward herniation of the hindbrain, a common complication in myelomeningocele (Stevenson, 2004).

Birth defects - Malformations resulting from abnormal development in utero (Burton, 2008).

Disability - “a permanent physical, mental, intellectual or sensory impairment that alone, or in a combination with social or environmental barriers, hinders the ability of a person to fully or effectively participate in society on an equal basis with others” (Persons with Disabilities Act, 2012).

Endoscopic Third Ventriculostomy - it is the endoscopic perforation of the floor of the third ventricle to treat obstructive hydrocephalus (Koch and Wagner, 2004).

Habilitation - “To rehabilitate a person born with a disability” (The Person with Disabilities Act 2012).

Hydrocephalus - “Excessive accumulation of cerebrospinal fluid (CSF) within the cranial vault” (Poenaru and Bauman, 2011).

Lipomeningocele - “Closed NTD posterior vertebral defect and with fatty tumor that might contain neuronal elements” (Burke and Lipak, 2011).

Neural Tube Defects - are structural congenital anomalies that exist as a broad spectrum (Gupta and Gupta, 2004).

Occulta - “Benign closed NTD posterior vertebral defect only without a meningeal sac” (Burke and Liptak, 2011).

Participation restriction - Problems an individual may experience in involvement in life situations (WHO, 2001).

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” (World Disability Report, 2011).

CHAPTER TWO

LITERATURE REVIEW

2.0 INTRODUCTION

SB is one of the congenital malformations of the Central Nervous System (CNS) that is a major and expensive public health problem in much of Africa; it remains unrecognized (Adeleye *et al.*, 2010; Blenchowe *et al.*, 2010; Warf and Kulkarni, 2010; Warf *et al.*, 2010; Warf and Champbell, 2008). According to WHO (2009) one of the highest causes of death in children under five is HIV infection and in countries with low mortality (e.g. <30 per 1000 live births), neonatal deaths account for more than 60% of mortality.



2.1 PREVALENCE AND INCIDENCE OF SPINA BIFIDA

The global incidence of NTDs has declined over the last three decades; estimates run between 1.0 and 10.0 per 1000 live births, high incidences were noted in China by the 21st century to be 19.94 per 100 live births. Shehu and Ameh (2004) report an incidence of between 0.16 and 7/1000 births in Sub Saharan African countries where as other report to 0.98 per 1000 births, South Africa stands between 0.77 and 6.1/1000 live births with higher incidences on rural areas. However, in Zambia incidences are still high (Au, Ashley- Koch and Northup, 2010; Gu *et al.*, 2007; Fieggen *et al.*, 2014; Mweshi *et al.*, 2011; Sayed *et al.*, 2008). SB occurs more than cranial neural tube defects, with the prevalence of Encephalocele ranging between 1 in 2000 and 1 in 5000 live births (Gorlin, Corhen and Hennekam, 2001), Asia reports high incidences.

NTDs birth prevalence is highly influenced by the availability of prenatal diagnosis and elective pregnancy termination (Mitchell, 2005). Globally, SB occurs in 1-2 per 1000 births (Bid, 2011). According to the SB Association of North Texas (2010) it occurs in 7 out of every 10000 births in America. It is most common in Hispanic women 4.17 per 10000 seconded by Non-Hispanic

white women at 3.22 per 10000 and lastly Non- Hispanic black or African American women 2.64 out of 10000 .

In the United Kingdom and Ireland, the prevalence of neural tube defects is between 10-15 per 10 000 births (Busby *et al.*, 2005b). According to the Australian Institute of Health and Welfare (AIHW) National Perinatal Statistics Unit (2011), the prevalence of neural tube defects was between 1998 and 2008 stood at 0.22 per 10 000 births per year.

Miles (2006) reports that in Africa of every 1000 births between one to three may have had SB and/or hydrocephalus. It is likely that 140 of every 1000 births will die within 5 years, although less than 20 would have serious impairments at birth. Out of 140 children affected, at least 110 could be saved but due to poor use of basic low practices by the families such as use of traditional methods it is a cheaper alternative for them, little can be done (Miles, 2006). According to Christianson, Howson and Modell (2006) the prevalence of neural tube defects in South Africa is estimated at 2.5/1,000 births. Simpamba (2012) reports that nothing has been published in Zambia on the prevalence of NTDs.

Approximately 70% NTDs can be avoided by adequate pre-conceptual folate supplements (Thompson, 2009). Countries with food fortification policies report to less than 10 per 10000 per birth (International Federation for Spina Bifida and Hydrocephalus (IFSBH), 2014). There has been a decline in the prevalence of encephalocele, as well as anencephaly and spina bifida following implementation folic acid fortification of the food supply in Chile (Castilla *et al.*, 2003). According to Miles (2006) studies showed that in the 20th century incidence of SB has reduced in Western Europe over the years due to folic acid supplements and early detection at 10 weeks and abortion, they stand a high chance of being operated on within 24 hours after birth.

In America the prevalence ratio pre- and post-fortification implementation was grouped according to races and ethnic groups: all the races and ethnic groups SB 0.97, non-hispanic white 0.98 non-hispanic black 0.86 and hispanic 0.99 (Boulet *et al.*, 2008). Mitchell (2005) argues that despite implementation of folic acid supplements, the American health promotion campaigns to use folic acid more has had little impact on the prevalence.

With all these variations in reports other researchers state countries with mandatory folic acid food fortification programs show a 30%–50% reduction in prevalence (Castilla *et al.*, 2003; De Wals *et al.*, 2003; Erickson, 2002; Honein *et al.*, 2001; Mersereau *et al.*, 2004; Persad *et al.*, 2002; Ray *et al.*, 2002). Kaufman (2004) recommends food fortification as a better method to reach the high risk groups in developed countries. UNICEF (2004) reported that 10% of African countries have been unable to implement the food fortification policies. In Zambia, policies pertaining to food fortification and programmes aimed at improving nutrition in young women to promote healthier lifestyles, despite the scientific knowledge and evidence of NTDs may exist; but the implementation and its effectiveness is questionable (Djientcheu *et al.*, 2008; Ministry of Health Report, 2009).

Some studies have shown lack of knowledge among health professional on the use of folate; a study conducted in Delhi, India on obstetricians: found that they were all aware of folic acid, only 63% knew it prevents NTDs, 30% knew it and prevented NTDs, however none recommended a diet or pre-conception folic and 80% didn't know the dosage for prevention (Gupta and Gupta, 2000). Another study conducted among pharmacy students showed conducted 94% knew it prevents NTDs, 74% knew to commerce before pregnancy, 55% knew the recommended levels and good source (Lynch, 2002). These findings are possible in other contexts and also may account for the lack of knowledge of folic acid use among many women besides the lack of action in implementing these policies. Busby *et al.* (2005b) and Gupta and Gupta (2000) agreed with the lack in knowledge especially with high rates of unplanned pregnancies which made NTD prevention strategy more difficult, most women were unaware of being pregnant. A survey had been conducted on the awareness of women on folic acid (n= 1661): 85% were aware, 77.7% had correct knowledge and 30.5% utilized it, this awareness was high among women with post-university education (25-29 years) (Amitai *et al.*, 2004). Gupta and Gupta (2000) conducted a study in India that reported 20% of the population interviewed had heard of folic acid but they all had no knowledge when it should be taken and its purpose. Oleary, Donnell and Johnson (2002) also carried out a survey among Irish women which reported that 92% had heard of it, 67% knew it prevented NTD and 30% had it prescribed and 18% adhered. A study has shown low use of folic among women of low educational levels and low economic status in Zambia; another showed that 51% used folic, 49% did not use folic pre-conceptually (Lungu, 2004; Simpamba, 2011).

2.2 TYPES OF SPINA BIFIDA

The common types of NTD specifically SB vary from country to country, in the European Union approximately 4500 pregnancies yearly are affected by NTD, a study was done in America that showed 76.8% had myelomeningocele (Deak *et al.*, 2008; Thompson, 2009).

Another study done in a West African city found that the most common defect in the children with NTDs was myelomeningocele, others conducted in Zaria and Nigeria on SB cystica showed prevalence in meningocele with meningocele compared with myelomeningocele. A study conducted in Uganda showed that 42.9% of the children had myelomeningocele, others done over different periods showed the prevalence of Myelomeningocele by a great margin from the other types by 72% in one and the other 61% (Lungu, 2004; Mweshi *et al.*, 2011; Shehu *et al.*, 2000; Warf, Wright & Kulkarni, 2011). The majority of the studies global weigh more towards Myelomeningocele being the most common which is a burden of disease from all spectrums clinically, the family and the individual.

Studies done by Djientcheu *et al.* (2008) and Maragon *et al.* (2010) Nigeria and Cameroon showed that SB was predominant among male. They further gave potential reasons for predominance among females due to embryonic developments' differing which is highly susceptible to teratogenic insult and spontaneous abortion rates. In Zambia studies conducted showed prevalence in girls by 56% and another showed the majority being male patients (Lungu, 2004; Mweshi *et al.*, 2011). This inconsistency reflects no pattern or trend in the most prevalent gender; however, the majority of studies done in different regions may show a pattern.

Kumar and Singh (2003) reported that the level of SB relies on referral patterns and access to care; usually about 40% are lumbosacral, 30% lumbar, and 30% thoracic or thoracolumbar that is In India. A study conducted in Malaysia reported that 79% of the lesions were located in the lumbar and sacral regions (Idris, 2011). Campbell, Vander and Palisano (2006) are likely to support findings that reported lumbar region as the most common because the lumbar region is the last part of the neural tube to close; approximately 80% of lesions occur in this region. Conversely, some studies have found that the lumbo-sacral region is the commonest site for SB (Shehu *et al.*, 2000; Idowu and Apemiye, 2008; Warf, Wright and Kulkarni, 2011). Lungu (2004) found that it was common in the sacral region by 36.1% between 1994 and 2004, whereas

Mweshi *et al.* (2011) between 2001 and 2010 found it common in the lumbo-sacral region by 61% in Zambia.

2.3 RELATED CONDITIONS

2.3.1 HYDROCEPHALUS

Hydrocephalus occurs in association with SB in at least 80 to 90% of cases; these two are the most recurrent and disabling malformations in neonates in Sub-Saharan Africa (Burke and Lipta, 2011; Macaldowie and Hilder, 2011; Miles, 2006; Qureshi, 2010). Congenital malformation of the brain posteriorly in early stages of development namely Arnold Chiari malformations type I and II contributes to hydrocephalus. Another study showed that ill health and smoking during pregnancy as well as premature births contributes (Baystone, 2005). It is recommended that all SB patients must be monitored because chances of hydrocephalus among them are high. Studies in Central Africa report that the common causes of hydrocephalus are NTDs and congenital aqueductal stenosis (Poenaru and Bauman, 2011). In East Africa, neonatal meningitis or ventriculitis are the common causes (Warf, 2005), and in Zambia the ratio stands at 2:1 for congenital hydrocephalus to post-meningitic hydrocephalus (Poenaru and Bauman, 2011). Adeloye (2001) found that was due to post infection in 57% of cases and non-post infection 29% and 13% myelomeningocele, which was in contradiction to the findings by Poenaru and Bauman (2011) on NTDs being cause of hydrocephalus.

The most effective method used to investigate malformations such as Chiari II malformation would be ultra-sonography and MRI are than CT scanning (Fieggen *et al.*, 2014). This leads to the two types which is congenital (detected at birth) and acquired (injury, illness and environmental factors) hydrocephalus.

The prevalence in every live birth per 1000 in congenital hydrocephalus is 1 and 0.2 in Acquired Hydrocephalus (Maifwani, 2009; WHO, 2005) and it affects both genders (Silvia, 2005). The prevalence of hydrocephalus together with SB is still high. A study done showed 61% of the patients had both between 2001 and 2010 (Mweshi *et al.*, 2011). Many studies globally reported that it is a burden disease, straining and requires constant monitoring in its management (Avellinos, 2008; Fieggen *et al.*, 2012; Miles, 2006). Shunting in children with hydrocephalus

imposes a burden for the child in the future (Thompson 2009). Its complications are not only detrimental to cognitive outcome (Barf *et al.*, 2003), but also affects survival in the long run (Davis *et al.*, 2005; Oakeshott and Hunt, 2003; Tuli *et al.*, 2003; Tuli *et al.*, 2004). Some researchers use this as reason to avoid shunting if possible where possible; conditions like moderate ventriculomegaly and even some post-operative increase in ventricular size frequently stabilise without intervention (Thompson, 2009), Chakraborty *et al.* (2008) reports 52% reductions in shunt replacement.

2.3.2 DEFORMITIES

Deformities are common in persons with myelomeningocele, especially in thoracic and lumbar clubfeet, equinus, valgus, cavovarus, hip subluxation and dislocation, scoliosis (in lesions above L2) and knee instability or contractures and these worsen as obese individuals grow older (Abresch, 2007; Fieggen, 2014). Kumar and Singh (2004) report that the most common orthopaedic problem in SB is Scoliosis seconded by Congenital Talipes Equino Varus (CTEV). Dias (2005) reported that in myelomeningocele cases present with spinal bony anomaly, neuromuscular imbalance, leg length discrepancies, spasticity together with pelvic and hip deformity; these are mostly present in half of the young adults. A study showed that muscular strength, deformities have an influence in myelomeningocele to determine independence in self-care (Schoenmakers *et al.*, 2005). This is further supported by Burke and Liptak (2011) who stated that correction of deformities, posture maintenance promote mobility leading to increase in function and independence.

2.3.3 INCONTINENCE

According to Burke and Liptak (2011) people with people with myelomeningocele normally have neurogenic bladders and fecal incontinence; baseline sonogram of kidneys and bladder must be conducted in infants to establish any congenital anomalies or renal involvement. Many studies have emphasised the need for children with myelomeningocele to see a urologists so as to plan ahead for the child and also prevent complications that can be avoided such as urinary tract infections (UTI), renal tract injury, progressive renal damage (youths and young adults which eventually leads to death) (Bauman and Poenaru, 2011; Fieggen *et al.*, 2014; Thompson, 2009; Woodhouse, 2008). A study reported that changes in urinary function may reflect UTI or

tethering in spinal cord (which can relate to shunt malfunction as well) (Poenaru and Bauman, 2011). Incontinence tends to affect one as it limits their social relations, independence and self-esteem is lowered.

2.3.4 SKIN PROBLEMS

In SB loss of skin sensation and autonomic responses to pressure or irritation is common with permanent damage that requires a life time managing; breakdown of skin and decubitus ulcerations accompany one and must be treated promptly to minimise the risk of complications (Burke and Liptak, 2011). The ulcerations are more frequent in children older than 5 years (Kumar and Singh, 2003).

2.3.5 DEVELOPMENT

Many individuals with myelomeningocele are within normal range intellectually, although many experience learning disabilities: non-verbal learning disorders, poor executive skills, attention deficits, and memory problems (Burke and Liptak, 2011; Lindquist *et al.*, 2008). According to Wilson (2012) the branch of disability that affects the cognitive functioning (learning, reasoning and problem solving) is called intellectual disability that hinders social, practical and conceptual behaviour (AAIDD, 2011).

In a study conducted on young adults with myelomeningocele to assess their neuropsychology, half of those with hydrocephalus presented with some impaired cognitive functioning and in those without hydrocephalus results were similar to the general population (Barf *et al.*, 2003). Researchers have rated the IQ of myelomeningocele patients as being between average and low, in others it is high (Barf *et al.*, 2003, Fieggen *et al.*, 2014). Oakeshott and Hunt (2003) reported that approximately 70% of the patients have an IQ of 80 and more, 70 or less is a sign of cognitive impairment (Wilson, 2012).

Shunting in hydrocephalus has been reported detrimental to cognitive outcomes (Barf *et al.*, 2003; Thompson, 2009), which contributes to the delay in maturation and abilities to acquire skills for independent living (Holmbeck *et al.*, 2003). Conditions such as lipomeningocele and

traumatic paraplegia are distinguished from myelomeningocele by their impact ending at spinal level where as myelomeningocele goes beyond (Schoenmakers *et al.*, 2005).

2.4 OVERALL MANAGEMENT OF SPINA BIFIDA

The overall management of SB reflects the process of care that any child will experience in their lifetime especially if it is the most severe type of SB, myelomeningocele. SB management is dependent on type of SB, severity and the location and most management revolves around myelomeningocele (Bid, 2011; Lungu, 2004). In developed and developing countries management is centred on the medical, surgical, orthopaedic, urological, physiotherapy and orthotic for the rest of their lives (Dicianno *et al.*, 2008).

The management of SB requires open communication among the team including the family of the patient and proper and thorough planning is of great importance. Fieggen *et al.* (2014) recommends a written discharge plan as well as planning discharge upon admission so as to meet the needs of the child and family and be able to provide support programs this is to ensure comprehensive management. Clinical management of SB is challenging, studies done in some African countries like Nigeria, Cameroon, Kenya and Uganda on the management of children with SB have reported challenges encountered in management (Adeleye *et al.*, 2009; Blenchowe *et al.*, 2010; Warf and Kulkarni, 2010; Kulkarni *et al.*, 2010). Most families of these patients come from harsh social and economic realities, myths and beliefs, inadequate medical manpower and inadequate health services hence they present in delay with numerous open, septic and dirty myelomeningoceles (Campbell *et al.*, 2000; Djientcheu *et al.*, 2008; Idowu and Apemiye, 2008), which is a fate most of these children have to face and this is something a developing country like Zambia cannot run from and comprehensive care is less possible. In a study conducted, Lungu (2004), he found that 86.1% of mothers participating in the study came from low-income families and 45.7% of the mothers had primary education. We can deduce from this information that if the majority of patients' families come from low economic backgrounds and with primary education that information dissemination is likely to be a challenge. Miles (2006) reported that more educated parents participate more actively in the rehabilitation process and that those from urban areas show a better prognosis. Management is sub-divided into groups:

2.4.1 SURGICAL MANAGEMENT

Surgery is a must in myelomeningocele management as the mass tends to enlarge over time; this involves closing the dura mater and skin over lesion to prevent an infection in the CNS although it does not reverse the neurological deficit which must be done within 72 hours after birth. The possibility of surgery within 48 hours of birth in European countries is higher than Sub-Saharan African countries (Fiegggen *et al.*, 2014; Miles, 2006). Fiegggen *et al.* (2014) also reports that in South Africa and other developing countries operations that are meant to be conducted by neurosurgeons are being done by other surgical specialists; we can speculate that in some scenarios it could be due insufficient manpower in some institutions that are closer to these families. However, in the process to save lives, some children are left with lifelong impairments and related to more complex cases, Miles (2009) observed that in North African countries and South Africa, the larger population of surgeons are located more densely in urban areas, which becomes a challenges for health care access. Post-operative complications of leaking CSF and wound infections have been reported in Cameroon, Nigeria, Uganda and Kenya due to economic and social situations; infections and late presentation (Shehu *et al.*, 2000; Djientcheu *et al.*, 2008; Idowu and Apemiye, 2008; Margaron, 2010).

According to Thompson (2009), in developing countries cases where there is known direct trauma, hydro-dynamic pressure and exposure to amniotic fluid repair can be performed in utero. It has been reported that it may help improve neurological motor outcome, morbidity and a reduced in shunt dependent hydrocephalus, although long term benefits have not been discovered. It is more risky than beneficial, risks include premature births, chorioamnionitis and abruption of the placenta - hence undergoing the risk is a gamble but not an option that should be overlooked (Johnson *et al.*, 2003; Tulipan *et al.*, 2003; Walsh and Azdick, 2003; Mayer *et al.*, 2010).

Ventriculoperitoneal is a commonly used method and the advantage is that the catheter used would have to be longer to accommodate growth, hence there is no need for many operations every time the individual grows. Other studies do not recommend it, as it is associated with over-draining of CSF, infections and shunt obstructions, and the safer and more reliable alternatives would be Endoscopic Third Ventriculostomy (ETV), ETV-CPC (Choroid Plexus Cauterisations) and Z-plasty (Kulkarni *et al.*, 2010; Maifwani, 2014). Previously ETV had been

used for cases of congenital aqueductal stenosis in older children or adults, however a study done in Uganda and Nigeria demonstrated that for all children irrespective of aetiology with an 80% rate to avoid replacements and hospital visits; ETV and CPC come highly recommended for developing countries and has been reported to have a high success rate. The children managed came from Kenya, Tanzania, Malawi, Somalia, Rwanda, Congo and Mauritius (Idowu and Apemiye, 2008; Sacko, 2010; Warf, 2005). Poenaru and Bauman (2011) agreed with other studies on the use of ETV but they felt it is limited by technology and skill, they went on to recommend VPS in early treatment as the best for African countries in preventing disabilities due to increased intra-cranial pressure. The most commonly used method in Zambia is Z-plasty that was combined with SB repairs at 70%, VPS and repairs by 10%, 8% for ETV-CPC and repairs and 1% for ETV and repairs, 11% were aborted surgeries (Mweshi *et al.*, 2011). In Uganda, ETV is mostly used and has been more effective in the management of Hydrocephalus; it is also low cost procedure (Sgouros *et al.*, 2006). Poenaru and Bauman (2011) and Dias *et al.* (2006) recommended a delay in shunting of at least 5 days after myelomeningocele repair due to high risks; Thompson (2009) stated that if it is evident at time repair that the infant has hydrocephalus, shunting in 15% can be performed simultaneously as long as there is no trace of increased infection as compared to what has been suggested in the study earlier mentioned.

Tethering in the spinal cord is usually overlooked and causes deterioration in SB myelomeningocele. Initial surgical repair causes a low spinal cord and eventually traction on cord due to growth leads to injury on the nerve roots and secondary neurological and urological deterioration, pain and progressive spinal and foot deformities. A recommended method is early detection of deformity and a procedure to untether the spinal cord (Hudgins and Gilreath, 2004; Yamada *et al.*, 2004). Some spinal deformities such as severe cases of scoliosis may require surgical interventions based on the neurological level, a study conducted in America showed that spinal fusion was given to patients with lesions in the thoracic level by 86% (Bowman *et al.*, 2001).

In the case of incontinence, a vesicostomy (a hole placed in the abdominal wall into the bladder) may be indicated where Clean Intermittent Catheterisation was unable to optimise pressure within the bladder (Burke and Liptak, 2011). Mweshi *et al.* (2011) shows 1% of patients managed received continence care. One would assume that since most of the patients managed

over the ten year period were under 6 months old, however the files contain all information up to date, indicating that some patients never returned; a good number were old enough for CIC.

Management of ulcers can be challenging, saline dressings are normally used and pressure areas must be supported, other types benefit from plastic surgery and others caused by incontinence required management of the underlying issues (Poenaru and Bauman, 2011).

Foot deformities in myelomeningocele patients require correcting with the goal of obtaining a plantigrade, mobile and braceable foot, and avoiding trophic ulceration. Some corrections may require surgical interventions such as posteromedial release, others stretching and casting in neonatal period (Fieggen *et al.*, 2014; Flynn *et al.*, 2004).

2.4.2 MEDICAL MANAGEMENT

In SB management, standard practice recommends use of prophylactic intravenous antibiotics especially in cases where there is a CSF leakage, as it may lead to ventriculitis not to give reassurance, but as an anti-microbial measure. Despite there being little evidence to support this practice, as long as closure occurs within 48 - 72 hours this is combined with sterile dressings on wound to prevent damage through excoriation or desiccation (Thompson, 2009; Fieggen *et al.*, 2014). Ventriculitis has been the highest cause of hydrocephalus in East Africa (Poenaru and Bauman, 2011). Medical management is effective for acute hydrocephalus. This is usually done to delay surgery in premature infants. The medicine is aimed at decreasing CSF secretion or increase CSF reabsorption.

Dik *et al.* (2006), Fieggen *et al.* (2014) and Thompson (2009), reported in the American and African context that the use of anti-cholinergic drugs helps to improve bladder capacity and aggressive management of constipation. Prognosis of renal damage is reduced, and social continence can now be achieved by 80% of the children with or without Clean Intermittent Catheterisation (CIC) (Bowman *et al.*, 2001; Kessler *et al.*, 2006). Dias (2005) reported that renal deterioration is prevented in 90% of children with SB and 85% are able to receive social continence through CIC; with or without medication.

2.4.3 OTHER MANAGEMENT

A study conducted in Zambia showed the most utilised management other than surgical and medical interventions: milestones 41%, HIV counselling of parents 32%, stretching and POP 11%, mobility 3%, social function 5%, self-care 5%, continence 1%, (Lungu, 2004; Mweshi *et al.*, 2011).

In SB, myelomeningocele bladder dysfunction is ever present, which gradually leads to incontinence and is usually accompanied by chronic bowel constipation or fecal incontinence. However in children with SB myelomeningocele, they tend to experience recurrent urinary tract infections, high bladder storage pressure which eventually leads to renal damage (Burke and Liptak, 2011). In low socio-economic situations and developing countries, early introduction of CIC (it is cheaper and effective) is utilized; it promotes social incontinence and normalizes bladder pressure and daily bowel washout; it is advised to commence in infancy to monitor bladder function (Verpoorten and Buyse, 2008). This close monitoring may not be possible in all patients in many hospitals and considering how far these children are coming.

Sawyer and Macnee (2010) reported that having a disabled child places strain, anxiety and stress on families, which contributes to dysfunction and instability in families. Siblings are bound to feel loss, frustration and anger which affects their relationships. Furthermore, it is financially strenuous on the family because an average child does not require that much money compared to that which one with Spina Bifida will require in their life time (Bellin, Kovacs and Sawin, 2008; Holmebeck and Devine, 2010; Kelly *et al.*, 2008). That is why counselling is essential for the families, they need support and education on the condition (Walker, 2008), SB being a life-long condition that needs helping one understands it fully. This is evident of the value that was placed on counselling in other studies conducted in the management of SB (Mweshi *et al.*, 2011). Burke and Liptak (2011) advised including the family in the planning process as they know their circumstances best, as well as to help them understand the entire process their child undergoes. Poor information dissemination is a barrier in the rehabilitation process (Harris *et al.*, 2008). The absence of information makes it difficult to manage the child, which is why it is important to help the family understand the need for all the procedures and their benefits for their child.

Nutritional problems are common among persons with SB; obesity is common in developed countries, whilst in developing countries they have nutritional deficits (Poenaru and Bauman, 2011).

Schoenmakers *et al.* (2005) early recognition and interventions in SB patients with developmental challenges help optimise learning and social participation.

2.4.4 PHYSIOTHERAPY MANAGEMENT

According to Meeusen (2005), physical exercise and activity are stimulants for the brain, it increases serotonin levels and contribute to behaviour patterns. In milestone development, mobility stimulates growth and development (Özek, Cinalli and Maixner, 2008). Mobility helps improve an individual's quality of life and contributes to his/her independence (Vladusic and Phillips, 2008). Physiotherapy in the management in SB is aimed at maximising function and minimising incapacity, and modifying the client's environment to ensure their fullest possible participation in society, thereby increasing autonomy and empowerment (World Confederation for Physical Therapy, 2011).

Vladusic and Phillips (2008) applied the ICF in the assessment of SB which had orthopaedics, orthotics and physiotherapists as an influence in environmental factors which would improve the patients' participation in sports, social activities, and education to enhance their quality of life. From the psychosocial perspective, personal and environmental factors might be of great importance (Pit-ten, Kennedy and Stevenson, 2000; Schoenmakers *et al.*, 2005).

The older patients with SB grow, the greater the needs that arise due to disability. Mobility worsens the older they become, depending on the level of lesion (Diccanno *et al.*, 2008). This affects their independence and limits them. Studies report that, based on traditional teachings, "independent ambulation is possible if the quadriceps are strong (L3–4)"; others conducted over longer periods show a decrease with age despite stable neurological status (Dias, 2005; Kaufman, 2004). Another study argues that the evaluation of independence in mobility can be based more on the patterns used in lower extremities than level of lesion (Schoenmakers *et al.*, 2005). Bruinings *et al.* (2007) supports these findings and attributes it to factors such as increasing weight, spinal and foot deformity, respiratory (which causes a preference for

wheelchair use) and for those with high located lesions wheelchair use is a requirement. Hence it is important to achieve gross motor milestones as they graduate from infancy through childhood to adulthood (Bid, 2011), hence the need for physiotherapy cannot be confined to a specific age group in SB. The studies show recommendation for early use of physiotherapy services and orthotics, being able to move around independently is important especially as they grow older, though studies show that the older these children grow (Poenaru and Bauman, 2011). This helps planning for prospects such as going to school and employment in the future. Educating transfers, use of assistive devices and other appliances is cardinal.

In both developing and developed countries, establishing muscle function in goal setting has shown an influence in posture, muscular balancing, ability to move as contractures arise (Bid, 2011). This eases observing progressive neuro-dysfunction; hence the maintenance of a range of motion in inactive limbs to maintain muscle bulk is of uttermost importance. Schoenmakers *et al.* (2005) questioned the extent to which physiotherapy can treat or manage contractures as surgical interventions help restore the muscular imbalances. Other studies report that physiotherapy has had more progress with the ponseti treatment than orthopaedic surgeons (Janicki *et al.*, 2009; Kampa *et al.*, 2008; Shack and Eastwood, 2006).

Physiotherapists play a role in educating caregivers on activities to help achieve goals set for physical rehabilitation, as they are also part of the planning process. One has to be considerate of the socio-economic status of the family when prescribing and making suggestions (Goodman and Fuller, 2009). Peng *et al.* (2014) recommends collaborative goal setting to achieve concrete strategies for the patient.

Exercise benefits the body generally in SB peripheral circulation, bowel function, reduces obesity, reduces sedentary lifestyle and urinary (Roussos *et al.*, 2001) which are all challenges SB patients are likely to experience. Most articles reviewed are more oriented on mobility in relation to physiotherapy management which is an indication of its importance as one grows older (Bid, 2011).

Mweshi investigated the number of children referred for physiotherapy that had needed physiotherapy and the findings showed: CNS assessments were investigated, 188 out of 253 files

(74%); 116 (62%) had reduced tone, 42 (22%) had increased tone and 30 (16%) had normal tone. Of those examined the following were referred for physiotherapy: 26 (24%) were referred and 90 (76%) were not referred with reduced tone, 10 (24%) were referred from those with increased tone and 32 (76%) were not referred. We may deduce from these findings that physiotherapy was not given a priority by the team members looking at the evidence of some being referred. It could also reflect that the some members of the multi-disciplinary team may not know the role of physiotherapy in the management of SB in Zambia.

Evidence of the efficacy of interventions for patients with SB regarding the best interventions is limited. Furthermore, a gap does exist in literature regarding physiotherapy being proven to play a major role in promotion of activity and participation in children with SB (Hinderer *et al.*, 2006) although there is little evidence to guide best practice in rehabilitation.

2.5 PHYSIOTHERAPISTS' EXPERIENCES IN MANAGING SPINA BIFIDA

Physiotherapists have had different experiences in managing SB children. Larsson *et al.* (2012) researched the experiences of physiotherapists in rehabilitation and found that health and disability paradigms led to different approaches to rehabilitation which in turn determined the intervention process strategies for the assessment and treatment. Furthermore, different aspects contribute to the approaches in physiotherapy and influence their experiences in rehabilitation. According to the European region of the World Confederation for Physical Therapy (2003), a cheerful and patient physiotherapist can draw the attention and co-operation of both parent and child in the course of therapeutic management. This helps achieve the desired goals set at the end of the day. Moreover, Harris *et al.* (2008) have shown that physiotherapy management works better if caregivers understand the purpose and goals set for physiotherapy management. Conversely, it has been reported that home programmes prescribed by physiotherapists may be poorly carried out by caregivers if they do not understand the scope of therapy (Sousa and Singhvi, 2011). The authors further added that educated parents are able to co-operate in the rehabilitation of their children with disabilities as opposed to others.

It has been reported that adherence to rehabilitation in rural areas is a challenge as many people in rural areas would turn to traditional methods and stop therapy (Magnussen, 2011). It is

possible that individuals may even be referred for physiotherapy and prefer to use traditional methods for treatment; they are more accessible, in-line with culture and concepts as perceived by the families (Baskind and Birbek, 2005). This is in accordance to the report by the World Health Organisation (2011), which reported that in low and middle income countries, myths and misconceptions have restricted attention and the implementation of interventions. However, Mlenzana *et al.*, (2013) argue that people with disabilities desire to be seen as a whole and not only their disability.

This is evident that if a child and their parents felt discouraged by the approach of the physiotherapist, it would affect the families' input in rehabilitation and the relationship with the physiotherapist. In another study, Joffe *et al.* (2003), reported that the perceptions of patients and their families, including how they perceive the physiotherapist and response to treatment or rehabilitation is correlated with respect and dignity. Baltacioglu *et al.* (2007) emphasized the importance of relationships amongst team members and the family, as it is common in the healthcare system in developing countries for this link to be overlooked; which is one of the ways to evaluate the effectiveness of the rehabilitation process.



2.6 RELATIONSHIP OF DISABILITY, POVERTY AND ACCESS TO HEALTH CARE

According to the United Nations (2006), the protocol for persons with disabilities (UNCRPD) is purposed to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Article 25 of the UNCRPD states that "...parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation".

The population of people living with disabilities globally is estimated at approximately 650 million: children and adolescents constitute 200 million of those with disabilities (about 10% of the world's youth), and about 80% of these live in the developing world and experience physical, sensory, visual, audio and intellectual or mental disabilities (United Nations Disability Fact

Sheet, 2006). In addition, 93 million children aged 0-14 in the world have moderate to severe disabilities (WHO-WB, 2011, p. 36).

Many children with disabilities have limited access to health care services, rehabilitation opportunities and live in poverty; which leaves them out on essential developmental opportunities (The United Nations Children's Fund (UNICEF), 2006). According to the WHO (2005), the majority of persons (at least 80%), with disabilities reside in low and middle income countries, and the numbers are still on the rise, with those in low income countries as the poorest (Bonnell, 2004). Such is evident in many Africa countries such as Kenya, Tanzania, Zambia, Uganda (Ingstad and Grut, 2007; Schellenberg *et al.*, 2003).

Loeb and Eide (2010) conducted a survey on the prevalence of disability at 13.3%, but the numbers are still on the rise; there is limited literature on disability in children and availability of services as they are (UNICEF, 2008). A study conducted in Zambia on health care services delivered to children with SB showed that the services are available; however, logistics are usually the challenge in travelling to hospitals that manage conditions such as SB (Simpamba, 2012). Miller and Ziegler (2006) report that of 79% of small-scale farmers in rural areas live in poverty, 66% of them being extremely poor. These findings are supported by a study by Lungu (2004) which showed parents of children with SB being farmers and other being in the low income category another study reported low literacy levels among PWD.

Disability and poverty form a cycle that continuously challenges the lives of those affected (Yeo and Moore, 2003). With disability comes poverty, and in the case of patients with SB which requires rehabilitation as an ongoing process, one is bound for such a fate. Bonnell (2004) found poverty severe in persons with impairments. Studies on the inter-relationship between poverty and disability are on the increase, showing interdependence (Filmer, 2008; Hoogeveen, 2003; Ingstad and Grut, 2007; Magnussen, 2011; Trani and Loeb, 2010).

The rights of PWDs in Zambia are considered of high importance by the government, an Act was passed in 2012 on the rights of PWDs (The Persons with Disabilities Act No.6, 2012) that had domesticated the UNCRPD. However, the policies may have taken longer to be implemented as the procedure takes time and resources, which happens gradually. Bedding, Mtonga and Chalwe (2013) developed a National implementation plan or national disability main streaming plan that

had incorporated the ICF, ACT 2012 and UNCRPD to help carry out the policies and empower persons with disabilities. The time frames between the PWDs Act No. 6 of 2012, and the National Implementation Plan is small to have great expectations of implementation from the government, however the implementation plan was a very beneficial, effective and efficient decision. The core purpose of the implementation plan was to develop strategies that facilitate and promote equal opportunities for PWDs to explore their potential in all areas of life and enjoy their rights (Bedding, Mtonga and Chalwe, 2013). Hjortsberg (2003) supports the reports that the providers of healthcare in Zambia have embedded in their system a priority between both diseases and individuals, thus, affecting how people experience medical services.

According to the Ministry of Health (2006) healthcare in Zambia is constrained by factors such as: "...shortage of essential human resources, inadequate funding, the deprived state of existing health facilities and available equipment, inadequacies in the empowerment of local communities to gain better health, geographical access barriers particularly in the rural areas and a lack of information about traditional medicine". Almost nine years later, the case may have changed in some ways but these factors are still a challenge and this impact is not only in Zambia but other developing and developed countries too (Miles, 2006). In the case of SB management, some studies have shown challenges with geographical access having to travel long distances for management in Lusaka, inadequate equipment for diagnosis, deprived state of health facilities and also lack of knowledge of traditional medicines as it is still utilized by parents in the management of SB as the closest and cheapest alternative (Miles, 2006; Mweshi *et al.*, 2011; Simpamba, 2012), especially that policies still show implementation in progress meaning all expenses fall on the family (Magnussen, 2012). Eide and Loeb (2010) oppose the reports that persons with disabilities have limited access to health care; they reported that health services were available to a large majority of those with disabilities. Some researchers had predicted that challenges would increase in the health care system healthcare such as complexity of processes, efficient utilisation of resources, need for improved quality of services and the need to control the workload of personnel (Baltacioglu *et al.*, 2007). This was bound to arise to meet policy requirements.

The burden of disease is higher among the poor, their use of health care services is even lower (Government of the Republic of Zambia (GRZ), 2011). The healthcare system is structured to

meet the needs of people in need, however the financially stable can access it faster than others (Hjortsberg and Mwikisa, 2002), which could answer to the governments' report. To support these findings Van Dijk *et al.* (2009) reported that many children in the rural areas that have to travel vast distances to reach hospital areas had no finances, transport, poor infrastructures, which is evident in many studies conducted in Zambia and other developing countries (Birbeck and Munsat, 2002; Ingstad and Grut, 2007; Lungu, 2004; Schellenberg *et al.*, 2003; Simpamba, 2012).

2.7 CONCEPTUAL FRAMEWORK

Every organisation needs a service supply chain management system. A service supply chain has been defined as “a network of suppliers, service providers, consumers and other supporting units that performs the functions of transaction of resources required to produce services; transformation of these resources into supporting and core services; and the delivery of these services to customers” (Baltacioglu *et al.*, 2007).

This study used the service supply chain (SSC) model IUE- SSCM that was derived from the initials of the affiliated organisation of authors and Service Supply Chain Model (Baltacioglu *et al.*, 2007) as illustrated in **Figure 1**. It highlights distinguished characteristics of service and is unique as it could be applied into different fields like the healthcare industry.

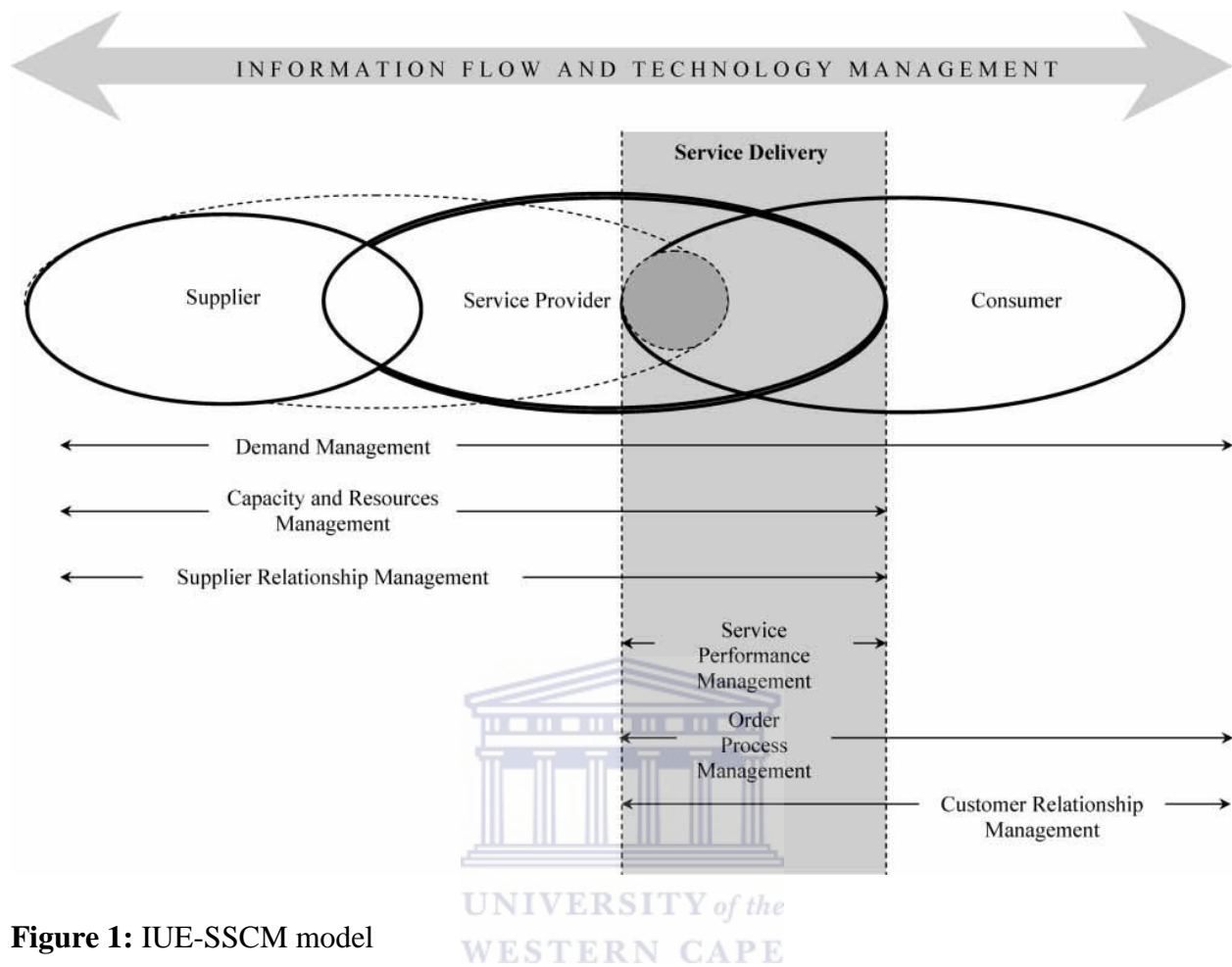


Figure 1: IUE-SSCM model

This framework is more comprehensive due to it being a combination of both the Supply Chain Operations Reference model (SCOR model) (Lambert, Cooper and Pagh, 1998) and the Service Supply Chain (Ellram *et al.*, 2004). The SCOR model is a cross-industry diagnostic tool for supply management widely used model and endorsed by the Supply Chain Council. It represents the company being the centre, buying from suppliers and selling to customers. Ellram *et al.* (2004) had proposed a framework that had been adapted from manufacturing-oriented supply chain management literature. It addresses issues such as “information flow, capacity and skills management, demand management, supplier relationship management, customer relationship management, service delivery management and cash flow”.

2.7.1 SERVICE SUPPLY CHAIN MANAGEMENT

The model has three components which are the supplier, service provider and the consumer which has been illustrated in Figure 2 to show its integration in the management of SB.

A. SUPPLIER

The supplier provides resources needed for the delivery of services to the service provider. In health care the supplier plays the role of the support services (Baltacioglu *et al.*, 2007). This order is place by the demand of the consumers. The quality of supplies is influenced by the supplier. Supplies in the case of SB may include shunts, assistive devices, Plaster of Paris and catheters.

B. SERVICE PROVIDER

The provider interacts with the consumer. The provider acts as the middleman between the supplier and consumer. There is an exchange of information between the consumer and the supplier that helps evaluate the service performance and place orders in the ordering process with the supplier. The provider also manages the capacity and the resources of the organisation. The provider plans ahead to prepare all the necessary resources required in the management such as transport for operations from other hospitals, bed space planning of treatment for patient and ensuring that the gets all the comprehensive rehabilitation needed.

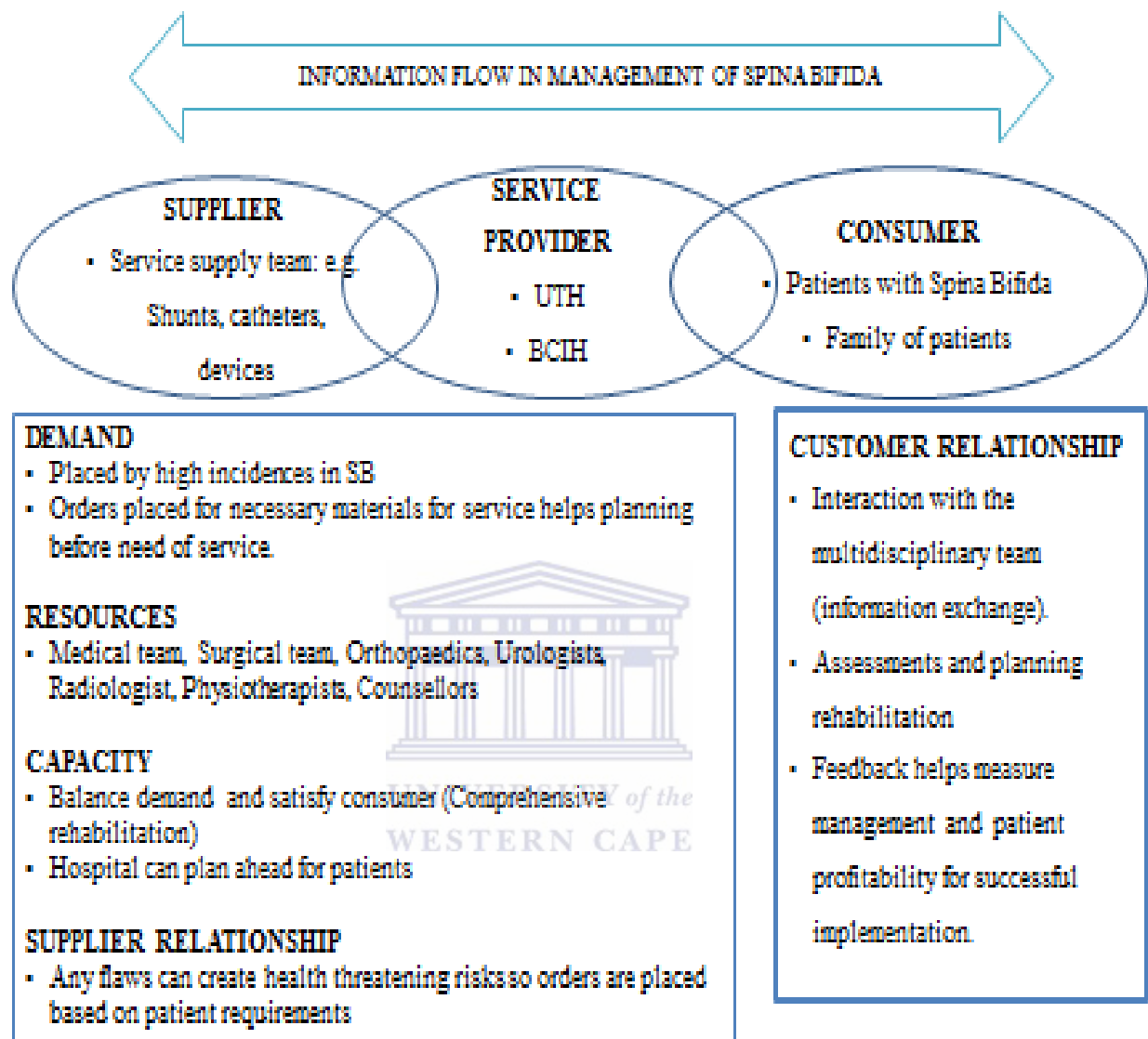


Figure 2: IUE-SSCM applied to SB management

C. CONSUMER

The consumer places the demand on services which engages identification, forecasting and referring to organisation’s resources (members of multi-disciplinary team) (Baltacioglu *et al.*, 2007). High incidences of SB increase the demand. The consumer also provides feedback for the multi-disciplinary team to help them evaluate the timing and the quality services they have

provided (Sakjuja and Jain, 2012). A failure in team collaboration will be seen in the patients' improvement and condition.

The effective supply chain results in outcomes for the service provider such as Impairment outcomes (measures of change as a result of intervention), Clinician Role Development (Role of a physiotherapist) and Clinician/Physiotherapist satisfaction (satisfaction of the physiotherapist). Consumer outcomes in an efficient and effective system results in patient satisfaction (competence and access satisfaction), cost outcomes (cost effectiveness) and physiotherapy outcomes (effectiveness).

2.8 CHAPTER SUMMARY

This chapter reviewed literature from developed and developing countries showed that Spina Bifida is a burden of disease. Literature shows that managing SB in some developed and developing countries is challenging. The process of care in the management of SB and experiences of physiotherapists managing SB was reviewed. The conceptual framework of service supply chain that helps evaluate the effectiveness and efficiency of an organization.

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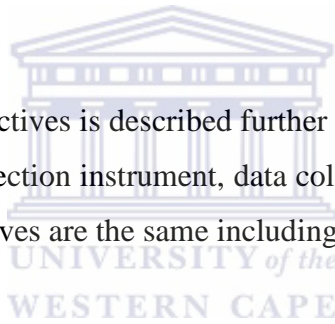
CHAPTER THREE

METHODOLOGY

3.0 INTRODUCTION

In this chapter, an overview of quantitative and qualitative methods used to collect data and analyze it is presented. The first two objectives of demographic profile of children with Spina Bifida and process of care are addressed in phase one, this was done retrospectively. The third objective is addressed in phase two of the experiences of physiotherapists in managing children with SB; this was done through a focus group discussion. Phase one preceded phase two in data collection.

The methodology for all three objectives is described further under headings: study design, study population and sampling, data collection instrument, data collection procedure and data analysis. The research settings for all objectives are the same including the ethical considerations.



3.1 RESEARCH SETTING

The study was conducted at The University Teaching Hospital (UTH) and Beit Cure International Hospital (BCIH) in Lusaka, Zambia. Lusaka is a province, district and also the capital city of Zambia (**Appendix 10**). The University Teaching Hospital (UTH) and Beit Cure are the only hospitals in Zambia that manage SB patients.

The University Teaching Hospital is the largest third level hospital in Zambia (MOH, 2012). It is a specialist hospital attending to patients from all over Zambia with modern technology for diagnosis and treatment. The hospital has approximately 1655 beds and 250 baby cots in the paediatric wing. The paediatrics department is divided into blocks A and D. A block is an in-patients unit, Intensive Care Unit for Neonates and also an out-patients unit, as well as an admission ward. D block is divided into two neonatal wards and paediatric surgical wards. The

records that applied to this study were found in the paediatric surgical wards. The physiotherapy department into three sections: active room, passive room and the paediatric wing.

Beit Cure International Hospital is a privately owned and first level hospital (MOH, 2011). It is located in the northern region of Lusaka. It specializes in paediatric care, orthopaedic surgery and neurosurgery, amongst other services. Referrals are made from all over Zambia, outreach programmes and shared between UTH and BCIH. BCIH is currently the only hospital that performs the Endoscopic Third Ventriculostomy (ETV) procedure. It has 45 patient beds in private wards, 38 beds and 16 baby cots in the children's wing. The children's wing is divided into orthopaedic and neurology wing. The Physiotherapy department has one active room that is also used for passive treatment and a treatment room. The records needed for this study were found by the reception records department.

3.2 RESEARCH APPROACH

Stange *et al.* (2006) reported mixed methods approach as an approach that “Involved integrating quantitative and qualitative approaches to generating new knowledge and can involve either concurrent or sequential use of these two classes of methods to follow a line of inquiry.” The mixed approach was used in this study to achieve extensiveness and depth (Johnson, Onwuegbuie and Turner, 2007) of the area to be studied through triangulation. The data collection methods combined strengthens and supports where one comes short.

3.3 RESEARCH DESIGN

A sequential explanatory design is a two phased mixed methods design (Creswell and Clark, 2008). The quantitative phase preceded the qualitative phase in data collection and the results were merged in the discussion. The qualitative explains and builds up on the initial results of the quantitative phase.

3.4 DATA COLLECTION METHODS

The data for this study was collected in two phases: the quantitative and qualitative phases.

3.4.1 QUANTITATIVE PHASE

According to Aliaga and Gunderson (2000) quantitative research is “Explaining phenomena by collecting numerical data that are analysed using mathematically based methods (in particular statistics)”. The study used a descriptive retrospective study design, which is appropriate in seeking past information stored through hospital records to meet a current phenomenon (Patidar, 2013). A data extraction sheet was developed to obtain patients information from the records department at UTH and Beit Cure. This approach helped the researcher gather information with regards to the two objectives, that is, the demographics and process of care of the patients with SB at UTH and BCIH in Lusaka, Zambia.



3.4.1.1 Study population and sampling

The study population consisted of all patients that had SB and had been managed from January 2010 to December 2014. The patients were purposively sampled, which is based on the characteristics of samples needed (Saumure and Given, 2008). All the files available in the records department of persons with SB during the period under inquiry were used. Inclusion was based on patients being managed during the time frame stated. Exclusion was based on patient files having inadequate information such as the absence of age on admission, diagnosis, location of SB, province of residence and management notes.

3.4.1.2 Data collection instrument

A data extraction sheet was developed based on the objectives, the researchers experience and others used in the studies of Mweshi *et al.* (2011) and Simpamba (2012) similar to this study (Appendix 1). The aim of extraction sheet was to obtain information from patient’s hospital files. The data extraction sheet was divided into three sections:

I. Section 1: Demographic data

This section was aimed at obtaining patient information such as the year of admission, referred from, province of residence, gender, diagnosis, location of SB. The results of this study would be used to observe a trend or pattern in the condition such as the diagnosis being consistent in this study and other studies. The current demographic profile of NTDs at UTH and BCIH in Lusaka, Zambia was carried out in January 2010 to December 2010 (Simpamba, 2012); the results of this study brought the current demographic profile of SB at UTH and BCIH.

II. Section 2: Management

PART ONE: OVERALL MANAGEMENT

Part one applied to the second objective that was a query into the process of care in SB management at these hospitals. It had one general question what medical, surgical and other management patient underwent. The patient files showed different types of management that didn't apply to other patients so the question was generalized to accommodate all patients as certain information would have been left out if specific questions had been asked. This information was aimed at having a full image of the process the child underwent and eventually it would reflect what service was given priority over the other.

PART TWO: PHYSIOTHERAPY MANAGEMENT

Part two had questions on referral whether the patients were referred before surgery or after, if there was follow-up conducted and if these patients were referred for physiotherapy to other departments on discharge as another study showed patients were not referred for physiotherapy and to observe if they still were not being referred for physiotherapy (Mweshi *et al.*, 2011).

III. 3.4.1.2.1 Validity

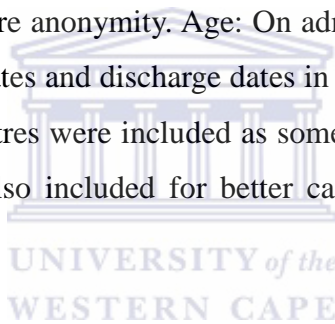
The instrument was subjected to reviewing for content validity by both research supervisors and senior physiotherapist at the university teaching hospital who did not participate in the study to ensure that it answers the intended objectives (Adams and Wieman, 2010).

The first draft was developed and submitted, and suggestions were to include the birth history of the patient, mothers' age at time of delivery, folic intake; as well as to remove the medical and surgical section and integrate it into the management such as the location and diagnosis into Section A.

IV. 3.4.1.2.2 Reliability

A pilot study for the data extraction sheet was conducted on 10 hospital files of confirmed SB patients that were managed which were randomly picked from 2009 to confirm the consistency of the results. This was also done to test the data collection instrument feasibility.

Changes were made on the instrument after the pilot study. Information such as hospital name in demographics was omitted to ensure anonymity. Age: On admission and on discharge. Some of the patient files had inconsistent dates and discharge dates in some were not indicated in some of the files. Under referral health centres were included as some patients were referred from health centres. Year of admission was also included for better categorization in the statistics in the results.



3.4.1.3 Data collection procedure

The procedure commenced after ethical approval from the relevant authorities. Having obtained permission from both hospitals management with the presentation of ethical clearance letters from the Senate Research Committee at the University of Western Cape, ERES CONVERGE ethics committee and a letter from the researcher asking for permission to conduct research, the researcher was introduced to heads of departments. The aims and objectives, rationale and significance of the study were explained and copies of the protocol were submitted to the Physiotherapy Head of Department UTH and the Medical Superintendent at BCIH. The researcher was then referred to appropriate person, the nursing officer in charge of the pediatrics surgical ward and records department BCIH (See 3.6 Ethics). The file arrangement was explained based on the years as applicable to this study. The files were arranged in order of any neurological condition managed, so the researcher had to look through all the files to find SB

cases. Some of the years had missing information. To ensure that all patients managed were found the researcher collected admission registers from the wards then obtaining the file numbers and extracting the relevant data in the files. The process of patient identification (Creswell and Clark, 2007) was conducted by the researcher. The files were located in batches of twenty and data extracted from each files. All patient files were returned when the researcher had completed data extraction. This process of reviewing the patient files at UTH took three days and BCIH required the same number of days, it was conducted in September 2015.

3.4.1.4 Data analysis

The raw quantitative data was first entered into an excel spreadsheet by an independent data capture and a researcher to make sure that all data is captures and cleaned. When that process was done data was exported to Statistical Package for Social Sciences version 23 by the researcher for analysis. This being a descriptive study, data was presented in form of frequency, percentage, mean and standard deviations on variables such as age, gender, province, sex, type of SB, level in spine, region, referral, physiotherapy requests. Data was presented in tables, charts and graphs. Cross tabulations were also done on some variables Chi- square and Phi and Cramers V tests were done. The significance was set at $p < 0.05$ alpha level.

3.4.2 QUALITATIVE PHASE

The qualitative phase commenced after the qualitative phase. Qualitative research is “characterized by its aims, which relate to understanding some aspect of social life, and its methods which (in general) generate words, rather than numbers, as data for analysis” (Patton and Cochran, 2002 page 2). This research method of data collection is the most effective method to explore the experiences of physiotherapists managing SB at UTH and BCIH in Lusaka, Zambia. The study used an explorative design. It helps the observer get into the world of the participants in their setting or environment and helps them interpret what is seen that cannot be quantified (Creswell, 2009).

3.4.2.1 Population sampling

The population used in this study was physiotherapists who are full time employees at UTH and BCIH managing children with SB. Convenient sampling is sampling based on sample available at time of inquiry (Saumure and Given, 2008), all participants who were available at both hospitals that work with children with SB were included. Six participants were used for a FDG (Creswell, 2007; Morgan, 2013) between both hospitals as they met the requirement. Inclusion applied for only physiotherapists who managed children with SB at UTH and BCIH, with 5 years or more experience worked with these children. Two heads of the departments of these hospitals were invited to participate in in-depth interviews to learn more about process of care of SB patients.

3.4.2.2 Data collection instrument

To collect the data for this study a semi-structured interview guide was developed based on available literature and other questions arose from the findings in the quantitative phase using the English language (Appendix 2). It consisted of four broad questions (the role of physiotherapy in SB management, interventions given to patients with SB, experiences of physiotherapists that had facilitators and barriers) followed by probes. The probes included: do you feel like you are included in the planning process. Probes to obtain more information were used such as: do you feel the information in patient files is adequate to have a clear understanding of the patients' state? Most of the files that required physiotherapy did not have physiotherapy notes? Other questions that had risen from phase one had been addressed in the process of participants answering other questions. The interview guide was used in conducting both in-depth interviews and FDGs. Consistency in questions was ensured by asking all participants the same questions.

3.4.2.3 Data collection procedure

The qualitative phase commenced after the quantitative phase was completed. The person in charge of the group discussed with her colleagues to set a date that would be appropriate for discussion as well as venue that would be convenient for the participants. However both hospitals are far apart and both physiotherapist could not go to the hospital where the majority were on the set date of FGD, therefore in-depth interviews were conducted with the two

physiotherapists who were the key informants. The FGD came after the in-depth interview which was conducted with the majority.

A preliminary meeting was not possible as most of the physiotherapists work in shifts and different times. So the researcher met them individually to give them the information sheet, consent forms, focus group confidentiality binding forms whilst creating a rapport with them (Patton and Cochran, 2002).

A number of six participants were present for the FGD however only five sat through entire FGD as one had an emergency during discussion and left. Before the discussion started the researcher went through the information sheet, consent forms, focus group binding confidentiality forms and the write to withdraw at any point. Participants said they were clear on everything and handed over all signed documents (see **3.6 Ethics**). They also asked how to answer the questions and the probes before it all began. The discussions and interviews were recorded on audio tape by the researcher. The FGD and interviews were held with both groups in two different venues for convenience. The FGD was held within hospital premises whilst the interviews were conducted at the participant's homes. The discussions were conducted using four open questions, followed by probes from points arising during the discussion. The questions in the interview were the same as those in FGD as they answered the same objective. The discussion continued until all points had been exhausted and saturation had been reached as recommended by Englander (2012).

The discussion lasted thirty minutes and the interviews thirty-five minutes, which came to one hour five minutes. They were conducted on different days in September 2015. Debriefing was done after the FGD and interviews to confirm what had been discussed and had been said. One correction was made on the information in the second discussion: Participant one clarified that the doctors and physiotherapists rarely meet, they actually do not meet at all.

3.4.2.4 Data analysis

The recordings were submitted to an independent transcriber for transcribing information verbatim and researcher also transcribed the recordings. The independent transcriber had to sign a confidentiality form to ensure confidentiality of information transcribed. Then comparisons

were made between the two transcripts and also proof read to ensure that information was correct.

The transcript pages were numbered to make referencing easier. The researcher read the transcripts, interview notes were also utilized and compared with recordings several times to verify accuracy and get a clear perspective and familiarize oneself with the concepts (Patton and Cochran, 2002). Common ideas and patterns observed were placed into themes. This information was then placed in categories according to the similarities of the information (Creswell, 2009). The categories were then linked together by examining the relevance of the information to answering the research question and objective. This process was repeated to gain clarity and grasp the full idea (Creswell, 2009). The research supervisors reviewed the codes, categories and themes to see if they were appropriately placed. The researcher shared the emerging themes with two participants one from the FDG and the other from the interview to review the themes. Smaller sub-themes were not included in the final report.

Cross-checking through the themes, categories and codes from the transcripts were done when all the data had been compiled for trustworthiness and also ensure that no information had been left out. The themes in the discussion included both negative and positive quotes of the interviewed participants that represent their responses that best answered the questions. The themes were compared with other studies and results have been discussed further in the next two chapters.

3.5 TRUSTWORTHINESS

Qualitative research is evaluated based on the basis of paradigmatic underpinnings of research and disciplinary standards (Morrow and Smith, 2000). According to Creswell (2009) to strengthen the authenticity the researcher has to show the accuracy of their findings, this can be done through trustworthiness which helps meet these disciplinary standards. Trustworthiness refers to the credibility, confirmability, dependability and transferability of the work (Graneheim and Lundman, 2004).

Dependability in qualitative research is described as “...the way in which a study is conducted should be consistent across time, researchers, and analysis techniques,” (Gasson, 2004, p. 94). The researcher ensured this was done by documenting the research design and implementation in detail chronologically, factors influencing data collection, analysis, use of code-recode method in data analysis, emerging themes, categories as recommended by Shenton (2004).

Credibility was ensured by member checking (respondent validation) and debriefing (Creswell, 2009) this involved the researcher going through interview notes and transcripts to confirm what had been discussed and clarify themes. A thorough description of data and emerging analysis was given. Triangulation was used by conducting two in-depth interviews with participants then a focus group discussion to further confirm the findings of the interviews.

Confirmability was ensured by using an independent transcriber to transcribe and proof reader for the transcripts, Shenton (2004) advises these methods. The themes were also audited the research supervisors (Gasson, 2004, p. 93) states “...findings should represent, as far as is (humanly) possible, the situation being researched rather than the beliefs, pet theories, or biases of the researcher.” Two participants had a session with the researcher where the themes that had emerged from discussion were reviewed to reduce bias.

Gasson (2004) and Morrow (2005) describe transferability as the extent to which one can generalize their theory. This study ensured transferability by describing fully the setting, processes, and methods undertaken and data analysis. Results merged in the discussion (Creswell, 2009). Shenton (2004) recommends a rich thick detailed description of results through quotations while maintaining the meaning of responses given. It help others understand it and be able to contrast and compare in other contexts. The characteristics of the participants include the physiotherapists that manage children with SB at the UTH and BCIH in Lusaka, Zambia.

3.6 ETHICS

The study obtained ethical clearance from the Senate Research Committee at the University of Western Cape (Appendix 3) and ERES Converge IRB (Appendix 4). Authorization was sought from University Teaching Hospital (Appendix 5) and Beit Cure International Hospital (Appendix

6) after writing a letter for permission to research and was accompanied by both letters from ethics committees. All participants received a thorough explanation of the aims of the study and information sheets (Appendix 7). Informed consent forms (Appendix 8) and focus group confidentiality (Appendix 9) forms were signed to maintain confidentiality amongst participants (Groenenald, 2004). The participants were informed that they have the right to withdraw from the study voluntarily without any penalty. Anonymity was ensured by use of code numbers instead of participant's names promoting sincerity from the participants and data extraction forms were coded (Groenenald, 2004). The laptop used for the study had a password only know to the researcher to ensure security and confidentiality (Patton and Cochran, 2002), the transcripts and all paper were locked up and the key kept by the researcher. The results will be documented and manuscript published. The researcher will give feedback to participants, Beit Cure International Hospital and University Teaching Hospital.

3.7 CHAPTER SUMMARY

In this chapter, the researcher summarized the methodologies used in this two-part data collection approach: Phase One reported on a retrospective review of hospital records of patients managed with SB at UTH and BCIH from January 2010 to December 2014. The researcher reported on the sampling, data collection instrument, procedure and analysis of the data obtained. Phase two reported exploration of physiotherapists experiences using FGDs and in-depth interviews that were audio taped recorded. Sampling, data collection instrument, procedure, analysis of data and the merging were reported. Validity and trustworthiness of both phases were addressed and all ethical considerations were reported in this chapter.

CHAPTER FOUR

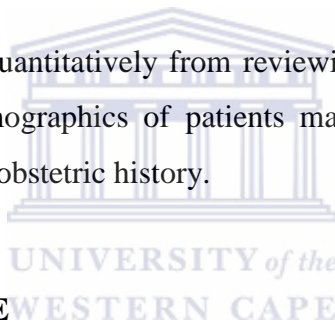
RESULTS

4.0 INTRODUCTION

This chapter contains the results of the analyzed data from both phases of data collection: quantitative and qualitative. Objectives one and two are addressed in Phase One and objective three in Phase Two.

4.1 PHASE ONE

Phase One shows data collected quantitatively from reviewing SB patient files retrospectively, which has been divided into demographics of patients managed at UTH and BCIH, further investigations, process of care and obstetric history.



4.1.1 QUANTITATIVE PHASE

This data was obtained to gain a demographic profile of the children managed from January 2010 to December 2014. All records were retrieved and reviewed. A population of 207 patients were managed, however, 27 files were disqualified for inadequate information in them, hence the study population was narrowed down to N= 180.

4.1.1.1. Demographics of patients managed with SB at UTH and BCIH

The demographics of the patients managed at UTH and BCIH from January 2010 to December 2010 included: year of management, referral hospital, province of residence, gender, age, diagnosis and location of SB. The findings presented in **Table 1** illustrate the frequencies and percentages of the variables.

Table 1: Demographics of patients with SB managed

VARIABLE	GROUPS	FREQUENCY (F)	PERCENT (%)
1. Year of admission	• 2010	28	15.6
	• 2011	39	21.7
	• 2012	33	18.3
	• 2013	45	25.0
	• 2014	35	19.4
	TOTAL	180	100.0
2. Referral hospital	• Provincial	6	3.3
	• District	134	74.4
	• Health centre	23	12.8
	• Direct contact	17	9.4
	TOTAL	180	100.0
3. Province of Residence	• Northern	20	11.1
	• Central	11	6.1
	• Eastern	25	13.9
	• North -Western	4	2.2
	• Luapula	1	0.6
	• Southern	34	18.9
	• Western	11	6.1
	• Lusaka	56	31.1
	• Copperbelt	18	10.0
	• Muchinga	0	0
	TOTAL	180	100.0
	4. Gender	• Female	100
• Male		80	44.4
TOTAL		180	100.0

5. Age on Admission	• Less than one month old	133	73.9
	• 1 to 6 months	32	17.8
	• 7 to 12 months	8	4.4
	• 1 to 5 years	3	1.7
	• 6 to 10 years	4	2.2
	TOTAL	180	100.0
6. Diagnosis	• Occulta	1	0.6
	• Meningocele	26	14.4
	• Myelomeningocele	28	15.6
	• Myelomeningocele and Hydrocephalus	125	69.4
	TOTAL	180	100.0
7. Location of Spina Bifida	• Cervical	7	3.9
	• Thoracic	2	1.1
	• Thoraco-lumbar	23	12.8
	• Lumbar	96	53.3
	• Lumbo-sacral	47	26.1
	• Sacral	5	2.8
	TOTAL	180	100.0

V. Year of admission

The table shows that 180 patients had been managed at UTH and BCIH. The first variable shows the years reviewed - from January 2010 to December 2014. The year with the highest managed patients was 2013 with 45 (25%) and the least was in 2010- 28 (15.6%). The frequencies of SB patients managed over the five year period are shown in **Figure 3**.

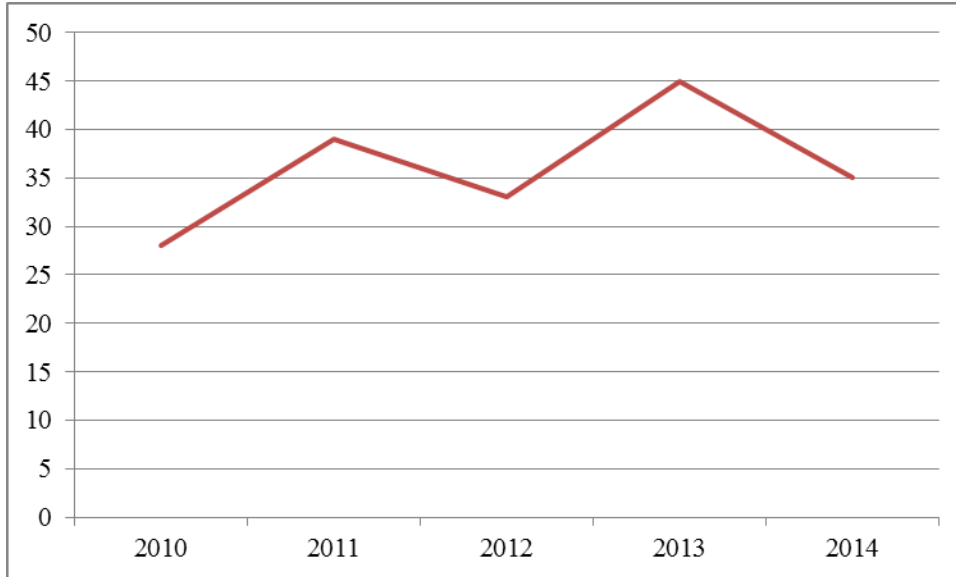
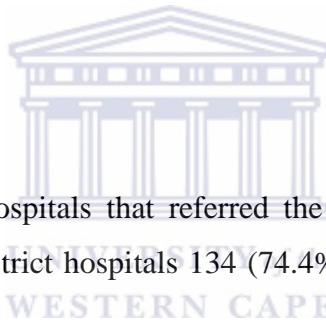


Figure 3: SB patients managed from 2010 to 2014.



VI. Referral hospitals

The second variable shows the hospitals that referred the patients to UTH and BCIH. The majority of patients came from district hospitals 134 (74.4%) and the least with 6 (3.3%) from provincial hospitals.

VII. Province of Residence

The third variable was the provinces where the patients were coming from that were managed at both hospitals. Lusaka province had the highest number of patients 56 (31.1%) and Muchinga had lowest number of patients 0 (0%). The provinces of residence are shown in **Figure 4**, using their frequencies.

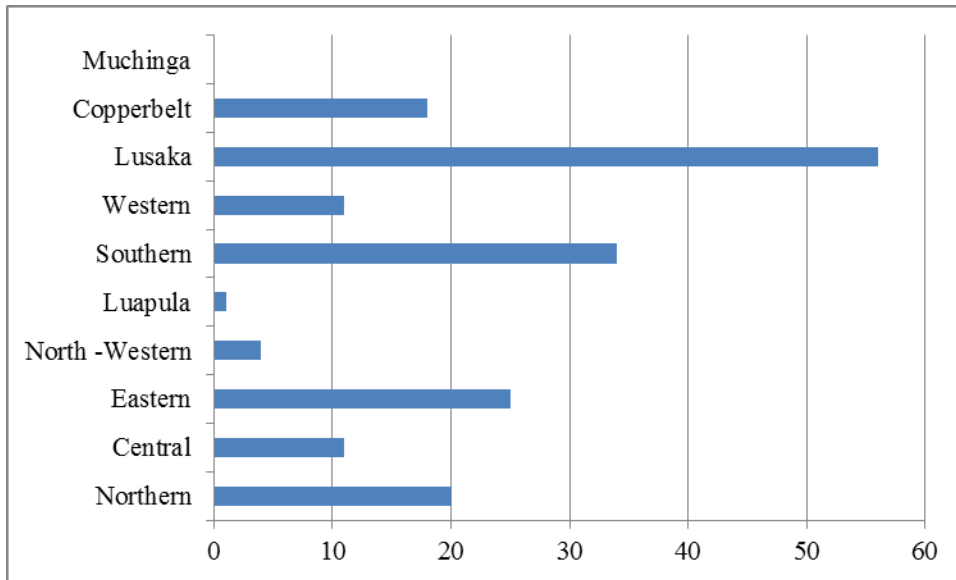
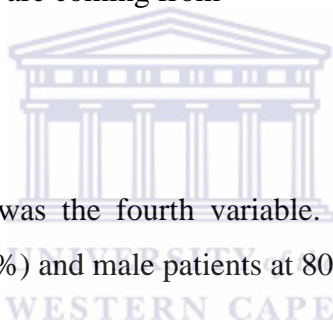


Figure 4: Provinces where patients are coming from



VIII. Gender

Gender of the patients managed was the fourth variable. It showed that the most managed patients were females, at 100 (55.6%) and male patients at 80 (44.4%).

IX. Age at Admission

The ages of the patients were categorized into groups of the five: the category: less than one month had 133 (73.9%) which was the majority and the minority was in the 1 year to 5 years category with 3 (1.75). **Figure 5** is a pie chart showing the ages of patients managed in percentage which clearly shows the majority of patients were less than one month.

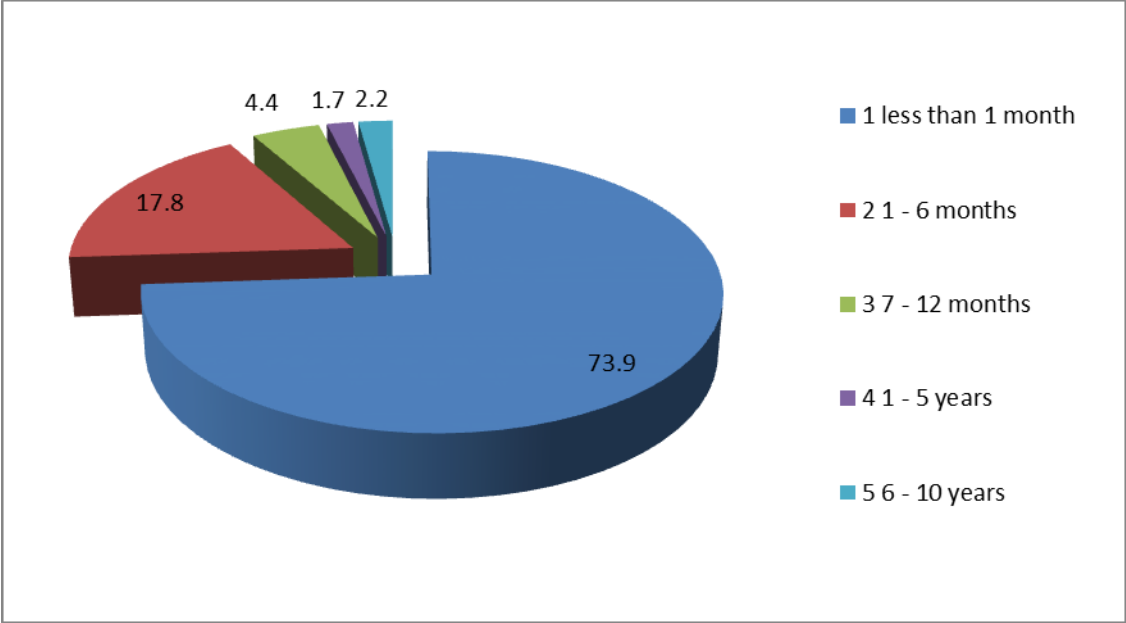


Figure 5: Age of children managed with SB.

X. Diagnosis

The sixth variable was diagnosis of patients with SB the most common diagnosis was myelomeningocele and hydrocephalus – 125 (69.4%) and the least was occulta – 1 (0.6%). A chart as shown in **Figure 6** has been used to show these results in percentage; M and H (myelomeningocele and hydrocephalus).

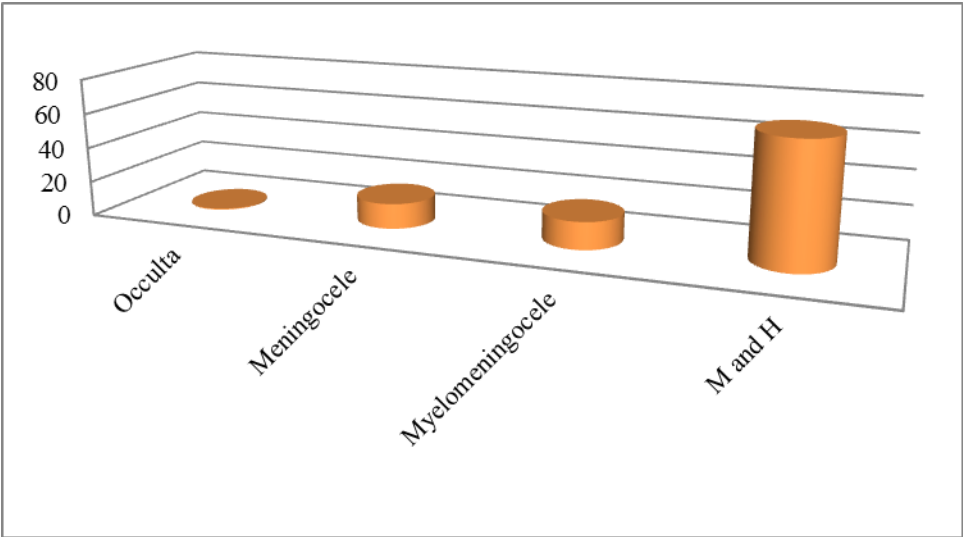


Figure 6: diagnosis of patients managed

XI. VII. Location of Spina Bifida

The last variable was the location or site of SB in vertebral column the findings show it was common in the lumbar region with 96 (53.3%) and less in the thoracic region with 2 (1.1%).

4.1.1.2 The relationships between Spina Bifida and other variables

Further analysis of the demographic data was conducted to find relationships in the variables using Chi- square and to test the strength of these relationships using Phi and Cramers V test. Cross-tabulations were done on some of the variables.

XII. 4.1.1.2.1 The relationship between diagnosis and year of admission

The year of management and diagnosis was further analysed and the results in **Table 2** show the most common type of SB is myelomeningocele accompanied by hydrocephalus with a total of 125 patients managed with a percentage of 69.4%, and it led in all five years. The year that managed the most number of children with SB was 2013 with 45 (25%) patients and the least number was in 2010 with 28 (15.6%).

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Table 2: Diagnosis and year

YEAR	Diagnosis				Total (%)
	Occulta	Meningocele	Myelomeningocele	Myelomeningocele and hydrocephalus	
2010	1	0	4	23	28 (15.6)
2011	0	7	6	26	39 (21.7)
2012	0	5	5	23	33 (18.3)
2013	0	7	7	31	45 (25.0)
2014	0	7	6	22	35 (19.4)
TOTAL	1 (0.6)	26 (14.4)	28 (15.6)	125 (69.4)	180 (180.0)

XIII. 4.1.1.2.2 The relationship between gender and diagnosis

The gender and diagnosis of SB patients was cross tabulated and the findings show that the majority of children had myelomeningocele and hydrocephalus: 63 of them were male 63 and 62 were female, as shown in **Table 3**. The second most common diagnosis in females was meningocele with 22 patients, whereas myelomeningocele was the second most commonly diagnosis in 12 male patients.

Table 3: Diagnosis in relation to gender

DIAGNOSIS	Gender		Total (%)
	Female	Male	
Occulta	0	1	1 (0.6)
Meningocele	22	4	26 (14.4)
Myelomeningocele	16	12	28 (15.6)
Myelomeningocele and Hydrocephalus	62	63	125 (69.4)
Total	100 (55.6)	80 (44.4)	180 (100)

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The Chi-square of gender and diagnosis found $p=0.007<0.05$. A t test was conducted to find strength of the relationship between gender and diagnosis which was strong (0.258).

XIV. 4.1.1.2.3 The relationship between gender and province of residence

The gender and province variables were cross tabulate and shown in **Table 4**. The majority of children managed between 2010 and 2014 were females at 100 (55.6%) and males at 80 (44.4%). The province in the lead with more referrals was Lusaka by 31.1%. The majority of female children managed came from the Lusaka province: 23 females and 33 males and the least from Muchinga province with 0:0 ratios in both genders.

Table 4: Gender in relation to province.

PROVINCES	Gender		Total (%)
	Female	Male	
Northern	15	5	20 (11.1)
Central	5	6	11 (6.1)
Eastern	13	12	25 (13.9)
North Western	4	0	4 (2.2)
Luapula	1	0	1 (0.6)
Southern	21	13	34 (18.9)
Lusaka	23	33	56 (31.1)
Western	8	3	11 (6.1)
Copperbelt	10	8	18 (10.0)
Muchinga	0	0	0 (0)
TOTAL	100 (55.6)	80 (44.4)	180 (100)

There is a significant relationship between gender and the province of residence using Chi-square to find $p=0.076 < 0.05$ and its strength a t test was conducted which confirmed a strong relationship of 0.281.



XV. 4.1.1.2.4 The relationship between the location of Spina Bifida and gender

The variables location of SB and gender were cross tabulated for further analysis. The majority of children managed had the SB located in the lumbar region as seen in **Table 5** : 53.3% (96), lumbo-sacral region 26.1% (47), Thoraco-lumbar region 12.8% (23), cervical region 3.9% (7), sacral region 2.8% (5) and thoracic region 1.1% (2) respectively. The majority of females had SB in the lumbar region (56) as did a total of 40 males. The least frequencies were 2 in sacral region for females and 0 for males in the thoracic region.

Table 5: Gender in relation to location of SB

LOCATION OF SPINA BIFIDA	Gender		Total (%)
	Female	Male	
Cervical	5	2	7 (3.9)
Thoracic	2	0	2 (1.1)
Thoraco-lumbar	13	10	23 (12.8)
Lumbar	56	40	96 (53.3)
Lumbo-sacral	22	25	47 (26.1)
Sacral	2	3	5 (2.8)
Total	100 (55.6)	80 (44.4)	180 (100.0)

A Chi-square test was done on the two variables and it showed that no relationship exists between the site of SB and the gender $p= 0.471 > 0.05$.

4.1.1.3 Process of Care

The process of care represents the overall management SB patient's at UTH and BCIH from admission to discharge based on information reviewed in files. The results have been divided into surgical management, other management, physiotherapy management and obstetric history.

XVI. 4.1.1.3.1 Surgical management

All surgical procedures the patient's underwent are shown in tables and figures. Cross-tabulations were done on the repairs and clubfoot shown in **Table 6**, the most common management was meningo-plasty 61.7% of the patients underwent the procedure, 36.7% did not need the procedure and 1.7% were managed by debridement. Clubfoot was managed using tenotomy and Ponseti. Out of 180 patients 38 had been managed for clubfoot. Seventeen of the patients had no mention of clubfoot in their files but tenotomy and ponseti was seen in records. The majority of clubfoot cases were managed by ponseti 12.2%, 3.9% and 78.9% had no clubfoot.

Table 6: Clubfoot in relation to repairs

REPAIRS	Clubfoot			Total
	Tenotomy	Ponseti	No Clubfoot	
Meningoplasty	4	16	91	111 (61.7)
Debridement	0	1	2	3 (1.7)
No	3	14	49	66 (36.7)
TOTAL	7 (3.9)	31 (12.2)	142 (78.9)	180 (100.0)

A Chi-square test was done to find $p=0.707 > 0.05$, p was greater than alpha; hence no relationship exists between repairs and clubfoot.

Other surgical procedures included shunting on hydrocephalus patients as shown in **Figure 7**. The most used procedure was among excluding those that didn't have any hydrocephalus was VPS 41.7%, VPS,ETV-CPC and ETV-CPC 6.1% each and lastly VPS and ETV 3.3%. 42.8% of them may not have had hydrocephalus or did not need a shunting.

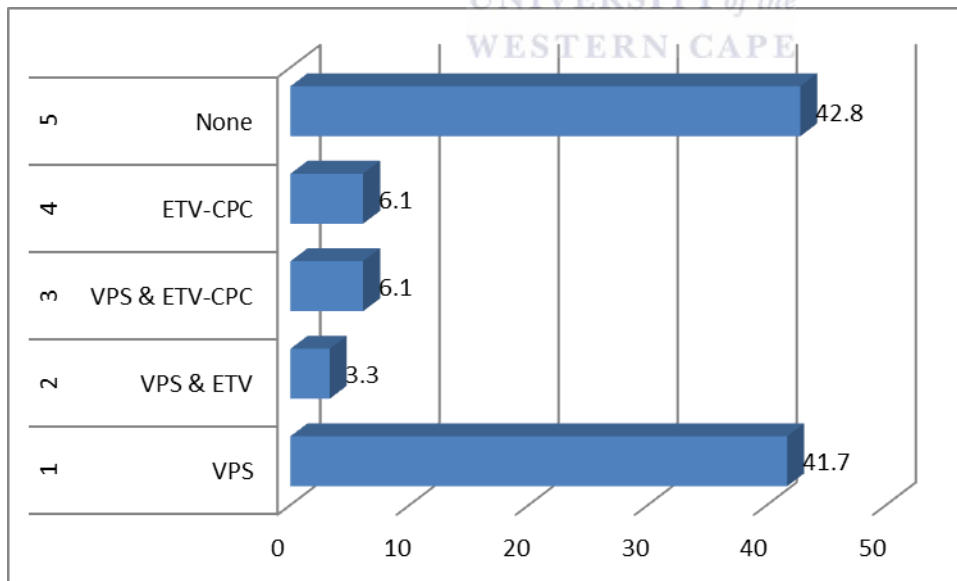


Figure 7: Shunting procedures used

XVII. 4.1.1.3.2 Other management

This management included any management recorded in patient files such as counselling, orthotics, orthopaedic, nutritionists as shown in **Figure 8**.

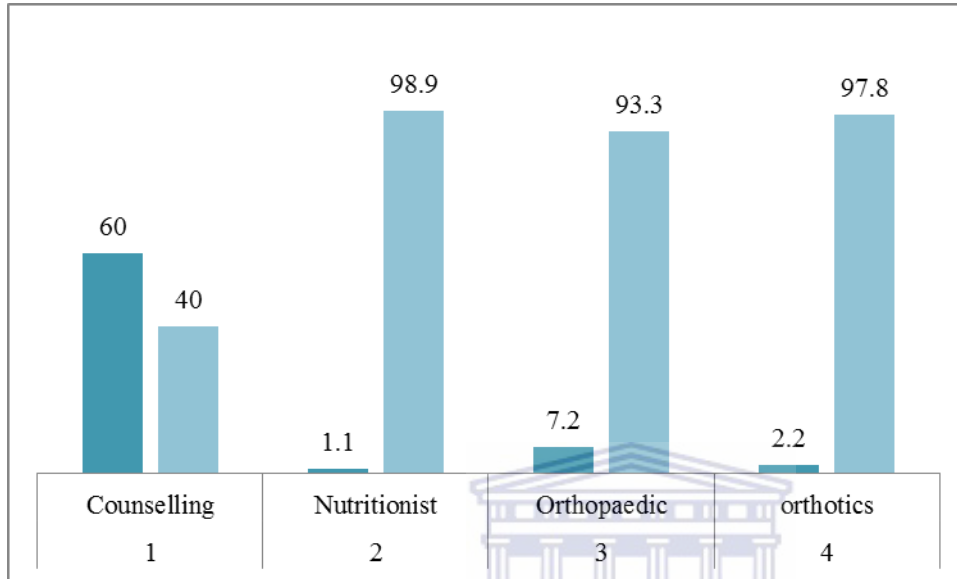


Figure 8: Other management; series 1 represent use of service and series 2 represent no use.

The most utilized services by the 180 patients managed in descending order were: counselling 60% of 100%, orthopaedics 7.2% of 100%, orthosis 2.1% of 100% and lastly nutrition 1.1% of 100%. The Kyphosis and knee problems were placed in orthopaedic management.

XVIII. 4.1.1.3.3 Physiotherapy and CNS examination

Patients were sent for CNS examination to before they were referred for physiotherapy. However, not all patients were sent. The data in **Table 7** shows the children who had undergone the CNS examination and where referred for physiotherapy. A total percentage of 67.2% (121) of the children did not undergo the CNS examination and 32.8% (59) of the 59 patients only 45 had information on the outcomes of their examination: increased tone- 3, reduced tone- 1, No CNS exam- 4 and Normal- 0.

Table 7: Referral for physiotherapy

CNS EXAMINATION			Total (%)
	Yes	No	
Examined	59 (32.8)	121 (67.2)	180 (100.0)
CNS OUTCOMES	Referred for physiotherapy		Total (%)
	Yes	No	
Normal	0	10	10
Reduced tone	1	40	41
Increased tone	3	5	8
None	4	117	121
TOTAL	8 (4.4)	172 (95.6)	180 (100.0)

The relationship between physiotherapy management and CNS evaluation exists with $p=0.000<0.05$. N=59 received CNS examination.

Figure 9 indicates further investigations on the number of children with SB that needed physiotherapy who were referred showed: out of 180 children 49 children needed physiotherapy. Under “Reduced tone”, 2.44% was referred for physiotherapy and 97.56% were not referred. With “Increased tone”, 37.5% were referred for physiotherapy and 62.5% were not referred for physiotherapy. No patients’ files showed referral to other physiotherapy departments in their locality. This is not a full reflection of the process of co-ordination.

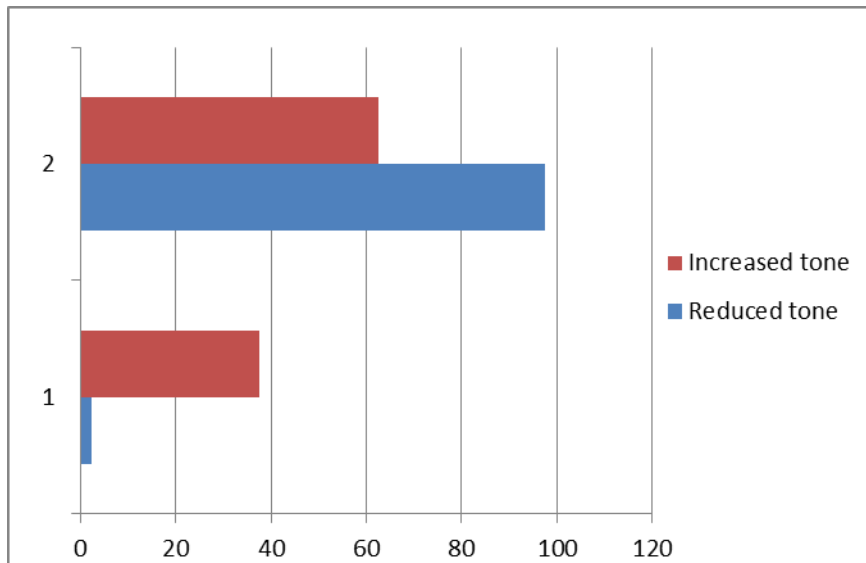


Figure 9: Children referred for physiotherapy.

The results of patients that were referred for physiotherapy before surgery, after surgery and follow-ups of patients managed are shown in **Table 8**. Before surgery 96.1% of the children were not referred for physiotherapy, after surgery 93.9% of the children were not referred for physiotherapy. Of the 180 patients managed with SB between 2010 and 2014 the findings show 98.3% were not followed up. The number of patients referred for physiotherapy before and after surgery included those whose CNS examination was not indicated but show evidence of referral for physiotherapy hence the increase in numbers from 8 patients in **Figure 9** to 18 patients (before and after surgery) in **Table 8**.

Table 8: Before surgery, after surgery and follow-up

Before surgery	Frequency (F)	Percentage (P)
Yes	7	3.9
No	173	96.1
Total	180	100.0
After surgery	F	P
Yes	11	6.1
No	169	93.9
Total	180	100.0
Follow-up	F	P
Yes	3	1.7
No	177	98.3
Total	180	100.0

XIX. 4.1.1.3.4 Obstetric history

Obstetric history applied to information pertaining to pre-conceptual phase till post-delivery. Some of the patient files had information on birth history, folic intake, maternal age of mother and HIV status of mother.

I. Birth history

The birth history of some of the SB patients managed is shown in **Figure 10**. Out of the 180 children with SB, 22 patients had information on their birth history which showed that of the 22 managed, 11 (50%) were born through normal delivery.

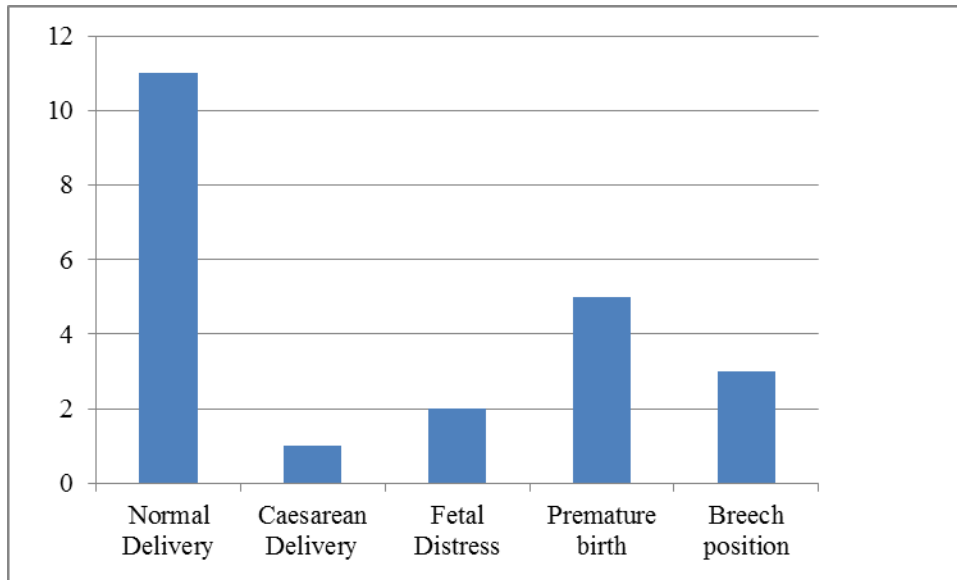


Figure 10: The birth history of children managed

II. Folic acid intake and maternal age

Table 9 shows the number of mothers who took folic acid before conception: 8.3% of the mothers of the children with SB took folic acid and 91.7% didn't take folic acid. 92.8% of the files had no data on the mother's maternal age, however, 13 files had information on their ages; Young mothers aged between 15 – 18 years old were 4.4% of the population, and older mothers aged over 40 years were 2.8% of the population.

Table 9: Folic acid intake in mothers and maternal age

Folic intake	Frequency	Valid percent
Yes	15	8.3
No	165	91.7
Total	180	100.0
Mothers maternal age	Frequency	Valid percent
Young mother	8	4.4
Older mother	5	2.8
None	167	92.8
Total	180	100.0

III. HIV status

The HIV status of the mother was included in some of the patient's files and others found out during Voluntary Counselling and Testing (VCT). **Figure 11** shows: 47% of the mothers were negative, 43% didn't know their status or it was not included in the file and 10% were positive. Therefore 57% of the mothers were counselled and tested for their status. Only one file showed that the mother had been on anti-retroviral drugs.

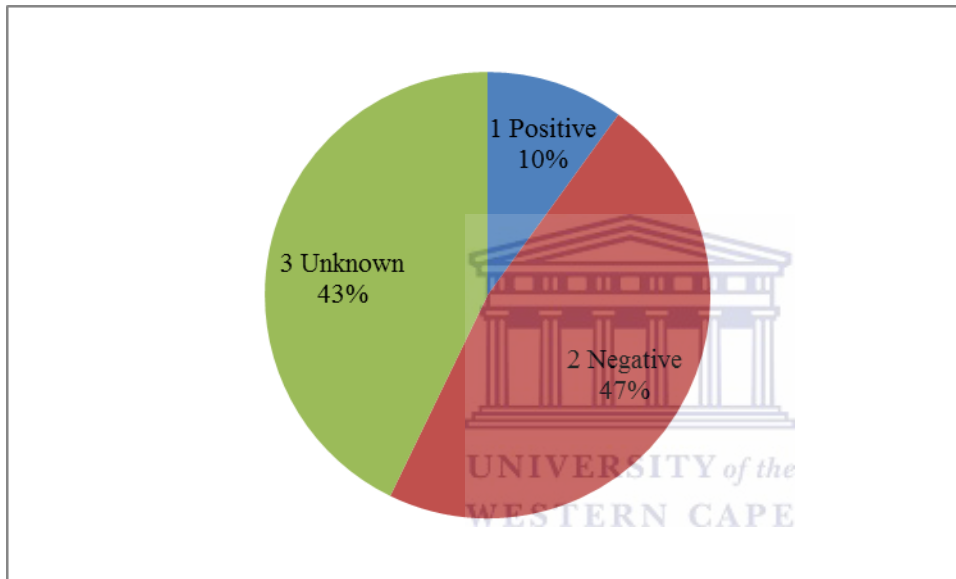


Figure 11: Mothers' HIV status

4.2 PHASE TWO

4.2.1 QUALITATIVE PHASE

4.2.1.1 CHARACTERISTICS OF PARTICIPANTS

Finding out the experiences of physiotherapists in managing children with SB at UTH and BCIH were explored through FDGs with five participants and in-depth interviews with two participants. The sixth participant withdrew on day of discussion, due to attending to patients and it was most convenient time to meet all participants. As shown in **Table 10**, the majority of

participants had diplomas in Physiotherapy. The majority of participants had more than six years of work experience managing children with SB at these hospitals.

Table 10: Characteristics of participants

CHARACTERISTIC	VALUES	No.
1. Gender	Female	8
2. Qualification	Diploma in Physiotherapy	4
	Bachelor of science Degree in Physiotherapy	3
	Degree of Master of Science in Physiotherapy	1
	TOTAL	8
3. Experience	Less than a year	2
	1 to 3 years	2
	4 to 6 years	2
	More than 6 years	3
	TOTAL	8

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4.2.1.2 THEMES

Two in-depth interviews were conducted with key informants. To confirm the findings further with a large group a FGD was conducted with six other participants, one interview guide was used as it answered the same objective. The themes emerged from the broad questions asked during the interviews and discussion. Both methods used in obtaining information to answer the third objective gave similar outcomes that were all combined and presented in **Table 11**.

Table 11: Themes and sub-themes

	QUESTIONS	THEMES	SUB-THEMES
1.	Role, Management, Intervention	<ul style="list-style-type: none"> • Quality of life 	<ul style="list-style-type: none"> • Independence • Restore function
		<ul style="list-style-type: none"> • Rehabilitation 	<ul style="list-style-type: none"> • Type and level of SB • Functional abilities • Passive, Active and Active assisted movements • Strengthening • Stretching • Assistive devices
		<ul style="list-style-type: none"> • Prevention 	<ul style="list-style-type: none"> • Prevention
		<ul style="list-style-type: none"> • Education 	<ul style="list-style-type: none"> • Counselling/ Psychological advice • Information dissemination
2.	Planning process	<ul style="list-style-type: none"> • Holistic management 	<ul style="list-style-type: none"> • Not inclusive • Inadequate information; assessment- establish cause, follow-up and outreach
3.	Experience	<ul style="list-style-type: none"> • Training 	<ul style="list-style-type: none"> • Workshops • Gain experience
		<ul style="list-style-type: none"> • Improvement in children 	<ul style="list-style-type: none"> • Satisfaction and encouragement
4.	Challenges	<ul style="list-style-type: none"> • Knowledge 	<ul style="list-style-type: none"> • Family's knowledge,

			<ul style="list-style-type: none"> expectations • Language • Level of education of caregivers • Inconsistency • Ante-natal services
		<ul style="list-style-type: none"> • Myths and misconceptions 	<ul style="list-style-type: none"> • Curses, Myths and misconceptions • Late presentations (Ignorance)
		<ul style="list-style-type: none"> • Multidisciplinary collaboration 	<ul style="list-style-type: none"> • No multidisciplinary work • Attitudes among health professionals • Role of Physiotherapy

Codes have been used to refer to participants in quotations as subthemes are addressed in codes from P1 to P8, P representing participant and KI representing Key informant.

XX. 4.2.1.2.1 THEME 1: QUALITY OF LIFE

The physiotherapists felt that the core purpose or role of physiotherapy in the management of SB is to improve the quality of the patient's life. The sub-themes that emerged include independence and restore function.

a) INDEPENDENCE

The participants stated that the beginning of physiotherapy is the road to gaining independence for each patient with SB. When asked their role in rehabilitating patients with SB they all agreed that it is to help patients gain independence, they felt that as they rehabilitate these patients, it empowered them even in the future years, as physiotherapy was an ongoing process for them to be able to do things physically on their own than be a burden to those around them.

“...and help these children gain independence...” Key Informant –Participant 7

Another participant added on in summary:

“I think to summarize on everything, the role is rehabilitate the patients to make them as independent as possible and improve the quality of life.” Participant2

b) RESTORE FUNCTION

Function was to be restored through the use of exercise therapy techniques. They had also addressed the interventions given to patients with SB at their hospitals. All seven participants agreed with this sub theme.

“...the main thing is bringing back or striving to bring back the lost function” Participant 6

“Educating use in the brain...” Participant 5

“...but usually we just take to near to normal as possible.” Participant 8

The participants had also stated that they put this factor into use when planning the inventions for the patients.

XXI. 4.2.1.2.2 THEME 2: REHABILITATION

The role of physiotherapy in SB management was to rehabilitate the patients and sub themes emerged from addressing the question.

a) TYPE AND LEVEL OF SB

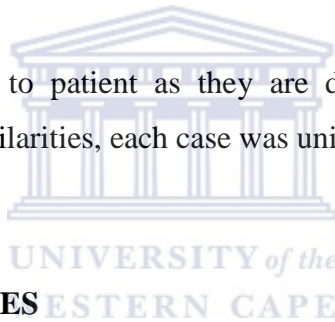
The participants all felt that rehabilitation of SB begins with being able to establish the type and level of SB as it determined the direction of interventions given to each patient.

“Usually you assess the child and decide what treatment would be beneficial to the type of SB that one is presenting and treatment is also holistic you don’t look at the patient you also look at the caregivers.” Key Informant - Participant 7

“I think our role depends on the condition of the child. Because we have different types of SB.”
Participant 1

“Each level of SB is accompanied by its own neurological impairments.” Participant 5

The role may vary from patient to patient as they are different individuals with different symptoms, despite some of the similarities, each case was unique.



b) FUNCTIONAL ABILITIES

The functional level of each patient set the pace of treatment when setting goals for rehabilitation.

“...and if possible you have a record of how the functional abilities are in the child before the operation so that if it is possible you can compare after the operation”. Key Informant – Participant 7

“...promotes functional activities as we physiotherapists facilitate them...” Participant 1

c) PASSIVE, ACTIVE AND ACTIVE ASSISTED MOVEMENTS

Two went further to state that the use of passive, active and active assisted movements is beneficial in the treatment plan as it helps maintain joint range of motion and also prevents deformities.

“It depends how you are going to see the patient some may say passive movements but it is you have assessed the patient...” Key Informant - Participant 6

“... passive movements should be done for the patient...” Participant 8

“... they help prevent complications...” Participant 5

d) STRENGTHENING

All participants agreed that the patients need strengthening exercises especially that SB affects the lower body hence one need to utilize the functionally active part to be independent e.g. upper limbs.



“They will tell you that some need strengthening exercises...” Participant 5

“We also give strengthening exercises depending on what the patient is presenting with.” Key Informant – Participant 7

e) STRETCHING

When asked on the interventions used stretching is utilized in the correction of congenital deformities and all participants agreed to that.

“If the child is presenting with congenital deformities, we will start our passive stretching to correct the deformities.” Participant 1

“Stretching and strengthening is important at a later stage when the child grows older...” Key Informant – Participant 6

f) ASSISTIVE DEVICES

The researcher asked if assistive devices were provided and the response was positive. They were then asked if patients are referred if the devices are unavailable. All participants agreed that would assess patients that needed assistive devices and would advise appropriately.

“...you make them start using aids.” Participant 2

“At least our hospital had aids, yeah. We would strive to provide them whatever was needed if not, we would refer them to other hospitals for braces, calipers and wheelchairs. We don’t have some things we would give the out freely. Crutches, some calipers if you chance them and they fit we would give them out freely.” Participant 5

Some of the patients get their assistive devices during readmissions.

“And for those especially the readmissions they’re some who would require maybe special chairs then we would maybe order for them an ask if they can go for measurements, if they are unable to pay then it would be given for free.” Participant 1

XXII. 4.2.1.2.3 THEME 3: PREVENTION

All of the participants felt that the role of physiotherapy in SB is to prevent primary and secondary deformities as well as complications.

a) PREVENTION

Three of the participants felt that their role in the rehabilitation process of patients of SB is for prevention.

“You see that is why it is it is important to start physiotherapy management earlier to prevent deformities but these patients are not referred and they don’t attend physiotherapy they only come when things get worse.” Key Informant – Participant 7

“To prevent pressure sores.” Participant 5

“...or maybe in just preventing deformities...” Participant 2

XXIII.4.2.1.2.4 THEME 4: EDUCATION

Education arose as a point in addressing the role of physiotherapy in SB management.

a) COUNSELLING AND PSYCHOLOGICAL ADVICE

Two of the participants agreed that it is not easy dealing with disability, and mothers need all the counselling they can get to help them understand their child’s condition because they are informants to their family members.

“So you have enough time for rehabilitation and counselling.” Key Informant – Participant 7

“...you give them psychological advice and when you see the patient before surgery or operation, you give psychological advice to the caregiver.” Key Informant –Participant 6

“...these mother especially those with small babies so that they are psychologically prepared of what needs to be done...” Participant 8

b) INFORMATION DISSEMINATION

The participants played a key role in the management in informing the caregivers on the condition and anything they did not to understand about it. They would also have to explain the relationship between physiotherapy and their child’s condition.

“...then will also teach the mother what to do with the child. Training also helps to inform these mothers especially those with small babies so that they are prepared psychologically and what needs to be done.” Participant 1

“The period they are admitted at the hospital, you try and show the caregiver the basics to go and practice at home and also review to see if they are doing it correctly as they may never be able to get this information especially if they live in rural areas where there no physiotherapy departments.” Participant 4

“In addition we teach the mothers how to take care of the wound itself for the possibility of infections like how to keep nappies dry all the time.” Participant 3

The information the caregivers would receive in the beginning would play a large role in their participation in the rehabilitation process as they are key figures. It also bears weight on their expectations of the multi-disciplinary team.



XXIV. 4.2.1.2.5 THEME 5: HOLISTIC MANAGEMENT

The participants were asked if they felt they were included in the planning process in managing SB at their hospitals.

a) NOT INCLUSIVE

All seven participants felt that they were not included in the planning process.

“When it comes to being included in the planning process the way it is at our hospital maybe the way it is supposed to be, you are supposed to meet as a multi-disciplinary team we sit together and plan the management of these patients. But the way it is, we rarely meet the doctors we know it is our role to go there on the ward, we see the patients but we don’t meet. No, there is no interaction.” Participant 2

“We don’t meet at all. We don’t receive consultation, we don’t even write in their files because they don’t consult. That child is somebody who has got another life so you are supposed to look at the patient as a whole not just by looking at the meningocele or the myelomeningocele. They are more concerned with the condition about the condition than the person.” Participant 1

Due to no consultations or requests in the files, the physiotherapists managed the children based on finding the patients with the need for physiotherapy while passing through the wards and finding them on coincidence and recorded the information in their registers, and not in the patients’ files as they felt the file did not apply to them. The management is selective and based on more important services. Other conditions received all round rehabilitation but SB did not. One participant had a different opinion.

“And again I think it depends with the surgeon. Some surgeons really include you in the planning, some include you in the ward rounds and others don’t...” Key Informant - Participant 6



c) INADEQUATE INFORMATION: assessment- establish cause, follow-up and outreach

The participants were asked whether the information in files was adequate enough for them as it was noticed by the researcher that the files were inconsistent, starting with diagnosis and other processes of management the patient underwent; some patients had different diagnosis and location of SB throughout their files.

“Relying on the files is not helpful, so I think the best thing I think is see the patient with your own eyes yourself, you do your own assessment.” Key Informant –Participant 6

“From what I have experienced most of the files for children with SB the files from the Neo-natal Intensive Care Unit (NICU) would have more information than those found in the surgical ward. Mix ups in diagnosis in the files are common...” Participant 3

“We do our own assessments...” Participant 1

They went further to raise points on follow-up, that due to inadequate information, follow-ups are difficult and the best referral they can provide for the children would be verbal after inquiry on where they reside and the physiotherapy departments around that area and who to approach when they are back home. Others times they would not get the chance to make a referral because the patient is discharged. In some cases, some patients return for reviews or re-admission and as physiotherapists you find them in the ward then one can inquire.

“The follow-up is quite difficult because from the word go we are not consulted we just go there because we know we are supposed to go there. So after patients are discharged sometimes we don’t even know where they will go or where they will end.” Participant 4

“The problem we have is that we don’t follow-up whether they have started physiotherapy but we do refer some to the nearest hospital...” Participant 2

“... if we are to sit together and plan follow-up...” Participant 3

Participant 1 had inquired from the ones who had returned for re-admission after being referred for physiotherapy and they did not have a reason for not attending physiotherapy sessions. The researcher also inquired about patients files that showed physiotherapy in them, but had inadequate physiotherapy information. Two of the participants said that it was dependent of the therapist attending to the child; otherwise they are supposed to write completely. However, they did admit that they did not consistently update the patient’s files and sometimes a brief summary of sessions held with them would be written.

XXV. 4.2.1.2.6 THEME 6: TRAINING

The participants were asked what helped them manage children with SB better they stated that training and experience has helped them manage them more effectively.

a) WORKSHOPS

They felt that workshops, seminars and symposiums empowered them on information they were lacking.

“...maybe we have this basic knowledge. We have attended seminars so to some extent we know what to do.” Participant 2

*“We attended some workshops on management of SB and Hydrocephalus from a certain hospital. That has been really motivating. It has been really motivating because we see the children there and how they are supposed to be treated and also the other ones which I attended showed us how they manage fecal incontinence even urinary incontinence...”*Participant 1

Participant one went on to state that this helped them disseminate information better to the caregivers.



b) GAIN EXPERIENCE

Two participants felt they had not been adequately prepared to manage children with SB, four felt prepared and one did not indicate. Some feel they were not adequately prepared to manage children with SB and have been gaining more experience by working with the patients.

“I gain more knowledge and experience...” Participant 4

“Just the thought of having an experience you know when we are getting a child with SB maybe twice a week and you get a new case you gain more experience every time.” Key Informant – Participant 6

XXVI. 4.2.1.2.7 THEME 7: IMPROVEMENT IN CHILD

Factors or facilitators that helped physiotherapists work effectively at their hospitals included seeing improvement in a patient, which led to satisfaction and encouragement.

a) SATISFACTION AND ENCOURAGEMENT

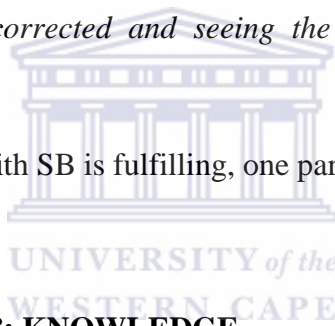
The participants felt that satisfaction and encouragement was brought about by improvement in the patients. They all agreed with this theme and that it motivated them to do better for these children.

“When you treat a patient and you see the progress is very good, you are satisfied with what you have...” Key Informant – Participant 7

“To see a patient improve, in terms of being able to stand with minimal support and take assisted steps...” Participant 3

“They are times when you see patients you treated and see improvement. Especially those coming for reviews or readmissions like when a baby was born and developed contracture and congenital deformities they are corrected and seeing the improvement is encouraging and motivating” Participant 4

The opportunity to help children with SB is fulfilling, one participated added.



XXVII. 4.2.1.2.8 THEME 8: KNOWLEDGE

When asked about the challenges they experienced in managing children with SB, their responses were further broken down into sub-themes. They all felt that the lack of knowledge in care givers lead to their behaviour as well as participation.

a) FAMILY’S KNOWLEDGE AND EXPECTATIONS

The surgeons, being first to see the caregivers, play a large role as they need to understand why they are giving consent to a procedure that they have no understanding of its effects and its benefits for their child. All of the participants agreed that the caregiver’s expectations were based on the information they were given or even assumptions due to the fact that as long as one undergoes a surgical procedure they are meant to get better.

“...on those who come from far on the expectations we inform them on the possibilities of incontinence and what should be done because some of them will never an opportunity to come back...” Participant 1

“Sometimes the doctors don’t really explain to the parents what this condition is and the outcomes so some of them tend to have this positive mind to say immediately after operation is done my child will be better and then afterwards if that doesn’t happen some of them now come back when they are re-admitted they say destroyed my child.” Participant 4

b) LANGUAGE

Five of the participants felt that language was a barrier in managing children for them as it was difficult to obtain the patients history as well as provide counsel and psychological advice. It was even more difficult to explain the condition and how important physiotherapy is for their child.

“...sometimes its communication, especially those coming from certain provinces.” Participant 2

“They won’t understand and you will not understand them. Language is a serious barrier. You have to find a mother who speaks the language but also understands some Nyanja. Now if there is nothing like that, problems.” Participant 1

*“Language was a challenge with mothers that came from outside Lusaka province...”*Key Informant – Participant 6

Communication is the key in rehabilitation. Participant 5 stated that a break down causes rehabilitation to be incomplete.

c) LEVEL OF EDUCATION OF CAREGIVERS

The physiotherapists found challenges in managing patients with parents who had low levels of education, it affected information dissemination.

“Sometimes it also depends with the mother. Sometimes maybe I don’t know if I can say the education or who they are. Some you find that they may when you are explaining to them they

understand and probably look forward to take this child for physiotherapy but others no matter how much you explain to them they may not understand.” Participant 5

“Mothers with lower education standard consider myths and misconceptions.” Key Informant – Participant 7

The participants all felt that more educated caregivers would understand the condition better than the less educated caregivers. With the less educated caregivers one would have to explain over and over again to help them understand their child’s condition better.

d) INCONSISTENCY

Inconsistency was a challenge that all the participants had encountered with the caregivers of these children. It made managing these children difficult, even setting goals for them. Every time these children were brought back for physiotherapy they presented worse than before and mothers had a habit of only coming when things look bad for the child. Other caregivers still combined other traditional methods when they felt they were not seeing improvement in physiotherapy some participants suggested.

“...mothers also give up. They lose hope so even follow ups are difficult. Some mothers don’t bring back the children after the operation especially you open up and tell them everything to say it might take long so they think nothing can be done.” Key Informant –Participant 7

“Even Lusaka based patients you find that they have never even gone for physio...” Participant 1

When some caregivers were probed on their non-attendance for physiotherapy sessions they had no answer.

“Parents’ adherence to treatment affects the child’s progress.” Key Informant – Participant 6

e) ANTE-NATAL SERVICES

The interviewer asked the participants on any matters they felt were necessary to add on any information, two participants brought up the issue of promoting birth history to be included in patient files and if early diagnosis had been made prenatally. They both agreed that most mothers did not attend ante-natal clinics; hence it was not possible to know the need for folic acid intake as well as having a scan of the fetus. And they did establish some of this in their assessments with the mothers that many did not attend ante-natal clinics.

“When you go for ante-natal they tell you everything about the baby, they examine you...”

Participant 2

“Even we mothers lack knowledge. Most women don’t know, few of them know they have to take folic acid and all those blood supplements before you conceive and three months before conception. We will only start taking folic 3 months into pregnancy which doesn’t reverse anything.” Key Informant – Participant 6

The researcher did come across one file out of the 180 that showed that the mother was aware of her child having hydrocephalus during pregnancy. Which led to the question: is it the hospitals that do not have adequate equipment, or if they do, it is just the mother who does not want to attend the clinics?

“...it is the mothers because some clinics are able to provide those services.” Participant 5

XXVIII. 4.2.1.2.9 THEME 9: MYTHS AND MISCONCEPTIONS

Myths and misconceptions arose as a challenge the physiotherapists who also suggested that other team members were experiencing. The participants felt that myths and misconceptions led to late presentations.

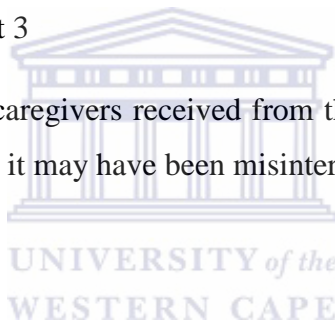
a) MYTHS AND MISCONCEPTIONS

Families that came from rural areas were likely to experience these ideas including those in urban areas. The participants all felt that myths and misconceptions were a challenge in the management of SB at these two hospitals.

“...others have completely no idea about SB, they have never heard of it and seen it. The first time they see it in the family to them it’s a curse and they will want to find someone in the family to be at fault.” Participant 5

“Do they even understand physiotherapy? You have to explain it to them, most of them don’t understand what we go to do there so you have to explain it them cause they end up going back to traditional methods.” Participant 3

However with the knowledge the caregivers received from the hospital, it did clear up on some superstitions in some and in others, it may have been misinterpreted.



b) LATE PRESENTATION

Due to myths and misconceptions, the participants felt that it was the reason why the caregivers presented late, other than logistical and financial challenges. Ignorance of SB played a big role.

“They try other interventions and they will include you at the time when it is very late.”
Participant 2

“Some of them maybe where they are coming from because some of them are from areas where things are hard so they may seek first to find other solutions.” Participant 4

“At our hospital late presentations were in two out of five cases...” Key Informant – Participant 6

XXIX. 4.2.1.2.10 THEME 10: MULTI-DISCIPLINARY COLLABORATION

Multi-disciplinary collaboration arose as a challenge experienced by the participants in the management of SB.

a) NO MULTIDISCIPLINARY WORK

The participants felt that there was no multi-disciplinary collaboration among the health workers and it was a challenge managing SB at their hospitals.

“I think we need to work as a team. We don’t work as a team. We should be involved in ward rounds, discuss and come up with solutions.” Participant 2

“The biggest challenge that we have is the fact that there is no team work amongst medical personnel. I feel like if this child is born we are supposed to be there to plan together. They know the surgical and medical aspects and we know physical rehabilitation” Participant 4

“I usually think we not really included in the first process though sometimes they would they would write in file that the child needs physio but no request reaches us” Key Informant – Participant 7

Others interviewed reported no specific request for physiotherapy, but based on the coincidence of going through the wards and finding it written in the file that the children needed physiotherapy. Participant 1 went further stating that they have no idea when ward rounds are held.

b) ATTITUDES AMONG HEALTH PROFESSIONALS

A good working environment helps one be effective. The participants all felt members of the team had negative attitudes that seemed to change after workshops and seminars. Their perceptions about physiotherapy in the management of SB seemed to have assisted them in working well together.

“I think the same workshop that I am talking about. I have noticed on two occasions the nurses that we have attended with those workshops immediately the attitude changes.” Participant 1

Participant one also said they felt like they impose their presence on the children because the environment does not feel welcoming as hostility is present.

“...some of the team members are like that they are helpful.” Participant 5

c) ROLE OF PHYSIOTHERAPY

The participants felt that the role of physiotherapy not being known may have contributed to the attitudes and no collaboration amongst team members.

“We don’t know even whether the doctors and nurses understand what we do there. So we just go because it is our role.” Participant 1

“Some doctors don’t even know what a physiotherapist does. So such is a barrier to me because the doctor doesn’t involve me in the beginning then I come to be involved at the end of the when the prognosis is bad.” Participant 7

All participants did agree that they felt like the other health professionals did not recognize them. Participant 6 had been invited to a ward round and the doctor showed the mother exercises when that was the job of the physiotherapist. This made the participant wonder the purpose of their presence in the round since the doctor seemed to know everything.

“I think it is best if we had clinical presentations once in a while where we present our role in certain conditions. Because if we continue sitting they will think we are just wasting their gloves and also messing up their offices as well as not understand our role.” Participant 2

They all recommended that clinical presentations among departments and their roles in conditions must be highlighted, and workshops and seminars must be held to help team members understand their role and work more effectively and rehabilitating these children.

4.3 CHAPTER SUMMARY

The findings of the quantitative phase one showed that 207 patients had been managed between January 2010 and December 2014, however only 180 patients had adequate information in their files. SB accompanied by hydrocephalus in myelomeningocele was at 69.4%, commonly located in the lumbar region more commonly in females than in males. SB was more prone among female patients than male patients but in myelomeningocele, the male patients dominated. The majority of SB patients were hours old to one month old. The majority of patient referrals came from district hospitals at 74.4%, and the majority resides in Lusaka province. A percentage of 61.7% of the children underwent meningocele and 1.7% underwent debridement. The most common shunting method used second to those who did not have it done was VPS.

Out of the 180 children managed, 59 had the CNS examination conducted and only 49 had the results in their files. Of those with reduced tone who were referred for physiotherapy, 2.44% attended and 97.6% were not referred. Those with increased tone 37.5% attended and 62.5% were not referred. The files also showed 0% follow-up. Of the other management the children went through, counselling was the most utilized, other than the surgical interventions. The findings also showed that only a small number of mothers had taken folic acid before conception, others remained unknown and the majority of mothers knew their HIV status.

In qualitative Phase Two, seven physiotherapists participated. Ten themes had emerged from the discussion and interviews. These were: the quality of life, rehabilitation, prevention, education, holistic management, training, improvement in patient, knowledge, myths and misconceptions and multi-disciplinary collaboration. The participants found motivation and encouragement in seeing patients improve. Training, workshops and seminars helped them improve their skills, as well as experience in the field. It was also discovered that workshops had caused a positive change in the attitude of team members that seemed to improve interactions with regard to patients.

Most physiotherapists managing children with SB found it challenging working at their hospitals. They felt they were not included in the planning process for the patients, that there was no collaboration amongst team members and the majority never received consultations and never met with the surgeons. They also found educational levels of caregivers and language a barrier in

management children with SB. They also felt that the team members may not know the role of physiotherapy in the management of SB. Poor collaboration and inadequate information in patient files contributed to poor follow-up.

Chapter 5 discusses the findings from the two phases and relates with current literature.



CHAPTER FIVE

DISCUSSION

5.0 INTRODUCTION

This chapter discusses the results of the study and how they relate to recent literature from other studies. The study had set two objectives. The first objective was to determine the demographic profile and the process of care for children with SB at the University Teaching Hospital and Beit Cure International Hospital in Lusaka, Zambia. The second objective was to explore the experiences of physiotherapists in the management of SB children at the University Teaching Hospital and Beit Cure International Hospital in Lusaka, Zambia.

5.1 DEMOGRAPHIC PROFILE OF PATIENTS MANAGED AT THE UNIVERSITY TEACHING HOSPITAL AND BEIT CURE INTERNATIONAL HOSPITAL

The profile of patients managed with SB at UTH and BCIIH in Lusaka, Zambia over the period of investigation will be discussed.

5.1.1 DEMOGRAPHIC AND CLINICAL ATTRIBUTES OF SB PATIENTS

The demographic and clinical attributes helped establish the characteristics of the patients managed at the two hospitals. This also helped understand the statistics of the children managed during the time of inquiry and gave statistics to investigate the number of children managed who needed physiotherapy and who were referred children. This would give reflection of the use of physiotherapy services in the hospitals which may help answer the knowledge of the role of physiotherapy.

There is currently little literature that shows of prevalence of SB in Zambia and this relates to studies conducted in other African countries; this has been attributed to under-reporting or no

reporting that exists in research (Adeleye and Olowookere, 2009). They all revolve around hospital-based studies, which is beneficial as it can improve services delivered and transferable.

Studies conducted in Zambia by Lungu (2004) between 1994 and 2004 showed 244 patients and Mweshi *et al.*, (2011) showed between 2001 and 2010: 253 patients managed between both UTH and BCIH. These patients were rehabilitated at the two hospitals and the patient information in these studies was obtained retrospectively from the patient files. The study population was 207 patients who met the criteria to participate in this study. When further screening was conducted, the researcher managed to get 180 participants due to insufficient information in the files. The 180 patients were patients that attended rehabilitation between January 2010 and December 2014. This shows a drop in the statistics compared to the other studies done in Zambia; however one would have to consider that these statistics are over a five year period. It is expected that the numbers were going to increase as statistics show increase of population yearly.

The year with the highest number of patients managed at these hospitals used in this study was in 2013 with 25% of the population that participated in the study, another study that was conducted showed that 1995 was the highest ranked. When the pattern is observed for the years of this study one would expect a decline in the number of cases with SB, however it keeps fluctuating which shows the possibility of preventive measures being non-existent or not effectively reaching the targets.

The most prevalent type of SB was myelomeningocele at 69.4%, and all of these patients had hydrocephalus. Most affected were male patients by 50.4%, and female patients by 49.6%. A further investigation was conducted to find the association between gender and diagnosis, p value was found to be 0.007 which showed a relationship between the two variables with strength of 0.258 based on Phi and Cramers V test. These findings are in agreement with other studies conducted in other African, some American, European and West Swedish countries (Deak *et al.*, 2008; Djientcheu *et al.*, 2008; Miles, 2006; Persson, 2007; Thompson, 2009). All other studies conducted in Zambia confirmed that myelomeningocele was prevalent amongst NTDs.

Myelomeningocele has been reported to be common among certain ethnic and social groups. A study conducted in America showed prevalence of NTDs more amongst hispanic women than non-hispanic white and black women (Fiegggen, 2014; SBANT, 2010). Frey and Hauser (2003) reported that the Irish, Scottish and Europeans from the North were highly at risk of having children with SB due to genetics. However, all patient records in this study found that they were of the same race and the comparison would have to be determined by province of origin. This was difficult to establish as not many people reside in the province of origin and only patient files were available. Mweshi *et al.* (2011) did report that although it is difficult to speculate the probable causes of NTDs in the Southern province of Zambia, it could include dependency on maize and milk and particular wild fruits, use of cow dung, droplets from mixed with soil eaten by expecting mothers, early and late child birth and toxoplasmosis.

Lungu (2004) found that 86% of patients with myelomeningocele came from poor economic backgrounds. The findings of this study support the reports of SB being common among families from low economic background. Studies conducted show a majority of Zambians with disabilities live in poverty and generally have low literacy levels compared to persons without disabilities (MOH, 2011). The majority of the studies globally weigh more towards myelomeningocele being the most common which is a burden of disease from all spectrums clinically, the family and the individual. Park *et al.* (2002) reports that disability causes families to go through multiple dimensions of poverty that gradually worsens, making it difficult to escape the state of poverty.

In Zambia there have been variations in the location of SB over the years; one study showed 36.1% in the sacral region and another 60% in the lumbar region. This study's findings support the lumbar findings. This study's findings further support the study that reported the lumbar region as the most common due to the fact that it is the last part of the neural tube to close, approximately 80% of lesions occurs in this region (Campbell, Vander and Palisano, 2006). There was no significant relationship between gender and location of SB as the p value was 0.471. This study found that the most frequent location in 100 female patients managed with SB in descending order: lumbar 56, lumbo-sacral 22, thoraco-lumbar 13, cervical 5, thoracic and sacral at 2 each. In 80 male patients managed, the most frequent location of SB in descending

order: lumbar 40, lumbo-sacral 25, thoraco-lumbar 10, sacral 3, cervical 2 and thoracic 0. Myelomeningocele lesions located in the sacral and lower lumbar regions are less likely to present with certain symptoms as compared to thoracic and higher lumbar which are more likely to be associated with motor and sensory deficits and structural abnormalities (Verhoef *et al.*, 2004). Functional defects of the urogenital and lower intestinal tract are likely at all levels (Clayton *et al.*, 2010).

The majority of patients (31.1%) referred, reside in Lusaka. Lungu (2004) found that 38.9% came from Lusaka and another 28% came from the Southern province (Mweshi 2011). Lusaka is the capital city of Zambia and both hospitals are located within Zambia making it easier for more residents to easily access health care services. The study found that 74.4% of the patients were referrals from district hospitals. According to Ministry of Health (2010), Zambia has more health centres than hospitals and the majority of files reviewed showed that the patients were referred from health centres, then district hospitals until they finally arrived at UTH and BCIH which is a long process that these families have to go through considering the urgency of the child's condition.

SB was dominant in females 58% and males 42% and another showed male dominating. The majority of male children came from Lusaka (33 patients) however, the overall majority were females with 55.4% and male patients at 44.6%. However, there was an association between the province and gender with a $p = 0.076$ with a strength of 0.281. Other studies report prevalence SB amongst male children in Zambia over different time frames, Cameroon and Nigeria (Djientcheu *et al.*, 2008; Maragon *et al.*, 2010; Mweshi *et al.*, 2011). The reason for female prevalence of SB was due to embryonic development differing, which is highly susceptible to teratogenic insult and spontaneous abortion rates. However, many other studies support the prevalence in females, for example, another study conducted in Zambia found 56% of the children managed were female, and other African countries (Elsheikh and Ibrahim, 2008; Lungu, 2004). A study found an equal number in the gender of patients with myelomeningocele and did not find any significant relationship between gender and diagnosis (Simpamba, 2012), whereas this study found a strong and significant relationship between the two variables. The study found a higher prevalence of myelomeningocele accompanied by hydrocephalus prevalent in males than females with a difference of one 63:62 ratio.

The most prevalent age was between hours old and 1 month at 73.9% which is possible since SB is seen at birth and many referrals are likely to occur within this period which agrees with many studies conducted worldwide. The birth history of 22 out of the 180 showed that 11 were born through normal delivery, 5 were premature, 3 were born in breech, 2 were distressed at birth and 1 was born through caesarean section. These findings would give a reflection of the mothers poorly attending ante-natal services, because cases of myelomeningocele with detection in- utero would be delivered through caesarean section, and more patients would have received earlier surgical management. According to the Ministry of Health (2011), ante-natal services have been poorly utilised by women, especially in the first trimester which has caused them to miss out on a number of services. A study conducted in rural parts of Zimbabwe, Kenya and Nigeria found that geographical access did not play in role in their failure to attend ante-natal services in the first trimester, but may have been due to cultural beliefs (vulnerability to witchcraft in the early period of pregnancy) (Aniebue and Aniebue 2011; Mathole *et al.*, 2004; Ndidu and Oseremen, 2010; Van Eijk *et al.*, 2006).

A study conducted in Lungu (2004) found that the majority of mothers' maternal age ranged between 27 –31 years old, with smaller numbers in young and older mothers. Poenaru and Bauman (2011) reported that at least approximately 30 per 1000 births would be affected by SB if the mother is older than 35 years. This study found that the mothers' maternal age at time of birth showed that 4.4% were aged between 15 and 19 years of age, 2.8% of the mothers were older than 39 years of age and 92.8% ages were not known. A percentage of 8.3% of the mothers had taken folic before conception and 91.7% remain unknown if they did take it. Mothers at high risk of having children with SB could have also been monitored but due to inconsistency in some mothers, it would be challenge monitoring them. Other African countries show no evidence of pre-natal diagnosis or inadequate equipment to identify SB; South Africa seems to be doing better with the use of The AFP concentration at 15 to 20 weeks of gestation. Release of CSF is common myelomeningocele and anencephaly cases; hence in closed SB it would not effectively detected (Adeleye *et al.*, 2010; Djientchu *et al.*, 2008; Fieggen *et al.*, 2014; Shehu and Ameh, 2004). The availability appropriate health care technology (medical equipment) determines the quality, efficiency and effectiveness of service delivery (MOH, 2011). A mother reported having been told that she was expecting twins when the child had occipital encaphalocoele, other mothers complained of having difficulties accessing ante-natal services (Simpamba, 2012), other studies

support poor prenatal diagnosis in developing countries that report normal even in cases of gross anomalies (Adeleye *et al.*, 2010).

5.2 THE PROCESS OF CARE OF PATIENTS MANAGED AT THE UNIVERSITY TEACHING HOSPITAL AND BEIT CURE INTERNATIONAL HOSPITAL

5.2.1 OVERALL MANAGEMENT

Many studies reported that most of SB management revolves around myelomeningocele, which is the case in Zambia (Bid, 2011; Fieggen *et al.*, 2014; Lungu, 2001). In developed and developing countries management is centred on the medical, surgical, orthopaedic, urological, physiotherapy and orthotic for the rest of their lives (Dicianno *et al.*, 2008). Rehabilitation is a collaborative service that works both ways and it depends on the patient and the family as service recipients and the multi-disciplinary team as the service providers.

A study reported that 56% of children underwent surgery during the first 48 hours after birth in Zambia. Many of the patients' files showed management within the first 48 hours especially for those coming from Lusaka province. The earlier provision of interventions affects the patients' outcomes as well as the measure of the change in the patients meaning prognosis is likely to be better than later operations performed. Simpamba (2012) reported that all patients who reside in Lusaka received repairs within 24 hours of birth; the delay came in from those in further provinces. Management of SB through meningocele was at 61.7%, debridement was at 1.7% and 36.7% had no procedure done. There were reports of infected wounds and leaking wounds in this study which was also found in other studies.

The management of hydrocephalus may entail inserting shunts, surgery and possibly choroid plexus coagulation (Fieggen *et al.*, 2014). Shunting using ETV and CPC procedure has been highly recommended for developing countries as being effective, cheaper and convenient for families and the patients. Success rates were reported in cases that came from Kenya, Tanzania, Malawi, Somalia, Rwanda, Congo and Mauritius (Idowu and Apemiye, 2008; Poenaru and Baunan, 2011; Sacko, 2010; Warf, 2005). The most utilized shunting procedure in hydrocephalus cases was VPS with 41.7%, ETV- CPC 6.1, VPS & ETV- CPC 6.1%, VPS & ETV 3.3% and

42.8% had no procedure performed. The findings utilized more of VPS and other studies conducted in Zambia showed the same outcomes. A small number of children experienced complications with the shunts that led to them undergoing second and third operations to change the shunts. Other studies reported that blocked shunts and meningitis were prevalent amongst some patients (Mweshi *et al.*, 2011; Simpamba, 2012). The use of cost effective interventions for patients helps the family be at ease, especially after having discovered their child's condition and also influences the impairment outcomes in patient for example the use ETV and CPC that are convenient, cheaper and effective.

Urological challenges are always faced by children with myelomeningocele in the form of bladder dysfunction that is accompanied by chronic constipation (Fiegggen *et al.*, 2014). In this study, not many records showed use of urology services but comments had been made regarding continence. A study conducted at the same hospital before this current study showed 30% of myelomeningocele patients having paraplegia and incontinence, 16% had paraplegia, 2% had incontinence only, 30% had neurological impairments, 22% unknown. It further showed that 44% of the patients with myelomeningocele had the most neurological impairments (Simpamba, 2012). This study found that there had been reporting of continence management done in the patients' files, aged from 6 to 10 years, which supports other studies on the evidence of bladder dysfunction as well as chronic constipation.

Congenital deformities such as clubfoot were present in the patients managed. Literature shows that low and middle income countries neglect the management of clubfoot (WHO, 2011), contrary to the findings of this study. Of the 180 patients, 142 did not have clubfoot and 38 did have clubfoot. However, the patient records did not show the children having clubfoot but theatre notes and consent forms showed 17 children received tenotomy and ponseti treatment which confirmed clubfoot. Tenotomies were performed on 3.9% of the patients and 12.2% patients had under gone ponseti management. There was no association between myelomeningocele repairs and clubfoot as the $p=$ value was 0.707. These findings have also been recommended by other studies in the management of clubfoot which are common in children with SB (Bid, 2011; Poenaru and Bauman, 2011; Thompson, 2009).

Yahiaoui, McGough and Voss (2011) HIV/AIDS is a deadly disease that is chronic and affects all body systems. In middle and low income countries infectious diseases such as HIV/AIDS

have attributed to 9% of years individuals live in disability (WHO, 2011). The mere presence of the disease causes disability which is highly likely to worsen the situation in a child with SB. In Sub-Saharan countries in Africa such as Zambia it has one of the highest rankings in burden of disease (IHME, 2010). The interdependence between disability and poverty exists (Filmer, 2008; Hoogeveen, 2003; Ingstad and Grut, 2007; Magnussen, 2011; Trani and Loeb, 2010) and the presence of HIV/AIDS and NTD in a child can be a huge burden on the child and the family leaving one with a sad scenario. There is scarce literature relating to HIV/AIDS and NTDs. The majority of the mothers underwent voluntary counselling and testing of their HIV status: 47% of the mothers tested negative, 43% did not know their status or it was not included in the file and 10% tested positive. Therefore 57% of the mothers were counselled and tested for their status. The studies conducted in Zambia on NTDs at UTH and BCIH relating to management, showed very few relating to the HIV status, most of the studies showed counselling in relation to the condition of the child. One of the mothers on anti-retroviral drugs showed use of a caesarian delivery without knowledge of the SB. Others only found out their status on admission at UTH, and in some cases mothers had discontinued their anti-retroviral drugs.

Investigations conducted on patients included Ultrasound, Computed Tomographic Scan and MRI. Fieggen *et al.*, (2014) recommends use of Ultrasound and MRI rather than CT to identify Chiari II malformations. Other studies conducted in developing and developed countries conduct these exams on SB patients.

5.2.2 PHYSIOTHERAPY

Physiotherapy in the management of NTDs aims at correction of deformities, postural maintenance, promotion of ambulation and independence in conjunction with Orthopaedicians (Burke and Liptak, 2011; Diccanno *et al.*, 2008; Verhoef *et al.*, 2005). According to the physiotherapists participating in this study, the role of physiotherapy in the management of SB according to physiotherapists, is improve the quality of life, rehabilitate patients, disseminate information, prevention of deformities and also counsel family members.

This study supports the report of the World Confederation for Physical Therapy (2011) which aims at maximising function and minimising incapacity, and modifying the client's environment to ensure their fullest possible participation in society thereby increasing autonomy and

empowerment. In Zambia this has been actively supported in the Persons with Disabilities Act (GRZ, 2012) which promotes enabling of PWDs attain full function and participation in all activities in all aspects.

The quality of life for SB patients is improved through increasing the patient's capacity and in the process helping the patient gain independence. Other studies showed that the quality of life is highly influenced by physical functioning; other studies conducted report that SB patients had a lower quality of life compared to hydrocephalus patients alone in relation to self-care, incontinence and mobility (Kirpalani *et al.*, 2000; Padua *et al.*, 2002; Pit-ten, Kennedy and Stevenson, 2000).

Schoenmakers *et al.* (2005) reported that independence in children with SB was determined by lesion level, mental status, contractures and muscle strength of lower extremities; whereas in functional independence the level of the lesion was excluded, which supported the findings of this study. Among the interventions used in managing these patients, it is evident that the physiotherapists took those factors into consideration.

The physiotherapists were asked about the role of physiotherapy in the management of SB. They felt that the rehabilitation involved assessing the functional level, planning treatment and consulting with the caregiver, exercise therapy and also the provision of assistive devices. This is in agreement with other literature on enhancing physical function to improve the patients' quality of life and independence. Planning and preparation is most effective when information is exchanged with caregivers and planning involves taking as many factors into consideration for the satisfaction of physiotherapist, patient and family. Prevention of deformities can be avoided through dissemination of information and understanding of the condition helps one manage it better. This is the reason for partnering with the caregivers.

Accepting a disabled child is not easy and the mothers need all the counsel they can get to help them understand their child's condition because they are informants for their other family members. Psychological advice before surgery or even post-operatively is very important. The physiotherapists explain the connection between physiotherapy and their child's condition. They also provide basic information on how to handle the child, advice on how to manage the child at home and observe the mother perform the exercise and correct wrong methods, wound care post

operatively and positioning. The information bears weight on their participation in the rehabilitation process and the effectiveness of the outcomes.

The comparisons were made in follow-up to a study conducted five years before. Children managed had to undergo a Central Nervous System (CNS) examination. A percentage of 67.2% (121) of the children did not undergo the CNS examination and 32.8% (59) of the 59 patients only 45 had information on the outcomes of their examination: increased tone - 3, reduced tone - 1, No CNS exam - 4 and Normal - 0. The relationship between physiotherapy management and CNS evaluation exists with $p= 0.000$ and strength of 0.348. The numbers of children with SB who needed physiotherapy and were referred out of 180 were 49. Under reduced tone 2.44% was referred for physiotherapy and 97.56% were not referred. With increased tone 37.5% were referred for physiotherapy and 62.5% were not referred for physiotherapy. Another study that was conducted at the same hospitals showed that 76% of those with increased tone and the same for those with reduced tone who needed physiotherapy were not referred. When compared to ten years before, the current number of patients with reduced tone not referred has increased by at least 21.6% and in increased tone has reduced by 14.5%. This confirms that physiotherapy is still being poorly utilised.

The study found that a small population was referred before surgery, after surgery and follow-ups of patients managed. Before surgery 3.9% and 96.1% were not referred for physiotherapy, after surgery 6.1 % were referred and 93.9% were not referred for physiotherapy. Of the 180 patients managed with SB between 2010 and 2014, 1.7% showed follow-up and 98.3% were not followed up. No patient's files showed referral to other physiotherapy departments in their locality. Others studies conducted before at the same hospitals also found that patient follow-up is very poor and these findings support this study. Follow-up is a way of evaluating the effectiveness of rehabilitation process however this medium gives an image of the rehabilitation process.

5.3 EXPERIENCES OF PHYSIOTHERAPISTS MANAGING CHILDREN WITH SPINA BIFIDA AT THE UNIVERSITY TEACHING HOSPITAL AND BEIT CURE INTERNATIONAL HOSPITAL.

According to Ljusegen *et al.* (2012), who researched on the experiences of physiotherapists in rehabilitation, found that health and disability paradigms led to different approaches to rehabilitation which in turn determined the intervention process strategies for the assessment and treatment. Larsson *et al.* (2012) agrees with Ljusegen *et.al.* (2012) that different aspects contribute to the approaches in physiotherapy and influence the experiences of physiotherapists in the rehabilitation process.

5.3.1 FACILITATORS TO REHABILITATION

5.3.1.1 Training programs

Every organisation requires positive incentives to maintain the quality of their services. Hongoro and Normand (2006) report that the continuation of professional development is a good incentive and helps retain staff members; it helps guarantee competence.

When the physiotherapists were asked what they felt helped them in rehabilitating children with SB at their hospitals during interviews and FDG, they responding stating that they felt training programmes such as workshops and seminars helped empower them on the management of SB and they had attended a number on SB and hydrocephalus. They were also taught how to manage urinary and bowel incontinence which is very helpful in information dissemination to the caregiver coming from rural areas, and of whom few have this opportunity. These workshops had mothers and health personnel in attendance. Some of the participants felt they were not adequately prepared to manage SB patients, but experience and training combined has helped them gain confidence and better understanding of SB.

Kurowski *et al.* (2003) reports that health care workers experience among many problems lack of technical skills, low motivation and poor support networks. According to Jha and Mills (2002), providing health workers with the appropriate skills and motivating them helps meet the Millennium developmental goals and is of uttermost importance, it helps empower them as well

as provide quality services to patients (Hongoro and Normand, 2006). Manongi, Marchant and Bygberg (2006) recommend motivating, providing more skill and support helps maximise the effectiveness of health workers.

5.3.1.2 Improvement in patients

Seeing progress and improvement in patients brought satisfaction and encouragement for the physiotherapist. Improvement brought job satisfaction and also motivated them to do better for these children especially in cases that have been seen from the time the child was an infant and seeing major improvements was enlightening.

5.3.1.3 Availability of assistive devices

A study conducted in Tanzania in a primary health care setting reported that physical infrastructure and the availability of medical equipment contributed positively to the morale and efficiency of health care providers (Manongi, Marchant and Bygberg, 2006). These findings are similar to those of this study. The availability of assistive devices at hospitals made the service to be more efficient, especially for patients coming from distant places at least one is assured that the child has an assistive device such as special chair (even modified chairs that accommodate patients with hydrocephalus and cerebral palsy), wheelchairs, crutches, braces, callipers. Reichman, Corman and Noonan (2008) reports that many families with disabled children rely on availability of public assistance this promotes social participation of the child and family. This is beneficial, although another study reported that low income families tend to have negative perceptions on resources available (Silverstein *et al.*, 2008), though one in desperate need would not be selective about assistance. Hartley *et al.* (2005, p. 173) reports that in families that were struggling, the assistive devices would not be priority and would not be bought, in order to meet other family needs. In this study these devices were freely given to those families that could not afford acquiring them. The physiotherapists would assess the patients that needed assistive devices and would advise appropriately in most cases on readmission. However, Schoenmakers *et al.* (2005) does recommend that assistive devices can be used but should never disadvantage the patients' independence, as is the case with many patients who give up and resort to depending on their devices full time.

5.3.2 CHALLENGES TO REHABILITATION

5.3.2.1 Communication

Communication is important in chronic conditions, as it is the only way for information to be disseminated (Harris *et al.*, 2008). This literature suggests that if there is a break in information about SB, its cause and how it can be managed, it will lead to failure of caregivers understanding the purpose of goals set for physiotherapy management of the child and this is a drawback. The surgeons, being first to see the caregivers, play a large role as the caregivers need to understand why they are giving consent to a procedure they have no understanding of its effects and its benefits for their child. According to Joffe *et al.* (2003), the perceptions of patients and their families including how they perceive the health professionals and response to treatment or rehabilitation is correlated with respect and dignity. Some studies have shown the relevance of integrating parents from the beginning, as the resources they have available determine the quality of life as well as the severity of SB independently found despite physiotherapy playing a focal role in the quality of life (Pit-ten *et al.*, 2000; Schoenmakers *et al.*, 2005).

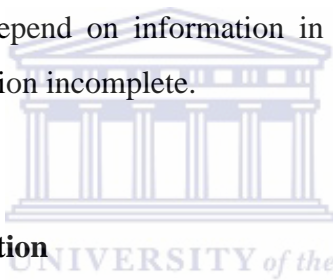
Caregiver's expectations were based on the information stated the physiotherapists. If they had assumptions, it would influence their expectations. For example, the fact that someone undergoes a surgical procedure means they will improve and everything would be normalized. In many cases, some parents would blame the doctors of having destroyed instead of making them better. A study found that some mothers felt that beliefs about disability had stemmed from a lack of information in society (Wilson, 2012). The same could apply if parents shared such information amongst themselves that surgery worsens their child's health.

Studies conducted globally show that communication is a challenge in chronic conditions that are disabling and can relate to SB. A study conducted in China, Turkey found that mothers had an urgent need for information to ease their lives (Bilgin and Kucuk, 2010; Wong *et al.*, 2004), in Iran mothers felt unsupported and uninformed (Kermanshahi *et al.*, 2008, p. 322); Edwardji *et al.* (2010) found in a study conducted in India that educated mothers had appropriate information but refrained from seeking treatment due to stigma and shame surrounding disability, meaning that it required desire and incentive from the mothers despite the negative attitudes from the society. In Uganda, a study found that there was a great amount of inaccurate information

surrounding disability. It was reported parents wanted to have accurate information so as to save up on expenses with irrelevant treatment and unrealistic goals (Ibid pg. 149 as cited by Wilson, 2012).

5.3.2.2 Language barriers

Language is a barrier in communication that also needs to be addressed. The physiotherapist found it challenging to communicate with some caregivers due to differences in languages. It was difficult to obtain the patients history as well as provide counsel, explain the condition, importance of physiotherapy in condition and provide psychological advice. In some instances mothers, nurses or hospital staff present in the ward at time of assessment who could understand more than one language would normally interpret. Some patients did not have anyone to translate so one would have to depend on information in the patient's file and the physical assessment, which made rehabilitation incomplete.



5.3.2.3 Caregivers' level of education

Levels of education play a pivotal role in the ability of an individual being able to gain insight on information. Harris *et al.* (2008) suggests that lack of information is a barrier when managing patients with chronic illnesses. Maloni *et al.* (2010) reported that a positive correlation between the level of education and use or sourcing disability services.

Many SB patients were reported to have come from rural areas and in rural settings education may not be at the top of their priority list of the caregivers (Pramila Padmini and Narasinga Rao, 2011). Studies conducted in Bangladesh, Uganda, found many mothers who had children with disabilities had low levels of education and were from rural areas (Diken, 2006; Maloni *et al.*, 2010; Wilson, 2012). Lungu (2004) reported that, 45.7% of parents had primary education, 28% secondary education and 25.7% had no education. According to Sousa and Singhvi (2011), educated parents are able to handle their children with disabilities better and learn easily, resulting in higher chances of being able to manage their children better. Glewwe (2009) further went on to suggest that the parents pass on the information to other generations since they are well informed.

The physiotherapists in this study stated that with some mothers you find that when you are explaining their child's condition to them, they would understand and probably look forward to taking the child for physiotherapy, but others no matter how much you explain to them they may not understand. This hinders following of home programme as they may not even understand its relevance to their child's wellbeing. Training is something some parents desired to help reduce stress and anxiety but also improves their child's life (Edwardraj *et al.*, 2010; Hartley *et al.*, 2005; Morgan and Tan, 2010).

5.3.2.4 Inconsistency of caregivers

Inconsistency of caregivers was a challenge in the rehabilitation process as they came whenever it suited them, making it difficult to monitor their child's health. The possibility of home advice not being implemented by them was high. It made managing these children difficult, even setting goals for them. Every time these children were brought back for physiotherapy they presented worse than before, and mothers had a habit of only coming when things look bad for the child. Other caregivers still combined other traditional methods when they felt they were not seeing improvement in physiotherapy.

According to Ingstad and Grut (2007), some parents lose their spirit to fight, due to being overwhelmed with the constraints in everyday life and consequently give up. This eventually brings rehabilitation to a halt. Mweshi *et al.* (2011) discovered that 253 children were attended to with SB and 18% of those children remained consistent for the 1st, 5% in the 2nd and 0.2 % in the 4th year. This shows non-compliance and inconsistency, which is a challenge for the physiotherapist to monitor the treatment planned. It is more disappointing to note that many caregivers based in Lusaka do not attend physiotherapy, and when asked by physiotherapists they never have any valid reason.

The lack in appropriate and accurate information has caused mothers to forgo treatment and give up, since they feel their child will not improve in any way (in some it would be a waste of time and money); this also contributed to unrealistic hopes in them (Edwardaji *et al.*, 2010; Wilson, 2012).

5.3.2.5 Inadequate hospital resources

Manongi, Marchant and Bygberg (2006) show that high workloads and inadequate equipment contributes to the effectiveness and efficiency of an individuals' service delivery. The fact that two hospitals manage the condition suggests that children with Spina Bifida can come from anywhere in Zambia. The shortage or absence of equipment (Ministry of Health, 2006) is a challenge in the identification of Spina Bifida and discovery maybe late and presented with dirt and infections (Idowu and Apemiye, 2008). A study conducted by Simpamba (2012) found that some of the health centres sent them back home after delivery, even with the SB and others had challenges accessing transport to UTH or BCIH as they had to be referred from one place to the other. This is a reason for late presentations and also negligence on the health professionals' part. This study came across one file out of the 180 that showed that the mother was aware of her baby having hydrocephalus pre-natally. The researcher asked the participants about the availability of adequate equipment for pre-natal diagnosis of SB in the ante-natal clinics, and they responded that some clinics are able to provide those services so it was more of the mothers' decision to attend ante-natal clinics. Two physiotherapists informed the researcher that they felt that most mothers did not attend ante-natal clinics; hence it was not possible to know the need for folic acid intake as well as having a scan of the fetus. Many of the mothers lacked knowledge and most of them did not know the purpose of folic acid before conception that others would take it four months into pregnancy which is irreversible on SB. Mathole *et al.* (2004) reported many did not utilize the ante-natal services, causing them to miss out a number of beneficial services. Gupta and Gupta (2000) and Lynch (2002) reported on knowledge amongst health professional on folic acid use, dosage and poorly recommended diet. These findings may account for the low levels of knowledge on folic acid in the African context in these women.

5.2.3.6 Myths and misconceptions

People being in formal employment, according to the Central Statistics Office (2009) rural poverty was at 80% and urban poverty was 34%. Poverty limits a person's ability to make decisions (Magnussen, 2011), if the family is unable to meet the costs, they tend to opt for cheaper and easily accessible alternatives such as traditional methods compared to travelling long distances to hospitals.

Magnussen's (2011) research in Zambia on health care service delivery found that most parents that had preferred to use traditional methods with the hope to cure their children rather than turn to medical services. After failing to accomplish any form of improvement once they notice their child's condition worsening, they would seek modern methods. In low and middle income countries stigma, myths, stereotypes and misconceptions have restricted attention and the implementation of interventions; it has also been a challenge for the family (Edwardraj *et al.*, 2010; WHO, 2012).

Beliefs that exist relating to disability globally include: parents having done something wrong in their past life, a test of endurance (a symbol of strength), Allah's fate for them, karmic destiny, possession by spirits, others may have fallen pregnant on a Friday or Monday (abomination), certain rites were not performed, witchcraft, angry spirits (Abasiubong *et al.*, 2008; Bilgin and Kucuk, 2010; Edwardji *et al.*, 2010; Holroyd, 2003; Kermanshahi *et al.*, 2008; McCabe, 2007; Morgan & Tan, 2011; Saetermoe *et al.*, 2004; Wilson, 2012). In India even some health workers believed the disability was preventable and were less sympathetic but the mother may eaten wrong foods or argued too much during pregnancy (Edwardji *et al.*, 2010).

According to Lungu (2004) 86% of parents to children with myelomeningocele come from low socio-economic backgrounds, it difficult for the parents to meet expenses. Cases of families combining both knowledge from physiotherapists and the traditional healers exist, which affects the implementation of goals set for rehabilitation. Some of the patients the physiotherapists worked with said some started a witch hunt in their family to find the person who bewitched the child. However, with the knowledge the caregivers received from the hospital, it cleared up on the some superstitions of their child being bewitched and others causes which may still have been misinterpreted. This has further led to locking up of children with disabilities to save face in earlier years in China, which is not new in the African context; it is possible that it is still happening (McCabe, 2007; Miles, 2006; Wang *et al.*, 2010).

Despite all the negativity surrounding myths and misconceptions Abasiubong *et al.* (2008) and Wilson (2012) found them empowering at times, as some families utilised the child's strength to empower them and utilise their capacity to the fullest.

Some studies have shown how fear, anxiety and social perspectives influence a mother's decision-making when it comes to their child's health (Aniebue and Aniebue, 2011; Mathole *et al.*, 2004; Ndidi and Oseremen, 2010; Van Eijk *et al.*, 2006). These findings agree with literature from other contexts and can account for low utilization of physiotherapy services by families of children with SB. Diken (2006) reports some families not utilizing health care services due myths and misconceptions.

5.2.3.7 No holistic management in Spina Bifida cases

The health care system in Zambia has been reported to have had an integrative way of considering both diseases and individuals, which affected how people experience services (Hjortsberg, 2003). This is contrary to what is happening in the management of SB at UTH and BCIH. The physiotherapists who participated in this study felt that patients were not managed holistically and physiotherapists were not included in the planning process for the SB patients. A participant was quoted:

They were not included in ward rounds and they did not receive any consultations for SB but other conditions such as tumors, road traffic accident victims. Some of the physiotherapist stated that there is no interaction with the doctors and they do not meet. The broadness of skills in the multi-disciplinary team is meant to promote holistic management of patients (Mann and Williams, 2003).

According to Article 26 of the UNCRPD (WHO, 2001) that addresses issues of habilitation and rehabilitation it states that services providers "shall organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health." This study found that there is no comprehensive treatment of patients and the rehabilitation of children with SB was more selective and favored other conditions. One physiotherapist went on to say the doctors seemed to focus more myelomeningocele than the person as a whole. The therapists managed these patients by coincidence, finding them in the wards when checking on other patients and they are recorded in the register in the departments and not the patient's files in the ward. It would have been beneficial or the patients to record the

information in their files than the register, as records are legal proof, can also communicate with the doctors, despite the lack of referral and research (Mann and Williams, 2003). It would have benefited this study to show how many patients were managed without referrals.

The inefficiency in the health care system in Zambia has been attributed to insufficient capacities at lower levels, inadequate man power, erratic supply of essential drugs and medical supplies, and inequities in the distribution of essential physical infrastructure and equipment to offer services that are appropriate to their level, and also due to the limited scope of services offered by facilities at lower levels (MOH, 2011). This may not account for the poor rehabilitation of children with SB.

5.2.3.8 Poor multi-disciplinary collaboration

The effective team work is crucial in the rehabilitation process as it produces better patient outcomes; no one professional can be skilled in all areas and be able to achieve optimal results alone (Balley and Sim, 2001; Neumann *et al.*, 2009). According to Neuman *et al.* (2009) team work includes agreed aims and understanding of how to achieve them, mutual trust and respect and whilst utilizing the versatile skills present with willingness to share knowledge and expertise and also speak openly.

This study found that there was no team work and collaboration amongst the multi-disciplinary team members managing SB at UTH and BCIH, which has been a challenge for the physiotherapists managing these children.

Balley and Sim (2001) supports this study's findings and reports that rehabilitative literature shows evidence of multi-disciplinary collaboration and co-operation being difficult to accomplish even despite them being determinants of consistency and continuity of the rehabilitation a patient receives. Burke and Liptak (2011) and Neumann *et al.* (2009) report that in many European countries the integration of other team members when managing a patient is dependent on the physician, whereas in other contexts; the team members decide. This study's findings support the European countries reports that physicians decide on behalf of the team members.

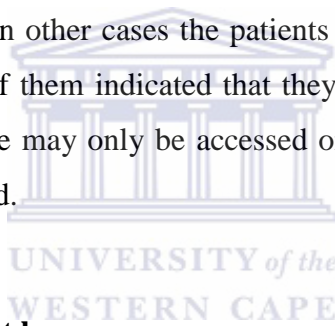
Two participants had said they found referrals in the patients' files; however, none came through to the department so it was a matter of going each file to find the patients. This can delay the rehabilitation process, as patients are often discharged. Another physiotherapist complained of having attended a ward round where the surgeon did everything the physiotherapist was meant to teach the patient in their presence which made them feel irrelevant in the ward rounds. Manongi, Marchant and Bygberg (2006) reported that collaboration involves supporting and developing team member roles, since everyone is a specialist in their field and they bring something to the table, without being devalued and respected (Neumann *et al.*, 2009).

5.2.3.9 Inadequate patient information

According to Owen (2005), to ensure continuity and communication amongst health professionals of ongoing care and treatment, accurate documentation is of the essence. Mann and William (2003) report that the purpose of medical records can be divided into primary functions which are to support direct patient care (Aide memoir and communication) and secondary functions which are legal medical records and source of information for resource allocations, service planning, research, auditing, performance monitoring and epidemiology.

This study found that patients' files had inadequate and inconsistent information written in them which made them a little unreliable, which disagrees with Nursing and Midwifery Council (2002) that states the records should be consistent, factual, current and comprehensive. The therapists found it challenging to use those files and preferred seeing the patients and conducting their own assessments. Some patient files had different diagnosis and locations in the same file. The researcher asked whether the information in files was adequate enough for them as it was noticed by the researcher in the files was inconsistent starting with diagnosis and other processes of management the patient underwent; some patients had different diagnosis and location of SB throughout their files. Literature shows that there is a drift from written patient records to computerizing them; however studies conducted in Wales and England showed that there were inadequacies in the written patient records which questioned its effectiveness when computerized (Health Informants Unit, 2002).

According to the Nursing and Midwifery Council (2002) communication is made effective through record keeping, as team members gain understanding of the patients past, present and possibilities to come. However, that is not the case in this study. The patient files showed poor use of physiotherapy services in the process of care which was further confirmed with findings in the FDG that there is poor use. This in turn affects follow up; it is essential in setting up of goals, monitoring progress and record keeping in physiotherapy. Inadequate patient information contributed to poor follow up in the few patients referred as well as some seen by the physiotherapists without referral. The findings are further supported by a study conducted years before at the same institutions that found that the majority of Spina Bifida patients, being more than 50%, were not Lusaka based (Lungu, 2004). This meant it would be difficult to make follow ups, worse still, furthermore, this study found 1.7% follow-up. “Poor people have a high burden of disease and use health services at a lower rate” (GRZ, 2011). Most physiotherapy referrals were made verbally and in other cases the patients were found discharged, and during re-admission, when asked, some of them indicated that they were not told about physiotherapy upon discharge. This health service may only be accessed only in the beginning; the years that follow it is likely to be discontinued.



5.2.3.10 Role of physiotherapy not known

Acknowledging the importance each other's role in the management of conditions is essential, other studies show that differences in role expectations and role perceptions exist among members of the rehabilitation team (Dalley and Sim, 2001). Ideologies between professions and negative attitude create barriers to functioning of the rehabilitation team (Dalley and Sim, 2001). The role of physiotherapy in the management of SB may not be known amongst team members, such as the surgeons, (who have a greater influence on the team, they decide who to include in the multi-disciplinary team), nurses and may have contributed to the attitudes and no collaboration amongst team members in this study. Dalley and Sim (2001) support the findings of this study and reports from other studies that there is a lack of information on the perceptions of other professions on physiotherapy.

The participants stated that some team members seem to have no understanding of the presence of physiotherapists in the wards. The lack of knowledge can be related to a lesser degree of inclusion in the planning process and decision-making to develop in their roles.

The relevance was not seen by the therapists for a referral letter when the child's condition worsened, as it felt like the last resort and not a priority. According to Manongi, Marchant and Bygberg (2006), members of the multi-disciplinary team are demotivated when they feel unsupported and not valued. Balley and Sim (2001) reported that other studies showed that some team members knew little of what physiotherapists do and evaluated their contribution. They had recommended that clinical presentations, workshops and seminars be conducted among departments to highlight their roles in the management of conditions such as SB. These attitudes and perceptions affect team work and the effectiveness of rehabilitation (Balley and Sim, 2001), and may have contributed to the management of SB at UTH and BCIH in Lusaka, Zambia.

A study conducted in the United Kingdom to explore the perceptions of nurses in relation to physiotherapists, found that they had an idea though it was limited, they also felt undervalued by physiotherapists and communication breakdown existed between them (Balley and Sim, 2001). This seems to be the opposite from the studies' findings, but communication is a challenge in both; this does not represent all members of the multi-disciplinary team in the management of SB but shows evidence of attitudes and perceptions among other members.

5.4 CHAPTER SUMMARY

Clinical management of SB is challenging, studies done in some African countries like Nigeria, Cameroon, Kenya and Uganda on the management of children with SB have reported challenges encountered in management (Adeleye *et al.*, 2010; Blenchowe *et al.*, 2010; Warf and Kulkarni, 2010; Kulkarni *et al.*, 2010), such is the case in Zambia. Most families of these patients come from harsh social and economic realities, myths and beliefs, inadequate medical manpower and inadequate health services hence they present in delay with numerous open, dirty myelomeningoceles, septic (Campbell *et al.*, 2000; Djientcheu *et al.*, 2008; Idowu and Apemiye,

2008). The implications of this study's findings are that there are problems in the multidisciplinary system managing children with SB and it goes both ways with the patient's family as well as the team managing them. It is evident with the use of the service supply chain in both patient, provider and service outcomes. Information flows between both groups and within the groups. Factors such as not being included in the planning process, no holistic management, poor knowledge of role of physiotherapy, attitudes amongst team members and no multi-disciplinary collaboration were seen in the providers' outcomes. In the patient outcomes, language barriers, myths and misconceptions, lack of knowledge, inconsistency and level of education were seen. These two groups have a great impact on the service outcomes. There is no satisfaction among the physiotherapists, other team members, the child and the family. Many of the children are not receiving holistic management with makes management and the rehabilitation process ineffective.



CHAPTER SIX

CONCLUSION, SIGNIFICANCE, LIMITATIONS AND RECOMMENDATIONS

6.0 INTRODUCTION

This chapter is has been divided into three conclusion, limitations and recommendations. It is an overall summary of the study and the limitations of this study will be highlighted. Recommendations for the future are made based on the findings of this study.

6.1 SUMMARY OF STUDY

The research question of this study was: what is the involvement of physiotherapy in the management of SB children at the University Teaching Hospital and Beit Cure International Hospital in Lusaka, Zambia? Thus, the study was aimed at investigating the role of physiotherapy in the management of SB children at the University Teaching Hospital and Beit Cure International Hospital in Lusaka, Zambia. Literature showed evidence of poor utilization of physiotherapy services in the management of SB at UTH and BCIH in Lusaka, Zambia (from January 2001 to January 2010). This study made a further inquiry whether the situation had changed or it remained the same.

The objectives of the study were to determine the demographic profile of children with SB and the process care for children with SB at the University Teaching Hospital and Beit Cure International Hospital in Lusaka, Zambia. The researcher also explored the experiences of physiotherapists in the management of SB children at the University Teaching Hospital and Beit Cure International Hospital in Lusaka, Zambia. This was further divided into three but addressed using two methods. The demographic profile and process of care was obtained through reviewing hospital records of patients with SB managed between January 2010 and December 2014 at UTH and BCIH. Currently there are limited studies conducted on SB management in

Zambia since 2010, and a follow-up was needed on the previous reports conducted by other researchers on the management of SB at UTH and BCIH. Limited literature exists on the experiences of physiotherapists managing children with SB in Zambia and this study hoped to find out what was happening at the two hospitals, whether patients were being referred for physiotherapy and they did not just include their sessions in the patient files. The researcher also hoped to inquire on results found in the first phase of the study. The last objective was explored using focus group discussions and in-depth interviews with physiotherapists managing these children at the two hospitals. The outcomes of the study are further represented under the headings that follow. The findings were related to the service supply chain (Kaplan, 2012) which relates through patient, provider and service outcomes.

6.1.1 DEMOGRAPHIC PROFILE OF PATIENTS WITH SPINA BIFIDA

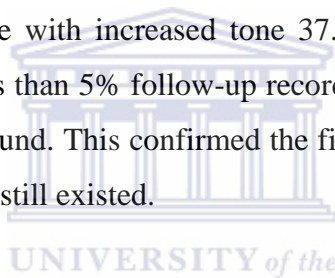
Hospital records at UTH and BCIH were reviewed from January 2010 to December 2014 of confirmed SB patients. 207 patients had been managed in that time frame but 27 files had inadequate information and so they were excluded n=180. The study found that 2013 was the year when the most patients with SB were managed 25% of the population and 2010 had the least number of patients at 15.6%. Amongst the types of SB, myelomeningocele was the most prevalent with 69.4%, and more in male patients than females with 63:62 ratio accompanied by hydrocephalus in those cases. The least common type of SB was occulta at 0.6% with 0 females and 1 male. The majority of patients had it in the lumbar region 53.3% and the minority had it in the thoracic region - 1.1% of the population. SB was commonly located in the lumbar region among female 55.6% and male 44.4% patients. Most of the patients managed were hours old to one month 73.9% and the majority of them were referred from district hospitals 74.4% (1st level hospitals) and the least came from provincial hospitals (3rd level hospitals) at 3.3%. Most of the patients came from Lusaka province 31.1% and Muchinga province had 0 patients. The findings of this study support other studies conducted in other developing countries in Africa.

6.1.2 PROCESS OF CARE OF PATIENTS WITH SB

The patients under went surgical procedures. Among all 180 patients 61.7% of the children underwent meningocele, and 1.7% had debridement done. The most common shunting procedure used second to those who did not have it done was VPS at 41.7%. The patient files

also showed complications such as CSF leaking, infections and shunt blockages; 9.4% of the children used more than one of the different procedures such as ETV, CPC and VPS. Patients with clubfoot underwent tenotomy 3.9%, others had nothing done but were confirmed with clubfoot 12.2% and 78.9% had ponseti procedure done. Other forms of management were counselling, orthopaedic, orthosis and lastly nutrition and the most utilized was counselling. The mothers also went through voluntary counselling and testing for their HIV status: 47% of the mothers tested negative, 43% didn't know their status or it was not included in the file and 10% tested positive.

Some of the patients underwent a CNS examination and the results show that out of the 180 children managed with SB 59 had the CNS examination conducted and only 49 had the results in their files. Of those with reduced tone who were referred for physiotherapy, 2.44% attended and 97.6% were not referred. Of those with increased tone 37.5% attended, and 62.5% were not referred. The files also showed less than 5% follow-up recorded. The patients had investigations done such as MRI, CT and Ultrasound. This confirmed the findings from the previous study that poor use of physiotherapy services still existed.



The birth history of 22 patients showed that the majority 11 (50%) were born through normal delivery. There was a record of mothers that took folic acid before: 8.3% mothers took folic acid and 91.7% had no folic acid on record. 92.8% of the files had no data on the mother's maternal age, however: 13 files had information on their ages - young mothers aged between 15 - 18yrs were 4.4% of the population and older mothers aged over 40 years were 2.8% of the population. The findings of this study agree with other studies conducted in other African countries.

6.1.3 EXPERIENCES OF PHYSIOTHERAPISTS MANAGING CHILDREN WITH SB AT UTH AND BCIH

The physiotherapists working at both hospitals experienced challenges managing children with SB at UTH and BCIH. When asked about the challenges they face, the physiotherapists felt that there was poor multi-disciplinary collaboration amongst members of team and management was not holistic. The focus was more drawn to the management of the lesion which further explains

the poor requests for physiotherapy in children who need physical rehabilitation. Consultations for other conditions would be addressed, but not SB. The physiotherapists felt that the role of physiotherapy was not known amongst some of the team members (surgeons, nurses) which can explain the poor referrals as well as attitudes amongst other team members. They went on to say there was no interaction with the surgeons and they never met for the planning process for rehabilitation of these patients. The physiotherapists, in their professional capacity, would still go ahead in the wards to check on patients who required physiotherapy and would still manage them but would record their activities in departmental records and not patient files. The patients' family contributed to the challenges. Lack of knowledge and understanding about SB as well as support could explain their participation in the rehabilitation process, delays in presentations, inconsistency, level of education and language barriers. The evidence from other studies showed that most children with SB come from low economic backgrounds which could also contribute to their participation, because SB requires adequate finances as rehabilitation is an ongoing process for these children.

Despite all these challenges, they felt that seeing an improvement in the patients they managed, brought satisfaction and increased their motivation to want to help more children with SB. The availability of assistive devices in hospitals also helped their work and provided this resource to children who needed them. For those who could not afford assistive devices, they were given freely. Lastly, training programmes were very helpful for the physiotherapist. They felt empowered in managing the condition better, and the team members in attendance seemed to have a change of attitude towards them and they were more inclusive.

6.3 CONCLUSION

This study's aim and objectives were achieved successfully. The findings of this study are further supported by studies conducted globally. Many matters arose that need to be addressed, such as high incidences in SB, despite food fortification policies in existence, the need for more prenatal diagnosis of SB in more hospitals, clinics, healthcare centres and poor follow up of patients managed. Another problem noted was some management was given a higher priority than others, despite the need to manage patients comprehensively and holistically. Physiotherapy

was one of those given less priority, despite the role it plays in improving the quality of life through physical function, mobility and independence in SB patients (Verhoef *et al.*, 2005).

The findings of this study are in agreement with Larsson *et al.* (2012) and Ingalil *et al.* (2012) that different aspects contribute to the approaches in physiotherapy and influence their experiences in rehabilitation. It was established that there is no multi-disciplinary collaboration, which has led to poor service delivery in the management of SB, largely influenced by the surgeons who select participants in the rehabilitation team. The knowledge of the role of physiotherapy in the management of SB amongst some team members is questionable and can be further researched. The knowledge the family member affects their ability to get the most of the services provided for their children. It is also possible that physiotherapy may not be the only under-utilised service in the management of SB at UTH and BCIH in Lusaka, Zambia.

6.4 SIGNIFICANCE

The findings of this study will help members of the rehabilitation team address the issue of team work and holistic management in children with SB. This will also encourage physiotherapists to market their role to team members to have a better understanding.

This will help Ministry of Health readdress the folic acid implementation programme, and further look into the matter of diagnosis of NTDs early and enhance information given out in ante-natal services as well as community outreach ante-natal services for those in further locations. This will also help them have an image of the health service delivery.

These findings will add to the body of knowledge on the management of SB in at UTH and BCIH in Lusaka, Zambia.

6.5 LIMITATIONS

The researcher experienced the following limitations:

- The hospital records had been stacked in piles and there was possibility of some files missing. There was also inadequate information in some of the patient files and some had

to be excluded. There was another possibility that some patients may have undergone some other management but it was not included in their files or even lost amongst the other stacks of files.

- Due to time and planning, surgeons who managed the patients were not included in study. It would have been more effective to interview both groups to have a deeper understanding of the situation.
- Insufficient participants for the focus group discussion as the sixth participant left during the discussion due to personal commitments. This may have limited the amount of information given to fully understand their experiences but may have been complimented by the two in-depth interviews conducted with other participants.

6.6 RECOMMENDATIONS

- All relevant team members must be present in ward rounds for better planning and effective service delivery that is holistic, physiotherapy request forms to be included on nurses' tray during ward rounds as well as better recording of patients' information, bearing in mind other team members. In the ward rounds the planning for referrals to physiotherapy departments closer their homes can be done and this will help monitor and make follow-ups on these children. More interaction with surgeons and other team members must be encouraged for better service delivery.
- The government to allocate more funds for more hospitals to have appropriate equipment and manpower for the management of more conditions surgically such as SB so as to make the services easily accessible and also help improve the prognosis of some conditions.
- Clinical presentations amongst departments for awareness and empowerment amongst multi-disciplinary team members. More training workshops on SB management can be rotated to ensure that other team members who have not attended previous workshops can get the chance to acquire knowledge.
- Reviewing of any folic acid implementation plans set out by Ministry of Health to see effectiveness and promote education among women of reproductive ages in both urban and rural areas especially its association with NTD's.

- Ultra sound screening for all pregnant women in all hospitals that have the equipment or even refer to ones that have them, to help detection of NTDs earlier, to plan for management, delivery and help the family prepare the child.
- A further query should be conducted to explore the perceptions and experiences of surgeons at the University Teaching Hospital and Beit Cure International Hospital in Lusaka, Zambia.
- An investigation to find out the patients managed at UTH and BCIH who were lost in follow-up and their current prognosis.



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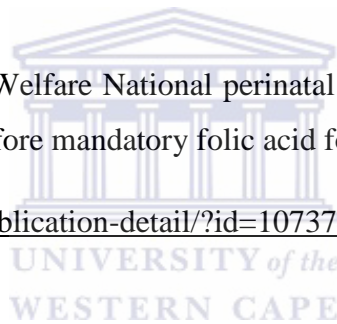
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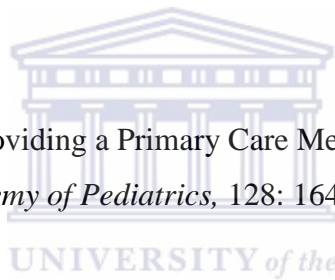
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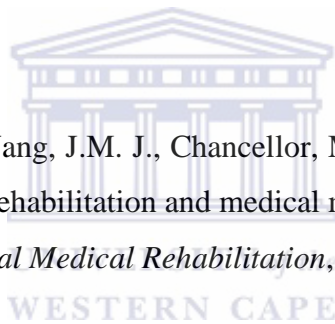
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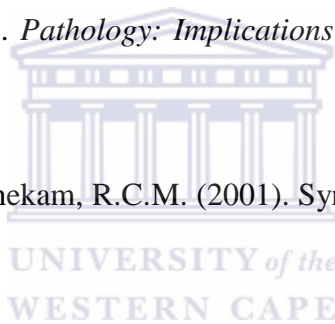
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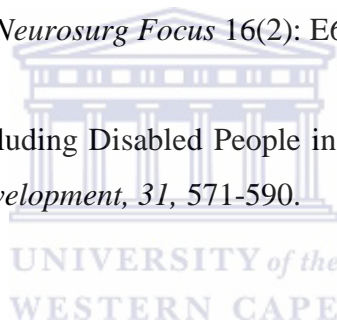
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APPENDICES

APPENDIX 1

DATA GATHERING INSTRUMENT

SECTION 1: DEMOGRAPHIC DATA

1.1 Code Number

1.2 Referral

Provincial (1)

District (2)

Direct contact to UTH /CURE (3)

Health centre (4)

1.3 Province of residence:

Northern (1)

Central (2)

Eastern (3)

North Western (4)

Luapula (5)

Southern (6)

Western (7)

Muchinga (8)

Lusaka (9)

Copperbelt (10)

1.4 Gender

Female (1)

Male (2)

1.5 Age on admission

Less than 1 month (1)



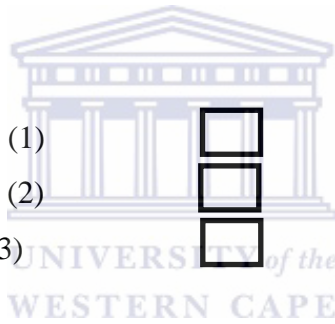
- 1 – 6 months (2)
- 7 – 12 months (3)
- 1 – 5 years (4)
- 6 – 10 years (5)

1.6 Birth history

- Normal delivery (1)
- Caesarean delivery (2)
- Fetal distress (3)
- Premature (4)
- Breech position (5)
- Unknown (6)

1.7 Mothers age at delivery

- Young mother (Less than 19 years) (1)
- Old mother (Over 40 years) (2)
- Unknown (3)



1.8 Mothers HIV status

- Positive (1)
- Negative (2)
- Unknown (3)

1.9 Folic Acid taken

- Yes (1)
- No (2)

1.10 Diagnosis

- Occulta (1)
- Meningocele (2)

- Myelomeningocele (3)
- Myelomeningocele & hydrocephalus(4)

1.11 Location of Spina Bifida

- Cervical (1)
- Thoracic (2)
- Thoraco- Lumbar (3)
- Lumbar (4)
- Lumbosacral (5)
- Sacral (6)

SECTION 2: MANAGEMENT

PART ONE: Overall management

2.1 What management did the patient undergo during their admission at UTH and BCIH?



PART TWO: Physiotherapy management

2.2 Referred for physiotherapy

A. Before surgery:

- Yes (1)
- No (2)

B. After surgery

- Yes (1)
- No (2)

2.3 Follow up:

- Yes (1)
- No (2)

2.4 Referral to other physiotherapy departments in areas closer to residence:

- Yes
- No

(1)

(2)



APPENDIX 2

INTERVIEW GUIDE: FOCUS GROUP DISCUSSION AND INTERVIEWS

Participant Number:

Qualification:

Gender:

Work experience:

1. What does physiotherapy management of Spina Bifida involve? What is your role as a physiotherapist in the rehabilitation process?
 - When do you see the patient pre-operatively or post operatively?
2. What interventions are used during the rehabilitation process?
3. How does the planning process at your hospital work? Do you feel included in the planning process?
 - Do you receive requests for physiotherapy?
 - The patient files did not show physiotherapy notes or even requests from doctors, is this information recorded in other files?
 - How are follow up programs conducted?
4. What has been your experience like managing children with Spina Bifida?
 - What factors have facilitated the rehabilitation process?
 - What factors have challenged the rehabilitation process?
5. Any recommendations you would like to make?
6. Anything else you would like to add?



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I.R.B. No. 00005948
E.W.A. No. 00011697

14th August, 2015

Ref. No. 2015-June-025

The Principal Investigator
Ms. Faith Banda
Northern Technical College – H.E.R
Chela Road, Kansenshi
P.O. Box 250093,
NDOLA.

Dear Ms. Banda,

RE: PHYSIOTHERAPY MANAGEMENT OF SPINA BIFIDA IN ZAMBIA.

Reference is made to your resubmissions. The IRB resolved to approve this study and your participation as principal investigator for a period of one year.

Review Type	Ordinary	Approval No. 2015-June-025
Approval and Expiry Date	Approval Date: 14 th August, 2015	Expiry Date: 13 th August, 2016
Protocol Version and Date	Version-Nil	13 th August, 2016
Information Sheet, Consent Forms and Dates	• English.	13 th August, 2016
Consent form ID and Date	Version-Nil	13 th August, 2016
Recruitment Materials	Nil	13 th August, 2016
Other Study Documents	Data gathering Instrument, Questionnaire, Interview Guide	13 th August, 2016
Number of participants approved for study	10	13 th August, 2016

Specific conditions will apply to this approval. As Principal Investigator it is your responsibility to ensure that the contents of this letter are adhered to. If these are not adhered to, the approval may be suspended. Should the study be suspended, study sponsors and other regulatory authorities will be informed.


Conditions of Approval

- No participant may be involved in any study procedure prior to the study approval or after the expiration date.
- All unanticipated or Serious Adverse Events (SAEs) must be reported to the IRB within 5 days.
- All protocol modifications must be IRB approved prior to implementation unless they are intended to reduce risk (but must still be reported for approval). Modifications will include any change of investigator/s or site address.
- All protocol deviations must be reported to the IRB within 5 working days.
- All recruitment materials must be approved by the IRB prior to being used.
- Principal investigators are responsible for initiating Continuing Review proceedings. Documents must be received by the IRB at least 30 days before the expiry date. This is for the purpose of facilitating the review process. Any documents received less than 30 days before expiry will be labelled "late submissions" and will incur a penalty.
- Every 6 (six) months a progress report form supplied by ERES IRB must be filled in and submitted to us.
- ERES Converge IRB does not "stamp" approval letters, consent forms or study documents unless requested for in writing. This is because the approval letter clearly indicates the documents approved by the IRB as well as other elements and conditions of approval.

Should you have any questions regarding anything indicated in this letter, please do not hesitate to get in touch with us at the above indicated address.

On behalf of ERES Converge IRB, we would like to wish you all the success as you carry out your study.

Yours faithfully,
ERES CONVERGE IRB


Dr. E. Munalula-Nkandu
BSc (Hons), MSc, MA Bioethics, PgD R/Ethics, PhD
CHAIRPERSON

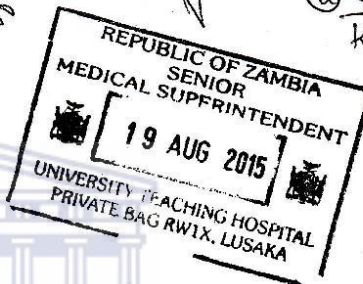
Ms .F. Banda
Clo Mr A.K. Banda
Northern Technical College – H.E.R
Chela Rd, Kansenshi
P.O BOX 250093
NDOLA

18th August, 2015

The Medical Superintendent,
University Teaching Hospital
P/Bag RWIX
Lusaka

① Head - Physio.
No objection
FJA
/h/v

② Supervisor D-Block
Kindly assist the
student to access
this information.
Maoma
25/08/15



Dear Sir/Madam,

RE: REQUEST FOR PERMISSION TO CARRY OUT STUDY AT YOUR INSTITUTION

Reference is made to the above stated subject. I am a student pursuing a Masters of Science in Physiotherapy at the University of Western Cape in Cape Town, South Africa.

PROPOSED TITLE: PHYSIOTHERAPY MANAGEMENT OF SPINA BIFIDA IN ZAMBIA

I therefore seek permission to enable me to carry out this proposed study at your institution. This will be carried out between August to October, 2015. The study will entail reviewing of Spina Bifida patient records and interviewing of Physiotherapists that manage these patients. All ethical issues will be addressed.

Find attached ethical clearance letters from University of Western Cape and ERES Converge. Your favourable response will be highly appreciated.

Yours Faithfully,

Banda

Faith Banda (Miss)

Contact: +260979878521



OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

19 June 2015

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:
Ms F Banda (Physiotherapy)

Research Project: Physiotherapy management of Spina Bifida in Zambia

Registration no: 15/4/46

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

P. Josias

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

Approved, 24 August 15

DR. G. LACROIX



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APPENDIX 7

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542 Fax: 27 21-959 1217

E-mail: bandafaithdoc@yahoo.com

INFORMATION SHEET

Project Title: PHYSIOTHERAPY MANAGEMENT OF SPINA BIFIDA IN ZAMBIA

What is this study about?

This is a research project being conducted by Faith Banda a student at the University of the Western Cape. We are inviting you to participate in this research project because you have important information that will benefit this research as it applies to the experiences of physiotherapists in the management of Spina Bifida in Zambia. The purpose of this research project is to explore the experiences of physiotherapists managing Spina Bifida in Zambia.

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

You will be asked to attend a focus group discussion and interview for others that will last at least 20 to 50 minutes. A debriefing session will be held after the focus group discussion/interview to confirm what has been discussed in the first discussion at hospital premises in a secure venue. The discussions and interviews will be recorded using an audio tape recorder. All participants are encouraged to participate without reservations. The discussion and interviews will involve questions such as: What is the role of the physiotherapist in the management of Spina Bifida? What are the interventions given to patients with SB? Do you feel included in the rehabilitation process? What has been your experience in managing Spina Bifida?

Would my participation in this study be kept confidential?

The researcher undertakes to protect your identity and the nature of your contribution. To ensure your anonymity, your name will not be mentioned in this research. All participants will be given identification codes and tags that will be used to address participants during the discussions and also used on the consent forms and focus group confidentiality binding forms. The recordings will be stored in filing cabinets under lock which only the researcher will have access to. The identification codes will only be known by the researcher.

The researcher will write a report about the findings of the research and your identity will be protected.

This study will use focus group discussions and the extent to which your identity will remain confidential is dependent on participants' in the Focus Group maintaining confidentiality.

I agree to be audiotaped during my participation in this study.

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

What are the risks of this research?

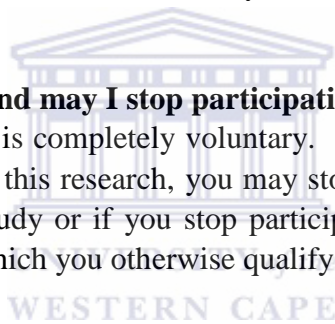
All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

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 your experiences as physiotherapists in managing Spina Bifida. We hope that, in the future, other people might benefit from this study through improved understanding of experiences of physiotherapists.

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, you will not be penalized or lose any benefits to which you otherwise qualify.



What if I have questions?

This research is being conducted by Faith Banda from the Physiotherapy Department at the University of the Western Cape. If you have any questions about the research study itself, please contact Faith Banda at:

Tel: +260979878521

+260955355237

Email: bandafaithdoc@yahoo.com

3416407@myuwc.ac.za.

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:

Head of Department:

Dr. N. Mlenzana

Head of department Physiotherapy

University of the Western Cape

Private bag X17

Bellville 7535

nmlenzana@uwc.ac.za

Dean of the Faculty of Community and Health Sciences:

Prof José Frantz

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

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



APPENDIX 8



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542, Fax: 27 21-959 1217

CONSENT FORM

Title of Research Project: PHYSIOTHERAPY MANAGEMENT OF SPINA BIFIDA AT UTH AND BEIT CURE INTERNATIONAL HOSPITAL.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name.....

Participant's signature.....

Date.....

CONTACTS:

Principal Investigator

Ms. F. Banda

Email: bandafaithdoc@yahoo.com

3416407@myuwc.ac.za

Tel: +260979878521

+260955355237

APPENDIX 9



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542, Fax: 27 21-959 1217

FOCUS GROUP CONFIDENTIALITY BINDING FORM

Title of Research Project: PHYSIOTHERAPY MANAGEMENT OF SPINA BIFIDA IN ZAMBIA

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality. I hereby agree to the following:
I agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

Participant's name.....

Participant's signature.....

Date.....

APPENDIX 10

MAP OF ZAMBIA





UNIVERSITY *of the*
WESTERN CAPE



LIENEKE BOESAK DEVELOPMENT PROJECTS

E-MAIL: lienekeboesak@webmail.co.za

Trading as:
Integrated Learning Systems
Reg No: 2012/172787/07

10 January 2016

This serves to confirm that the Masters of Science thesis of **FAITH BANDA** entitled:
"Physiotherapy management of Spina Bifida in Lusaka, Zambia" has been proof-read and
edited for submission to the University of the Western Cape.



LIENEKE BOESAK

