

ACKNOWLEDGEMENTS

**THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE
PBN DEPARTMENT**

RESEARCH REPORT

TOPIC

**A STUDY TO DETERMINE THE KNOWLEDGE, ATTITUDE AND
PRACTICES OF CARERS TOWARDS CHILDREN WITH
HYDROCEPHALUS.**

BY

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To all, I say may the good Lord richly bless you.

TABLE OF CONTENTS

Acknowledgements_____	i
Table of contents_____	ii
List of figures _____	v
List of tables_____	vi
List of abbreviations_____	viii
Declaration_____	ix
Statement_____	x
Dedication_____	xi
Abstract_____	xii

CHAPTER ONE

1.0 Introduction_____	1
1.1 Background information_____	1
1.2 Statement of the problem_____	5
1.3 Factors contributing/influencing problem_____	7
1.3.1 Social-cultural factors_____	8
1.3.2 Service related factors_____	10
1.4 Diagram of problem analysis _____	12
1.5 Justification_____	13
1.6 Objectives_____	13
1.6.1 General Objectives_____	13
1.6.2 Specific Objectives_____	13
1.7 Hypotheses_____	14
1.8 Operational definition of terms_____	14
1.9 Variables and cut-off points_____	15

CHAPTER TWO

2.0 Literature review	16
2.1 Introduction	16
2.2 Global perspective	16
2.3 Regional perspective	24
2.4 National perspective	26
2.5 Conclusion	27

CHAPTER THREE

3.0 Research methodology	28
3.1 Introduction	28
3.2 Research design	28
3.3 Research setting	29
3.4 Study population	29
3.5 Sample selection	29
3.6 Sample size	29
3.7 Data collection tool	30
3.8 Data collection technique	30
3.9 Pilot study	31
3.10 Validity and Reliability	32
3.11 Ethical and Cultural consideration	33
3.12 Plan for data analysis	33
3.13 Plan for dissemination of findings	34

CHAPTER FOUR

4.0 Presentation and data analysis	35
4.1 Introduction	35
4.2 Data analysis	35
4.3 Presentation of findings	35

CHAPTER FIVE

5.0 Discussion of findings	52
5.1 Introduction	52
5.2 Socio-demographic data	52
5.3 Knowledge	54
5.4 Attitude	56
5.5 Practice	57
5.6 Knowledge, Attitude and Practices	59
5.7 Implications on the health care services	61

CHAPTER SIX

6.0 Introduction	63
6.1 Conclusion and recommendations	63
6.2 Study limitations	65
References	66

Appendices

Appendix 1: Questionnaire

Appendix 2: Letter seeking permission to conduct a pilot study

Appendix 3: Letter seeking permission to conduct a study

Appendix 4: Letter seeking permission from the coordinator-ADD to
conduct a study

Appendix 3: Letter granting permission to conduct a study

LIST OF FIGURES

Figure 1: Problem analysis diagram_____ 11

Figure 2: Respondents level of knowledge_____ 43

Figure 3: Respondents attitude toward children with hydrocephalus_____ 44

Figure4: Respondents practice towards the care of children with hydrocephalus_ _____ 45

LIST OF TABLES

Table 1: Variables and cut-off points _____	14
Table 2: World population as projected by U.N _____	16
Table 3: Countries with a medical system that provides services to persons with disabilities. _____	18
Table 4: Countries according to treatment given. _____	18
Table 5: Numbers of children treated with hydrocephalus at the University Teaching Hospital. _____	25
Table 6: Demographic data _____	33
Table 7: Knowledge of diagnosis of child _____	36
Table 8: Knowledge of what hydrocephalus is _____	36
Table 9: Knowledge of the causes of hydrocephalus _____	36
Table 10: Knowledge on physiotherapy _____	37
Table 11: Knowledge on hydrocephalus _____	37
Table 12: Amount of information given on hydrocephalus _____	37
Table 13: Where child is taken when ill _____	38
Table 14: How often child is taken for physiotherapy _____	38
Table 15: Immunisation status of child _____	39
Table 16: How often mother attended antenatal clinic _____	39
Table 17: Reception by health personnel _____	39
Table 18: Responsibilities in the care of the child _____	40
Table 19: Whether child is allowed to play with other children _____	40
Table 20: Why child is not allowed to play with other children _____	41
Table 21: Family's supplement efforts of physiotherapy _____	41
Table 22: Sources of support in the care of the child _____	42
Table 23: Form of support _____	42

Table 24: Respondents knowledge in relation to their educational level____	43
Table 25: Respondents attitude towards children with hydrocephalus____	44
Table 26: Frequency table on practice in relation to age_____	45
Table 27: Respondents practice in relation to occupation_____	46
Table 28: Respondents knowledge in relation to attitude_____	46
Table 29: Respondents knowledge in relation to practice_____	47
Table 30: Respondents attitude in relation to practice_____	47
Table 31: Respondents sex in relation to relationship with child_____	47
Table 32: Respondents residential address in relation to where child is taken when ill_____	48
Table 33: Respondents means of transport in relation to nearest health centre_____	48

ABBREVIATIONS

ADD	Action on Disability and Development.
APTERS	Appropriate Paper Technology Enterprises
BSc	Bachelor of Science.
CBoH	Central Board of Health.
CBR	Community Based Rehabilitation.
CSF	Cerebral Spinal Fluid.
CSO	Central Statistical Office.
IFSBH	International Federation of Spina Bifida and Hydrocephalus.
MoH	Ministry of Health.
MLRWs	Mid – Level Rehabilitation Workers.
SAP	Structural Adjustment Programme.
UNDP	United Nations Development Programme.
UTH	University Teaching Hospital.
WCPT	World Confederation of Physical Therapy.
WFOT	World Federation of Occupational Therapists.
WHO	World Health Organisation.

DECLARATION

I, hereby declare that the work presented in this study for a Bachelor of Science degree in nursing has not been presented either wholly or in part, for any other degree and is not being currently submitted for any other degree.

Signed: Sigwalii

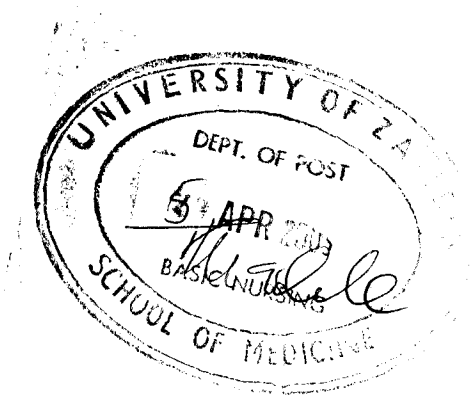
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Approved by: M. M. M. M.

Date 5.4.07

(Supervisor)



STATEMENT

I hereby, certify that this study is entirely the result of my own independent investigations. The various sources to which I am indebted are clearly indicated in the text and references.

Sipnalli

Signature (Student).

DEDICATION

This research is dedicated to my mother, Ms. I.M. Imwiko who has always wanted to see me succeed in life and from this encouragement I have always worked hard.

ABSTRACT

Hydrocephalus is a congenital or acquired condition marked by dilatation of the cerebral hemispheres, usually secondary to obstruction of Cerebral Spinal Fluid (CSF) pathways accompanied by its (CSF) accumulation within the skull. Once a child develops hydrocephalus, they may have a combination of altered mental state, vomiting, strabismus, full fontanel, drowsiness, fits, varying degrees of intellectual dysfunction and a larger than normal head. While the symptoms range from mild to severe, the condition does not get worse as the child gets older. The intellectual ability of the affected child far more than the physical ability determines the child's progress. However with treatment, most children can significantly improve their abilities.

The main aim of the study was to determine knowledge, attitude and practices of carers towards children with hydrocephalus who attended paediatric surgical clinic at the University Teaching Hospital, Lusaka.

The literature reviewed was on global, regional and local studies. Literature on knowledge, attitude and practices of cares towards children with hydrocephalus was very scanty.

In this study, a pilot study was carried out at Matero Clinic and the actual study was done at the University Teaching Hospital from August to September, 2006. The research participants were conveniently chosen. A sample consisted of fifty (50) respondents both female and male cares. Data collection was done by using structured questionnaires in form of interviews.

The data was analysed manually using a data master sheet, frequency tables, pie charts and cross tabulation tables which were used to determine the relationships between variables.

Study findings revealed that all respondents knew that hydrocephalus could not be caused by witchcraft. The majority 33 (66%) of the respondents could

state what physiotherapy was (entailed). All respondents could define what hydrocephalus was. 33 (66%) of the respondents had adequate knowledge.

Majority 43 (86%) of the respondents had a negative attitude towards children with hydrocephalus and also took their children for physiotherapy sessions less than the prescribed number of times per month.

The study revealed that 29 (58%) of the respondents gave supplementary care to the children and that 26 (52%) of the respondents allowed their children to play with other children. However, 28 (56%) of the respondents had poor practices.

The study findings imply that despite the respondents having medium-high knowledge on the condition and its' treatment, they still had negative attitudes and poor practices.

It was concluded from the study that the carers had adequate knowledge on hydrocephalus despite the negative attitude poor practices,

Amongst the recommendations made to the Government of making physiotherapy one of the Primary Health Care priorities. The Ministry of Health should also ensure that health care givers as well as the community get education on care of the disabled mainly through media programmes.

CHAPTER ONE

1.0 INTRODUCTION

1.1 BACKGROUND INFORMATION

Zambia is a third world country located in the central region of Africa. It is a landlocked country covering an area of 752,612 kilometres, which is about 2.5 % of the total space area of the continent of Africa (CSO\CB0H, 2003).

The country lies between latitude 8 and 18 south and between 20 and 35 longitude east. It has a tropical climate and vegetation with three distinct seasons, the cool and dry winter from May to August, the hot and dry season from September to October and the warm and wet season from November to April. Zambia has an average rainfall range of 600mm to 1400mm per year.

Administratively, the country is divided into nine provinces and seventy two districts. Two of the nine provinces, that is Lusaka and the Copperbelt are predominantly urban while the other seven, Northern, Luapula, North-western, Western, Southern and Central provinces are predominantly pre urban in nature

According to the census carried out in 2001, the population of Zambia stands at 10,285,631. Of the 10,285,631 people, 45% live in urban areas and 55% live in rural

areas. The average density of the country has gradually reduced since 2000. The proportion of the population living in urban areas reduced from 40% in 1980, to 38% in 1990 and 36% in 2000 respectively (CSO\CB0H 2003).

Zambia has a mixed economy consisting of a modern urban sector that geographically follows the line of rail and a rural agricultural sector. The

modern urban sector has been dominated by parastatal organisations, while private businesses have predominated in construction and agricultural sectors. Since 1991, with the introduction of a liberalised market-oriented economy, the parastatals have been privatised and in some cases liquidated (CSO\CBoH, 2003).

Copper mining is the country's main economic activity and contributed 45% of the government revenue during the decade following independence (1960-1975). In the mid 1970's following a sharp decline in copper prices, and a sharp increase in oil prices, the country's economy deteriorated. The 1980's marked the start of the first phase of implementing Structural Adjustment Programmes amidst a stagnating economy. This worsened the economic situation making the poverty levels among Zambians high. Currently, about 73% of Zambians are classified as poor. Poverty is more prevalent in rural areas than urban areas (83% and 56% respectively), (CSO\CBoH 2003).

The population of Zambia was sparsely distributed before independence especially in the rural areas. Likewise the health facilities were also not adequate. Health care facilities were concentrated along the line of rail. This prompted the government to review its health care provision after independence.

In 1964, shortly after independence, the Zambian government declared free health services for all and the main emphasis at that time was curative as opposed to preventive medicine. Within a few years, the country's population grew very fast and the health care standards began to fall. This followed the rural urban drift which led to overcrowding in the cities with poor housing and sanitation. The government therefore embarked on a programme to redress the imbalances through rapid expansion of rural health centres and district hospitals in addition to providing free medical care to entire populations. However, between the 1970's and 1980's, the rapid population growth of 3.2%, rural urban migration and a collapsing

economy led by the decline in copper prices on the world market, compromised the governments ability to maintain health care at a reasonable level (CBoH 1997). The Structural Adjustment Programme brought about the removal of subsidies on social services including health and education. Therefore, the living standards dwindled as a lot of people were rendered jobless. The children and women were negatively affected since they were the most vulnerable group.

Given the above background, access to proper medical attention for both pregnant women and their children becomes a problem. Proper medical attention during pregnancy and delivery are very essential in the reduction of certain preventable conditions in the mother as well as disabilities in the child. However, having an economy with falling standards of health care has not only affected the rural areas alone, but also urban areas like Lusaka.

The University Teaching Hospital which is the largest referral hospital in the country is situated in Lusaka. It caters for various referred cases including those dealing with disabilities resulting from congenital conditions in children. Some of the referred disability cases that the hospital deals with include Cerebral palsy, Spina bifida, and Hydrocephalus.

The University Teaching Hospital is involved in the care of children with conditions resulting into disabilities through the physiotherapy department as well as surgical care through the department of paediatric surgery. The physiotherapy department provides physiotherapy as well as related services to the children as well as their carers. The physiotherapists also work hand in hand with the Action on Disability and Development (ADD), a non-governmental organisation to identify and carry out assessments on children that need these services. At the University Teaching Hospital, infrastructure has been provided for Action on Disability and Development in which to conduct their physiotherapy sessions.

In addition, the Ministry of Health through the district hospitals has allowed the Action on Disability and Development to conduct physiotherapy sessions in clinics. During the same sessions, teachers from various schools attend to those children who have reached school entry age and teach them on voluntary basis. In spite of all the efforts made by Action on Disability and Development, the University Teaching Hospital and the district hospitals, more needs to be done in order to help improve the wellbeing of a child with disabilities resulting from a condition like Hydrocephalus.

A disabled person is considered to be one in their society who has a difference in appearance and or behaviour. In most cases, a disabled person has functional limitations or activity restrictions. Hydrocephalus however, is a condition that is synonymous with disability. It also continues to be one of the major leading causes of disability in sub Saharan Africa. It affects both males and females equally (Silva, 2000). The only exception she states are those inherited as an X linked genetic trait which affects males only.

In the United States of America (USA), one in every fifty new born is born with a congenital anomaly. An estimated 34 – 43 million people in the United States of America have chronic disabilities (Disability Centre for Injury Prevention and Control, 2005).

There are several factors associated with Hydrocephalus depending upon the age of the child (Medline plus Medical Encyclopaedia, 2004). It further states that in small children, Hydrocephalus may be associated with infections acquired before birth, injury occurring during birth, congenital effects, tumours of the Central Nervous System, infections such as meningitis and encephalitis, myelomeningocele as well as subarachnoid haemorrhage. In older children, risks include history of congenital or developmental defects, space occupying lesions or

tumours of the spinal cord, central nervous system infections and bleeding in the brain or trauma (WFUBMC 2004).

Hydrocephalus most often occurs in children but may also occur in adults (Medline plus Medical Encyclopaedia 2004).

Children with Hydrocephalus have developmental and learning difficulties. This leads to families experiencing stress as well as severe financial strains. Families therefore, need to be aware of the complexities of hydrocephalus to ensure their children receive comprehensive ongoing care and appropriate intervention services and therapies (HFAO 2005).

The global prevalence of hydrocephalus is 0.06% (Silva 2000). The report from Health Information Management Systems (HIMS – 2004) Unit of the Central Board of Health\ Ministry of Health could not provide the prevalence of hydrocephalus. However, according to the University Teaching Hospital D-block attendance register, a total of 9,884 children attended paediatric surgical clinic during the period April 2004 to February 2006. A total of about 1,495 had hydrocephalus representing about 15% of the total number of children who attended paediatric surgical clinic.

1.2.1 STATEMENT OF THE PROBLEM

The situation of people with disabilities in the developing countries should be a matter of great concern. There are today close to 250 million severely and moderately disabled persons in these countries, the annual increase is 10 million. Most of them are poor, dependent, abused, neglected, excluded from education, training and jobs, they die early and have no power while they live. The majority of them have no share in community development programmes and are virtually excluded from the public services they need to be prepared for a life in the community. Their human rights are not well protected. It is clear

that in this situation an effort should be made to improve the quality of life of persons with disabilities.

Hydrocephalus is one of the disabilities which is a condition that affects growth and development of an individual. The condition is quite common in Zambia. The Zambian government is concerned about the disabilities resulting from hydrocephalus. It does so through the provision of Primary Health Care services throughout the country. In so doing, diseases are detected early and treated before they advance into complications such as hydrocephalus. However, the government has no specific activities in place for the management of children with hydrocephalus. The role of government is to provide infrastructure for non-governmental organisations such as Action on Disability and Development. The organisation operates from the University Teaching Hospital and the various district hospitals and clinics. Children with hydrocephalus enrolled in the programme have benefited a lot from the above mentioned organisation.

Hydrocephalus is a congenital or acquire condition marked by dilatation of the cerebral hemispheres, usually secondary to obstruction of Cerebral Spinal Fluid (CSF) pathways accompanied by its (CSF) accumulation within the skull. Once a child develop hydrocephalus, they may have a combination of altered mental state, vomiting, strabismus, full fontanel, abnormal tone of extremities and spasticity, drowsiness, fits, varying degrees of intellectual dysfunction and a larger than normal head.

From the above information, we can say that hydrocephalus may either be progressive or non progressive depending on the cause. However, it should be realised that whatever the cause, there is need for physiotherapy and other supportive care. This is costly on the part of the carer since they will need to spend money and time in order to improve the child's condition to a socially functional individual. The child suffers delayed development, mentally, socially and physically.

The carer may not be willing to endure the lengthy supportive care but instead opt to isolate the child by locking them up in the home while they go about their duties. It therefore becomes important that these carers are imparted with enough knowledge to assist them understand the condition which in turn will aid in changing their attitude towards caring for individuals with hydrocephalus.

Currently, the health system has a critical shortage of staff and is unable to provide enough services to cater for the current number of children with hydrocephalus. It would be better if health care staff were trained in the emergency care of hydrocephalus so that even at health post level, we could have a health care provider who will deal directly with the affected children and carers instead of the referrals that are now being seen and on the increase. At the moment one or two physiotherapists attend to more than 30 children per day with the help of two voluntary teachers and one or two other volunteers. These are not sufficient in the provision of meaningful care.

1.2.2 FACTORS CONTRIBUTING TO KNOWLEDGE, ATTITUDE AND PRACTICES OF CARERS TOWARDS CHILDREN WITH HYDROCEPHALUS

1.3.1 DISEASE RELATED FACTORS

1.3.1.1 Perceived seriousness of the condition

When a condition is thought to be a serious one, carers do not waste time seeking medical attention. However, if the carers do not perceive hydrocephalus as being a serious condition, they may delay (seeking medical attention) taking the child to the nearest health service provider for medical attention.

1.3.1.2 Stigma associated with the condition

The child with hydrocephalus and their family may be stigmatised by the community they live in. This may lead to the family isolating itself

from the social activities of the community and the family may not even take the child to the health care providers as a result of the stigmatisation.

1.3.2 SOCIO – CULTURAL ECONOMIC FACTORS

1.3.2.1 Cultural Beliefs

In the Zambian society, hydrocephalus may be attributed to the belief that ancestral spirits are angry with the family of the child with hydrocephalus. As a result, the carers may see no need of taking the child to the hospital where specialised care may be given. Instead, the carers may opt to take the child to traditional healers who they believe may have the ability to communicate with the spirits of the dead who in turn could heal the child with hydrocephalus.

1.3.2.2 Age of the carer

If the child with hydrocephalus is born from a young or old parent who may not have adequate knowledge on the condition, the care provided to this child may not be adequate because the carer may not see the need of seeking medical care.

1.3.2.3 Lack of resources

The decrease in the economic status of the country has seen a rise in the poverty levels of many Zambians. This in turn has affected most households including those having children with hydrocephalus who need constant hospital checkups and physiotherapy. This might lead to some households with minimum income have other priorities such as food and shelter compared to taking the child for medical reviews or physiotherapy.

1.3.2.4 Religious beliefs

In the Zambian context, a disability may be seen as a curse from God. This in turn may affect the way a child with hydrocephalus and his family may be viewed in the eyes of the community. The family therefore may opt to consult spiritualists to help them undo the curse that is upon the family so that no more bad omen may befall the family, thus breaking the curse. With this view, the carer may not see the need of seeking medical advice because they do not perceive it a medical problem, to them it could be a spiritual problem.

1.3.2.5 Literacy levels / Educational levels

In Zambia, most of the population is composed of women and out of these only a few are literate as shown in the census results of 2000 which gave that 55% of the population is literate with 61.1% of males and 49.8% of females able to read and write. This means that their educational levels may also be low and in most cases these women are also the majority of carers in the homes. It means that given a condition like hydrocephalus, these carers may not see the significance of taking a child with hydrocephalus for treatment and physiotherapy because they do not understand the importance of these activities in caring for such a child.

1.3.2.6 Poor communication

In our Zambian society, the men usually make most of the decisions in the home and the women usually have little to say. As a result, the women may not report to the husband the need of taking the child to the hospital when they identify a problem or when the child needs the medical reviews because they fear losing their marriages as a result of constant hospital visits which in most cases take days. This in turn may deprive the child with hydrocephalus the opportunity to receive the much needed medical attention.

1.3.3 SERVICE RELATED FACTORS

1.3.3.1 Distance to the health facility

Most of the cases of hydrocephalus are found in the rural areas of Zambia while a few are found along the line of rail. All these cases are referred to the University Teaching Hospital, the only hospital in the country offering care to children with hydrocephalus. This makes it difficult for the carers to bring the children with hydrocephalus for specialist care given that most households live below the poverty datum line and are far from the referral hospital. Distance to the University Teaching Hospital could be attributed to low patient review turnout because most households caring for children with hydrocephalus stay far away, thus may not manage to bring the child for physiotherapy as well as the constant reviews required.

1.3.3.2 In adequately trained personnel to handle children with hydrocephalus

The health care system in Zambia does not train health personnel to specialise in caring for children with conditions such as hydrocephalus. This may contribute to the giving of care that is not very specialised for such children with hydrocephalus. It may also in turn lead to the health personnel not giving adequate care that may improve the livelihood of a child with hydrocephalus. This may contribute to the child with hydrocephalus being referred to a higher level health facility for even minor problems that would have been handled by the health personnel at the nearest health care station had they adequate knowledge on how to handle a child with hydrocephalus. For example, a blocked shunt may not necessarily need to be changed, all it may need is to be milked to unblock it.

1.3.3.3 Attitude of staff

In Zambia, the poor economic status of the country has led to poor working conditions among the health professionals which in turn may affect their attitudes towards carers seeking assistance in the management of children with hydrocephalus. As a result, the carers of

children with hydrocephalus may not seek advice from the health personnel for fear of being ridiculed or being ignored.

1.3.3.4 Adequate Information, Education and Communication.

Information and Education should be given to the community at large by the health personnel if the masses are to have adequate knowledge on various health matters that warrant medical attention. If information on hydrocephalus is not given adequately, the carers may not know when to bring the child who has hydrocephalus to hospital because they would have no idea as to how hydrocephalus presents.

1.3.3.5 Poor referral system

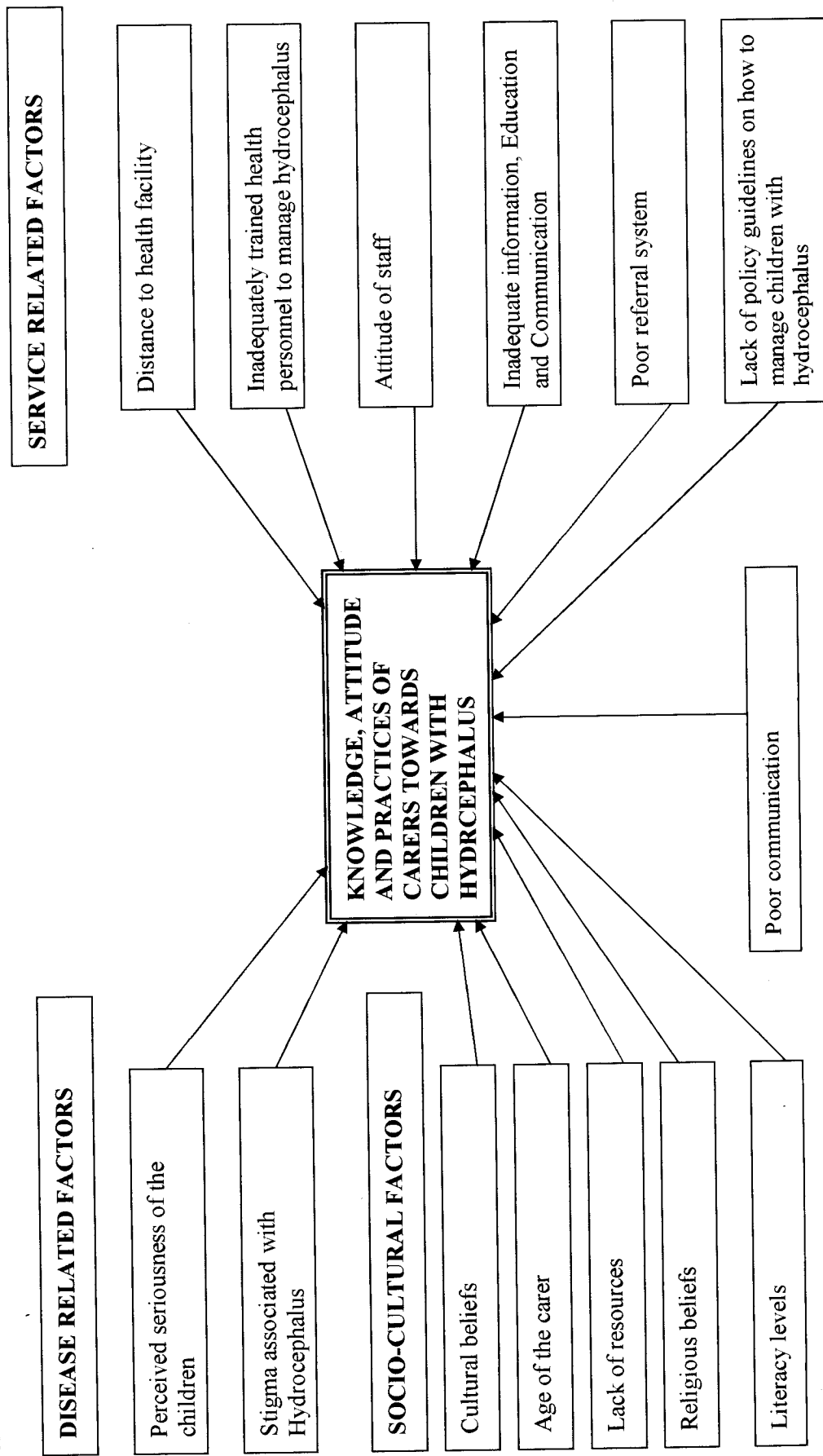
When the referral system is not clearly laid down, it may be difficult for the health care provider to know how to go about referring a child with hydrocephalus to the hospital that takes care of such children.

1.3.3.6 Lack of Policy guidelines on how to manage children with hydrocephalus

Policy guidelines provide information on how to carry out certain procedures as well as how to manage certain conditions. If however, these guidelines are not clearly spelt out, it becomes difficult for health care providers to completely know how to manage a child with hydrocephalus, thus such a child will not receive the care that they require.

Figure 1

1.4 PROBLEM ANALYSIS CHART



1.5 JUSTIFICATION

There has been no study conducted to assess the knowledge, attitude and practices of carers towards children with hydrocephalus in Zambia. These carers need to be assisted to undergo what is involved in the lengthy treatment which involves physiotherapy and education and the lifetime care needed to be rendered to these children. Improvement in the child's condition can only be seen in those children that had a mild type of hydrocephalus or those whose tumours that were obstructing the normal flow of cerebral spinal fluid (CSF) have been surgically removed.

Through this study the knowledge, attitude and practices of carers towards children with hydrocephalus will be explored. It is hoped that the study will identify the gap that will need emphasis or adjustments. This will help to make recommendations to the appropriate authorities to improve the knowledge, thus aid the care provider understand how to handle carers of such children.

1.6 OBJECTIVES OF THE STUDY

1.6.1 General Objectives

To assess the knowledge, attitudes and practices of carers towards children with hydrocephalus.

1.6.2 Specific Objectives

1. To determine the knowledge that the carers have on hydrocephalus.
2. To identify the attitude of carers of children with hydrocephalus towards the condition.
3. To determine the practices that carers of hydrocephalus children have.

4. To establish the extent to which other factors influence the knowledge, attitude and practices of carers of children with hydrocephalus.
5. To make recommendations to relevant authorities which would assist in the quality of care of children with hydrocephalus.

1.7 HYPOTHESIS

- 1.7.1. Inadequate knowledge on hydrocephalus leads to poor attitude of carers towards children with hydrocephalus.
- 1.7.2. Adequate knowledge on hydrocephalus leads to good attitude of carers towards children with hydrocephalus.

1.8 OPERATIONAL DEFINITIONS

1.8.1 Attitude: A settled opinion or way of thinking toward children with hydrocephalus.

1.8.2 Carer: A person with legal responsibility to look after a child, biological parents or guardians.

1.8.2 Knowledge: A person's range of information of awareness or familiarity.

1.8.3 Hydrocephalus A congenital or acquired condition marked by dilatation of the Cerebral hemispheres, usually secondary to obstruction of the cerebral spinal fluid pathways and its accumulation in the skull.

1.8.4 Practice Performance or execution of care towards the care of children with hydrocephalus.

1.9 VARIABLES AND CUT OFF POINTS

A variable is an attribute or characteristic that can have more than one value such as height, weight and blood pressure (Dempsey and Dempsey, 2000).

The variables identified in this study are; Knowledge, Attitude and Practice.

Independent variable: The variable that is believed to cause or influence the dependent variable (Dempsey and Dempsey, 2000).

The depended variables in this study are; Knowledge and Attitude.

Dependent variable – Is a variable that changes as a result of manipulation of the

independent variable (Dempsey and Dempsey, 2000).

The depended variable in this study is Practice.

TABLE 1: VARIABLES, INDICATORS AND CUT OFF POINTS

	VARIABLES	INDICATORS	CUT OFF POINTS
1	KNOWLEDGE	Medium to High	Response to questions with scores 4 to 7
		Low	Responses to questions with score 0 to 3
2	ATTITUDE	Positive	Acceptance of a child with hydrocephalus. Scores above 4.
		Negative	Non acceptance of a child with hydrocephalus. Score 0 to 3.
3	PRACTICE	Good	Takes appropriate action when child needs special care. Score above 4.
		Poor	Does not act promptly when child needs care. Scores 0 to 3.

CHAPTER TWO

2.0. LITERATURE REVIEW

2.1. INTRODUCTION

Literature review is a critical summary of a research on a topic of interest often prepared to put a research problem in context or as the basis for an implementation project (Polit and Hungler, 1997) The purpose of literature review in this study will determine what is already known about the topic under study so that a comprehensive picture of the state of knowledge on the topic can be obtained. It will also give the researcher clues to the methodology and instruments that people have used before and therefore provide information on what types of data collecting instruments exist and which ones do not work. It will also assist the researcher refine certain parts of the study.

The literature review will focus on carer's knowledge, attitude and practice towards children with disability in general and hydrocephalus in particular. It will be presented and discussed from the works of various scholars from around the world. It is arranged in three (3) parts, global perspective, regional perspective and national perspective respectively.

2.2. GLOBAL PERSPECTIVE

Disability is a global phenomenon of huge proportion as reported by UNDP, 1999. Before estimating its magnitude, an account was given of the projected development of the world population as surveyed by the United Nations. The projections are shown in the table below.

TABLE 2: WORLD POPULATION AS PROJECTED BY UN, 2000-2005.

YEAR	IN MORE DEVELOPED COUNTRIES	IN LESS DEVELOPED REGIONS	TOTAL
2000	1,187	4,904	6,091
2005	1,197	5,293	6,491
2010	1,206	5,684	6,890
2015	1,214	6,072	7,286
2020	1,219	6,458	7,672
2025	1,221	6,819	8,039
2030	1,212	7,159	8,371
2035	1,201	7,468	8,669

Table: World Population, as projected (medium-variant) by United Nations, 2000-2035

Although it is two decades since the United Nations International Year of Disabled People, people with disabilities throughout the world still encounter severe economic, cultural and social deprivation. The problem is generally worse for those living in rural areas and is especially acute for all disabled people living in low income states (WHO, 2001). Clearly, health and rehabilitation can no longer be understood solely in terms of orthodox medical interventions and conventional nations of care. These centres almost exclusively on the perceived limitations of individuals rather than on society's failure to accommodate the needs of people with disabilities. Thus, there is an urgent need for an approach that cares not only about disabled people but for society and its structure as well.

Responding to this insight, the World Health organization – Rethinking Care Initiative and Conference brought together disabled people and other stakeholders from high and low income countries to identify key

issues and propose recommendations for member states to address this need (WHO, 2001).

Several global estimates on the prevalence of disability have been made in the past. However, the most often cited is the one made by the authors in 1974, which was published by World Health Organization in 1976. This estimate; 10% of the worlds population was based on calculations of disability available at that time.

According to the World Health Organization (1993), in any population 10% is expected to have a disability and of those 40% are likely to be children. In a related consultation report on equal opportunities for all published by the World Health Organization in 1996, it is stated that at the beginning of the 'Decade for Disabled Persons' a series of international experts stated that 10% of the worlds population was disabled. Whilst it can be debated, the precise numbers and percentages, it is clear that a very significant portion of the world population is in need of help. Moreover, as long as poverty, malnutrition, war and conflict, ignorance and superstition characterize huge areas of the globe, the numbers will continue to rise.

The same report (WHO, 1996) goes on to say that the great majority of persons with disability at present live their lives without dignity, in absolute poverty, victimized by beliefs that they are possessed by evil spirits or that their very presence in society is proof of divine punishment.

In a survey conducted by World Health Organization (WHO, 2001) over government response to the implementation of the rules on medical care rehabilitation, support services and personnel training, most countries provided information on the question about the medical care system, the professionals involved in the provision of medical care, exclusion or inclusion of persons with disabilities in regular medical care services, finance of medical care and percentage of the population covered by social insurance schemes. The first question on medical

care was whether the medical care system provides services to persons with disabilities. According to the opening paragraph in the rule on medical care, “states should ensure the provision of effective medical care to persons with disabilities” (WHO, 2001:8). The first question indicates the extent to which states comply with this recommendation. As the table below shows, an overwhelming majority do provide services to persons with disabilities. The five (5) countries that do not (out of the 104 respondents to this report) are developing countries.

TABLE 3: COUNTRIES WITH A MEDICAL SYSTEM THAT PROVIDES SERVICES TO PERSON’S WITH DISABILITIES.

SERVICES TO PERSONS WITH DISABILITIES	FREQUENCY	PERCENTAGE
Provided	99	95.2
Not provided	5	4.8
TOTAL	104	100

Source: WHO, 2000.

In the same survey, according to paragraph 3 in rule on medical care, states should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society. As the table below shows, of the 95 countries that provide medical care for persons with disabilities there are 46 countries in which there is a tendency to treat certain groups of disabled people outside the medical care services, which is high frequency. The tendency is against the spirit of rule 2 on medical care and the whole idea on non-discrimination against persons with disabilities, which is a cornerstone in the standard rules.

TABLE 4: COUNTRIES ACCORDING TO THE TREATMENT GIVEN.

TREATMENT OF PERSONS WITH DISABILITIES	FREQUENCY	PERCENTAGE
Outside	46	48.4
Inside	49	51.6
TOTAL	95	100

Source: WHO, 2001.

The survey shows that there is a tendency of unjustifiable form of discrimination of certain groups of disabled people. It is also a remarkable fact that this tendency is so widespread (48.4%).

In 1996, the World Health Organization (WHO, 1996) through the Rehabilitation Unit of the World Health Organization published a guide for mid-level rehabilitation workers looking after infants and young children with spina bifida/or hydrocephalus. This was in collaboration with the International Federation of Spina Bifida and Hydrocephalus (IFSBH). This publication was stimulated by the World Health Organization document of cerebral palsy that had been prepared in collaboration with the World Federation of Occupational Therapists (WFOT) and World Confederation of Physical Therapy (WCPT) for use by Mid-level Rehabilitation Workers (MLRWs). As a representative of national organizations that share a concern about these children, the International Federation of Spina Bifida and Hydrocephalus (IFSBH) expressed the need in many countries for practical information concerning the rehabilitation of children who have spina bifida, hydrocephalus or both. This manual is for the mid-level rehabilitation workers to use when they work with infants, children and young adults who have spina bifida and hydrocephalus and their families. The manual includes information on the types, signs and causes of spina bifida and hydrocephalus, assessment of the level of development of the child and complications caused by spina bifida and hydrocephalus.

Training suggestions are given for promoting normal development, mobility, self care and education.

In a study conducted by Kirk, E. A et al (1992) in Tennessee (United States of America) to determine the effects of an educational programme on carers knowledge of hydrocephalus in a sample of carers of children with hydrocephalus using a pre and post test design, showed that there was a statistically significant change in the scores from the pre and post tests for participants. The nursing education appears to have a positive effect upon the group's knowledge of hydrocephalus and shunts.

Similarly, the International Federation in Helsinki, Finland held a conference in May 2006 with the theme "Access" which included a discussion about access to life, health, activities and social life by Doctors as well points of view from different stages of peoples lives, adults, young people with spina bifida and/or hydrocephalus and their families. Attention was given to the attitude and environment of people with spina bifida and/or hydrocephalus and how that relates to them and their families daily life. Lectures on services provided and support given to such was also outlined. This conference was aimed at improving the overall livelihood of patients and children with hydrocephalus with or without spina bifida by imparting information necessary concerning spina bifida and hydrocephalus.

In the state of Illinois (United States of America), the National Hydrocephalus Federation was incorporated in 1979 as a voluntary non profit making organization, 501C (3) public service organization whose objectives were to assemble and disseminate information pertaining to hydrocephalus, its treatment and outcome, establish and facilitate communication network among affected families and individuals, help others gain a deeper understanding of those affected by hydrocephalus, to increase public awareness and knowledge of

hydrocephalus and promote or support research on the cause, treatment and prevention of hydrocephalus.

In a study conducted over a period of 10 years by Therburn, M. J (1988-1997) to determine the extent of services for persons with disabilities in Jamaica through a questionnaire sent to 23 agencies of which 22 responded showed that coverage varies considerably and there is inequitable distribution of services for adults compared to children. The majority of clients are in rural areas and clients in school age group were the main beneficiaries. In all categories of disability, and in most age groups, more males receive services than females. While there has been an increased demand for the services over the past 10 years, there has been only a very small increase in service provision. The main expansion has been in the field of Community Based Rehabilitation (CBR). There have been increases in budgetary provision to offset rapidly increasing costs, but very little investments in new programmes.

Furthermore, a study conducted by Landry, S. H et al (1990) on goal oriented behaviour in children with spinal bifida and/or hydrocephalus found out that these children are less likely to maintain task oriented behaviour in an unstructured situation than are normal children. The child with spina bifida and/or hydrocephalus may be dependent upon the external structure provided by others to complete tasks. Therefore, from the study, it may be said that early parental intervention can support the development of goal-directed behaviour for children with spina bifida and/or hydrocephalus. It also suggests that methods of teaching children with spina bifida and/or hydrocephalus which emphasize goal directed behaviour need to be developed.

An article written by Prussing. E. et al (2005), on parenting children with disabilities showed that a growing number of studies examine the cultural marginalization of parenting children with disabilities (Gary, 2001; Landsman, 1998S, 1999, 2000, 2003; Larson, 1998, Rapp,

1999; Skinner, Bailey, Correa, and Rodriguez, 1999; Stockall, 2001). Many emphasize how a child's disability disrupts conventional cultural narratives of parenting, posing threats to the personhood of both children and parents. For example, Rapp (1999) describes the barriers that disability presents for achieving social identity through conventional United States kinship categories and how parents respond by fashioning on "alternative kinship" system that meaningfully links their child to a larger disability community (Rapp, 1997:277). Others explore how parents discursively construct their own identities as nurturant and sacrificing caregivers, contesting prevalent cultural explanations that frame a Childs disability as a mother's personal failure (Landman, 1998, 2003) or as a divine punishment (Skinner, et al, 1999).

Several recent analyses further explore the content, form and limitations of the discursive tools available to parents of children with disabilities, for example, Gary (2001) and Rapp (1999) consider how parents engage a broader cultural repertoire of terms, concepts and plots (or story lines) in articulating their experiences. This repertoire is composed of rhetorical traditions associated with medical science (such as constructing medico-scientific research) and technology as a source of hope and progress, Judeo-Christian traditions (such as finding transcendent and sacred meaning in difficult experiences) and the liberal humanism of disability rights (such as advocating for inclusion, autonomy, social progress, and respect for universal human rights). Analyses by Landman (1998) and Larson (1998) describe how parents struggle to articulate their lived realities of ambiguity and paradox (love and sorrow, hope and fear) within the parameters of these conventional cultural discourses.

2.3. REGIONAL PERSPECTIVE

Management of hydrocephalus throughout Sub Sahara Africa is made difficult by economic constraints and the difficulties patients and families face regarding transportation and access to proper care.

In a study done by Schoyen.R. (2004) in Sudan on hydrocephalus and cognitive functions states that cognitive problems include difficulty in adopting and working with impressions and information, problems with carrying out and accomplishing actions and difficulties in socializing and problem with controlling one's behaviour. In the study, it was emphasized that parents and the family are the key to the development and early learning of any child. Children with spina bifida and/or hydrocephalus who might have cognitive problems need the same stimulation (talking to, music, games, adventure and love) that any child needs, but they need more. They need more help and repeated activities in order to use their minds and their bodies more.

In a related presentation by Zulianello, M. R (2004) of Uganda, Zulianello discussed mobility problems and early stimulation exercises for children with hydrocephalus. She emphasized the importance of early treatment, transferral information to carers where professionals need to share skills with the carers on the correct handling and treatment of these children at home.

In a prospective study conducted by Warf. B. C (2005) on the causes of hydrocephalus in Uganda, he writes that hydrocephalus is very common in East Africa in general and Uganda in particular. He however goes on to say that in recent studies, it has been stated that the most common cause of the condition in central African countries of Zambia, Zimbabwe and Malawi is congenital associated with neural tube defects and aqueductal stenosis. The ratio of congenital to 'post meningitic' hydrocephalus in Zimbabwe was reported as 2:1. Furthermore, in his experience (Warf, B. C 2005), hydrocephalus

secondary to a central nervous system infection is actually the single most common cause of hydrocephalus in Uganda accounting for 60% of cases.

Out of the 468 patients who presented with hydrocephalus in Uganda at CURE children's hospital between January 2001 and March 2003, 256 cases (57%) was determined to be post infectious, 136 cases (29%) no post infectious, 61 cases (13%) associated with myelomeningocele, 5 cases (1%) associated with encephalocele and 1 case of probable result of neonatal intraventricular haemorrhage (Warf, 2005). However, with such statistics from Uganda, access to proper management is quite difficult given the financial and logistical barriers that carers face.

In Malawi, support groups for parents with children living with spina bifida and hydrocephalus was launched in February 2004 (Kaunda. S. 2005). This was after noticing that children and families having spina bifida and hydrocephalus were being stigmatized. Living with a child having such a condition can be a big challenge to the carers if they lack knowledge and encouragement on how to care for the child. It was for this reason that some objectives were formulated in the belief that encouragement will be fostered through close interaction among carers living with spina bifida and/or hydrocephalus children. The formulated objectives were as follows: -

- To reach patients living with the spina bifida and/or hydrocephalus as early as possible.
- To help and save the lives of affected children.
- To share the different life experiences among parents hence encouraging each other.

- To expose the affected children thus encourage self acceptance as well as help boost their self esteem. This in turn will instil independence in the affected children thus encourage them to be integrated into the community.
- In all, 13 support groups were formed comprising of 205 hydrocephalus patients and 56 spina bifida patients.

2.4. NATIONAL PERSPECTIVE

In Zambia, like many other African countries, very few studies have been done that are related to hydrocephalus specifically. However, (Chitambala, 2003) in his report on the management of hydrocephalus children at the University Teaching Hospital states that hydrocephalus is a major problem in Zambia and that about 60% of the cases result from congenital causes, 20% as a result of infections like meningitis, ventriculitis and 10% is due to tumours while about 2 – 3% is as a result of trauma.

The same author (Chitambala, 2003) goes on to write that most patients come from up country and that these patients are brought in late for treatment due to financial and logistical barriers like lack of instruments to use in the district hospitals. As a result the University Teaching Hospital is the only referral hospital in the country catering for all referrals being made of hydrocephalus.

The first patient with hydrocephalus to be treated in Zambia was seen in 1970 and was sent abroad for treatment. This was later followed by visiting neurosurgeons that operated on patients at the University Teaching Hospital and the formation of the Surgical Society of Zambia following the inauguration of the neonatal and paediatric surgical unit in 1984. This later strengthened the programme of treating patients with hydrocephalus. Since then a large number of patients with hydrocephalus have been seen at the University Teaching Hospital.

Below is the table representing the number of hydrocephalus children treated at the University Teaching Hospital with various shunts.

TABLE 5: NUMBERS OF CHILDREN TREATED FOR HYDROCEPHALUS AT THE UNIVERSITY TEACHING HOSPITAL.

PROVINCE	NUMBER OF PATIENTS	FEMALE	MALE
Northern	17	7	10
Southern	864	412	452
Eastern	25	9	16
Western	30	15	15
Luapula	25	15	10
Lusaka	409	191	218
Central	200	72	128
Copperbelt	178	65	83
TOTAL	1740	800	940

Source: Chitambala, 2003.

From the table above, more male patients with hydrocephalus than females were seen and that males are more predisposed to hydrocephalus than females.

CONCLUSION

The success in the caring of children living with spina bifida and hydrocephalus is a big challenge not only to the carers but also to medical professionals in the developing countries such as Zambia. Adequate trained manpower and resources is the key to quality care for children living with spinal bifida and/or hydrocephalus.

When the carer's knowledge, attitude and practice towards children with hydrocephalus are well understood, it will provide solutions needed to aid in the caring of children with hydrocephalus.

CHAPTER THREE

3.0 RESEARCH METHODOLOGY

3.1 INTRODUCTION

Research methodology allows for a reflection on plan, structure and execution of research in order for the truth, objectivity and validity to be compiled with. This chapter is on methodology used for the study. It explains the design and instruments used to collect data as well as the target population, sample size and study setting.

3.2 RESEARCH DESIGN

Research design is the overall plan for collecting and analysing data including specifications for enhancing the internal and external validity of the study. The design provides answers to the research questions or for testing the research hypothesis. It spells out the basic strategies that the researcher adopts to develop information that is accurate and interpretable, Polit and Hungler (1995).

The purpose of the study was to determine knowledge, attitude and practices of carers towards children with hydrocephalus. In order to achieve this, an exploratory, non – experimental design was carried out. The nature of the data that was collected helped the researcher gain insight into the situation. This was because not much has been done to explore the knowledge, attitude and practices toward children with hydrocephalus on the carers.

3.3 RESEARCH SETTING

A research setting is a brief description of the area where the study is to be conducted. It looks at location, community composition, road network, climate condition and the other important factors of interest to the researcher and the reader. Polit, Denise and Hungler (1995).

The study was carried out in Lusaka at the University Teaching Hospital. This is the only referral hospital in the country that attends to children with hydrocephalus after which they may be referred to other health care facilities for services such as physiotherapy. The study units were the carers who brought their children to the paediatric surgical clinic (D – block) at the University Teaching Hospital.

3.4 STUDY POPULATION

A study population is the total group of individual people or things meeting the designated criteria of interest to the researcher (Dempsey and Dempsey, 2000). In this study, the study population will comprise carers of children with hydrocephalus brought to D- block paediatric surgical clinic for care and reviews.

3.5 SAMPLE COLLECTION METHOD

Sampling is the process of collecting a portion of the population to represent the entire population, Polit and Hungler (1995). The subjects included female and male carers of children with hydrocephalus who brought the affected children to D – block paediatric surgical clinic for care and reviews. They were aged between 20 and 50 years of age. A convenient sampling procedure was used to select the subjects. An informed consent to participate in the study was obtained from the subjects before collecting data.

3.6 SAMPLE SIZE

A sample size is a subset of a population selected to participate in a research study. Polit and Hungler (1995). The sample size comprised

50 respondents who were selected conveniently from all carers of children with hydrocephalus brought to D- block paediatric surgical clinic for care and reviews. The number was considered to be reasonable considering the limited time and resources that will be available for the study to be completed.

3.7 DATA COLLECTION TECHNIQUE AND TOOLS

Data collection is the process of getting information needed to address a research problem, Polit and Hungler (1995). A data collecting instrument is a device or technique that a researcher uses to collect data, Polit and Hungler (1995).

A structured interview schedule was used. This is an interview where the instrument used for data collection is the interview schedule. Interview schedule is the formal instrument used in structured self report studies that specifies the wording of all questions to be asked to respondents, Polit and Hungler (1995).

The questionnaire was designed in a way to solicit for appropriate information pertaining to the study. It had both open and closed ended questions. The questions were written in English but were translated into Bemba, Nyanja, and Tonga respectively during the interview for those carers who did not understand English. The structured interview was chosen for the following reasons;

- It is suitable for illiterate and literate respondents.
- There is high response rate in a written questionnaire.
- In – depth responses can be obtained.
- Responses can be obtained from a wide range of subjects.
- Non – verbal behaviour and mannerisms can be observed during the interview.

3.7.1 ADVANTAGES OF A QUESTIONNAIRE

1. Questionnaires are relatively simple methods of collecting data.
2. They are a rapid and efficient method of gathering information.

3. The researcher is able to gather data from a widely scattered sample.
4. They are less expensive to distribute.
5. Respondents remain anonymous.

3.7.2 DISADVANTAGES OF A QUESTIONNAIRE

1. The researcher may not probe topic in depth without being lengthy.
2. Printing of questionnaire is costly if the questionnaire is lengthy and is printed on high quality paper.
3. Respondents may omit or disregard any item he/she chooses without giving an explanation.
4. Some items may force the subject to select responses that are not his actual choice.
5. The researcher may influence how the respondents answer the questionnaire.

Clinic cubicles were used for the interview. The cubicles were clean and well ventilated. The purpose of the study and use of the findings was explained. Anonymity and confidentiality was assured. Verbal consent was obtained. Then the researcher filled in the questionnaires during the interview.

Completion of the questionnaire took about 20 to 30 minutes for each carer. It took the researcher four weeks to collect data from the respondents.

3.8 PILOT STUDY

A pilot study is a small version of the actual study conducted with the purpose of testing and potentially refining the research plan. Sometimes called an exploratory study (Dempsey and Dempsey, 2000).

It includes every step expected in the major study. This study enabled the researcher to obtain information for improving the project and assessing its feasibility by detecting any errors in the questionnaire and assessing the appropriateness of questions.

The pilot study was conducted a week before the actual study on a sample that consisted five cares of children with hydrocephalus. These were chosen from one of the clinics that conduct clinics for the disabled children in Lusaka. The clinic was not be used for the actual study. The purpose was to assess the appropriateness of the questions, whether or not they were phrased properly and if they could be answered concisely.

3.9 VALIDITY AND RELIABILITY

3.9.1 Validity: is the degree to which an instrument measures what it is intended to measure (Polit and Hungler, 1997). Validity also asks questions such as; what does the instrument measure?, what do the results mean?. If the researcher is sure that the instrument is measuring what it is supposed to measure, data interpretation will be easy. Validity was upheld especially after the pilot study when the instrument in this case the questionnaire measured what it intended to measure because it had covered all the variables in the study topic and addressed set objectives.

3.9.2 Reliability: is the degree of consistency or dependability with which an instrument measures the attribute it is designed to measure (Polit and Hungler, 1997).

The instrument should be able to bring out the accurate information whereby the same instrument after sometime, should have the same response. The researcher made sure that the instrument was reliable by conducting a pilot study, asking the same questions to all respondents and aligning the questions in sequence. This eliminated biasness and minimised data collection.

3.10 ETHICAL AND CULTURAL CONSIDERATIONS

Ethics are a system of moral values that is concerned with the degree of which research procedures adhere to professional, legal and social obligations to the research subjects, Polit and Hungler (1995).

In the department of Post Basic Nursing, the supervising lecturer approved the proposal and allowed the student to conduct the study. Permission was sought from the University Teaching Hospital and from the respondents. This was after explaining the purpose and nature of the study and what the results were going to be used for. The interviews were done after the respondents and the University Teaching Hospital Management agreed. The researcher maintained confidentiality and anonymity. Serial numbers and not names were used.

3.11 PLANS FOR DATA ANALYSIS

Planning for data analysis is the process of carefully planning on how data will be scrutinised by placing it in categories, calculating the mean and applying statistical procedures (Treece and Treece, 1986).

Data was presented in the form of tables and cross tabulations, numerical descriptions were given for each table. Data was analysed manually using a scientific calculator.

The study was done on 50 respondents chosen conveniently from among the carers of children with hydrocephalus attending the surgical clinic at the University Teaching Hospital. The main aim of the study was to determine the knowledge, attitude and practices of carers of children with hydrocephalus.

The study was conducted using a structured interview in order to probe by asking open and closed ended questions. This method allowed the researcher clarify questions from respondents on the spot.

After data collection, the questionnaire was checked for completeness, consistency and uniformity in the interpretation of the questions. Data was then be edited for completeness and coding of the responses was done using numbers. Open ended questions were categorised and coded. Data was processed manually and entered on the data master sheet. It was then presented in form of tables, pie charts and bar graphs so that a summarised picture of the findings was gotten.

3.13 PLANS FOR PRESENTATION OF FINDINGS

The presentation of findings will in the form of frequency tables, scaling to indicate those which fit nominally, in ordinal scales and interval, cross – tabulations to compare two or more variables, thus testing their relationships. Pie charts, bar charts, histograms and polygons will also be used.

3.13 PLAN FOR DISSEMINATION OF FINDINGS

The results will be disseminated to he authorities as follows;

- .A copy of the research report will be given to the Ministry of Health who are the sponsors and policy makers.
- A copy will remain in the medical library for use as reference by other researchers.
- A copy will remain in the Department of Post Basic Nursing also as a reference.
- The respondents will be given the findings of the research through a talk that will be organised by the researcher. A separate budget for this meeting shall be made and sold out to the various non – governmental organisations for possible findings.

CHAPTER FOUR

4.0 PRESENTATION OF FINDINGS AND DATA ANALYSIS

4.1 INTRODUCTION

Data analysis is a systematic organisation and synthesis of research data and the testing of research hypothesis using those data (Polit and Hungler, 2001). The purpose of the study was to determine the knowledge, altitude and practices of carers towards children with hydrocephalus.

4.2 DATA ANALYSIS

After data collection, the data from closed ended questions were entered on the data master sheet. Responses from open ended questions were coded, categorised and entered on the data master sheet. There after data was processed manually with the aid of a calculator.

4.3 PRESENTATION OF FINDINGS

The findings have been presented in frequency tables, pie charts and have been cross tabulated to show the relationships among variables.

Table 6: Demographic Data.

CHARACTERISTICS	FREQUENCY	PERCENTAGE
SEX		
Male	3	6
Female	47	94
Column Total	50	100
AGE GROUP		
Below 20 years	10	20
21-30 years	18	36
31-40 years	20	40

41-50 years	2	4
	50	100
RESIDENTIAL ADDRESS		
High	44	88
Medium	2	4
Low	4	8
Column Total	50	100
MARITAL STATUS		
MARRIED	39	78
SINGLE	6	12
Divorced	1	2
Widowed	4	8
Column Total	50	100
DENOMINATION		
Reformed Church	3	6
SDA	14	28
Pentecostal	5	10
Roman Catholic	27	54
Column Total	50	100
EDUCATIONAL LEVEL		
PRIMARY	29	58
SECONDARY	17	34
College	1	2
University	-	-
Column Total	47	94
CHARACTERISTICS		
EMPLOYED		
Yes	4	8
No	46	92
Total	50	100
INCOME PER MONTH		
Less Than K300,000.00	26	52
K301,000 – K600,000.00	7	14
K601,000 – K900,000.00	2	4
Above K901,000.00	5	10
Total	40	80
OCCUPATION		
Housewife	33	66
Business man/woman	3	6
Professional	1	2
Other	13	26
Total	50	100

TRIBE		
Bemba	9	18
Lozi	2	4
Tonga	15	30
Nsenga	4	8
Tumbuka	2	4
Nyanja	2	4
Other	16	32
Total	50	100
RELATIONSHIP WITH CHILD		
Mother	46	92
Father	1	2
Aunt	1	2
Sibling	-	-
Others	2	4
Total	50	100
CHARACTERISTICS	FREQUENCY	PERCENTAGE
MEANS OF TRANSPORT TO H.CENTRE		
By Foot	28	56
Bicycle	4	8
Car	2	4
Bus	15	30
Other	1	2
Total	50	100
HOW LONG TO NEARST H. CENTRE		
30 Minutes	24	48
31 – One Hour	14	28
More than One Hour	11	22
Not sure	1	2
Total	50	100

Table 1 shows that the majority of respondents 47 (94%) were females 20 (40%) of the respondents were aged between 31-40 years while 36% were aged between 21 – 30 years. The majority of respondents 44 (88%) resided in high residential areas and 39 (78%) of them were married.

The majority of respondents 27(54%) congregated with the Roman Catholic church. 29(58%) of them had primary education 46 (92%) of the respondents were not employed and 26 (52%) had an income of less than K300,000.00 per month. Majority of the respondents 33(66%) were house wives from various parts of the country.

46(92%) of the respondents indicated that the child they had brought was their child and that 28 (56%) of them accessed the nearest health centre by foot. 24(48%) of the respondents indicated that it took them about 30 minutes to reach the nearest health centre.

TABLE 7: KNOWLEDGE OF DIAGNOSIS OF CHILD (n=50)

KNOWLEDGE OF CHILD DIAGNOSIS	FREQUENCY	PERCENT
Yes	50	100
No	-	-
Total	50	100

All respondents 50 (100%) had knowledge of the diagnosis of the child.

TABLE 8: KNOWLEDGE OF WHAT HYDROCEPHALUS IS (n=50)

KNOWLEDGE OF WHAT HYDROCEPHALUS IS	FREQUENCY	PERCENT
Fluid in the Head	50	100
Do not know	-	-
Total	50	100

All the respondents 50 (100%) knew what hydrocephalus was.

TABLE 9: KNOWLEDGE OF THE CAUSES OF HYDROCEPHALUS (n=50)

KNOWLEDGE ON THE CAUSES OF HYDROCEPHALUS	FREQUENCY	PERCENT
Infections of the mother	01	2
Infections of the baby	07	14
Birth Trauma	01	2
Do not Know	41	82
Total	50	100

Majority of the respondents 41 (82%) did not know the cause of hydrocephalus while 7 (14%) stated infections of the baby caused hydrocephalus.

TABLE 10: KNOWLEDGE ON PHYSIOTHERAPY (n = 50)

KNOWLEDGE ON WHAT HYDROCEPHALUS IS	FREQUENCY	PERCENT
Offering Exercises	33	66
Do not know	17	34
Total	50	100

The majority of respondents 33(66%) had knowledge of what physiotherapy was while 15(30%) did not know.

TABLE 11; KNOWLEDGE SOURCE ON HYDROCEPHALUS (n = 50)

KNOWLEDGE ON WHAT HYDROCEPHALUS IS	FREQUENCY	PERCENT
Hospital	49	98
Auntie	1	2
Total	50	100

Majority of the respondents 49(98%) knew about hydrocephalus form the hospital

TABLE 12: AMOUNT OF INFORMATION GIVEN ON HYDROCEPHALUS

AMOUNT OF INFORMATION GIVEN ON HYDROCEPHALUS	FREQUENCY	PERCENT
Moderate	31	62
Minimum	2	4
None	8	16

**** Multiple Answers**

Most of the respondents 31 (62%) had been given moderate information on hydrocephalus, while 2% had minimum and 16% had no information at all.

ATTITUDE

TABLE 13: WHERE CHILD IS TAKEN WHEN ILL (n=50)

WHERE CHILD IS TAKEN WHEN ILL	FREQUENCY	PERCENT
Clinic	49	98
Traditional Healers	1	2%
Total	50	100

Majority of the respondents 49 (98%) took their child to the clinic when ill.

**TABLE 14: HOW OFTEN CHILD IS TAKEN FOR PHYSIOTHERAPY
(n = 50)**

HOW OFTEN CHILD IS TAKEN FOR PHYSIOTHERAPY	FREQUENCY	PERCENT
Four (4) times a month	19	38
Three (3) times a month	3	6
Twice (2) a month	2	4
Occasionally	8	16
Total	42	84

Majority 19 (38%) of the respondents took their children for physiotherapy four (4) times a month while 8 (16%) occasionally.

TABLE 15: IMMUNISATION STATUS OF THE CHILD (n=50)

IMMUNIZATION STATUS OF CHILD	FREQUENCY	PERCENT
Fully Immunized	40	80
Not fully immunized	10	20
TOTAL	50	100

Majority 40(80%) of the respondents had their children fully immunized while 10 (20%) had children who were not fully immunized.

**TABLE 16: HOW OFTEN MOTHER ATTENDED ANTENATAL CLINIC
(n = 43)**

HOW OFTEN MOTHER ATTENDED ANTENATAL CLINIC	FREQUENCY	PERCENT
Monthly	24	48
When unwell	-	-
Occasionally	17	34
Do not know	2	4
TOTAL	43	86

Fourty eight percent (48%) of the respondents with children with hydrocephalus attended antenatal clinic monthly, 17(34%) occasionally and 2(4%) did not.

TABLE 17: RECEPTION BY HEALTH PERSONNEL

HOW OFTEN MOTHER, ATTENDED ANTENATAL CLINIC	FREQUENCY	PERCENT
Doctors: Friendly	50	100
: Not friendly	-	-
Nurses : Friendly	49	98
: Not friendly	1	2
Physiotherapist : Friendly	34	68
: Not Friendly	-	-

**** Multiple Answers**

All the respondents 50(100%) had a good reception from the doctors, 49(98%) of the nurses were friendly while 1(2%) of the respondents stated nurses of not being friendly. 34(68%) had a good reception form the physiotherapists.

PRACTICE

TABLE 18: RESPONSIBILITIES IN THE CARE OF THE CHILD (n=50)

RESPONSIBILITIES IN THE CARE OF THE CHILD	FREQUENCY	PERCENT
Take care and feed the child	30	60
Take care to clinic when sick	20	40
Total	50	100

Majority of respondents' 30 (60%) responsibility in the care of the child included feeding and taking care of the child while 20 (40%) took the child to the clinic when ill.

TABLE 19: WHETHER CHILD IS ALLOWED TO PLAY WITH OTHER CHILDREN (n = 50)

WHETHER CHILD IS ALLOWED TO PLAY WITH OTHERS	FREQUENCY	PERCENT
Yes	26	52
No	24	48
Total	50	100

The majority of respondents 26(52%) allowed their children to play with other children while 24(48%) did not.

TABLE 20: WHY CHILD IS NOT ALLOWED TO PLAY WITH OTHER CHILDREN (n = 50)

WHY CHILD IS NOT ALLOWED TO PLAY WITH OTHERS	FREQUENCY	PERCENT
Child still young	14	58.3
Child cannot sit	10	41.7
Total	24	100

Majority of the respondents 14(58.3%) did not allow their children to play with other children because they were too young while 10(41.7%) of the respondent's children could not sit.

TABLE 21: FAMILYS' SUPPLEMENT EFFORTS OF PHYSIOTHERAPIST (n = 50)

FAMILY SUPPLEMENT EFFORTS OF PYSIOTHERAPISTS	FREQUENCY	PERCENT
Exercise Baby	29	58
None	21	42
Total	50	100

Majority of the respondents 29 (58%) supplement efforts of physiotherapists while 21 (42%) do not do anything to supplement.

TABLE 22: SOURCES OF SUPPORT IN THE CARE OF THE CHILD (n=50)

SOURCES OF SUPPORT IN THE CARE OF THE CHILD	FREQUENCY	PERCENT
Extended Family	24	48
Community	1	2
Church	6	12
NGO	2	4
Others	16	32
Total	50	100

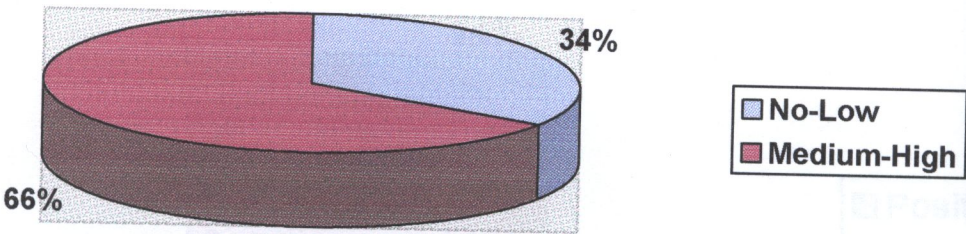
Majority of the respondents 24(48%) received support from the extended family, while 10(32%) received support from other sources other than the ones listed above.

TABLE 23: FORM OF SUPPORT (n=50)

FORM OF SUPPORT	FREQUENCY	PERCENT
Money	21	42
Food	10	20
Spiritual	4	8
Moral	15	30
Total	50	100

Majority of the respondents 21 (42%) received support in form of money, 10 (20%) in form of food, 4(8%) in form of spiritual support while 15(30%) received moral support.

FIGURE 1 RESPONDENTS LEVEL OF KNOWLEDGE (n=50)



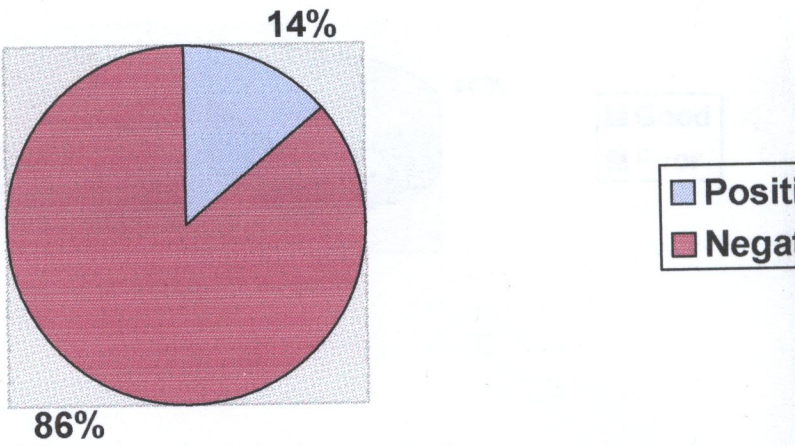
The majority of respondents 33(66%) had medium-high knowledge.

TABLE 24: RESPONDENTS KNOWLEDGE IN RELATION TO THEIR EDUCATION LEVEL (n = 50)

EDUCATIONAL LEVEL					
KNOWLEDGE	Primary	Secondary	College	University	Total
Medium-high	15(51.7%)	14(82.4%)	1(100%)	-	30(64%)
No-low	14(48.3%)	3(17.6%)	-	-	17(36%)
Total	29(58%)	17(34%)	1(2%)	-	47(100%)

Majority of the respondents 30(64%) had medium-high knowledge.

FIGURE 2: RESPONDENTS ATTITUDE TOWARDS CHILDREN WITH HYDROCEPHALUS (n = 50)



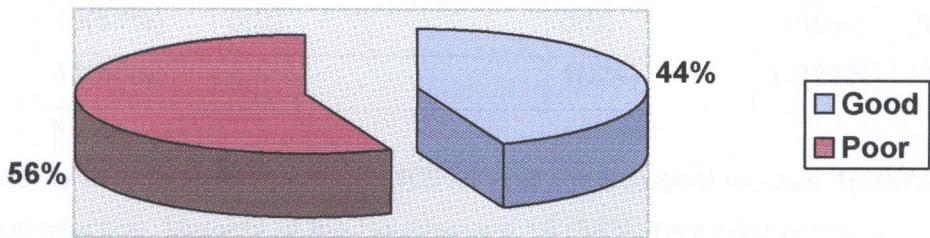
Majority of the respondents 43(86%) had a negative attitude towards children with hydrocephalus

TABLE 25: RESPONDENTS ATTITUDE IN RELATION TO HOW OFTEN THE CHILD ATTENDS PHYSIOTHERAPY (n = 50)

ATTITUDE	HOW OFTEN CHILD ATTEND PHYSIOTHERAPY			Total
	Prescribed Frequency (4 times)	Less than 4 times		
Positive	7(100%)	-		7(14%)
Negative	-	43(100%)		43(86%)
Total	7(14%)	43(86%)		50(100%)

The majority of respondents 43 (86%) with a negative attitude took their children for physiotherapy sessions less than the prescribed number of times a month.

FIGURE 3: RESPONDENTS PRACTICE TOWARDS THE CARE OF CHILDREN WITH HYDROCEPHALUS (n = 50)



The majority 28(56%) of the respondents had poor practice.

TABLE 26: FREQUENCY TABLE ON PRACTICE IN RELATION TO AGE (n = 50)

	AGE				TOTAL
PRACTICE	Below 20 years	21-30 years	31-40years	41-50 years	
Good	1(10%)	6(33%)	15(75%)	0	22(44%)
Poor	9(90%)	12(67%)	5(25%)	2(100%)	28(56%)
Total	10(20%)	18(36%)	20(40%)	2(4%)	50(100%)

All respondents aged 41-50yeras had poor practice. Majority of the respondents below 20 years of age and those between the ages 21-30 years had poor practices. Majority 15(75%) of respondents aged 31-40 years had good practice.

TABLE 27: RESPONDENTS PRACTICE IN RELATION TO OCCUPATION
(n = 50)

	OCCUPATION				
Practice	Housewife	Businesswoman/Man	Professional	Other	Total
Good	14(42%)	3(100%)	1(100%)	4(31%)	22(44%)
Poor	19(58%)	0(0)	0(0)	9(69%)	28(56%)
Total	33(66%)	3(6%)	1(2%)	13(26%)	50(100%)

The majority of business women 3 (100%) and Professional women 1(100%) had good practice. Majority of the housewives 19 (58%) had poor practice.

TABLE 28: RESPONDENTS'KNOWLEDGE IN RELATION TO ATTITUDE
(n = 50)

	ATTITUDE		
KNOWLEDGE	Positive	Negative	Total
Medium-High	7(100%)	26(60%)	33(66%)
No-Low	0(0)	17(40%)	17(34%)
Total	7(14%)	43(86%)	50(100%)

26(52%) of the respondents who had negative attitude had medium-high knowledge.

17(34%) of the respondents who had a negative attitude also had no- low knowledge levels.

TABLE 29: RESPONDENTS KNOWLEDGE IN RELATION TO PRACTICE
(n = 50)

	PRACTICE		
KNOWLEDGE	Good	Poor	Total
Medium-High	18(82%)	15(54%)	33(66%)
No-Low	(18%)	13(46%)	17(34%)
Total	22(44%)	28(56%)	50(100%)

18(36%) of the respondents with good practice had medium 2 high knowledge levels.

TABLE 30: RESPONDENTS ATTITUDE IN RELATION TO PRACTICE
(n = 50)

	ATTITUDE		
PRACTICE	Positive	Negative	Total
Good	3(43%)	19(44%)	22(44%)
Poor	4(57%)	24(56%)	28(56%)
Total	7(14%)	43(86%)	50(100%)

24(48%) respondents with negative attitude also had poor practices.

TABLE 31: RESPONDENTS SEX IN RELATION TO RELATIONSHIP WITH CHILD (n = 50)

	RELATIONSHIP			
SEX	Mother	Father	Auntie	Total
Male	0	2(100%)	-	2(4%)
Female	47(100%)	0(0)	1(100%)	47(96%)
Total	47(84%)	2(4%)	1(2%)	50(100%)

47(94%) of the female respondents were mothers to the children while 2(4%) males were fathers to the children.

TABLE 32: RESPONDENTS RESIDENTIAL ADDRESS IN RELATION TO WHERE CHILD IS TAKEN WHEN ILL (n = 50)

	RESIDENTIAL ADDRESS			
Where Child is taken when sick	Low	Medium	High	Total
Clinic	4(100%)	2(100%)	43(98%)	49(98%)
Traditional Healer	0(0)	0(0)	1(2%%)	1(2%)
Total	4(8%)	2(4%)	44(88%)	50(100%)

Majority of the respondents 43(80%) living in high residential areas took their children to the clinic when ill.

**TABLE 33: RESPONDENTS MEANS OF TRANSPORT IN RELATION TO
NEAREST HEALTH CENTER (n = 50)**

	DISTANCE IN RELATION TO TIME TAKEN				
Means of transport	30 mins	31-1hour	More than 1 hour	Not sure	Total
By Foot	11(46%)	9(64%)	7(63.3%)	0(0)	28(56%)
Bicycle	1(4%)	2(14%)	1(9%)	0(0)	4(8%)
Car	2(8%)	0(0)	0(0)	0(0)	2(4%)
Bus	9(38%)	3(22%)	3(27%)	0(0)	15(30%)
Other	1(4%)	0(0)	0(0)	1(100%)	1(2%)
Total	24(48%)	14(28%)	12(24%)	0(0)	50(100%)

Majority of the respondents (25%) went by foot to the nearest health centre and took about 30 minutes or less to reach the facility.

CHAPTER FIVE

5.0 DISCUSSION OF FINDINGS

5.1 INTRODUCTION

This study sought to explore the knowledge, attitude and practices of carers towards children with hydrocephalus. It was carried out at Lusaka UTH D-Block and Matero clinic. The increasing number of children with hydrocephalus attending the surgical clinic in D-Block prompted the study. The chapter also discusses the implications of findings to health, recommendations to relevant authorities and limitations.

5.2 SOCIAL DEMOGRAPHIC CHARACTERISTICS

Section A of the questionnaire (appendix 1) explored information on socio demographic characteristics.

The study revealed that most of the respondents 94% were females and only 6% were men. This can be because women more often care for children and this is a traditionally acceptable situation. For this reason, more women turned up at the clinic with the children. This confirms that fewer men participate in childcare due to their traditional role.

The majority of respondents 40% were aged between 31-40years. This is significant because this is the child bearing age. According to the Zambia Demographic Health Survey (ZDHS) report (2001) this age is when women are reaching the end of child bearing years because of the reduction in their peak fertility rates. This explains why so many of these mothers had children below the age of six at this age. On the other hand the 4% who had children with hydrocephalus were aged above 41 years. These had also reached satisfied parity. According to ZDHS reproductive histories of women range from 14-49years with the peak age of specific fertility rates in the 25-29 years age group, this

could be the reason why there are fewer mothers below ages 20 and above 40.

Most of the respondents 39(78%) were married followed by 6(12%) who were single. This could be because marriage is universal in Zambia and that almost every woman is expected to be married at a certain age. Traditionally, some Zambian parents pressurize their female children to marry, especially after they reach puberty. The ZDHS report of 2001 states that six in ten women (61%) were in marital union. This is in agreement with the findings of this study in which the majority respondents were married.

Majority of the respondents 47(94%) had at had attained some level of education. 29(58%) had primary education, 17(34%) had secondary education, 1(2%) had college education and 3(6%) had never been to school. There are fewer respondents with higher education compared to those with lower education. According to ZDHS report of 2001, 75% of female and 82% of males had at least some education. This is in agreement with the study findings in which majority of the respondents had some education.

This finding assists health care givers as they decide on the content and teaching strategies of their health education strategies on hydrocephalus.

33(66%) of the respondents were full time housewives. The majority of them had children with hydrocephalus below the age of five and preferred to stay at home to look after the child. 13 (28%) of the women were involved in other activities such as farming which helped supplement the family income. The 2001 ZDHS report reveals that some women are engaged in sales and services to supplement the family income, which is in agreement with the findings of the study. The respondents in the study showed a willingness to devote time to anything which could help improve the income base of the household.

The majority of respondents 26(52%) had a low income as revealed by the study. According to the ZDHS report of 2001, over half the women both in rural and urban areas were not currently employed. Rural women are more likely to have seasonal jobs than urban women. This could also be attributed to that more males are allowed to attend school compared to the female child. This has continued to affect poverty levels of the population in the country live below the poverty datum line. The significance of this variable on income is that the less money one has the more difficult it is for them to afford proper treatment for their child at the right time.

5.3 KNOWLEDGE

Section B of the questionnaire (appendix 1) had questions that would aid in assessing the knowledge possessed about hydrocephalus. According to Hawkins 1991, a knowledgeable person is a "well informed person". All the respondents 50(100%) were able to define what hydrocephalus was (Table 8) because all of them had been informed by the Doctor about the diagnosis of the child (Table 7).

Majority of the respondents 41(82%) did not know the causes of hydrocephalus while 7(14%) said infections of the baby caused hydrocephalus, the other remaining respondents stated infections of the mother and birth trauma caused hydrocephalus respectively (Table 9). 7(14%) of respondents associated hydrocephalus with infection of the baby because their children had some sort of illness before developing hydrocephalus. Each of them only know one cause of hydrocephalus. Warf (2005) states that hydrocephalus secondary to a central nervous system infection is actually the single most common cause of hydrocephalus accounting for 60% of cases. However from the study all of the respondents believed that hydrocephalus could not be caused by witchcraft. This could be attributed to the fact that they were all Christians. Majority of the respondents 49(98%) know about hydrocephalus through the hospital (Table 11). When a carer is well informed on the causes of hydrocephalus, they will be able to

comfortably outline some of the causes of hydrocephalus because they would have had adequate information given to them.

The majority of respondents 33(66%) were able to state what physiotherapy was (Table 10). This is most likely because they were advised to take the child for physiotherapy sessions to their nearest health care providers with physiotherapy services. The majority of respondents 28(56%) accessed the nearest health centre by foot (Table 6) and most of them 24(48%) took about 30 minutes to reach the health centre. (Table 6). 31 (62%) of the respondents were given moderate information on hydrocephalus while 2(4%) had minimum information and 8(16%) had not been given information on hydrocephalus at all (Table 12).

From the findings of the study, it is clear that carers need more education on hydrocephalus, its causes and the benefits of physiotherapy. This is in order to gain the carers co-operation in the intensive and lengthy management of hydrocephalus. Kirk, E.A et al (1992) showed that an educational programme on carers knowledge of hydrocephalus appeared to have a positive effect upon the groups knowledge of hydrocephalus and shunts. This is in agreement with the study findings which show that more knowledge needs to be imparted on hydrocephalus.

Majority of respondents with some form of education had medium to high knowledge (Table 24). Hawkins (1991), states that education is the process of training people's minds and abilities so that they acquire knowledge and develop skills. In view of the findings of the study we can say that the more education one attains the easier it is for them to acquire knowledge. The respondents with college education had medium to high knowledge levels. It may be attributed to the fact that the respondent understood the condition better given their level of education.

5.4 ATTITUDE

Section C of the questionnaire (appendix 1) had questions that aided in assessing the attitudes of the carers towards children with hydrocephalus. The study revealed that 43(86%) of the respondents had a negative attitude towards children with hydrocephalus (figure 3). According to Prussing E. et al (2005) a child's disability disrupts conventional cultural narratives of parenting, posing threats to the personhood of both children and parent thereby contesting prevalent cultural explanation that frame a child's disability as a mothers failure or as a divine punishment. 7(14%) of the respondents had a positive attitude towards children with hydrocephalus.

Majority of the respondents 49(98%) took their children to the clinic compared to 1(2%) who did not (table 13). This could be attributed to that access to the nearest clinic was by foot and that it took less than 30 minutes to reach the health care provider. Despite the above description of the findings, the study also revealed that majority of the respondents who took their children to the clinic when sick either attended physiotherapy sessions less than the recommended times or did not take their child for any physiotherapy at all. This could be attributed to that since most of the respondents were referred cases from outside Lusaka, physiotherapy services were not being offered from the health care facilities they attended even though they had been given the information on physiotherapy at UTH. This scenario is presented in the findings of the study that show 19(38%) as the majority of the respondents taking their children for physiotherapy sessions as recommended compared to the rest of the respondents who only managed taking their children for physiotherapy sessions three times or less per month (table 14).

Majority of the respondents 40(80%) had their children fully immunized while 10(20%) did not (table 15) and 24(48%) of the respondents with children with hydrocephalus attended antenatal clinic monthly while 17(34%) occasionally and 2(4%) did not. The findings of the study

show that the majority of respondents had their children fully immunized as well as attended antenatal clinics. This may be so because as women attend antenatal clinic emphasis on immunization of the baby is usually made thus the high number of children being fully immunized.

All the respondents 50(100%) had good reception from the doctors, 49(98%) from the nurses and 34(68%) from the physiotherapist. Only 1(2%) found the nurse to be unfriendly. From these finding the carer is first told of the child's condition by the doctor while the physiotherapist is not usually available in rural health centres, thus a minimal number of them mentioned the physiotherapist as being friendly. The nurse on the other hand is the most available cadre of the health care team in rural health centres. As much as only a small fraction of the nurses was stated as being unfriendly, it can be attributed to mean that the nurse either did not know the type of care to be given to the child or was too busy with other issues to notice the condition of the child. The study revealed that 43(86%) of the respondents who took their children for physiotherapy less than the recommended times per month also had a negative attitude while 7(14%) of the respondents had a positive attitude (table 25). The study revealed that few respondents had an encounter with the physiotherapist showing that physiotherapy services are not being accessed by everyone who needs the service in the rural areas.

5.5 PRACTICE

Section D of the questionnaire (appendix 1) had questions that aided in assessing the practices of the carers towards children with hydrocephalus.

Analysis by Landman (1998) and Larson (1998) describe how parents struggle to articulate their lived realities of ambiguity and paradox (love and sorrow, hope and fear) within the parameters of conventional cultural discourses.

Table 20 shows that the respondents below the age of 20 years (90%) and above 44 years (100%) had poor practices. These are carers who were either too young or too old. The young were not mature enough to take up the responsibility of looking after their children. The elderly were also too old and lacked the vigour of looking after children.

Schoyen 2004 emphasised that parents and the family are the key to the development and early learning of any child. Children with hydrocephalus need the same stimulation (talking to, music, games, adventure and love) that any child needs, but they need more. As a result it is not easy for the very young and the very old to cope with the demands.

Majority of the respondents 19(58%) who were housewives and 9(69%) who were involved in other activities such as farming through which they helped supplement family income had poor practices (table 27). A willingness to devote time to anything which can help improve the income base of the household necessitates engagement in low paying jobs with long working hours for the carers. A fact that rather depletes their energies and decreases their capacity for involvement in the health and education of their infants and toddlers. This is true in our Zambian situation. Poverty levels according to priority survey report of 2000 are that 80% of the total population live in poverty. Parents, mothers inclusive prefer to find money for food before they can pay for other household activities such as buying special sitting/walking aids needed by their children. The majority of carers kept their children at home and only travelled to the clinic for either physiotherapy sessions, reviews or when the child was ill.

The findings of the study reveal that as much as the majority of the respondents 26(52%) allowed their children to play with other children, most 24(48%) did not because these children could neither sit nor play (table 19). This can also be seen that the majority of respondents who were mothers to these children were also not employed.

Majority of the respondents got financial support from the extended family. In this view it can be deduced that given the Zambian situation, scenario, extended families play a role in the caring of other family members in need.

5.6 KNOWLEDGE, ATTITUDE AND PRACTICES

The majority of the respondents with negative attitudes (60%) had medium to high knowledge. Negative attitude could be attributed to the fact that despite the carers having been told the diagnosis and care needed for the child with hydrocephalus, they felt that nothing could really be done for the child. Physiotherapy sessions could not be accessed from their nearest health centres because of the shortage of physiotherapists in these health care facilities. The negative attitude could also be attributed to the fact that as much as the carers are taught how to supplement the efforts of the physiotherapists, they lack support groups to help encourage each other. This in agreement with Kaunda (2005) who stated that living with a child having such a condition can be a big challenge to the carers if they lack the knowledge and encouragement on how to care for the child.

The study revealed that most families 29(58%) supplement efforts of physiotherapists while 21(42%) do not. This can be attributed to that majority of the Zambian population entrust their health care in the hands of the health care giver. Culturally most people just agree without questioning what the doctor says. The study revealed that most respondents knew what the condition involved but could not explain what it was. WHO (1996) through the Rehabilitation Unit of the World Health Organisation published a manual for mid-level rehabilitation workers when looking after children with hydrocephalus. Training suggestions are given for promoting normal development, mobility, self care and education. Child care personnel and all personnel involved in therapy tasks should know how important and comprehensive the

management of these children is. Therefore knowledge without comprehension eventually affects the attitude of carers especially if they do not understand the importance of the treatment activities.

The majority of respondents with good practice 18(82%) had medium to high knowledge (table 29). Practice in anything eventually makes one skilful in the area of practice. In order for one to practice, one must be knowledgeable. This would help understand the need for a particular plan of practices. In this case if the carer understands the need to allow the child to play with other children despite disability, they would not be reluctant to let them do so. They would rather find ways of ensuring that the child is protected whilst at play. In view of this, after educating the carer, they are expected to be knowledgeable as well as subsequently improve on good practices. In order to appreciate the new knowledge, the carers must put it into practice upon seeing the effects of constant practice. However the findings of the study revealed that despite the carers having had adequate knowledge on hydrocephalus, they still had poor practices. This can be attributed to that the carers find little support as they put into practice what they are taught (supplementing physiotherapy) and also their educational level may not allow them the comprehension that is needed to perform certain activities.

Majority of respondents with poor practices also had negative attitude (table 30). This could be that as much as the carers had medium-high knowledge on hydrocephalus, they lacked support from health care provider in services that would help them provide care to their children thus the poor practices. Adams 1973 states that frightening instructions to a mother may make her too anxious, as a result she will become over protective and restrict the child's activities beyond the limits set by the physician. The mothers with medium-high knowledge were also over protective and hence failed to practice as expected.

The study revealed that most carers preferred extreme special care to the child for fear of the child injuring her/himself. This is because the mother has a bond that develops with her baby through pregnancy and the bond is strengthened after the baby is born. This is in agreement with Marlow (1973) who stated that mother love is the strongest emotional tie between two human beings. It begins as a symbolic relationship in utero which continues after the child is born.

According to the study hypothesis, inadequate knowledge on hydrocephalus leads to poor attitudes of carers towards children with hydrocephalus. This is contrary with the study findings which revealed that 53% of the respondents with medium-high knowledge also had poor attitude. The hypothesis further stated that adequate knowledge on hydrocephalus leads to good attitude of carers towards children with hydrocephalus. However the findings of the study revealed that only 14% of the respondents with medium-high knowledge also had positive attitude. The hypothesis was therefore rejected.

5.7 IMPLICATIONS ON THE HEALTH CARE SERVICES

Hydrocephalus is a condition resulting from congenital and acquired factors, which may be mild or severe. There has been an increase in the incidence of hydrocephalus over the years. This could be attributed to an increase in infections such as meningitis and cerebral malaria. It could also be as a result of improved neonatal care where babies are diagnosed early. This means that the incidence of hydrocephalus should be given as much attention as other conditions like malaria.

Currently the carers of children with hydrocephalus are very willing to do as much as possible to improve their children's condition. However, they are unable to practice care because they do not have adequate support and adequate resources. There is need therefore to develop strategies on how these carers can be given support at their nearest health facility.

The Action on Disability and Development (ADD) department with the help of volunteers (carers to children with hydrocephalus, teachers of the disabled as well as members of the community) are doing their best to work with these children. However only those children who stay near centres where ADD operates benefit. This means that the good services cannot be enjoyed by all the clients in those areas where ADD has not established centres yet. Through the ADD department, carers knowledge and attitude is improved though at the same time carers cannot carry out all the good practices because despite having knowledge they cannot afford certain resources such as special chairs due to their economic status. Efforts should be made to make physiotherapy affordable and accessible. Using appropriate technology to make mobility aids, so far, is only provided by Appropriate Paper Technology Enterprises (APTERS), Lusaka. This is still expensive. APTERS should be assisted by Ministry of Health, the business community and able individuals to expand their workshops to all towns in the country.

Physiotherapists are doing a commendable job, but need support from the rest of the health care team, Government and other well wishers. Nurses should develop a genuine wish to engage in a human endeavour, a real sense of responsibility towards the child for whom she provides care and for his carers. She should not make judgements for them. Being the first person that the child and carers meet, she needs to observe their behaviour and respond to both the adult and child. She needs to accept them as they are and assist them make their own decisions. The nurse should not be an authority figure but should exhibit kindness and love towards the carers and the children as a human requirement.

CHAPTER SIX

6.0 INTRODUCTION.

This chapter discusses the researcher's conclusion, study limits as well as the recommendations made to relevant authorities.

6.1 CONCLUSION AND RECOMMENDATIONS

The study reveals that many people perceive hydrocephalus as a serious condition but do not have good practices despite the adequate knowledge they have. Majority of the carers had a negative attitude towards children with hydrocephalus leading to poor practices. However, most of the respondents could not meet their basic needs thus an added responsibility of looking after the child was beyond their means.

Action on Disability and Development provides free physiotherapy to which all carers would respond positively if it were found in every District of the country. Given more facilities, the carers would be able to attend. The attitude of the carer plays a vital role in caring for these children with hydrocephalus and support is required in developing the child's full potential and guiding him to his full role of adulthood in society. Carers of children with hydrocephalus are most often overprotective. In turn this has a negative effect on the carers practice towards the child's condition. This may lead to the child's failure to gain his full independence.

There is need therefore to intensify education on hydrocephalus, its causes, treatment and treatment benefits and the support groups available. This will improve on the carer's practices and strengthen their attitude.

6.2 RECOMMENDATIONS.

In view of the study findings, the researcher would like to make the following recommendations;

1. The Ministry of Health should ensure that all health care givers as well as the community get Information, Education and Communication on care of children with hydrocephalus mainly through media programmes.
2. Other non Governmental Organisations such as the church and Home Based Care should be involved in the care of children with hydrocephalus.
3. The Government as a result of the growing number of hydrocephalus cases should initiate a system such as that of Primary Health Care services as close to the family as possible.
4. Carers should be educated on what hydrocephalus is, its causes, treatment, treatment benefits and the support that can be offered.
5. Health care personnel should be educated on the importance of treating each child as an individual to enable satisfaction on the child and carer.
6. Future research should be done on the health workers to determine knowledge and attitudes towards hydrocephalus.

6.3 STUDY LIMITATIONS.

- It was possible to have interviewer bias as a result of using an interviewer-administered questionnaire.
- Time given for the collection of data was not adequate for a larger sample to be used and so it is difficult to generalise the findings.
- Funding was limited.
- Literature on carer's knowledge, attitude and practice towards children with hydrocephalus was very scanty. This lead to the investigator using literature on related subjects and opinion papers instead of research findings.

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APPENDIX 1
THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE

DEPARTMENT OF POST BASIC NURSING

**AN INTERVIEW SCHEDULE FOR CARERS OF CHILDREN WITH
HYDROCEPHALUS**

TITLE OF THE STUDY

**A study to determine the knowledge, attitude and practices of carers towards
children with Hydrocephalus**

Place of interview:-----

Date:-----

INSTRUCTIONS TO THE INTERVIEWER

1. No name should appear in this questionnaire.
2. Information given will be kept strictly confidential.
3. Tick against the appropriate number of the response on the space provided.
4. For responses without alternatives, write the responses in the space provided.
5. Ask questions whenever necessary for clarification.
6. Thank the respondent at the end of the interview.

SECTION A

DEMOGRHIC DATA

**OFFICIAL
USE ONLY**

1. Sex

- | | | |
|------------|---------|---------|
| (a) Male | [] | |
| (b) Female | [] | [] |

2. Age at last birthday

- | | | |
|--------------------|---------|---------|
| (a) Below 20 years | [] | |
| (b) 21 – 30 years | [] | [] |
| (c) 31 – 40 years | [] | |
| (d) 41 – 50 years | [] | |

3. What is your residential address?

- | | | |
|-----------------------------|---------|---------|
| (a) Low residential area | [] | |
| (b) Medium residential area | [] | [] |
| (c) High residential area | [] | |

4. Marital status

- | | | |
|--------------|---------|---------|
| (a) Married | [] | |
| (b) Single | [] | |
| (c) Divorced | [] | [] |
| (d) Widowed | [] | |

5. What is your denomination?

- | | | |
|------------------------|---------|---------|
| (a) R C Z | [] | |
| (b) S D A | [] | [] |
| (c) Pentecostal | [] | |
| (d) Other specify..... | | |

6. Level of Education

**OFFICIAL
USE ONLY**

(a) Primary []

(b) Secondary []

(c) College []

(d) University []

7. Are you employed?

(a) Yes []

(b) No []

8. What is your family income per month?

(a) Less than K300, 000 per month []

(b) K301, 000 – K6000, 000 []

(c) K601, 000 – K9000, 000 []

(d) K901, 000 and above. []

9. What is your occupation?

(a) House wife []

(b) Business man\ woman []

(c) Professional []

(c) Other specify.....

10. What is your tribe?

.....

11. What is your relationship with the child?

(a) Mother []

(b) Father []

(c) Aunt []

- (d) Sibling []
 (e) Other specify.....

**OFFICIAL
USE ONLY**

12. What means of transport do you use to get to the nearest health centre?

- (a) By foot []
 (b) Bicycle []
 (c) Car []
 (d) Bus []
 (e) Other specify.....

[]

13. How long does it take to get to the nearest health centre?

- (a) 30 minutes or less []
 (b) 31 minutes to 1 hour []
 (c) More than 1 hour []
 (d) Not sure []

[]

SECTION B

KNOWLEDGE DATA

14. Were you told the diagnosis of the child?

- (a) Yes []
 (b) No []

[]

15. If yes to question 14, by whom?

.....

16. What do you understand by the term Hydrocephalus?

.....

17. What are the causes of Hydrocephalus?

- (a) Infections of the mother []
 (b) Infections of the baby []
 (c) Which craft []
 (d) Birth Trauma []
 (e) Do not know []

[]

18. What do you understand by physiotherapy?

**OFFICIAL
USE ONLY**

19. How did you know about Hydrocephalus?

- | | | |
|---------------|---|---|
| (a) Media | [|] |
| (b) Hospital | [|] |
| (c) Friends | [|] |
| (d) Relatives | [|] |

[]

20. How much information were you given on physiotherapy?

- | | | |
|--------------|---|---|
| (a) Moderate | [|] |
| (b) Minimum | [|] |
| (c) None | [|] |

[]

Section c

Attitude Data for carers and staff

21. Where do you take when he/she is sick?

- | | | |
|-------------------------|---|---|
| (a) Clinic | [|] |
| (b) Traditional Healers | [|] |

[]

(c) Other specify.....

22. How often do you take the child for physiotherapy?

- | | | |
|---------------------|---|---|
| (a) 4 times a month | [|] |
| (b) 3 times a month | [|] |
| (c) Twice a month | [|] |
| (d) Occasionally | [|] |

[]

23. Is your child fully immunised?

- | | | |
|---------|---|---|
| (a) Yes | [|] |
| (b) No | [|] |

[]

24. How often did the mother attend antenatal clinic?

- | | | |
|----------------------|---|---|
| (a) Monthly | [|] |
| (b) Only when unwell | [|] |
| (c) Occasionally | [|] |

[]

(d) Don't know

[]

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25. How was the reception by the following health care providers?

Doctors

(a) Friendly

[]

(b) Not friendly

[]

[]

(c) Other specify.....

Nurses

(a) Friendly

[]

(b) Not friendly

[]

[]

(c) Other specify.....

Physiotherapists

(a) Friendly

[]

(b) Not friendly

[]

[]

(c) Other specify.....

SECTION D

PRACTICE DATA

26. What are your responsibilities in the care of this child?

.....

.....

27. What activities does your child participate in at home?

.....

.....

28. Does your child play with other children?

(a) Yes []

(b) No []

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ONLY**

[]

29. If the answer to question 28 is No, please explain.....

.....

30. Would you be willing to send your child to school?

(a) Yes []

(b) No []

[]

31. If No to question 30, please explain.....

.....

32. How should children with Hydrocephalus be treated?

(a).....

(b).....

33. What measures does the family undertake to supplement the efforts of physiotherapists?

(a)

(b)

(c)

34. Where do you get support from in the care of your child?

(a) Extended family []

(b) Community []

(c) Neighbours []

[]

(d) Church []

(e) NGO's []

(f) Other specify.....

35. In what form is the support which you get?

- (a) Money

[]
- (b) Food

[]

[]
- (c) Spiritual

[]
- (d) Moral

[]
- (e) Other specify.....

36. Do you have any comments on the care of children with Hydrocephalus?

.....

.....

.....

.....

.....

**THANKYOU FOR YOUR PARTICIPATION AND
COOPERATION**

APPENDIX 2
University of Zambia
School of Medicine
Department of Post Basic Nursing
P. O. Box 50110,
LUSAKA

August 2006

The Executive Director
University Teaching Hospital
P. O. Box 50001
LUSAKA

U.F.S. Head of Department
 School of Medicine
 Post Basic Nursing

Dear Sir,/Madam

**RE: PERMISSION TO CARRY OUT A STUDY ON KNOWLEDGE,
ATTITUDES AND PRACTICES OF CARERS TOWARDS
CHILDREN WITH HYDROCEPHALUS**

I am an undergraduate student in the department of Post Basic Nursing at the University of Zambia. I wish to seek permission to carry out a study on the above mentioned topic. This is in partial fulfilment of the BSc Nursing programme.

I intend to carry out the study in D-Block during the clinic days Tuesday and Thursday. The research will entail interviewing carers of children with hydrocephalus visiting the clinic.

Confidentiality will be maintained by not writing their names and informed consent will be obtained from all respondents. The study will be conducted between August and September 2006.

I shall be most grateful for your favourable response.

Yours faithfully,



Sanana Liywali

APPENDIX 3
University of Zambia
School of Medicine
Department of Post Basic Nursing
P. O. Box 50110,
LUSAKA

August 2006
District Director
LUDHMT
Makishi Rd
LUSAKA

U.F.S. Head of Department
 School of Medicine
 Post Basic Nursing

Dear Sir,/Madam

**RE: PERMISSION TO CARRY OUT A A PILOT STUDY ON
KNOWLEDGE, ATTITUDES AND PRACTICES OF CARERS
TOWARDS CHILDREN WITH HYDROCEHALUS**

I am an undergraduate student in the department of Post Basic Nursing at the University of Zambia. I wish to seek permission to carry out a pilot study on the above mentioned topic. This is in partial fulfilment of the BSc Nursing programme. I hope to carry out the pilot study in Matero clinic, during the specific clinic attended by children with disabilities (hydrocephalus included).

This research will entail interviewing carers of children with hydrocephalus visiting the clinic. Confidentiality will be maintained their names and informed consent will be obtained from all respondents. The study will be conducted between August and September 2006.

Your favourable response will be greatly appreciated.

Yours faithfully,



Sanana Liywali

APPENDIX 4
University of Zambia
School of Medicine
Department of Post Basic Nursing
P. O. Box 50110,
LUSAKA

August 2006

The Co-ordinator
Action on Disability and Development (ADD)
P. O. Box 50001
LUSAKA

U.F.S. Head of Department
 School of Medicine
 Post Basic Nursing

Dear Sir,/Madam

**RE: PERMISSION TO CARRY OUT A STUDY ON KNOWLEDGE,
ATTITUDES AND PRACTICES OF CARERS TOWARDS
CHILDREN WITH HYDROCEHALUS**

I am an undergraduate student in the department of Post Basic Nursing at the University of Zambia. I wish to seek permission to carry out a pilot study on the above mentioned topic. This is in partial fulfilment of the BSc Nursing programme.

I hope to carry out the study in Matero clinic where community based rehabilitation programmes are provided. The interview will entail interviewing carers of children with hydrocephalus visiting the clinic.

Confidentiality will be maintained by not writing their names and informed consent will be obtained from all respondents. The study will be conducted between August and September 2006.

Your favourable response will be greatly appreciated.

Yours faithfully,



Sanana Liywali

Box 50827
260-1-235554
260-1-236429



Republic of Zambia

*In reply please quote
No.*



MINISTRY OF HEALTH

LUSAKA DISTRICT HEALTH MANAGEMENT TEAM

30th August, 2006

Sanana Liywalii
University of Zambia
Department of Post Basic Nursing
LUSAKA

Dear Sir,

RE: PILOT STUDY – MR SANANA LIYWALII

I wish to inform you that permission has been granted for you to carry out a pilot study on knowledge, attitudes and practices of careers towards children with Hydrocephalus.

However this should not disturb day to day activities at the Health Centre.

By copy of this letter the Health Centre In-Charge Matero Main has been informed forthwith.

Yours faithfully,

DR. M. KABASO
CLINICAL CARE MANAGER
FOR DISTRICT DIRECTOR OF HEALTH

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