

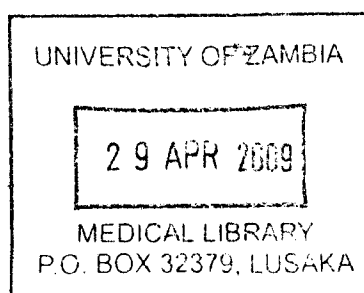
KNOWLEDGE, ATTITUDE AND UTILISATION OF
HOSPICE SERVICES BY FAMILIES WITH
CHRONICALLY AND TERMINALLY ILL
PATIENTS AT THE UNIVERSITY TEACHING
HOSPITAL, KALINGALINGA AND CHAWAMA
HEALTH CENTRES IN LUSAKA DISTRICT.

BY

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ZRN (1999) LUSAKA

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UNZA

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THE UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE, DEPARTMENT OF POST BASIC NURSING

A STUDY TO DETERMINE KNOWLEDGE,
ATTITUDE AND UTILISATION OF HOSPICE
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MED
MAL
2008

A research submitted to the School of Medicine, Department of
Post Basic Nursing, in partial fulfilment of the requirements of
the award of Bachelor of Science in Nursing Degree.

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LIST OF ABBREVIATIONS.

ACS	American Cancer Society.
AIDS	Acquired Immune Deficiency Syndrome
CBOH	Central Board of Health
CSO	Central Statistical Office
FBO	Faith Based Organisation
GNC	General Nursing Council of Zambia
HBC	Home Based Care
HIV	Human Immuno Deficiency Virus
IEC	Information Education Communication
LDHMT	Lusaka District Health Management Team
MOFNP	Ministry of Finance and National Planning
MoH	Ministry of Health
NAC	National AIDS/HIV Council
NGO	Non Governmental Organisation
PBN	Post Basic Nursing
PHC	Primary Health Care
RCZ	Reformed Church of Zambia
SDA	Seventh Day Adventist
SWAP	Sector Wide Approach
TB	Tuberculosis
UCZ	United Church of Zambia
UNAIDS	Joint United Nations programme on HIV/AIDS
UNZA	University of Zambia
UTH	University Teaching Hospital
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation
ZDHS	Zambia Demographic and Health Survey

DECLARATION

I, **Patrick Malisawa**, do 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 to any other Degree.

Signed:
(Candidate)



Date: 14/04/08.....

Approved:
DNIS
(Supervising Lecturer)
8002 617 71

Date: 14/04/08.....

STATEMENT

I, **Patrick Malisawa**, do 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 reference.

Signed:  Date: 

DEDICATION

To

My wife Sibongile Mumba, my son and daughter Mwamba and Mwango whose patience, understanding and consideration sustained me through the years of my studies.

To

My mother Mrs Beatrice Kapambwe Malisawa, my (late) father Mr Samuel Fedelis Chola Malisawa for taking me to school in the first place and inspired me to aspire.

To

Mrs Martina Katema and Dr G.D.M. Katema (late), Mr and Mrs Matthias Mpundu, whose love and affection inspired this endeavour.

To

All the chronically and terminally ill patients; you matter because you are you and you matter to the last moment of your life. We would have to do all we could not only to help you die peacefully, but to live until you die (Clark,2002).

ABSTRACT

Hospice service concept is quite new in Zambia; this service plays a key role in improving the quality of life of patients and their families facing critical illnesses, by preclusion and relief of suffering through assessment, treatment of physical, psychosocial and spiritual problems. More emphasis is put on care than cure. The first hospice in Zambia was built in 1997 to provide the service to the chronically and terminally ill patients who occupy a good number of bed spaces in most hospitals.

With the advent of HIV/AIDS, there has been an increase in number of admissions in health institutions. The patients who are admitted do not stay long, but they are discharged to be nursed at home by their families in order to decongest the health care institutions. In a normal situation the chronically and terminally ill patients could benefit from hospice and palliative care however, families seem not to know about the existence of such services. The government and service providers have not done enough to impart knowledge to the general public, specifically to families with chronically and terminally patients. If the general public were to be imparted with knowledge, this may influence their attitude and utilisation of the available hospice services. In view of this, the study established knowledge, attitude and utilisation of hospice service by families with chronically and terminally ill patients in Lusaka District.

The general objective of the study was to determine knowledge, attitudes and utilisation of hospice services by families with chronically and terminally ill patients in Lusaka District.

The review of literature globally, regionally and nationally revealed that knowledge plays an important role in the development of positive attitudes and utilisation of the hospice services. Other factors that may influence hospice service utilisation are community involvement and an understanding of their social-culture aspect.

A descriptive non intervention cross section design was used, which aimed at quantifying the distribution of knowledge, attitude and utilisation of hospice service in the study population. The study was conducted at the University Teaching Hospital, Kalingalinga and Chawama Health Centres in Lusaka District.

The study population were family members of patients with chronic and terminal illnesses, admitted at the University Teaching Hospital, Chawama and Kalingalinga Health Centres. The respondents were family members found and selected by using simple random sampling method, which is one of the probability sampling designs. A sampling frame was established and a lottery technique was used to give each family member a chance of being selected.

The sample under study were fifty (50), of which thirty (30) were selected from the University Teaching Hospital, ten (10) from Kalingalinga and Chawama Health Centres.

A pilot study was carried out at the University Teaching Hospital's Gynaecology ward, on families with patients with similar characteristics as those in the main study; a pilot study sample was 10% of the actual study that is five respondents in a pilot study.

Data was collected using structured interview schedule. Data was analysed manually, through use of valid scientific methods like sorting data, coding data and data was later entered on the data master sheet and further analysed with the aid of scientific calculator.

This project started with proposal development. Permission was sought from the School of Medicine, University Teaching Hospital and Lusaka District Health Management Team to conduct a pilot study and the main study. The actual data collection was in September to October 2007.

The findings of the study were that majority 33 (66%) of the respondents had low knowledge of hospice service, 13 (26%) had moderate knowledge, while 4 (8%) had high knowledge of hospice service in Lusaka District. The majority 40 (80%) of the respondents had positive attitude towards hospice services. In terms of utilisation majority 44 (88%) of the respondents had not utilised a hospice service before.

This calls for concerted effort both from Government and the Service providers to improve on information dissemination on Hospice services; especially its benefits if consumers were to be imparted with knowledge later on access the services.

In view of these findings in the study, it was recommended that the Government through the Ministry of Health and the Palliative Care Association of Zambia should speed up the process of policy formulation on palliative and hospice services. The Government should invest in human resource and infrastructure development and adequately and consistently fund the Faith Based Organisations (FBOs) and Non Governmental Organisations (NGOs) who are currently offering these services to the general public. The FBO and NGO should devise mechanism for effective information dissemination on hospice services.

CHAPTER 1.

1.0 INTRODUCTION.

Hospice service concept is quite new in Zambia. The first hospice in Zambia was built in 1997 and the purpose was to offer care to the chronically and terminally ill patients. In Lusaka there are about four hospices which offer palliative care services. In this report, knowledge, attitude and utilisation of hospice by families with chronically and terminally ill patients in Lusaka District were determined. The write-up would briefly describe the background information, health care system in Zambia, statement of the problem, objectives of the study, literature review, the methodology that was used in the study, project management plan, presentation of data as well as discussion of finding, implications to the health care system and some recommendations.

1.1 BACKGROUND INFORMATION.

Zambia is a land locked Country covering an area of 752,612 square kilometers. It shares boundaries with the Democratic Republic of Congo and Tanzania in the north; Malawi and Mozambique in the east; Zimbabwe and Botswana in the south; Namibia in the south west and Angola in the west [Central Statistical Office (CSO), 2003]. It is located in the sub-Sahara African region which is hardest hit by Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) [World Health Organisation (WHO), 2002]. According to United Nations Joint Programme on AIDS (2003), 26.6 million people in sub-Saharan Africa are living with HIV, and new cases are estimated at 3.2 million while AIDS related deaths at 2.3 million. Administratively, the country is divided into nine provinces and 72 Districts. Lusaka and the Copperbelt are predominately urban regions and the rest are rural provinces (CSO, 2003).

Zambia has a population of approximately 10.5 million (Central Statistical Office, 2003), giving an average population density of about 14 people per sq km (37 people per sq mi). The Central areas, the Copperbelt, and along the railway lines are the most densely populated. In all, more than 40 per cent of Zambians live in towns, making it one of the most highly urbanised countries in Africa. Lusaka Province has a population of

approximately 1.4 million with an annual growth rate of 3.5. It has four districts namely Chongwe, Luangwa, Kafue and Lusaka. Lusaka District has a population of approximately 1.1 million which is about 78% of the total population of the province (CSO, 2003). According to CSO (2005), Lusaka District is said to have the largest population of people living with HIV/AIDS. However, besides HIV/AIDS there other chronic illnesses for example Tuberculosis (TB), Diabetes mellitus, and Cancer that are common in the province. Lusaka Province recorded the highest cancer cases from 2004 to 2006 of approximately 5236 (Ministry of Health, 2007). Traditionally cancer was the common condition that used to be cared for in hospices (Mayo, 2006), but currently AIDS has taken the lead especially in the sub-Saharan Africa.

1.1.2 HEALTH CARE SYSTEM.

The vision of the Ministry of Health (MoH) under health reforms in Zambia is to “*provide equity of access to cost-effective, quality health care as close to the family as possible*” (Central Board of Health, 2001). Zambia has been implementing health reforms since 1992 under the framework of the Sector Wide Approach (SWAP), which takes a holistic development view of the sector. The mission of MoH is to significantly increase life expectancy in Zambia by creating environments and promoting life styles that support health. The financing of the basic health care package is a priority to try and reduce both morbidity and mortality rates and contribute to poverty reduction (Ministry of Finance and National Planning, 2006).

The financing of basic health care package focuses on promoting Primary Health Care (PHC) activities. In the SWAP, resources from government and other stakeholders are put together to ensure efficient utilisation. This system of financing health service delivery is called Basket Funding.

Despite the above system of financing health care being put in place, the government could still not afford to provide health services to the Zambian population equitably. This was partly due to increasing disease burden and decreasing resources in the country. In view of this, the government in 1993 introduced a Cost Sharing Scheme (Daura and Mtonga, 2002). This targeted the able-bodied Zambians to contribute towards the health

care system both financially and in kind as stipulated in the *Zambian Health Policy* “every able-bodied Zambian with an income should contribute to the cost of his or her health” (Ministry of Finance and National Planning, 2006). However, exemptions existed based on age (children under 5 years and adults over 65 years), and chronic diseases (TB, HIV/AIDS, Cancer and treatment of chronic Hypertension and Diabetes mellitus etc). This was aimed at enhancing an equitable and appropriate delivery of health services to all. This cost sharing scheme has since been done away with, especially in the rural areas following the presidential directive. This has affected the smooth running of the health centres because of inconsistent funding from the Government.

In Zambia, household expenditures on health vary according to location, which are urban and rural areas. Poor households in the rural areas spend the highest proportion of their income on health, which is estimated around 10% of their total expenditure when in kind costs are included (Ministry of Finance and National Planning, 2006). This includes amount spent on transport as well as to meet medical expenses when one family member is sick. This is one of the key determinants of health seeking behaviour in Zambia. To try and mitigate this problem the Government introduced the Public Welfare Assistance Scheme in 1995 to address inequalities in accessing health care services. In this programme, patients with chronic illnesses who cannot pay are supposed to be referred to the District Social Welfare Office for assessment and assistance. However, the referral system has not functioned well and those who cannot pay fail to access the health services especially patients with chronic illnesses such as HIV/AIDS.

In trying to meet the challenges brought by HIV/AIDS, Zambia has devised a number of programmes. One of the effective programmes designed to help those who are affected is the Home Based Care (HBC). This was developed in response to the unprecedented costs within the formal health sector and the increasing demand for hospital beds [National HIV/AIDS Council (NAC), 2004]. Home Based Care in Zambia is implemented in two ways. The outreach programmes initiated by Government Health Institutions such as hospitals and health centres, reach out to the communities. Other programmes are run by Non Governmental Organisations (NGOs), Faith Based Organisations (FBOs) and other voluntary organisations. NAC (2004) has observed that HBC is an effective alternative to

hospital services. However, cost implications place economic burden on those providing care on voluntary basis and often HBC providers are severely constrained. This results in failure of services to spread to all needy populations, especially the hospital initiated community programmes. The FBOs and NGOs have gone a step further in meeting the challenges of AIDS by provision of institutional care apart from HBC of the sick.

In view of these problems, these organisations have made an effort to come up with Hospices in most parts of the country, where chronically and terminally ill patients can be nursed. Dame Cicely Saunders at St Christopher's Hospice in London first coined the term 'Hospice' in 1967, to denote a place where specialised care is offered for the dying patient (American Cancer Society, 2007). Hospice is a concept of care that provides compassion, concern and support for the dying (Lewis et al., 2004). Hospice and palliative care are frequently used interchangeably. Hospice exists to provide support and care for persons in the last phases of incurable diseases so that they might live fully and comfortably. It also ensures that patients and family needs are the focus of intervention. Today hospice services provide humane and compassionate care for terminally ill patients, so that they may live as fully and comfortably as possible. Currently, there are more than 3 200 hospices available in the United States of America (Kinsella, 2004).

Most African countries have accepted this concept of hospice and palliative care. Zimbabwe was the first country that established hospice services in Africa. However, the Ugandan hospice model is currently being followed by most African countries, and was the first to be incorporated in that countries' health care system. According to Merriman (2006), the Ugandan model looks at the following:

- It promotes working with Government through already existing health facilities.
- It grafts palliative care in to already existing support teams for HIV/AIDS.
- Palliative care needs a team with a strong commitment to caring for patient, family and each other.
- There is a belief that palliative medicine can change attitudes of health professionals to the end-of-life care.

In Zambia, most Hospices were introduced in the 1990s and are managed by FBOs and NGOs. There about 10 Hospices in the country out of which four are in Lusaka Province. Mother of Mercy was the first to be established in 1997. It is situated in Chilanga approximately 16km south of Lusaka. It has a bed capacity of 22 and about 520 clients under mobile hospice in the community (www.eolc.org). Jon Hospice was opened in 1999 under Kara counseling. It is situated in Kamwala-Kabwata Site and Service area. It has a bed capacity of 26 and approximately 500 patients under mobile hospice (Shabwe, 2007). The other hospice is Our Lady's Hospice run by the Catholic Church. The Hospice is located in Kalingalinga Compound, east of Lusaka. It has a bed capacity of 33 (Sister O Neil, 2007). The others are Martin Hospice in Choma, Ranchhood in Kabwe, Cicetekelo in Ndola, and Human Service Trust in Lusaka. The rest are, one in Mpasha and Eastern province of Zambia.

In Zambia today, most of the hospitals are full of chronically ill patients who may be stable as well as those in the terminal phase of their lives. An increase in such conditions is as a result of a move up in Acquired Immune Deficiency Syndrome (AIDS), which potentiates conditions like cancer, chronic renal and cardiac diseases. In the long run this would result in increased utilisation of home based care and hospice services. It is to this effect that, it is important to determine the knowledge level as well as attitudes of family members towards hospice service.

1.2 STATEMENT OF THE PROBLEM.

Lewis et al (2003), explains that palliative care is the frame work for hospice care, which could start much earlier in the disease process, although traditionally hospice care is limited to the projected last six (6) months of life. In most cases hospice and palliative terms are used interchangeably.

With the advent of HIV/AIDS, there has been an increase in the number of admissions in Health Institutions. It is the responsibility of the Government to care for the chronically and terminally ill patients admitted in hospitals and health centres (MoH, 1992). The Government recognizes the challenges of caring for HIV/AIDS and other chronic/terminal

illnesses. Among the strategies adopted in order to meet such challenges include the provision of institutional and home care of the sick. The institutional care is mostly done in hospitals and health centres. NAC (2004) observes that the patients with HIV/AIDS command a disproportionate share of beds at the hospitals as well as health centres. Usually these patients are admitted but do not stay long in hospitals. After they are discharged, they are nursed at home by their families in order to decongest hospitals. The numbers of people who are being discharged to be cared for in the community is increasing. The impact of caring for the patient is felt by the families, who are in closer contact with patients. These families are overwhelmed by the nature of this responsibility. Their resources are further stretched and this burden may affect the families socially, psychologically and economically.

Chronic and terminal illnesses are required to be nursed in a hospice where they could benefit from the services such as pain relief, emotional and spiritual care, and where families are included in the intervention. However, many families seem not to have knowledge of hospice service, this could be manifested by negative attitude and misconceptions about the function of the hospices. This is evidenced by what Sister Smarzoch (2007) observed at Mother of Mercy Hospice in Chilanga, and I quote “*many families access the services for other conditions like malaria. Sometimes conditions we see are attributed to poverty*”. However, there is no literature or research done to support this. Hill (2007) concede to say, hospice is available that function like the hospital, dealing with opportunistic infections, monitoring and aggressively treating bacterial infection and stretching the definition of hospice to incorporate more aggressive therapies. This is because the poor communities access the services for any disease and they could not be turned away.

In a study by Muliwana (1993) to establish acceptability of Hospices in Lusaka, it was reported that 73.3% of people welcomed the establishment of hospice service in Lusaka. The majority of the people were for the idea that hospices could be a better alternative to the hospital based care for the terminally ill patients. However, this study did not assess knowledge and utilisation of hospice services available.

The Government through the MoH has not done enough to look at the alternatives. They have just ended at the provision of home care and there is no policy on palliative and hospice care in the country at the moment. This may have an influence on the health care providers, to initiate health education programmes in order to impart knowledge in the general public about the importance of hospice service. Furthermore, the public have not received enough information from the organisations that are running the hospices. This has a potential to influence attitudes towards hospice service because of lack of knowledge. Most families/care givers do not have knowledge on hospice care, despite having the services available for sometime now. This may have an influence on their attitudes towards the service and affects the effective utilisation of the services.

Inadequate knowledge on the hospice service has a bearing on the attitudes towards the service and its utilisation. This problem is countrywide and it affects the general public. Government has done well in other programmes e.g. HIV/AIDS sensitisation and preventive measures. Curative services as demonstrated by the recent opening of the Cancer Disease Hospital in Lusaka. There is information almost every where in the country on the above mentioned programmes. However, the MoH and professional health workers have not come any closer to promote hospice services, so that families could be imparted with knowledge and develop positive attitudes towards the service. The organisations providing this service have done so well but not enough to reach out to those not aware of the services. They have restricted themselves to those whom they come in contact with as they provide the services. In respect of this, the study wanted to establish the knowledge, attitudes and utilisation of hospice service by families with chronically and terminally ill patients in Lusaka District.

1.3 FACTORS AFFECTING / INFLUENCING THE PROBLEM.

There are several factors that could affect knowledge, attitude and the utilisation of a hospice services. They are grouped in three categories which are social cultural, service related and disease related factors.

1.3.1 Social cultural factors.

Ignorance.

Ignorance about the roles and benefits of palliative and hospice service may lead to negative attitude and low utilisation of the services. Families may view hospices just like hospitals where they could go to seek cure. This means that they may go there with a view of being treated completely. Clients may go to a hospice not for care and be helped with activities of daily living, suppression of the symptoms and live as comfortable as possible but otherwise. Hence families may not be satisfied with the services because of ignorance on hospice service. This, if not looked into may result in negative attitude towards hospice service.

Distance/location.

Distance and location of the hospice may result in a situation where many families would not know their existence. Distance and location could also make it impossible for families to access the services. This may contribute to under utilisation of the hospice services.

Religious affiliation.

Most of the hospice services in the country are provided by the Catholic Church and a few by Kara, a Non Governmental Organisation. Families from other religious circles may not have adequate knowledge about the services. Other families may have negative attitudes towards the Catholic beliefs and doctrines because of difference in religious affiliations. Other people may perceive the services offered by the church as only for their members.

Education level.

Education helps families to make appropriate decisions, because the educated can easily understand the health concepts and implications of chronic and terminal illness (American Cancer Society, 2007). It is more likely that an educated family would not only depend on health workers' advice on health matters but would read and understand documented information on hospice care. This implies that they are likely to be knowledgeable and have a positive attitude towards the service and may have high utilisation record.

The low level of education also affects one's ability to interact with other people. Inadequate interaction can limit one's exposure to information on health; this could be a recipe for negative attitude. Therefore, a family's level of education has a significant influence on the knowledge levels, attitudes and utilisation of hospice services.

Poverty.

Generally majority of the people in Zambia are poor (CSO, 2003). In this case the economic status of families influences their choices of health care regardless of their HIV status. The fact that they can not afford to pay for the services at hospitals and feed the client adequately at home, they may seek services from hospice because of poverty. Poverty is also the cause of illiteracy among various families which may lead to lack of knowledge.

1.3.2 Service related factors.

Inadequate information education communication (I.E.C.).

Inadequate IEC skills by Home Based Carers or other care givers like volunteers who are the majority in providing the services. This leads to poor understanding of the benefits, misunderstandings or lack of knowledge on palliative and hospice care by clients. This may lead to negative attitudes and underutilisation of a hospice services.

Inadequate IEC could also lead to lack of knowledge among families on the conditions that usually need palliative or hospice care. Lack of information on disease process or the meaning of palliative or terminal care may also cause under utilisation of the services. In addition, the family members may not understand the prognosis of the condition. This may lead to negative attitudes towards a hospice care service.

Lack of IEC may lead to inadequate sensitisation. Families may not have knowledge on the services as well as the benefits, because of inadequate or lack of sensitisation from health workers or relevant authorities such as owners of the hospices. This may lead to under utilisation of hospice services.

Families may not know that hospice facilitate could provides respite care for the families especially those who could not manage to care for their patients (Mayo, 2006). This could lead to under utilisation of the hospice service.

Non availability of the services in some areas.

In many parts of Lusaka and the Country as a whole there are no hospice services. This means the families may not have the knowledge simply because it is non existence. Families with knowledge about hospice service may have an opportunity to seek such service in places where they are available like Lusaka. For example Mother of Mercy Hospice receives patients from as far as Livingstone (Sr Smarzoch, 2007).

Non recovery.

Long stay in hospice may be viewed as a failure by families who anticipated cure not care from the hospice due to lack of knowledge. This is a recipe for negative attitude development.

1.3.3 Disease related factors.

Stigma

Families/Patients may fear to be discriminated against and labeled in a hospice. This may cause them to seek the services in privacy. This is as a result of lack of knowledge and negative attitude or stigmatisation of the diseases that are cared for in a hospice. Therefore, families may prefer to nurse their patients at home even if the condition needs admission at a hospice.

Hospice services are viewed to be for patients with HIV/AIDS only, and that it is a place where they are left to die without any help. Hospice services are aimed at caring not curing. The services are not only for patients with HIV/AIDS but any condition that may be chronic and lead to terminal illness such as cancers, renal as well as cardiac conditions. Families may stigmatise the service and disease because of inadequate knowledge and negative attitude.

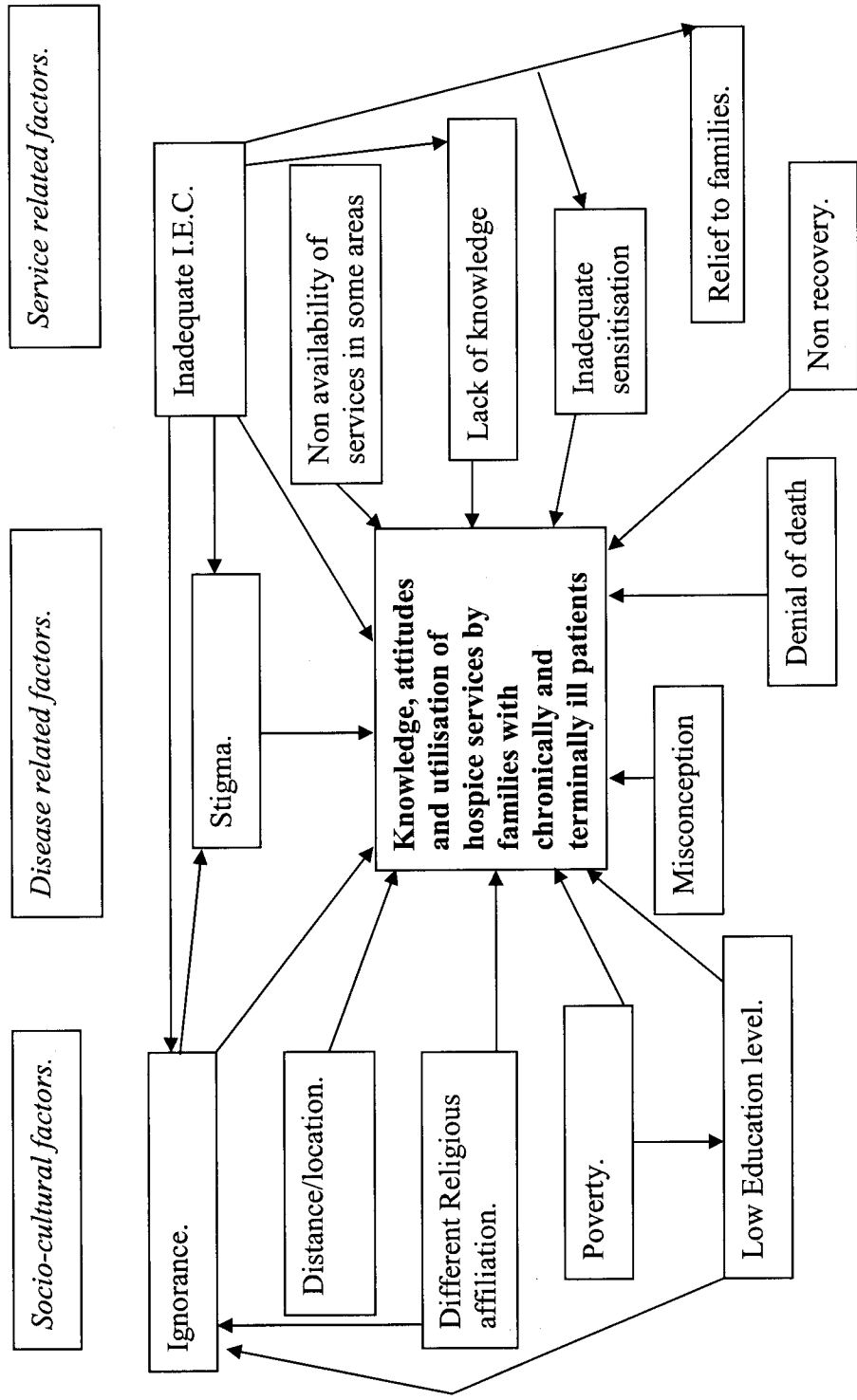
Denial of death.

Patients or family members may find it very difficult to accept the reality of death due to inadequate knowledge. This may be due to lack of understanding of the condition, inadequate preparation or counseling on the condition.

Misconceptions

People may view hospice facility as the place where only patients with HIV/AIDS are admitted, there by failing to access the service based on misconception, stigma and negative attitude consequently leading to under utilisation of the hospice services.

1.4 FIGURE 1: PROBLEM ANALYSIS DIAGRAM.



1.5 JUSTIFICATION.

Palliative or hospice care aims to maximize quality of life and relieve the suffering of patients with life-limiting incurable diseases, and to support their families and carers. It is provided through specialist services such as hospice and palliative care teams (Human Service Trust, 2007).

We have a number of hospices in the Country. The hospice services may have a significant impact on clients that is on the patients and family members if promoted and incorporated in the health care system of our country. If hospice services could be part of the health care system, health workers may take up the task to give families information on hospices, so that they could become knowledgeable and develop positive attitudes towards the service thereby increase its utilisation.

In the research conducted by Muliwana in 1993 to assess the acceptability of the hospice service in Lusaka; it was concluded that people were ready for the service. However no research has been done to determine the knowledge, attitudes and utilisation of the hospice services in Lusaka District and Zambia as a whole. Besides there are no accurate records or statistics to show utilisation pattern of the hospice services and we do not know the families' knowledge level and their attitudes towards this service. In addition there are very few studies done on hospice service in the Country.

The research findings would be used to determine the level of knowledge, attitudes and utilisation of hospice services by the families or communities in general. These findings could be used by the Government of the day, other NGOs, FBOs as well as private sector to review the health care system and seriously incorporate or come up with policies on palliative treatment as well as on hospice care.

It may also help the Government play a pivotal role in supporting the existing NGOs and FBOs health care services in terms of financial, material as well as human resources provision and investing in the infrastructure development. It could also be used in scaling up government owned hospice service programmes.

The institutions may also use the information to establish utilisation and impact of the services offered to the communities, so that programmes could be modified or built on

where it could be lacking. It could also high-light the strength and weaknesses of Information Education Communication programmes, which is currently in place to reach out to the communities and make them knowledgeable.

This study can also serve as a baseline to monitor future changes in health care delivery as the country is forced to adapt to the increase in cancer cases and the HIV/AIDS pandemic. It may also provide valuable insight in to the current health care resource allocation.

1.6 OBJECTIVES OF THE STUDY.

1.6.1 General objective.

- To determine the knowledge, attitudes and utilisation of hospice services by families with chronically and terminally ill patients in Lusaka District.

1.6.2 Specific objectives.

- To establish the knowledge level on hospice service by families with chronically and terminally ill patients in Lusaka District.
- To determine the attitude of families with chronically and terminally ill patients towards hospice service in Lusaka District.
- To assess the utilisation of a hospice services by family members in Lusaka District.
- To determine factors that influences the utilisation of hospice services in Lusaka District.
- To make recommendations on findings to relevant authorities.

1.7 HYPOTHESES.

- There is a relationship between knowledge level on palliative and hospice care services and utilisation.
- Negative attitude towards hospice care is associated with low utilisation among family members.

1.7.1 NULL HYPOTHESES

- There is no relationship between knowledge level on palliative and hospice care services and utilisation.
- Negative attitude towards hospice care is not associated with low utilisation among family members.

1.8 OPERATIONAL DEFINITIONS OF TERMS.

Attitude.

A feeling or opinion about hospice.

Knowledge.

An understanding of or information about a subject which has been obtained by experience (Woodford et al., 2003). This is an understanding of or information about hospice care service.

Family members.

Members of household as well as extended family members who help in the care for chronically ill patients.

Hospice.

Hospice is a range of health and comfort care services that are delivered to patients who are nearing the end of life (Kinsella, 2007).

Palliative care.

The World Health Organisation (WHO) define palliative care as “ an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual care”(Harding and Higginson, 2004).

Home Based Care.

Care given to patients/client in their homes.

Client.

A person or persons with chronic and terminal illnesses accessing the services of hospice.

Terminal illness

A life threatening end stage illness.

Chronic illness

A disease of long duration involving very slow changes (Oxford, 2003).

Criteria for determining chronic and terminal illnesses.

Duration of illness and clinical judgment on appearance of a patient.

1.9 VARIABLES AND CUT OFF POINTS.

“A variable is anything that can change or anything that is liable to vary” (Treece and Treece, 1986).

An independent variable is a characteristic or factor that is selected or manipulated in order to determine its influence on another variable. In contrast, a dependent variable is a characteristic that is observed and measured to determine how it responds to variations in an independent variable.

Independent variables

- Educational level
- Distance.
- Stigma.
- Religious affiliation.
- Information education communication
- Sex
- Age

Dependent variables

- Knowledge
- Attitude.
- Utilisation.

TABLE 1 : VARIABLE, INDICATORS AND CUTOFF POINTS.

Variable	Indicator	Cut off points	Questions
Knowledge	High knowledge	<ul style="list-style-type: none">• Define hospice care• State purpose of hospice.• Mention diseases nursed at hospice.• Know where chronically and terminally ill are to be nursed.• Name and location of Hospice.• Score at least 4 out of 5	Questions number 10 to 16
	Moderate knowledge	Score 2 to 3 out 5 Questions above	10 to 16
	Low knowledge	Score 0 to 1 out of 5 Questions above.	10 to 16

Attitude	Positive	<ul style="list-style-type: none"> • Would seek services at hospice (2points). • Would like to be referred (1pt). • Could not be ashamed about the service(2pts) • Would share experience at hospice with others (2pts). • Would advise others seek the services (2pts) • Score at least 5to 9 out of 9 graded answers. 	17 to 28
	Negative	Scores 0 to 4 out of 9 questions,	17 to 28
Utilisation	Good utilisation (utilised before)	<ul style="list-style-type: none"> • Families with chronically/terminally ill patients who have sought services from a Hospice before. 	24 to 35
	Poor utilisation (not utilised before)	<ul style="list-style-type: none"> • Families who never sought services from a hospice. 	

Stigma	Yes	<ul style="list-style-type: none"> • Feel ashamed and embarrassed to access the services at hospice, because of what an individual feels about a disease. 	Questions 18 and 19
	No	<ul style="list-style-type: none"> • Not ashamed and embarrassed to seek the services 	
Religious affiliation	Catholics	<ul style="list-style-type: none"> • Member of the Roman Catholic congregation. 	Questions 6 and 7
	Non Catholics	<ul style="list-style-type: none"> • Not a member of the Catholic congregation. 	
Education attainment	High education attainment	<ul style="list-style-type: none"> • Tertiary education for example College and University. 	Question 5
	Medium	<ul style="list-style-type: none"> • Secondary education Grade 8 to 12 	
	Low	<ul style="list-style-type: none"> • Primary education for example grade 1 to 7. 	
	None	<ul style="list-style-type: none"> • Never been to school 	

CHAPTER 2.

2.0 LITERATURE REVIEW.

2.1 INTRODUCTION.

Hospice services play an important role in the provision of care to the chronically and terminally ill patients. This is a world wide practice and therefore, in this literature review discussion will be concentrated on studies done on knowledge, attitude and utilisation of hospice as well as some related studies.

It is estimated that 60% of dying people could benefit from some form of palliative care (Wright, 2003). Many families have chronic and terminal illnesses among their midst who need hospice services or palliative care. However, people could only decide to utilise these services if they have knowledge about there availability, benefits and have developed a positive attitude towards the services. It has been noted that only a small minority dying people ever receive the support of hospice and palliative care services. Wright (2003) reported that, the developing countries of the world have two thirds of the global disease burden, but only 5% of the world's resources. The developing countries may benefit from hospice services if stake holders could put their heads together, and see how best they could enhance the knowledge of local people on the services; this may improve their attitudes towards the service and eventually increase the utilisation.

The purpose of this literature review is to learn from what other researchers have reported on knowledge, attitudes and utilisation of hospice services and other related areas. The sources of this information mostly are pubmed on the internet, unpublished work from the school of medicine, University of Zambia library, some articles news letters and magazines. The review will be discussed under global, regional and national perspectives.

2.2 GLOBAL PERSPECTIVE.

Many countries world over especially the developed ones have well developed health care systems, which incorporates hospice service and palliative care. Mayo (2006) narrated that not until the 20th century, most people spent their last days at home, surrounded, cared for, and comforted by family and friends. The tradition faded as Hospitals became places for treating in many western countries, although hospice care began in England as an inpatient

facility. In the United States people usually receive hospice care at home, because most American prefers to spend their last days with their families (Mayo, 2006).

There are certain barriers to effective utilisation of hospice services world over. Freeman and Payne (2000) studied on the barriers to utilisation of hospice and palliative care services. They noted the unequal access to care in general or a lack of access to palliative and end-of-life care services. They further observed that few physicians know about palliative care alternatives, so they do not advise their clients adequately. They went on to report that the African-American community lack knowledge on benefits associated with end-of-life health care needs. The failure to address specific cultural and spiritual needs of patients that may not be articulated well by the patient and family, could also contribute to underutilisation of these services. If families with patients have access to the hospice services, and health workers effectively advise them on benefits, the families may become knowledgeable and utilise the services to the fullest.

It is a well known fact that apart from the unequal access mentioned above as barriers to effective utilisation of hospice services, there also other factors. Crawley et al (2000), noted that historical and societal factors also contributed to under utilisation of hospice and palliative care in the African-American community. They attribute this to abuses they suffered during slavery and its aftermath, which resulted in poorer management of diseases and more reliance on alternative or folk medicine. Added to this history are the recent reports of unequal treatment or mistrust and denial of best practices in the health care system as illustrated by Freeman and Payne (2000). Such documentation indicates that mistrust reported by African-American about the United States of America health care system is well founded in many instances. Payne also reports that African-American tends to have a higher incidence of violent deaths and higher death rates from cancer, AIDS, and other related chronic illnesses. He further suggested that it was imperative to have these communities be educated about palliative care and end-of-life preparatory issues. When an element of mistrust exist among the consumers of this service, counseling and information, education, communication could help in creating a good rapport, later an understanding of the situation and services that are there to offer support and care. People involved in providing this service should not show any sign of racial discrimination as this may bring back memories of abuses among the families. This may contribute to the development of negative attitudes towards hospice services.

Knowledge on the Hospice also plays a fundamental role in the effective utilisation of hospice services. Doorenbos (2003) conducted a study on the Asian Indian immigrant population to determine why they have not been served by Hospice. He used a descriptive correlation design with a sample of 43 subjects. He reported that most of the Asian Indian had limited or no knowledge of Hospice. It was established that financial resources were not a barrier to utilisation of hospice service because other such services may be subsidised by the state. Cultural differences related to death and dying rituals were misunderstood by the hospice staff. He suggested that there was need to increase knowledge of hospice service among the Asian Indian population. It is a responsibility of all health workers to adequately impart knowledge of hospice services on to the families, and they should understand the cultural beliefs of clients receiving the services to prevent misunderstandings. Otherwise, this misunderstanding of culture related to death and dying rituals by health workers could lead to development of negative attitudes and consequent underutilisation of the services.

Lack of awareness may also affect Hospice utilisation just like inadequate knowledge on the services. In the study conducted by Born et al (2003), they determined knowledge, attitudes and beliefs about end-of-life care among inter-city African American and Latinos in Kansas United States of America. The objective of the study was to explore end-of-life care preferences and barriers among low income, urban African-American and Latino/Hispanic American, to uncover factors that may influence hospice utilisation. They reported similar results across the two groups. Both preferred having families provide care for loved ones but expressed desire for respite care. The two groups emphasised spirituality as the primary means of coping and valued the holistic wellbeing of the patient and family. Participants reported low utilisation because of lack of awareness of hospice and the prohibitive cost of health care. In all health services, family involvement is fundamental and it should be encouraged in the care of their relatives, this increases awareness and develops that sense of togetherness in the care.

In Australia, a study was conducted by the National Palliative Care Programme for the Australian Government Department of Health and Aging to establish the community attitudes towards palliative care in 2006. They used both qualitative and quantitative methods, focus group discussion and in-depth interviews. The findings indicated that;

- a) Majority of the people were aware about the service and information was everywhere that is on print and electronic Medias.
- b) People had knowledge on location and service, although not specific to the aspect of care.
- c) Providers of care perceived the community knowledge to be lower than was actually demonstrated by the community.
- d) The older and those with patients had high knowledge of the services.
- e) There were no major differences in terms of locality, be it rural or urban areas.
- f) Australians held very positive attitude towards palliative care etc.

This study suggests that, the interaction that care givers may have with relatives, should be utilised to the fullest so that they could share with others their experience in the communities. If these services are widely distributed both in urban and rural areas, people would be knowledgeable in almost the same way. We should also remember that people appreciate good services, and this helps them to develop positive attitudes towards the service. It is our responsibility to sensitize communities about the services if they are to utilise them.

In Thailand, Daud (1998) conducted a cross sectional study to determine knowledge and attitude of family members in accepting home based care and hospice service for HIV/AIDS in Thongphapoom District, Kanchanaburi Province. A sample of 165 adult family members aged 20 to 70years was recruited in the study. The findings showed that more than half (55.8%) had good knowledge of home based care and hospice service for HIV/AIDS, and 55.2% had positive attitudes towards Home Based Care and Hospice service. He therefore concluded that there was a relationship between knowledge and acceptance of home care and hospice service. 'Knowledge is power', it is practically impossible to accept something that you do not know or understand. If families are knowledgeable about the services, once an opportunity to utilise it presents, they do so with both hands and open hearts.

2.3 REGIONAL PERSPECTIVE.

Hospice and palliative care services in Africa has not been fully utilised. This may be attributed to low knowledge levels among families and possible negative attitudes toward the services. With the increased cases of chronic and terminal conditions in hospitals and homes, people- deserve to know the benefits of the above services. Clark and Wright

(2003) argue that health issues in Africa are first, compounded by the impact of poverty, population growth and HIV/AIDS pandemic. They also observed that Africa is the most affected region and about 20 million deaths have been linked to the disease. In Africa there are inadequate studies specifically on knowledge, attitudes and utilisation of hospice services.

In Swaziland there is no different history in the development of hospice services (WHO, 2001). It was established by Stephanie Wyer a former Macmillan Nurse from Wales. She established Swaziland Hospice at home in 1990. This is what she wrote when founded a hospice and I quote *“we used the media; and we had been on TV, Radio and we had an awful lot of help from all over. The people of Swaziland were very interested and I was invited to go out and give some talks about what I was doing and why”*. Sensitisation of the community is essential if people’s attitudes towards hospice care are to be acceptable and if people are to be knowledgeable about the services offered, as well as the impact on the life of the patient and family (Wyer, 2003). The tools used by Wyer in making the community knowledgeable are so powerful in information dissemination, which should be used by all those who wish to make this programme a success. Once the community is sensitized, there is no way that they could give a blind ear to health related matters.

In Africa lack of knowledge on the Hospice service has an influence on the utilisation of the services. In a study conducted by Adenipekun et al (2005), whose objective was to assess the knowledge and attitudes of patients and their relations to palliative and hospice services and to fashion out appropriate services for the patients in Nigeria. They had a sample of 130 of which 69 were patients and 61 family members. They reported that 72.3% had no knowledge of palliative care and hospice regardless of the level of education and social status, 84% agreed that symptoms of the terminally ill patients should be treated to improve their quality of life and 75% of the respondents agreed that this could be better done in a Hospice, 83% respondents desired to have hospice established in every community. In conclusion, it was established that there was gross lack of knowledge about palliative care and hospice services. However, there was a positive attitude towards hospice and palliative care suggesting a general acceptance of the services. Sometimes it could be taken for granted by health workers that when people are educated, then they know about all health related matters, this study revealed lack of knowledge among

educated people in Nigeria. This tells us that dissemination of information on hospice services should target the general public regardless of their education attainments.

Family or patient attitudes are not the only factors that may influence utilisation of hospice services but community attitude as well. Another related study in Kenya by Olenja (2004) assessed the community attitude towards Home Based Care for people with AIDS. Olenja (2004) established that due to inadequate information about the disease and care expectations, people were uncertain toward the sick and some instances outright rejection prevailed. He further observed that, this formed the basis for their preference for institutional based care as opposed to home based care. This was further compounded by the economic difficulties of the families. He also observed the need to initially share the issue with the community in order to work out mechanisms that would lessen the burden of, and facilitate home care. If people are to be imparted with the right knowledge they would change their attitude towards care of relatives and services offered to the clients.

Apart from community or family attitude towards hospice services, distance to service area may also affect the utilisation of the services. In Uganda, according to Foley et al (2000), 88% of the population live more than 10km away from any kind of health facility, and many of these facilities lacks trained personnel and the most basic medical supplies and medicine. They also stressed the importance of basic facility, professional staff in the effective delivery of hospice services. When consumers of health service accessing the service, receive unsatisfactory services this could lead to development of negative attitudes and underutilisation.

In South Africa, the Department of South Africa, South Coast Hospice (1999), observed that through out Africa, model programmes are demonstrating the benefits of integration of hospice, community and home based care for people with HIV/AIDS. They showed that people with chronic diseases are cared for in the community by nurses and trained health care givers in their own homes. People with HIV/AIDS and their families are cared for in their immediate communities with help from outside agencies by health care professions who are committed to implement palliative care. They further stated that people of these communities utilise the services effectively and people have adequate knowledge of hospice because of the presence of the service within their communities.

2.4 NATIONAL PERSPECTIVE.

The development of Hospice care or Palliative care in Zambia is not different from the rest of Africa, in terms of people who first saw the need to have such services available. The Faith Based Organisations, to be specific the Roman Catholic Church, but these services are said to be open to anyone of any or without faith (Smarzoch, 2007). In Zambia, very few studies have been conducted and not specifically to determine the knowledge level, attitudes and utilisation of hospice service by family members with chronically and terminally ill patients.

Family and patients attitudes have been singled out at national level just like it was in the region. Muliwana (1993) carried out a descriptive explorative non experimental study in Lusaka whose objectives were to determine the attitudes of HIV/AIDS patients and families towards the establishment of hospice for HIV/AIDS patients. She reported that the majority welcomed hospice establishment. She also observed that 56.7% were willing to take their ill relatives to a Hospice centre. On utilisation, she reported that, age groups mostly likely to utilise the service were between 26 – 30 years, followed by those above 40 years. She further reported that 30% of respondents were not for the idea of taking their relatives to a hospice as it would appear like giving up or isolating their relatives. When introducing this service in the community, the cultural aspect and family values should be taken in to consideration if positive attitudes are to be fostered. It is encouraging to note the age range, that was reported most likely to utilise the services as it is the one most affected by the chronic diseases in Lusaka District.

Some of the determinate to hospice utilisation in Lusaka are to do with ineffective referral system. Nota and Shalunga (2001) who determined the use of hospice among terminally ill patients in Lusaka, Zambia: a high HIV prevalence and resource limited setting. The main issues in the study were determinants of hospice and community home based care service uptake, and factors that disadvantage terminally ill patients from accessing and utilising hospice and home based care services. In this study, it was reported that patients are referred to a hospice for a number of reasons such as:

➤ Home Based Care Centres refers patients who have no carers at home and also as a way to relieve the families from the burden of looking after patients in these disadvantaged communities.

- Public and Private health institutions refer patients as way of decongesting these places and create room for patients with manageable conditions.
- Various other groups and individuals refer patients because they believe that these patients would receive the best medical care at a hospice.

The study also revealed that, the role of hospice as a place where terminally ill patients can choose as a place of end-of-life care has changed to that of diagnosing and caring for patients with adequate resources but do not want to be seen in public or private health institutions. They further reported that those terminally ill patients from families without sufficient resources who require intensive nursing care end up disadvantaged. The referral system that is used by the home based carers influences the utilisation and it is difficult to conclude whether the clients' attitudes towards the service are positive or not.

Mukombo (2003) determined the role of a hospice in a high Tuberculosis (TB) and HIV prevalence area in Lusaka. The findings were that different home based care centres refer patients to a hospice who are already on TB treatment or diagnosed in a hospice. A number of patients with chronic cough end up being diagnosed with TB at a hospice at a late stage of their disease. This showed an increased utilisation of hospice among TB patients. Eventually, concluded that lack of proper screening facilities by referring Home Based Care and difficulties in accessing health care facility leads to patients ending up in a hospice before diagnosis is made. Even the issue that was apparent in the study by Nota and Shalunga (2001) of HBC referring patients without carer at home. This shows some of the challenges HBCs are facing in the community in ensuring that hospices are used for the intended purposes. HBC should be empowered with basic screening equipment, so that patients with curable conditions could be diagnosed and correctly referred for treatment at the hospitals instead of hospices.

There are other factors that influence nature of terminal illness that determines the utilisation of hospice services. Clarke (2004) conducted a study in Lusaka whose aims were to establish the factors which influence the nature of terminal care. Whether the nature of the terminal illness reported with chronic wasting condition are more likely to be discharged from the hospital to receive home terminal care and utilises the hospice service. It was reported that patients with more treatable infections are more likely to die in hospital. Low hospital bed capacity lead to a greater likelihood for home care once discharged, especially among patients with wasting conditions, may have an influence on

hospice utilisation. An increased cost of care will force patients to receive home care and hospice service. Treatment availability is a mediating factor in determining if hospital care is warranted. The longer the patient has been identified as HIV positive, the more likely they will receive and utilise home terminal care and hospice service. This, in a way has contributed to negative attitude by other families towards hospice service.

For a hospice service to be successful and appreciated there must be community and family involvement. Thomas (2003) observed the important lessons that have been learnt from the development of hospice and palliative care in Zambia and elsewhere. The volunteers in the community have been extremely effective in providing care for people in their homes. Volunteers act as important community based platform and entry point from which other services can be delivered. This leads to the linking of hospices and hospitals with communities and families, in helping to reduce pressure on health care system. These community health workers educate families there by increasing their knowledge levels about palliative and hospice service. Thomas further reported that good quality care is not only welcomed by many people living with AIDS and influence their positive attitudes, but also allows for better allocation of resources through out the health system. This could improve overall standards of care. Once standards have been improved upon, utilisation also increases. He also argued that, by involving families and communities, it helps them to change their attitudes towards stigmatised diseases, and services put forward to mitigate such sufferings from diseases. This could increase the knowledge and reduce fear as well as stigmatisation. For the families to develop positive attitudes towards hospice services, health professionals and any other health workers involved in the service must have a positive attitude to the service he/she offers, if communities are to follow suit.

2.5 CONCLUSION.

Literature review has shown that studies have been done on a hospice and palliative care globally, regionally as well as nationally. In all the three perspectives, it has been shown that knowledge and attitude influences the utilisation of hospice services. There also other barriers to hospice utilisation like cultural practices, mistrust and financial constraints in some aspects. However, in most of the studies reviewed, it has been shown that through out the world people seem to have accepted and welcomed the concept of hospice service. The majority have positive attitude especially at international level. What should be emphasised more is information dissemination for people to become knowledgeable on the

use of the Hospices. Lack of knowledge has been pointed out especially at regional and local perspectives. The Hospices should be used for the right purpose but this again depends on availability of basic health care services in the communities. However, Hospices in the developing countries face a lot of challenges, such as, those people who access the services for unintended purposes, for example TB patients who could be treated and cured in an ordinary hospital. Nevertheless, they could not be denied the service once there because they are poor. Zambia is not an exception where the majority of people live below poverty datum line (CSO, 2003).

CHAPTER 3

3.0 RESEARCH METHODOLOGY

3.1 INTRODUCTION

Research methodology is the method or technique used by the scientist to collect data, to use statistical manipulation and to arrive at a logical conclusion. Research methodology can be defined as steps, procedures and strategies for gathering and analyzing data in a research investigation (Polit and Hungler, 2001).

The study determined the knowledge, attitude and utilisation of hospice care services by families with chronically and terminally ill patients in Lusaka District. Simple random sampling was used in the study, which is one of the probability sampling designs that gave a chance to all subjects to be picked.

3.2 RESEARCH DESIGN

A research design is defined as a plan of the proposed research work (Treece and Treece, 1986). A descriptive non-interventional cross sectional research design was used. It aimed at quantifying the distribution of certain variables in a study population at one point in time, or the phenomena which was knowledge, attitude and utilisation of hospice services. The reason for cross sectional study design was to collect data from a large group of families with chronically and terminally ill patients. The design covered physical characteristics of people, social-economic characteristics of people such as age, sex, education, marital status; and occupation. The study described in detail the knowledge, attitudes and utilisation of hospice service by families with chronically and terminally ill patients, which would help to explain the research question. In a descriptive study the researcher observes, describes and document aspects of the situation such as knowledge, attitudes and utilisation. The design was chosen to quantify the knowledge, attitude and utilisation of hospice services, and it was found appropriate for this study because it did not make any manipulations thus reporting the problem as it was.

3.3 RESEARCH SETTING.

The study was conducted at the University Teaching Hospital, the largest hospital in the country located in Lusaka District. The two health centres that were included in the study are Kalingalinga and Chawama. Lusaka District is one of the four districts in Lusaka

Province, it has a population of approximately 1.1 million (Central Statistical Office, 2003).

The University Teaching Hospital is situated along Nationalist road in Lusaka and is the only national tertiary referral hospital. Due to the absence of a district and provincial hospital, UTH provides 1st, 2nd and 3rd level health care services, it covers an area of half kilometers (80 hectares) of land and manned by 3000 medical personnel (CBoH, 2002). UTH is not only a national referral hospital but also functions as a provincial and district hospital servicing five districts namely Kafue, Chongwe, Luangwa, Mumbwa and Lusaka Districts with an estimated 3 million catchment population. The hospital has a bed capacity of 1800 with the adult medical-surgical covering approximately 432 beds (CBoH, 2002).

Chawama Health Centre is in Chawama Community a peri urban area located about 5 kilometers south of Lusaka town centre along Kafue road. The health centre is located deep within the community and it serves a population of about 100, 000 (CBoH, 2002). It shares boundaries with three (3) other Health Centres which have been described as Lusaka District Health Management Team sub-Districts. The nearest referral hospital is University Teaching Hospital (UTH) which is about 10km from the Health Centre and is accessible by tarred road.

Kalingalinga Community is also a peri urban area, located 12km east of Lusaka from town centre. It is surrounded by both low and medium density residential areas. The health centre is located in the western part of the community along Alick Nkhata road near Total filling station. The health centre has a catchment population of approximately 80 000 (CBoH, 2002). The nearest referral hospital is University Teaching Hospital (UTH) which is about 7km from the health centre and is accessible by tarred road.

3.4 STUDY POPULATION.

Dempsey and Dempsey (2000) define the study population as a population on whom information can be obtained from. The target population in the study comprised any family member (one) at the bedside of a patient with chronic and terminal illness, admitted at the University Teaching Hospital, Kalingalinga and Chawama Health Centres. Family members were chosen because they are involved in decision making, when a member of the family is ill. They offer psychosocial support, provide financial assistance especially

when the family is advised to buy certain drugs that may be out of stock in the health institutions and when patient is put on special diet.

3.5 SAMPLE SELECTION.

Sample selection is a process of selecting a number of individuals from the delineated target population in such a way that individuals in a sample represent as nearly as possible the characteristics of the entire target population (Dempsey and Dempsey, 2000). This is a fundamental part of the research process because the section sample must be representative of the entire units under study.

The selection of the three sites above was through a non-probability sampling method known as purposive sampling. According to Polit and Hungler (2001) purposive sampling is a method in which the researcher selects the units for the study on the basis of personal judgment about which one will be most representative. In addition, the selection was by design and choice not by chance. The study used purposive sampling because there was good evidence in the institutions that they were representative of the total population in the district it studied. UTH has the largest catchment area, it offers curative and palliative services to the general public. Kalingalinga and Chawama catchment areas are also large and they offer curative and palliative services as well to patients with different chronic and terminal conditions. Some special group were selected i.e. relatives for patients with chronic and terminal illnesses, this was determined based on clinical appearance as well as duration of the illness.

In selecting the study sample, simple random sampling technique was used, which is one of the probability sampling methods. A sampling frame was established comprising each family member at the bedside of a patient with chronic and terminal illness, receiving curative or palliative care services at respective health institutions. The family members were chosen from the listed sampling frame in such a way as to accord every family the equal chance of being selected. The selection was entirely objective and free from personal prejudice. It was done by giving numbers written on slips of paper and put in a box. Then the slips were mixed carefully by shaking the box and the desired number for that day would be picked from the box for sampling (lottery technique). The sampling was conducted on any days of the visits at various sites, until the targeted sample of fifty (50) respondents was reached. At the University Teaching Hospital 30 respondents were

selected because of its vast catchment population. Then 10 were selected from Kalingalinga Health Centre and 10 from Chawama Health Centre.

3.6 SAMPLE SIZE.

A sample size is the total number of subjects to represent the population under study (Polit and Hungler, 2001). A sample is a subset of a population. In this study, a total of fifty (50) respondents were picked, that is each family member of a patient with chronic and terminal illness at the bedside comprised the sample. The respondents were 20 years old and above. The reasons for selecting that size included limited time as well as scarce resources, both material and monetary.

3.7 DATA COLLECTION TOOL

A data collection tool is a measuring device used in gathering of information needed to address a research problem (Polit and Hungler, 2001). The structured interview schedule was used. This tool was used because it is suitable for both illiterate and literate family members. The schedule contained four sections and in section one, demographic characteristics of research subjects were established. Some of the variables that were measured were age, sex, income, level of education etc. These variables helped the to understand the characteristics of subjects understudy. In the second section, there was information on knowledge of hospice, e.g. such as, what is hospice? Purposes and diseases that are supposed to be admitted in a hospice were asked etc. In section three, the variable measured was attitude; questions such as how they felt about hospice were asked. In section four, questions were on utilisation to try and establish whether they have ever used the services. It did not take time to organise respondents and they were asked same question in the same sequence.

3.7.1 Validity

Validity is the degree to which an instrument measures what it is supposed to be measuring (Basson and Uyus, 2000). Validity constitutes the external and internal validity. Internal validity concerns the extent to which conclusions can be drawn about the effects of one variable on another. The validity of instruments used in the study was guaranteed by making questions straightforward, concise, to the point and brief. External validity is concerned with the extent to which research findings can be widespread beyond the sample of research tested. In this study, validity was determined by ensuring that, the instrument

consisted of questions on each variable to be measured. The questions in the schedule were checked by my supervisor to see if responses could be brought out on variables to be measured. The instrument was pre tested to determine if the desired information could be attained. Pre testing the instrument assisted to eliminate needless questions and necessary amendments were done accordingly.

3.7.2 Reliability

Reliability is the degree of consistency or accuracy with which an instrument measures the attributes it is designed to measure (Basson and Uyus, 2000). The results from the pilot study or pre test study were used as base line data to test reliability. By administering the same schedule through out the study biases were eliminated. Reliability of the instrument was measured by conducting a pre test study. During this phase respondents were interviewed in order to identify vagueness of the questions and problems with understanding were clarified. Pre-tested questions yielded similar results when compared with the main or actual study.

3.8 DATA COLLECTION TECHNIQUES.

Data collection technique is the actual method on how the data is going to be collected (Polit and Hungler, 2001). It allows for systematic collection of information from respondents. In this study data was collected by structured interviews in a private room. To minimize some of the limitations of interviewing, it was necessary to establish a rapport with the respondents. Before the interview, personal introduction was necessary and verbal permission was sought from respondents after explaining the objectives of the study carefully and reassured of confidentiality and privacy. Those who agreed to participate were recruited in the study. Privacy was provided by use of the Unit or Ward Sisters' Office and confidentiality was put in place by making sure that information was not released to anyone not involved in the research, and by use of serial numbers instead of respondents' names that could make it difficult even for the investigator to relate responses to actual respondents. The questions were asked and followed as they were listed down on the interview schedule. Since an interview is a verbal face to face communication between two people, the interviewer was able to clarify or rephrase questions which were not clear to the respondents. The interview schedule also gave chance to the interviewer to probe for more answers. The interviewer entered the responses as given by the respondents on the schedule. Each respondent was given ample time to give their response which were ticked

or written down against the asked questions. At the end of the interview, the investigator went through the interview schedules to check for consistency in the answers given and for completeness of the interview schedule. The respondents were also given a chance to comment, ask for clarification, and suggest a way forward according to their opinion but relating them to the asked questions. The researcher thanked the respondents for taking part in the study.

3.9 PILOT STUDY.

Pilot study is a small version of the actual study conducted with the purpose of testing and potentially refining the research plan (Dempsey and Dempsey, 2000). The reasons for the pilot/pre test study were to find out how feasible the study would be, and how valid and reliable the data collection tool would be. This helped determine how possible it could be to analyse the data collected. It also enabled necessary adjustments to be undertaken to the data collecting instrument before the main study was carried out. The pilot/pre test study was carried out in the gynaecology ward from families with chronically ill and terminally ill patients, who had similar characteristics as those in the main study. The pilot/pre test study was conducted on 10% of 50 sample size ($10\% \text{ of } 50 = 5$).

3.10 ETHICAL AND CULTURAL CONSIDERATIONS.

Ethical consideration involves an understanding of the ethical code and guidelines for protecting the rights of the research subjects (Dempsey and Dempsey, 2000). When humans are used as research subject, great care is exercised to ensure that their rights are protected. Before conducting the study written permission from UTH Management, the Lusaka District Director of Health and respective health centre's In-Charges were obtained. Permission was also requested from the UTH Manager/Sister in charge of Gynaecology ward to carry out a pilot/pre test study. The purpose and nature of the study was explained to the subjects and all the respondents' request was made verbally upon agreeing to participate in the study. The respondent's opinions were respected and no one was forced to be part of the study. Respondents were further assured of confidentiality and anonymity by using only serial numbers on the schedule and not their names. Asking for permission from management was important because it facilitated cooperation and prevented unnecessary conflicts from authorities and promoted smooth conduct of the study. The schedule was kept in such a way that no one else would have access to them. They were kept under lock and key.

CHAPTER FOUR

4.0 DATA ANALYSIS AND PRESENTATION OF FINDINGS

4.1 INTRODUCTION

The purpose of this chapter is to present information on how the research data were analysed and what information was obtained. Data was collected from 50 families with chronically and terminally ill patients in Lusaka District. The aim of the study was to determine knowledge, attitude and utilisation of hospice services by families with chronically and terminally ill patients at the University Teaching Hospital, Kalingalinga and Chawama Health Centres in Lusaka District. The data was collected by use of a semi-structured interview schedule.

4.2 DATA ANALYSIS

Data analysis is the process of categorizing, scrutinizing and cross-checking the research data (Treece and Treece, 1986). Data can only be useful when arranged in a meaningful manner, in order to be able to derive patterns of relationships (Polit and Hungler, 2001).

Data was collected using a semi-structured interview schedule. The data was sorted, edited for completeness and recorded on each interview schedule. Responses to closed-ended questions were coded using numbers, and open-ended responses were categorized and coded. Data was processed manually and entered on a data master sheet. Data was analysed using a scientific calculator and frequency counts.

4.3 PRESENTATION OF FINDINGS

The findings of the study have been presented in frequency tables, pie charts, bar graphs and histograms. The frequency tables summarised the results of the study to ensure that the readers understand the findings of the research study. The use of pie charts and graphs in the presentation of findings makes the work neat, presentable and easy to read by the reader. Cross tabulations of the variables help to show clearly the relationship between variables and enable the researcher to draw meaningful inferences. The findings from this study are presented according to the sequence and sections in the interview schedule i.e. demographic data, knowledge of hospice, attitudes towards hospice service and utilisation of hospice services.

4.3.1 SECTION 1: SOCIAL DEMOGRAPHIC DATA

Table 2: Distribution of Social Demographic characteristics of respondents.

Variables	Frequency	Percentage
Location of a study		
UTH	30	60
Chawama Clinic	10	20
Kalingalinga Clinic	10	20
Total	50	100
Sex		
Male	16	32
Female	34	68
Total	50	100
Age range		
20 - 25	6	12
26 - 35	18	36
36 - 45	18	36
Above 46	8	16
Total	50	100
Marital Status		
Single	7	14
Married	33	66
Widowed	8	16
Separated	1	2
Divorced	1	2
Total	50	100

Variables	Frequency	Percentage
Occupation		
House Wife	4	8
Businessman	19	38
Formal Employment	7	14
Unemployed	20	40
Total	50	100
Residential area		
High Density	34	68
Medium Density	10	20
Low Density	6	12
Total	50	100
Education level		
None	7	14
Primary	19	38
Secondary	17	34
College	6	12
University	1	2
Total	50	100
Denomination		
Catholic	9	18
UCZ	7	14
RCZ	2	4
SDA	2	4
Pentecost	28	56
J. Witness	2	4
Total	50	100

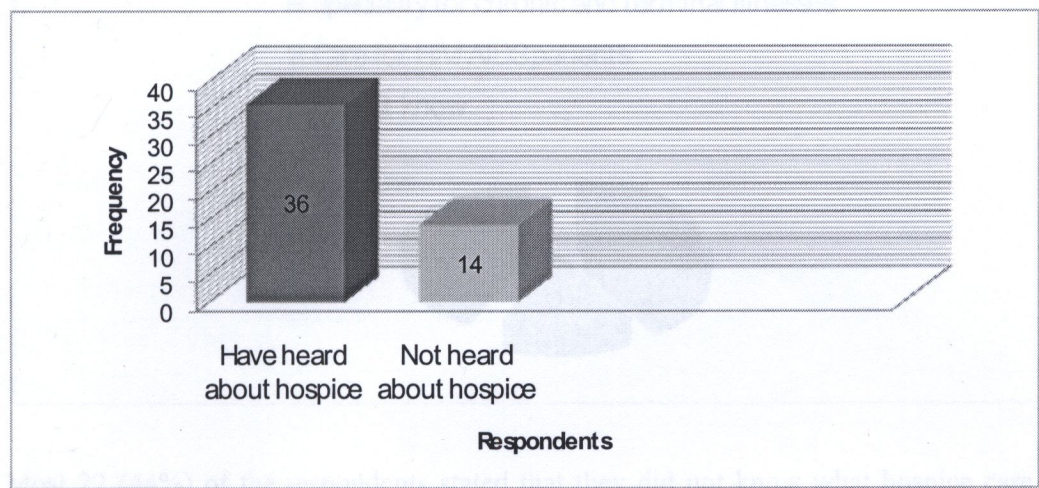
Variables	Frequency	Percentage
Family income per month		
< K100,000.00	5	10
Between K100,000.00 and K450,000.00	22	44
K450,000.00 and K750,000.00	3	6
>K750,000.00	10	20
Seasonal	4	8
None	6	12
Total	50	100
Duration of looking after ill relative		
<Two Weeks	6	12
3 – 4 Weeks	5	10
>A Month	39	78
Total	50	100

Table 2 shows the social demographic characteristics of respondents which included location of a study, sex, age, marital status, occupation, residential area, education level, denomination, income and duration of looking after ill relative. Majority of respondents were selected from UTH 30 (60%) while Kalingalinga and Chawama had 10 (20%) each. Majority 34 (68%) of the respondents were female. Most 18 (36%) of the respondents were aged 26-35 years and 36- 45 years. Majority 33 (66%) of the respondents were married, while 7 (14%) were single. In terms of employment, 20 (40%) were unemployed, 19 (38%) were in business, while 7 (14%) were in formal employment. The majority 34 (68%) of respondents were from high density areas, while 6 (12%) were from low density areas. Most 19 (38%) of the respondents had primary education, 7 (14%) had never been to school, while 7(14%) had tertially education. All 50 (100%) respondents were Christians. In terms of denomination majority 28 (56%) of the respondents were Pentecost Christians,

while 9(18%) were Catholics. Most 22 (44%) of the respondents reported that their monthly family income ranged between K100, 000.00 and K450, 000.00, while 6 (12%) reported no monthly income at all. Majority 39 (78%) of the respondents stated that they had looked after their patient for more than a month.

4.3.2 SECTION 2: KNOWLEDGE OF HOSPICE SERVICE.

Figure 2: Distribution of respondents’ response on whether they have heard about Hospice



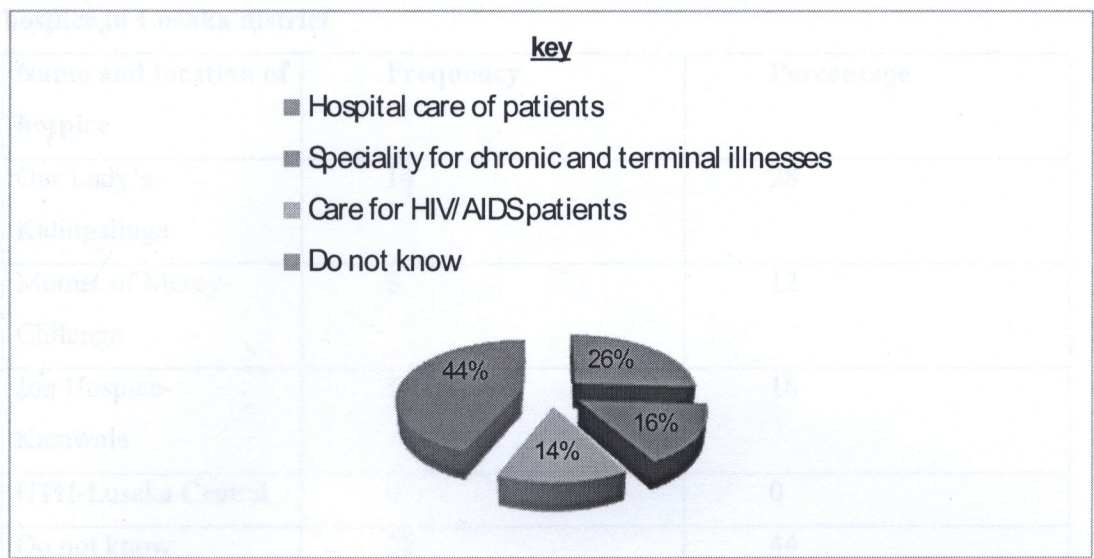
Majority 36 (72%) of the respondents reported that they had heard about hospice.

Table 3: Distribution of respondents’ source of information about Hospice. n=36

Source of information.	Frequency.	Percentage.
Church members	9	25
Friends	16	44
Hospital	3	8
Relatives	4	11
Media	1	3
Neighbour	1	3
Total.	36	100

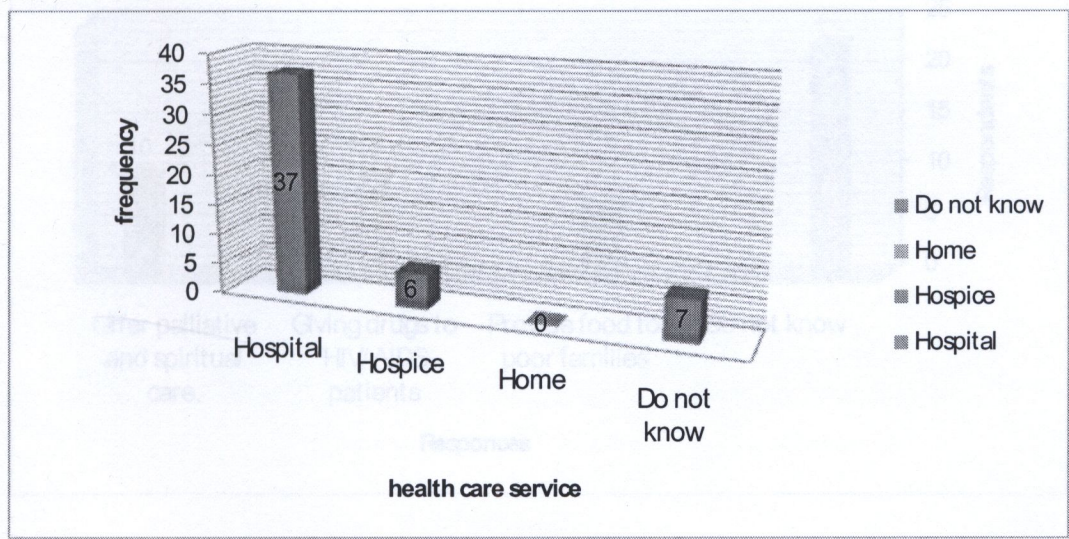
Most 16 (44%) of the respondents stated that they heard about hospice from friends, 9 (25%) from church members, while 3 (8%) stated that they heard about hospice from the hospital.

Figure 3: Distribution of respondents’ knowledge on definition of hospice care.



Most 22 (44%) of the respondents stated that they did not know what hospice care is, 8 (16%) stated that it was a speciality for the chronically and terminally ill patients, while 7 (14%) stated that it was care for HIV/AIDS patients.

Figure 4: Respondents’ knowledge on where the chronically and terminally ill are cared for.



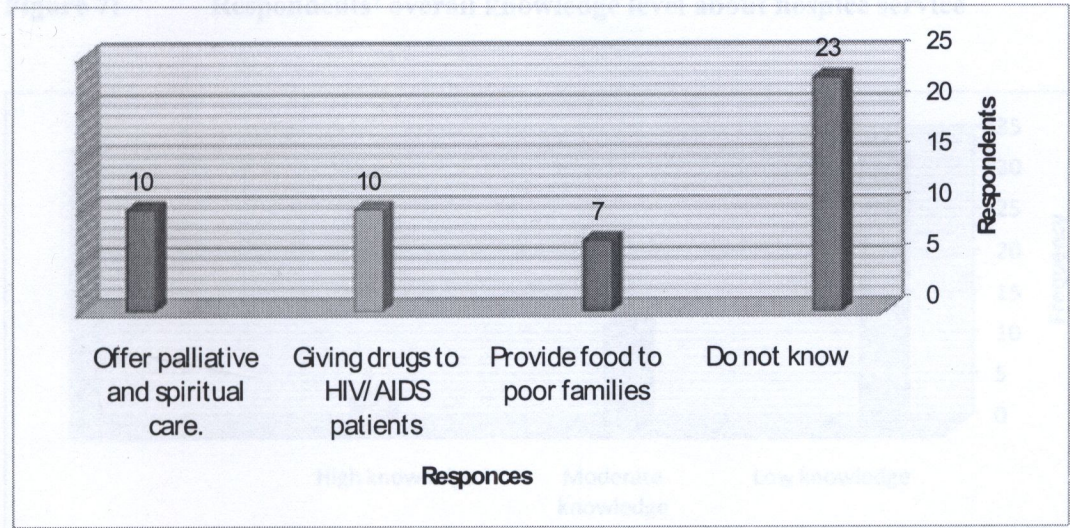
Majority 37 (74%) of the respondents stated that the chronically and terminally ill are cared for in the hospital, 6 (12%) stated that they are cared for in a hospice while, 7 (14%) stated that they did not know.

Table 4: Respondents’ responses on whether they know any name and location of hospice in Lusaka district

Name and location of hospice	Frequency	Percentage
Our Lady’s-Kalingalinga	14	28
Mother of Mercy-Chilanga	6	12
Jon Hospice-Kamwala	8	16
UTH-Lusaka Central	0	0
Do not know	22	44
Total	50	100

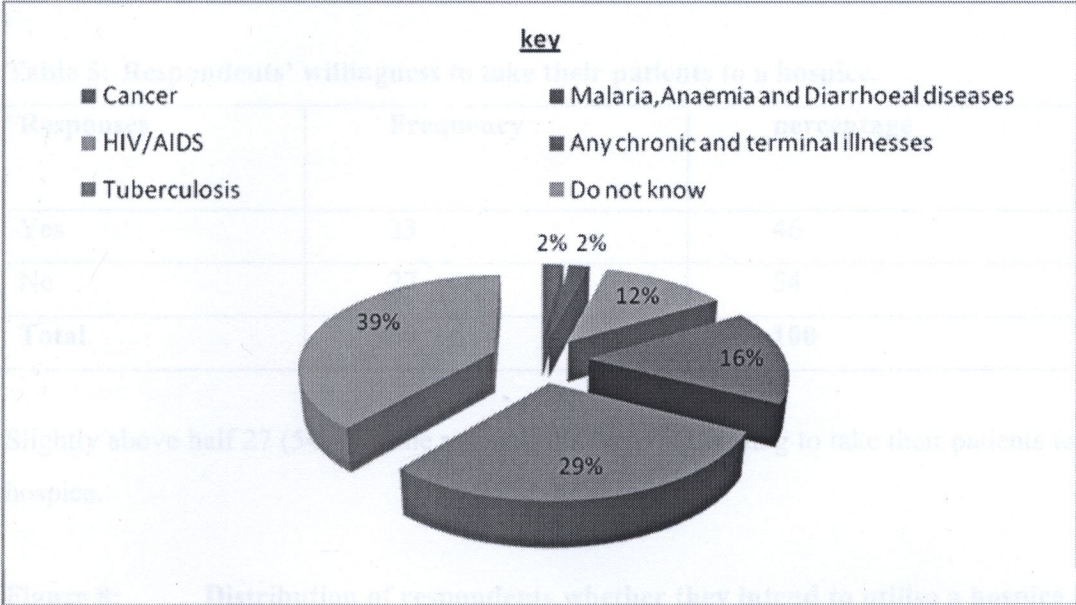
Most 22 (44%) of the respondents did not know the name and location of any hospice in Lusaka District, while 14 (28%) stated Lady of Mercy Hospice in Kalingalinga.

Figure 5: Respondents’ responses on whether they know the purpose of hospice



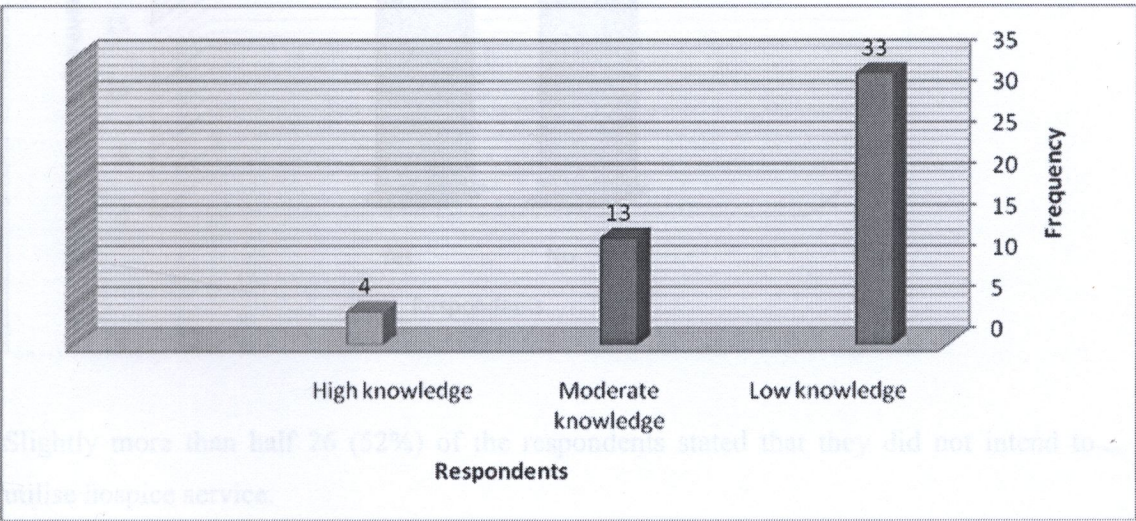
Most 23 (46%) of the respondents stated that they did not know the purpose of a hospice, while 10 (20%) stated that the purpose was to offer palliative and spiritual care.

Figure 6: Respondents’ knowledge of diseases that are nursed at a hospice.



Most 19 (39%) of the respondents stated that they did not know the diseases that are nursed at a hospice, 14 (29%) stated that it was Tuberculosis, while 8 (16%) stated that any chronic and terminal diseases are nursed at a hospice.

Figure 7: Respondents’ overall knowledge level about hospice service



Majority 33 (66%) of the respondents had low knowledge, 13 (26%) had moderate knowledge, while 4 (8%) had high knowledge of hospice.

4.3.3 SECTION 3: ATTITUDE TOWARDS HOSPICE SERVICE

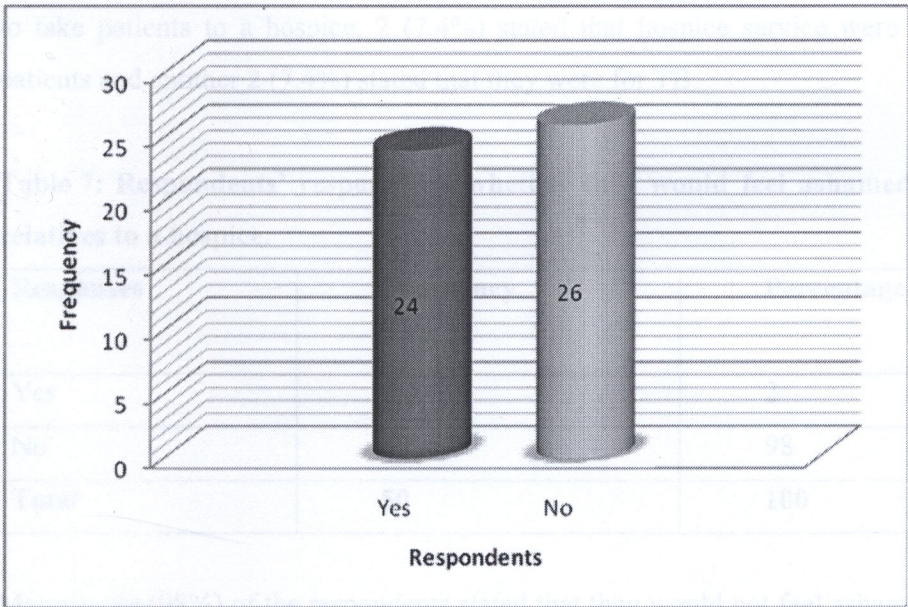
Table 5: Respondents’ willingness to take their patients to a hospice.

Responses	Frequency	percentage
Yes	23	46
No	27	54
Total	50	100

Slightly above half 27 (54%) of the respondents were not willing to take their patients to a hospice.

Figure 8: Distribution of respondents whether they intend to utilise a hospice in future.

n = 50



Slightly more than half 26 (52%) of the respondents stated that they did not intend to utilise hospice service.

Table 6: Respondents’ reasons for unwillingness to take patients to a hospice
n=27

Responses	Frequency	Percentage
Its for HIV/AIDS	2	7.4
Its for TB patients	2	7.4
For Catholics only	0	0
Lack of knowledge	22	81.5
Could manage at home	1	3.7
For poor families	0	0
Total.	27	100

Out of the 27 (54%) respondents who stated unwillingness to take patients to a hospice, majority 22 (81.5%) of them stated lack of knowledge as a reason for their unwillingness to take patients to a hospice, 2 (7.4%) stated that hospice service were for HIV/AIDS patients and another 2 (7.4%) stated that they were for TB.

Table 7: Respondents’ response on whether they would feel ashamed to take their relatives to a hospice.

Responses	Frequency	Percentage
Yes	1	2
No	49	98
Total	50	100

Majority 49 (98%) of the respondents stated that they would not feel ashamed to take their ill relatives to a hospice.

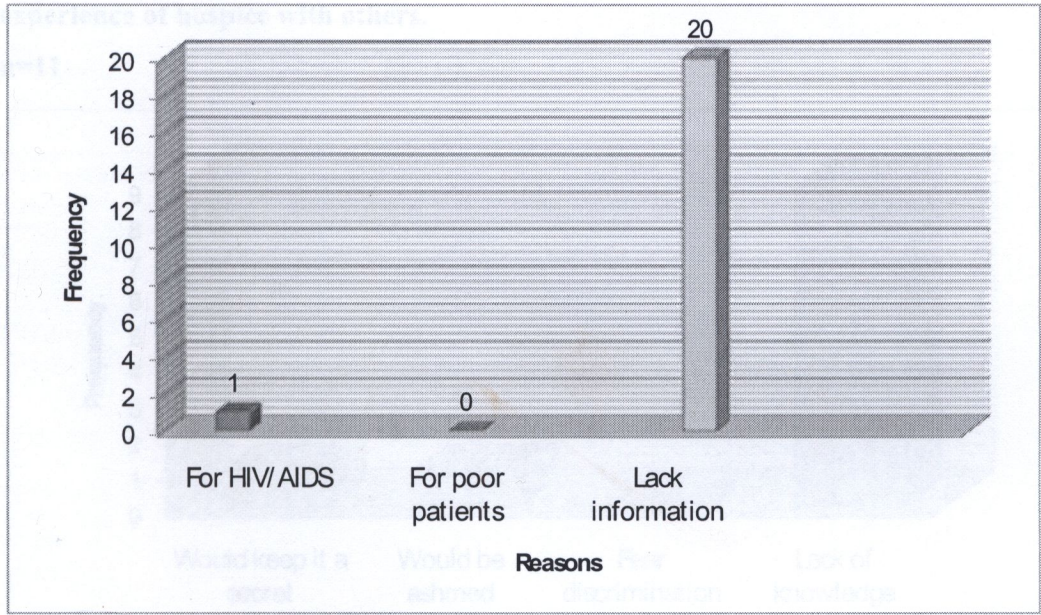
Table 8: Respondents’ responses on whether they would like to be taken to a hospice

Responses	Frequency	Percentage
Yes	29	58
No	21	42
Total	50	100

More than half 29 (58%) of the respondents stated that they would like to be taken to the hospice if they were chronically and terminally ill.

Figure 9: Reasons given by respondents’ who would not like to be taken to a hospice.

n=21



Majority 20 (95%) of the respondents who stated that they would not like to be taken to a hospice mentioned lack of information as a reason, while 1 (5%) stated that it was for HIV/AIDS patients.

Table 9: Respondents’ responses on whether they would share their experience at a Hospice to others.

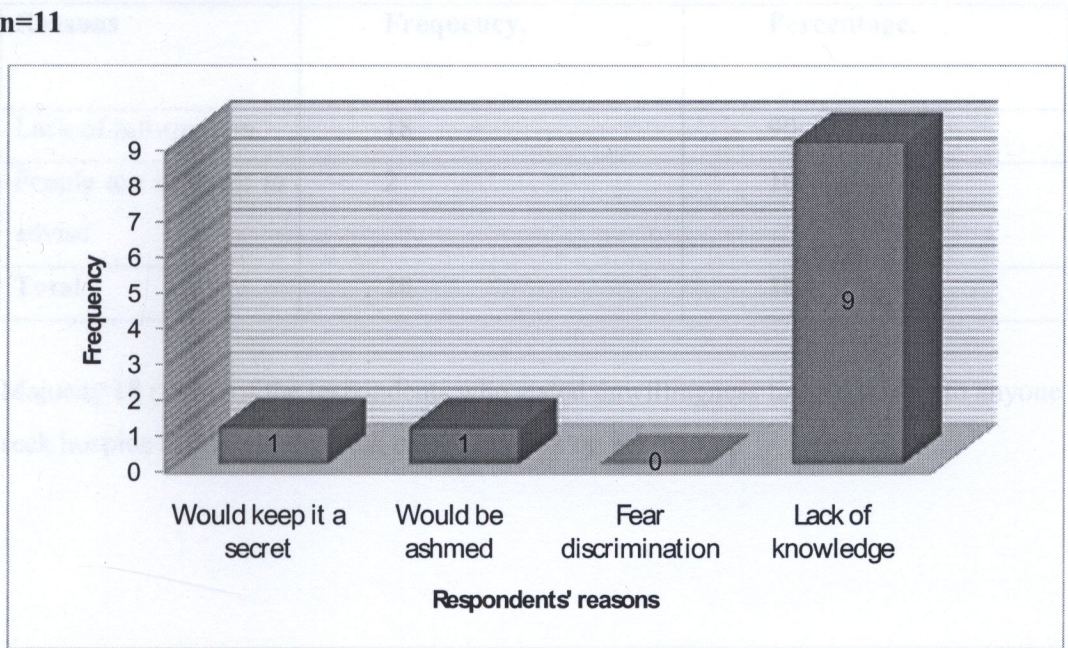
n=50

Responses	Frequency	Percentage
Yes	39	78
No	11	22
Total	50	100

Majority 39 (78%) of the respondents stated that they would share their experience at hospice with others.

Table 10: Respondents’ reasons for unwillingness to give advice to anyone at

Figure 10: Reasons given by respondents’ why they would not share their experience of hospice with others.



Majority 9 (81.8%) of the respondents who stated that they would not share their experience of hospice reported lack of knowledge as the reason, while 1 (9.1%) stated that they would be ashamed to share their experience with others.

Table 10: Respondents’ responses on whether they would give advice to others to seek hospice service **n=50**

Responses	Frequency	Percentage
Yes	30	60
No	20	40
Total	50	100

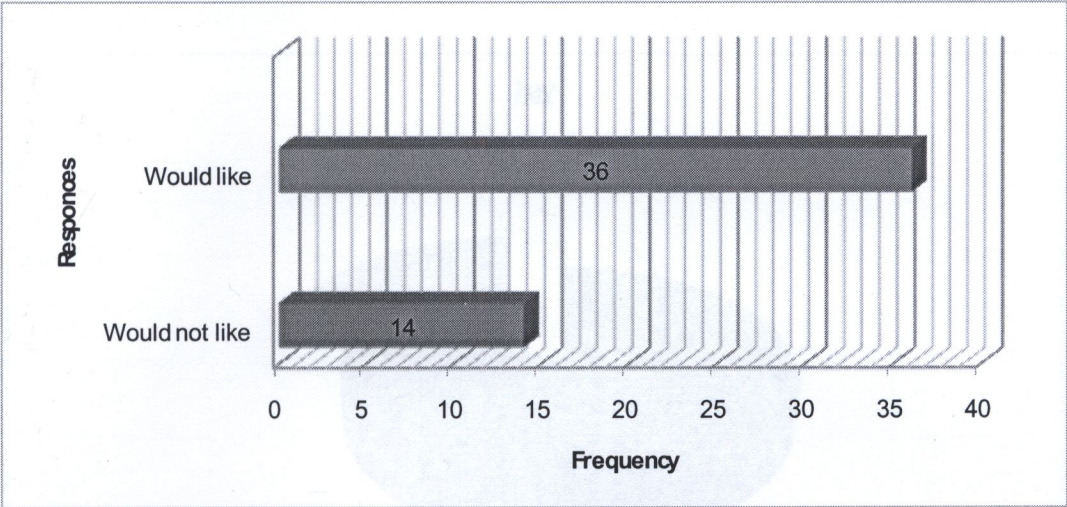
Majority 30 (60%) of the respondents stated that they would give advice to others to seek hospice service.

Table 11: Respondents’ reasons for unwillingness to give advice to anyone on hospice service.
n=20

Reasons	Frequency.	Percentage.
Lack of information	18	90
People are difficult to advise	2	10
Total	20	100

Majority 18 (90%) of the respondents who stated unwillingness to give advice to anyone to seek hospice service, stated lack of information on hospice.

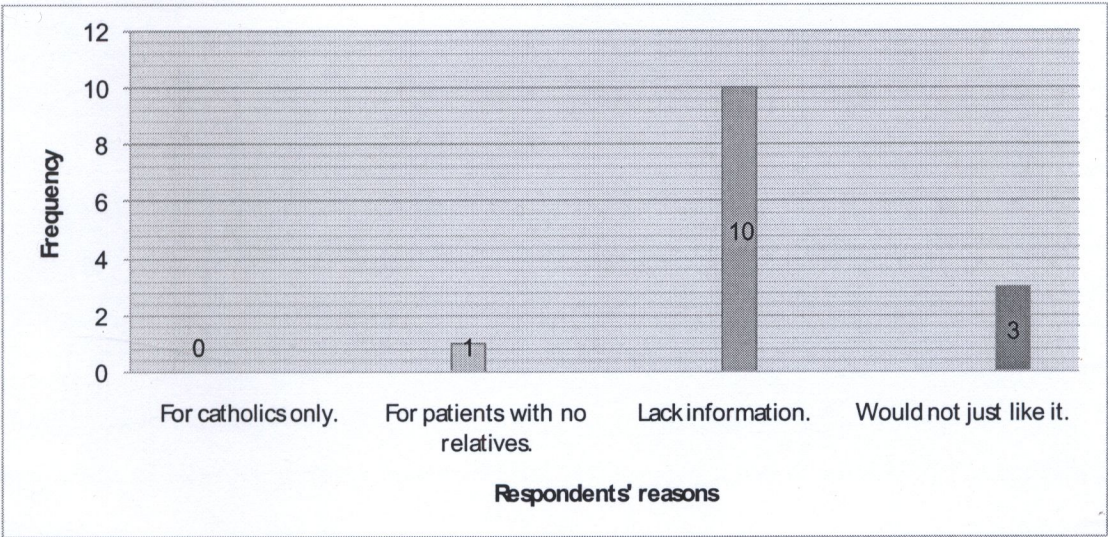
Figure 11: Respondents responses whether they would like to be referred to the hospice by a Doctor. n= 50



Majority 36 (72%) of the respondents reported that they would like to be referred to a hospice by a doctor.

Majority 40 (80%) of the respondents had positive attitude towards hospice service

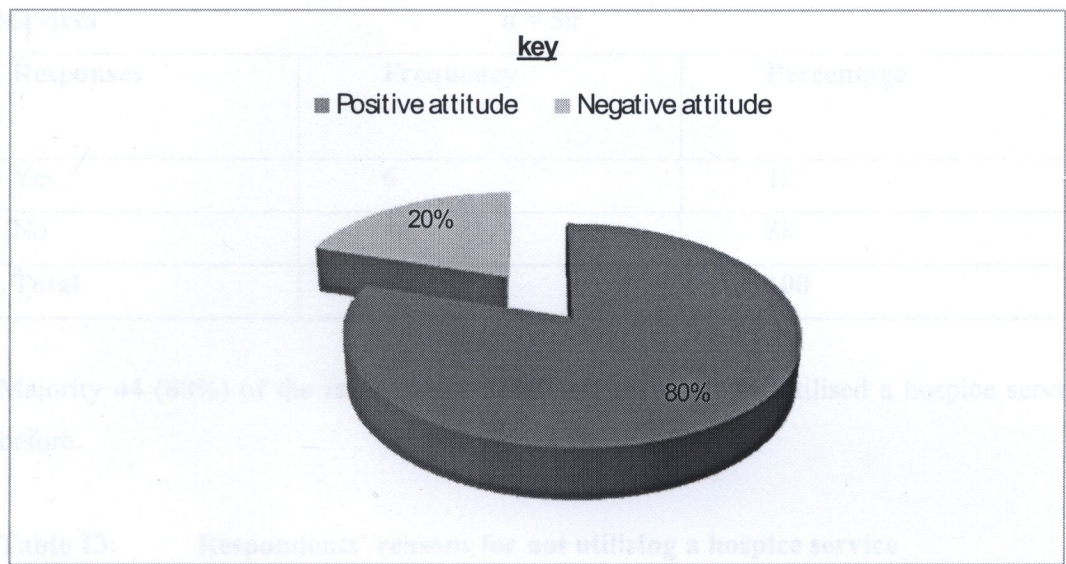
Figure 12: Reasons given by the respondents for unwillingness to be referred to a hospice. n=14



Out of the 14 (28%) who stated that they would not like to be referred to a hospice by a Doctor, majority 10 (71.4%) of them stated lack of information about hospice.

Figure 13: Respondents' overall attitudes towards hospice service.

n=50



Majority 40 (80%) of the respondents had positive attitude towards hospice service.

Lack of knowledge	24	55%
Could manage at home	7	16%
First admission	8	18%
Its for HIV/AIDS/TB patients	5	11%
Total	44	100%

Slightly more than half 24 (55%) of the respondents who had not utilised hospice service, stated lack of knowledge as the reason, while 5 (11%) stated that it was for HIV/AIDS/TB patients

4.3.4 SECTION 4: UTILISATION OF HOSPICE SERVICE.

Table 12: Respondents responses on whether they have utilised a hospice services
n = 50

Responses	Frequency	Percentage
Yes	6	12
No	44	88
Total	50	100

Majority 44 (88%) of the respondents stated that they had not utilised a hospice service before.

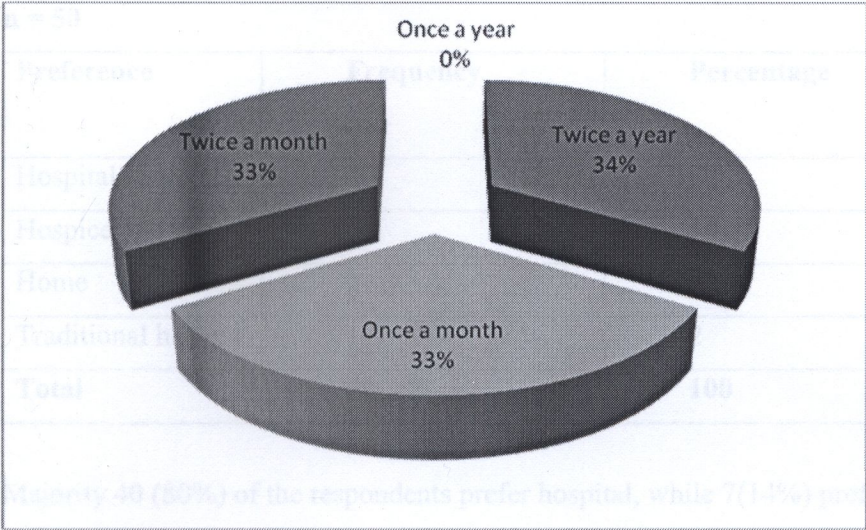
Table 13: Respondents’ reasons for not utilising a hospice service
n = 44

Reasons	Frequency	Percentage
Lack of knowledge	24	55
Could manage at home	7	16
First admission	8	18
Its for HIV/AIDS/TB patients	5	11
Total	44	100

Slightly more than half 24 (55%) of the respondents who had not utilised hospice service, stated lack of knowledge as the reason, while 5 (11%) stated that it was for HIV/AIDS/TB patients.

Figure 14: Respondents' frequency of hospice service utilisation.

n=6



Most 2 (34%) of the respondents who had utilised hospice service, stated that they utilise hospice service twice a year.

Table 14: Respondents' opinion about services offered at a hospice.

n=6

Opinion	Frequency	Percentage
They offer good services	5	83
Just like the hospital	1	17
Total	6	100

Out of the 6 respondents who had utilised hospice service, majority 5 (83%) of them stated that the services offered at a hospice were good.

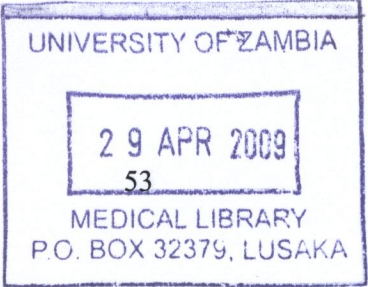


Table15: Respondents’ preferred health care service.

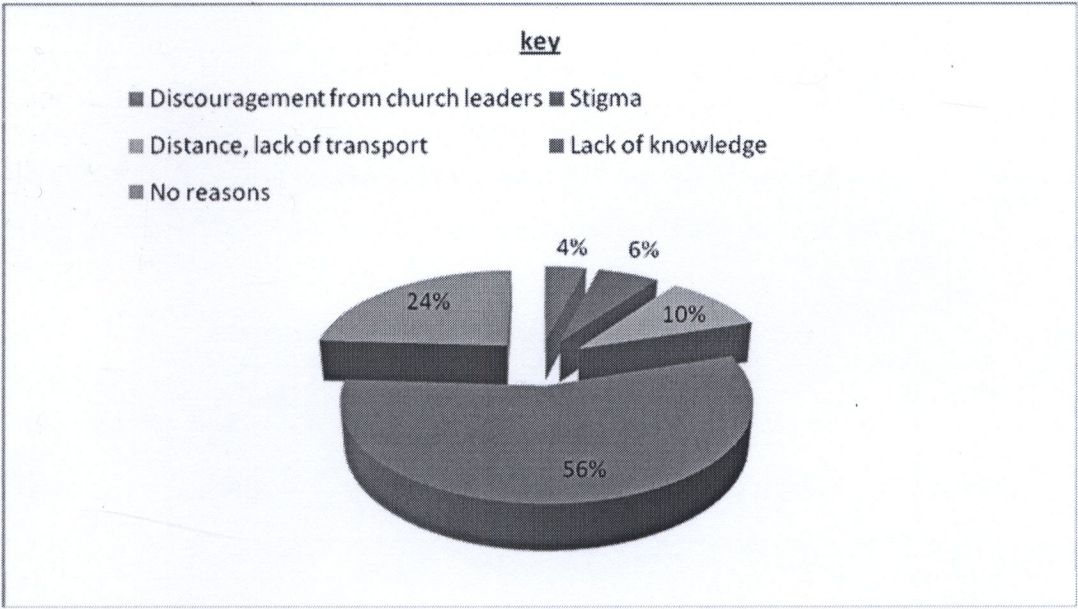
n = 50

Preference	Frequency	Percentage
Hospital	40	80
Hospice	7	14
Home	2	4
Traditional healers	1	2
Total	50	100

Majority 40 (80%) of the respondents prefer hospital, while 7(14%) prefer hospice.

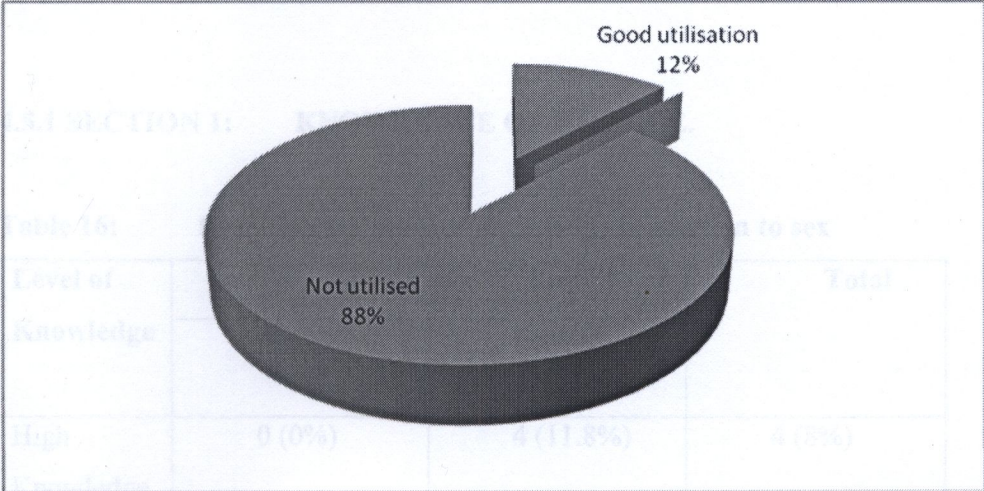
Figure 15: Factors that influence respondents’ utilisation of hospice services

n = 50



More than half 28 (56%) of the respondents stated lack of knowledge, and 12 (24%) did not state any factors in relation to their utilisation of hospice service.

Figure 16: Respondents’ level of hospice utilisation.



Majority 44 (88%) of the respondents had not utilised hospice service, while 6 (12%) had utilised hospice services.

Majority 13 (31.3%) of the male respondents had low knowledge of hospice, while more than half 20 (58.8%) of the female respondents had low knowledge of hospice.

Table 17: Respondents’ level of knowledge in relation to age

Level of Knowledge	Age				Total
	20-25	26-35	36-45	Above 46	
Low knowledge	0 (0%)	2 (11.1%)	2 (11.1%)	0 (0%)	4 (8%)
Moderate knowledge	1 (16.7%)	3 (16.7%)	5 (27.8%)	4 (50%)	13 (26%)
Low knowledge	5 (83.3%)	13 (72.2%)	11 (61.1%)	4 (50%)	33 (66%)
Total	6 (12%)	18 (36%)	18 (36%)	8 (16%)	50 (100%)

Majority 5 (83.3%) of the respondents in the age range of 20-25 had low knowledge of hospice, while majority 13 (72.2%) of the respondents in the age range of 26-35 had low knowledge of hospice.

4.5 THE RELATIONSHIP BETWEEN VARIABLES.

4.5.1 SECTION 1: KNOWLEDGE OF HOSPICE.

Table 16: Respondents’ level of knowledge in relation to sex

Level of Knowledge	Sex		Total
	Male	Female	
High Knowledge	0 (0%)	4 (11.8%)	4 (8%)
Moderate knowledge	3 (18.7%)	10 (29.4%)	13 (26%)
Low knowledge	13 (81.3%)	20 (58.8%)	33 (66%)
Total	16 (32%)	34 (68%)	50 (100%)

Majority 13 (81.3%) of the male respondents had low knowledge of hospice, while more than half 20 (58.8%) of the female respondents had low knowledge of hospice.

Table 17: Respondents’ level of knowledge in relation to age

Level of Knowledge	Age				Total
	20-25	26-35	36-45	Above 46	
Low knowledge	0 (0%)	2 (11.1%)	2 (11.1%)	0 (0%)	4 (8%)
Moderate knowledge	1 (16.7%)	3 (16.7%)	5 (27.8%)	4 (50%)	13 (26%)
Low knowledge	5 (83.3%)	13 (72.2%)	11 (61.1%)	4 (50%)	33 (66%)
Total	6 (12%)	18 (36%)	18 (36%)	8 (16%)	50 (100%)

Majority 5 (83.3%) of the respondents in the age range of 20-25 had low knowledge of hospice, while majority 13 (72.2%) of the respondents in the age range of 26-35 had low knowledge of hospice.

Table 18: Respondents' level of knowledge in relation to their marital status.

Level of Knowledge	Marital Status					Total
	Single	Married	Widowed	Separated	Divorced	
High knowledge	1(14.3%)	3 (9.1%)	0 (0%)	0 (0%)	0 (0%)	4 (8%)
Moderate knowledge	2(28.6%)	6 (18.2%)	4 (50%)	1 (100%)	1 (100%)	14 (28%)
Low knowledge	4(57.1%)	24(72.7%)	4 (50%)	0 (0%)	0 (0%)	32 (64%)
Total	7(14%)	33 (66%)	8 (16%)	1 (2%)	1 (2%)	50(100%)

More than half 4 (57.1%) of the single respondents had low knowledge, while majority 24 (72.7%) of the married respondents had low knowledge of hospice.

Table 19: Respondents' level of knowledge in relation to location of the study.

Level of Knowledge	Location of a study			Total
	UTH	Chawama Clinic	Kalingalinga Clinic	
High knowledge	2 (6.6%)	0 (0%)	2 (20%)	4 (8%)
Moderate knowledge	8 (26.7%)	1 (10%)	4 (40%)	13 (26%)
Low knowledge	20 (66.7%)	9 (90%)	4 (40%)	33 (66%)
Total	30 (60%)	10 (20%)	10 (20%)	50 (100%)

Majority 20 (66.7%) of the respondents from UTH had low knowledge, while majority 9 (90%) of the respondents from Chawama had low knowledge of hospice.

Table 20: Respondents level of knowledge in relation to residential area

Level of Knowledge	Residential area			Total
	High density	Medium	Low density	
Low knowledge	3 (8.8%)	1 (10%)	0 (0%)	4 (8%)
Moderate knowledge	7 (20.6%)	5 (50%)	1 (16.7%)	13 (26%)
Low knowledge	24 (70.6%)	4 (40%)	5 (83.3%)	33 (66%)
Total	34 (68%)	10 (20%)	6 (12%)	50 (100%)

Majority 24 (70.6%) of the respondents from high density area had low knowledge, and majority 5 (83.3%) of the respondents from low density area had low knowledge.

Table 21: Respondents level of knowledge in relation to religious denomination

Level of Knowledge	Denomination						Total
	Catholic	UCZ	RCZ	SDA	Pent	J.Wit	
High knowledge	0 (0%)	1(14.3%)	0 (%)	0 (0%)	3 (10.7%)	0 (0%)	4 (8%)
Moderate knowledge	5(55.6%)	0 (0%)	0 (0%)	0 (0%)	7 (25%)	1(50%)	13 (26%)
Low knowledge	4(44.4%)	6(85.7%)	0(0%)	2(100%)	18(64.3%)	1(50%)	33 (66%)
Total	9 (18%)	7 (14%)	2 (4%)	2 (4%)	28 (56%)	2(4%)	50(100%)

Slightly more than half 5 (55%) of the Catholic respondents had moderate knowledge, while majority 18(64.3%) of the Pentecostal respondents had low knowledge of hospice services.

Table 22: Respondents’ level of knowledge in relation to education attainment.

Level of Knowledge	Education attainment					Total
	None	Primary	Secondary	College	University	
High knowledge	0 (0%)	0 (0%)	2(11.8%)	2(33.3%)	0 (0%)	4 (8%)
Moderate knowledge	1(14.3%)	6(31.6%)	3(17.6%)	3 (50%)	1(100%)	14(28%)
Low knowledge	6(85.7%)	13(68.4%)	12(70.6%)	1(16.7%)	0(0%)	32(64%)
Total	7 (14%)	19 (38%)	17 (34%)	6 (12%)	1 (2%)	50(100)

Majority 6 (85.7%) of the respondents with no education attainment had low knowledge, and majority 12 (70.6%) of the respondents with Secondary education attainment had low knowledge.

Table 23: Respondents’ level of knowledge in relation to occupation.

Level of Knowledge	Occupation				Total
	House wife	In business	Formal employment	Unemployed	
High knowledge	1(25%)	2(10.5%)	1(14.3%)	0 (0%)	4(8%)
Moderate knowledge	0(0%)	6(31.6%)	2(28.6%)	5(25%)	13(26%)
Low knowledge	3(75%)	11(57.9%)	4(57.1%)	15(75%)	33(66%)
Total	4(8%)	19(38%)	7(14%)	20(40%)	50(100%)

Majority 3 (75%) of the respondents who were house wives had low knowledge, while majority 15 (75%) of the respondents who were unemployed had low knowledge of hospice.

Table 24: Respondents’ level of knowledge in relation to family income.

Level of knowled ge	Income						Total
	<K100,000	Between K100,000 and K450,000	Between K450,000 and K 750,000	> K 750,000	Seasonal	None	
High knowled ge	0 (0%)	1(4.5%)	1(33.3%)	2 (20%)	0 (0%)	0 (0%)	4 (8%)
Moderate knowled ge	2 (40%)	4(18.2%)	1(33.3%)	2 (20%)	0 (0%)	2(33.3%)	11 (22%)
Low knowled ge	3 (60%)	17(77.3%)	1(33.3%)	6 (60%)	4(100%)	4(66.7%)	35 (70%)
Total	5 (10%)	22(44%)	3(6%)	10(10%)	4 (8%)	6(12%)	50(100 %)

Out of the 22(44%) respondents with family income of between K100, 000.00 and K450, 000.00, majority 17(77.3%) of them had low knowledge of hospice, while out of the 10 (10%) respondents with more than K750, 000.00, 6 (60%) of them had low knowledge.

Table 25: Respondents’ level of knowledge in relation to attitude.

Level of Knowledge	Attitude		Total
	Positive attitude	Negative attitude	
High knowledge	4 (9.6%)	0 (0%)	4 (8)
Moderate knowledge	12 (29.3%)	1 (11.1%)	13 (26%)
Low knowledge	25 (61.1%)	8 (88.9%)	33 (66%)
Total	41 (82%)	9 (18%)	50 (100%)

Most 25 (61.1%) of the respondents with positive attitude had low knowledge of hospice, while majority 8 (88.9%) of the respondents with negative attitude had low knowledge.

Table 26: Respondents level of knowledge in relation to hospice utilisation.

Level of Knowledge	Utilisation		Total
	Utilised	Not utilised	
High knowledge	0 (0%)	4 (9.1%)	4 (8%)
Moderate knowledge	3 (50%)	10 (22.7%)	13 (26%)
Low knowledge	3 (50%)	30 (68.2%)	33 (66%)
Total	6 (12%)	44 (88%)	50 (100%)

Half 3 (50%) of the respondents who had utilised a hospice service had low knowledge and another 3 (50%) of them had moderate knowledge, while majority 30 (68.2%) of the respondents who had not utilised a hospice service before had low knowledge of hospice.

4.5.2 SECTION 2: ATTITUDES TOWARDS HOSPICE SERVICE.

Table 27: Respondents’ attitude in relation to sex.

Attitude	Sex		Total
	Male	Female	
Positive	11 (68.7%)	29 (84.3%)	40 (70%)
Negative	5 (31.3%)	5 (14.7%)	10 (30%)
Total	16 (32%)	34 (68%)	50 (100%)

Most 11 (68.7%) of the male respondents had positive attitude towards hospice service, while majority 24 (84.3%) of the female respondents had positive attitude towards hospice services.

Table 28: Respondents’ attitude in relation to age

Attitude	Age				Total
	20-25	26-35	36-45	Above 46	
Positive	5(83.3%)	13(72.2%)	13(72.2%)	4(50%)	35(70%)
Negative	1(16.7%)	5(27.8%)	5(27.8%)	4(50%)	15(30%)
Total	6(12%)	18(36%)	18(36%)	8(16%)	50(100%)

Out of the 6 respondents aged 20-25, 5 (83.3%) of them had positive attitude, while out of the 18 respondents in the age range 26-35, majority 13 (72.2%) of them had positive attitude and another 18 in the age range 36-45, of them had positive attitude towards hospice service.

Table 29: Respondents' attitudes in relation to education attainment.

Attitude	Education attainment					Total
	None	Primary	Secondary	College	University	
Positive	4(57.1%)	15(78.9%)	11(64.7%)	5(83.3%)	1 (100%)	36 (72%)
Negative	3(42.9%)	4(21.1%)	6(35.3%)	1 (16.7%)	0 (0%)	14 (28%)
Total	7 (14%)	19 (38%)	17 (34%)	6 (12%)	1 (2%)	50(100%)

Majority 15 (78.9%) of the respondents with primary education attainment had positive attitude towards hospice, while most 11 (64.7%) of the respondents with secondary education attainment had positive attitude.

Table 30: Respondents' attitude in relation to the marital status.

Attitude	Marital status					Total
	Single	Married	Widowed	Separated	Divorced	
Positive	6(85.7%)	21(63.6%)	8(100%)	0 (0%)	1(100%)	36 (72%)
Negative	1(14.3%)	12(36.4%)	0 (0%)	1 (100%)	0 (0%)	14 (28%)
Total	7 (14%)	33 (66%)	8 (16%)	1 (2%)	1 (2%)	50(100%)

Majority 6 (85.7%) of the single respondents had positive attitude towards hospice, while most 21 (63.6%) of the married respondents had positive attitude.

Table 31: Respondents' attitude in relation to residential area.

Attitude	Residence			Total
	High density	Medium	Low density	
Positive	22 (64.7%)	10 (100%)	3 (50%)	35 (70%)
Negative	12 (35.3%)	0 (0%)	3 (50%)	15 (30%)
Total	34 (68%)	10 (20%)	6 (12%)	50 (100%)

Majority 22 (64.7%) of the respondents from high density area had positive attitude towards hospice, while all 10 (100%) of the respondents from medium density area had positive attitude towards hospice service.

Table 32: Respondents' attitude in relation to religious denomination.

Attitude	Denomination						Total
	Catholic	UCZ	RCZ	SDA	Pent	J.Wit	
Positive	8(88.9%)	4(57.1%)	1 (50%)	1 (50%)	19(67.9%)	2 (100%)	35 (70%)
Negative	1(11.1%)	3(42.9%)	1 (50%)	1 (50%)	9(32.1%)	0 (0%)	15 (30%)
Total	9 (18%)	7 (14%)	2 (4%)	2 (4%)	28 (56%)	2 (4%)	50(100%)

Most 19 (67.9%) of the respondents from the Pentecostal denomination had positive attitude towards hospice service, while majority 8(88.9%) of the respondents from the Catholic denomination had positive attitude towards hospice services.

Table 33: Respondents’ attitudes in relation to their knowledge level of hospice service.

Attitude	Knowledge			Total
	High	Moderate	Low	
Positive	4 (100%)	11 (84.6%)	26 (78.8%)	41 (82%)
Negative	0 (0%)	2 (15.4%)	7 (21.2)	9 (18%)
Total	4 (8%)	13 (26%)	33 (66%)	50 (100%)

Majority 26 (78.8%) of the respondents with low knowledge had positive attitude towards hospice service, and majority 11 (84.6%) of the respondents with moderate knowledge had positive attitude towards hospice services.

Table 34 : Respondents attitude in relation to utilisation of hospice service.

Attitude	Utilisation		Total
	Utilised	Not utilised	
Positive	6 (100%)	35 (79.5%)	41 (82%)
Negative	0 (0%)	9 (20.5%)	9 (18%)
Total	6 (12%)	44 (88%)	50 (100%)

Majority 35 (79.5%) of the respondents who had not utilised hospice service before had positive attitude, while all 6 (100%) of the respondents who had utilised the service before had positive attitude.

4.4.3 SECTION 3: UTILISATION OF HOSPICE SERVICE

Table 35: Respondents’ service utilisation in relation to sex.

Utilisation	Sex		Total
	Male	Female	
Utilised	3 (18.7%)	3 (8.8%)	6 (12%)
Not utilised	13 (81.3%)	31 (91.2%)	44 (88%)
Total	16 (32%)	34 (68%)	50 (100%)

Majority 31 (91.2%) of the female respondents had not utilised hospice services, while 13 (81.3%) of the female respondents had not utilised hospice services.

Table 36: Respondents’ hospice service utilisation in relation to residential area.

Utilisation	Residential area			Total
	High density	Medium	Low density	
Utilised	4 (11.8%)	2 (20%)	1 (16.7%)	7 (14%)
Not utilised	30 (88.2%)	8 (80%)	5 (83.3%)	43 (86%)
Total	34 (68%)	10 (20%)	6 (12%)	50 (100%)

Majority 30 (88.2%) of the respondents from the high density area had not utilised hospice services, while 8 (80%) of the respondents from the medium density area had not utilised the services.

Table 37: Respondents’ hospice utilisation in relation to religious denomination.

Utilisation	Denomination						Total
	Catholic	UCZ	RCZ	SDA	Pent	J.Wit	
Utilised	3(33.3%)	0 (0%)	0 (0%)	1(50%)	2 (7.1%)	0 (0%)	6 (12%)
Not utilised	6(66.7%)	7(100%)	2(100%)	1 (50%)	26(92.9%)	2(100%)	44 (88%)
Total	9 (18%)	7 (14%)	2 (4%)	2 (4%)	28 (56%)	2 (4%)	50(100%)

Majority 26 (92.9%) of the Pentecostal respondents had not utilised hospice services, while most 6 (66.7%) of the Catholic respondents had not utilised the service.

Table .38: Respondents’ utilisation of hospice in relation to their attitudes.

Utilisation	Attitude		Total
	Positive	Negative	
Utilised	6 (14.6%)	0 (0%)	6 (12%)
Not utilised	35 (85.4%)	9 (100%)	44 (88%)
Total	41 (82%)	9 (18%)	50 (100%)

Majority 35 (85.4%) of the respondents with positive attitude had not utilised hospice services, while all 9 (100%) of the respondents with negative attitude had not utilised hospice services.

CHAPTER 5

5.0 DISCUSSION OF FINDINGS AND IMPLICATIONS TO THE HEALTH CARE SYSTEM

5.1 INTRODUCTION

The results of the study were based on the analysis of responses from a sample of fifty (50) families with chronically and terminally ill patients who were admitted to the University Teaching Hospital, Kalingalinga and Chawama Health Centres for curative and palliative treatment. A structured interview schedule was used to collect data on knowledge, attitude and utilisation of hospice services (*Appendix 1*). This chapter looks at the interpretation and discussion of the findings as well as the implications of hospice services to the health care system.

5.2 CHARACTERISTICS OF THE SAMPLE

The study sample consisted of fifty (50) respondents who had patients admitted for curative and palliative care at the University Teaching Hospital, Kalingalinga and Chawama Health Centres. The target population were family members on the bedside of a patient with chronic and terminal illness.

Section 1 of the interview schedule had questions on demographic data from the respondents (*Appendix 1*). The study revealed that the majority 34 (68%) of the respondents were female (*Table 2*). This is probably because of the traditional way of responding to illnesses; usually females are at the center stage of looking after the sick. This is similar to what the Pathfinders international (2005) observed, that is looking after the chronically ill relates well to the traditional African way of responding to illnesses whereby a family member usually female would move over to tend to the ill, sometimes for a protracted period of time. The other reason could be that most females in Zambia are not in formal employment and they assist in looking after the sick members of the family, besides women have the natural tender way of nursing patients.

The results revealed that most 18 (36%) of the respondents who were on the bedside were in the age range 26-35 and 36-45 years (*Table 2*). This could probably mean that these are

the ages when people become responsible and play various roles in the families, while 8 (16%) of the respondents aged above 46 years were few because the proportion in the age group tend to reduce with increasing age. This is similar to the 2001-2002 Zambia Demographic and Health Survey (ZDHS) report which indicated that the proportion in age groups tends to decrease with increasing age of the population (CSO, 2003). This is probably due to reduced life expectancy which stands at 37 years (Henriot, 2005).

The study further revealed that majority 33 (66%) of the respondents were married while 8 (16%) of the respondents were widowed. Seven (14%) of the respondents were single (*Table 2*). The high number of respondents in the study who were married could be regarded a normal practice or culture when one reaches the reproductive age. The relatively high number of respondents who were widowed could be attributed to the impact of HIV/AIDS and other related diseases.

The study also revealed that more than half 29 (58%) of the respondents were unemployed, 19 (38) were in informal employment and 4 (8%) were full time housewives (*Table 2*). This implies that majority 43 (86%) of the respondents were not in formal employment. This is contrary to the Living Conditions and Monitoring Survey Report by the Central Statistical Office (2005) that rated Lusaka to have unemployment rate of 21%, further that high unemployment is a phenomenon more prevalent in urban areas. Only 7 (14%) of the respondents were in formal employment. The low formal employment rate could be attributed to the Structural Adjustment Programme the Government engaged in the early 1990s to improve the country's depressed economy that saw closure of most parastatal and private companies leading to an increase in unemployment rate.

The study revealed that the majority 34 (68%) of the respondents were from high density areas, 10 (20%) were from medium density area, while 6 (12%) of the respondents were from low density areas (*Table 2*). This is probably due to the fact that most people from the low density areas have well paid jobs with good income, and when it comes to seeking health care services, they go to private hospitals where they may not wait for many hours on a queue for them to be attended to. Besides most privately owned health institutions have readily available drugs. On the other hand most of the residential areas in the urban setup are high density areas. The majority of the residents in high density areas belong to

the low income group and as such they seek health care services from public institutions like the University Teaching Hospital and many other Government Health Centres like Chawama and Kalingalinga. The other reason for having the majority of the respondents from the high density area could be attributed to the life style in the high density areas that predisposes the residents to most chronic diseases. Unfavourable conditions such as over crowding, social activities like beer drinking consequently leading to the possibilities of having casual unprotected sex with different partners. All these may have a serious repercussion on an individual's health.

On the education attainment of the respondents, the study revealed that most of the respondents 19 (38%) had attained Primary education, while 17 (34%) attained Secondary education, 7 (14%) of the respondents had never been to school. 6 (12%) had been to a College, Only 1 (2%) of the respondents had attained University education (*Table 2*). This means that 7 (14%) of the respondents had attained tertiary education. According to the CSO (2003) surveys the situation regarding education attainment is almost similar; it revealed that education attainment varies greatly with type of and different social economic situations. The rural places of Zambia had the highest proportion of respondents with no schooling for example in the Eastern Province of Zambia it was established that 23% females and 13% males did not attain any educational.

The study revealed that all 50 (100%) of the respondents were Christians from various denominations. This could be attributed to the fact that Zambia is predominately a Christian nation. Slightly more than half 28 (56%) of the respondents were Pentecostals, this is probably due to the increased numbers of new Pentecost churches that are being established especially in peri urban areas, others are established for a good cause while others as a source of income. Catholics were 9 (18%), UCZ 7 (14%), while RCZ, SDA and Jehovah's Witness were 2 (4%) each (*Table 2*). The findings suggest that non Catholics were the majority in the study.

Data on family income revealed that about 5 (10%) of the respondents earned less than K100, 000 per month, while 22 (44%) earned between K100, 000 and K450, 000 monthly (*Table 2*). This could be due to the fact that most of the respondents were not in formal employment, if they were in formal employment, they could be general workers or casual workers. Similarly, the CSO's Living Conditions and Monitoring Survey Report (2004)

reported that the majority (65%) of the Zambian people had income below K450, 000.00. Six (12%) stated that they had no income, 4 (8%) stated that they had a seasonal income, and most of them were subsistence or peasant farmers, while 10 (20%) stated that their monthly income was above K750, 000.00 (*Table 2*). Generally this picture shows that majority of the respondents struggle to fend for their families because of their low wages or salaries, and could not even afford decent accommodation, meals and access quality health care services. According to Muweme's (2007) monthly food basket report November- December 2007, it was estimated that a family of six could spend about K1, 600,000.00 to meet its needs per month. Majority of the Zambians are poor who could not afford the above stated amount, for example most civil servants salaries are below K1, 600,000.00. According to Henriot (2005) majority of Zambians are poor with 70% to 80% living below the poverty line, a life expectancy of 37 years, and a rank on the most recent United Nations Human Development Index of number 164 out of 173 countries.

5.3 DISCUSION OF VARIABLES

The dependent variables in this study were knowledge of hospice service, attitude towards hospice and utilisation of hospice services. The independent variables were age, sex, education attainment, religious practice, residential area, family income and marital status. The independent variables are discussed in relation to the dependent variables.

5.3.1 KNOWLEDGE OF HOSPICE SERVICE

Knowledge is the theoretical or practical understanding from the sum of what is known (WHO, 2004). This variable helped to explore the level of knowledge or information that respondents had on hospice. Information is a collection of facts and data (WHO, 2004). Knowledge of hospice would determine the extent to which a service could be accessed and utilised or accepted in the community.

In order to determine how much respondents know about hospice services, questions were asked to find out if they had ever heard about the term hospice, and responses were compared to other research findings. Majority 36 (72%) of the respondents had heard about hospice, 14 (28%) of them had not heard about hospice (*Figure 2*). This shows that the majority had an idea about the existence of hospice services. These findings are similar to those found in a study done by Campbell in Australia (2006) which established that 16% of Australians had never heard of palliative and hospice care.

The source of information is very fundamental because information, just like knowledge is power, and consumers have to be well informed if they are to make an informed choice. In trying to establish the source of information this is what the study indicated; 36 (72%) of the respondents who had heard about hospice, most 16 (44%) of them stated that their source of information were friends, 9 (25%) were church members, 4 (11%) were the relatives, 3 (8%) were from the hospital, while 1 (3%) mentioned the Media (*Table 3*). The study revealed that respondents learn about health care services, social amenities and many other services through interaction with friends or through personal experience. The assumption here could be that the 44% had at one point a relative or friend who accessed and benefited from the service. For the Hospitals to have such a low figure it signifies that, there is inadequate health education being offered and clients are not being given information on hospice services. As for the Media under normal circumstances one could expect the Media to be the leading source of information but to the contrary, this means that both the public and private Media, electronic and print media have not done well in this area in so far as information dissemination on hospice is concerned. This could mean that there is inadequate community service or social responsibility by such organisation, or it suggests that even the journalists themselves, they do not have information on hospice service. This is similar in one way and different in the other way in the findings by Campbell (2006) in Australia which established that 50% of the people become aware of palliative and hospice services through contact with family members or friends, while 18% become aware through the Media. The findings in our case could be attributed to the fact that there is no strong intersectoral collaboration between the health care service providers or the Ministry of Health and the Ministry of Information and Broadcasting.

Consumers of health care services should be able to explain in brief the health services that are available. Most 22 (44%) of the respondents stated that they did not know the definition of hospice care, 13 (26%) stated that it was hospital care of patients, 8 (16%) stated that it was a speciality for caring for the chronically and terminally ill, while 7 (14%) stated that it was care for HIV/AIDS patients (*Figure 3*). This study revealed that majority 84% of the respondents did not know the definition of hospice care. This means that only 16% of the respondents knew the definition of hospice care. This is contrary to what Doyle (1997) established when he conducted a study in Melbourne on community knowledge of hospice and palliative care. In his study it was reported that 61% of the

respondents were able to give a correct definition of hospice care. In our set up the statistics were low probably because the concept is quite new and people are still learning about it. However, the study indicates that the service providers have not done enough in as far as giving adequate information on hospice service is concerned.

Having knowledge of something is not just knowing its definition, but having a theoretical or practical understanding from the sum of what is already known as stated earlier on in the definition. In order to determine the knowledge level, respondents should be able to explain briefly what goes on in a hospice and is only specific to hospice. One of the criteria was to establish whether respondents knew the illnesses that are cared for at a hospice. Majority 37 (74%) of the respondents reported that the chronically and terminally ill patients were supposed to be cared for in the hospital, 6 (12%) stated that they are supposed to be nursed at a hospice while 7 (14%) stated that they did not know where the chronically and terminally ill were supposed to be nursed (*Figure 4*). Majority mentioned hospital because the concept of hospice is foreign and new in our setup and all they know is hospital. This is similar to Dyer's (1999) study on family expectation from health care services conducted in California which revealed that, 65% of the families go with hope and implicit promise of cure for chronic conditions like cancers by surgery. The first place where they rush to for care and cure is the hospital.

A service could be meaningless to the society if it has no established function. Services could be beneficial to the society if their purposes are known and understood. Most 23 (46%) of the respondents stated that they did not know the purpose of a hospice, 10 (20%) stated that the purpose was to offer palliative and spiritual care, 10 (20%) stated that the purpose was to give drugs to patients with HIV/AIDS, while 7 (14%) stated that to provide food to poor families (*Figure 5*). Most of the respondents did not know probably because the concept is new as earlier alluded to, and lack of sensitisation to the general public. The study also revealed some elements of stigma; this is all because of lack of accurate information or inadequate knowledge of hospice services.

It is necessary to differentiate a hospice from a hospital. Someone who is well informed would even appreciate the conditions that are best cared for in a hospice. Most 19 (39%) of the respondents did not know the diseases that are cared for at a hospice, 14 (29%) stated Tuberculosis, 8 (16%) stated that any chronic and terminal illnesses while 6 (12%) stated

that it was HIV/AIDS (*Figure 6*). From the findings, it is clear that most of the respondents do not know the diseases that are supposed to be nursed at a hospice. Others have attached stigma to a hospice by specifically pointing out TB and HIV/AIDS as diseases that are cared for at a hospice. This is as a result of lack or inadequate information on the service. The picture that is painted by some respondents need to be corrected if the general public is to access a hospice services without fear or being ashamed.

Normally consumers who are well informed and knowledgeable about health care service, know the name of the service and its location. This study revealed that most 22 (44%) of the respondents did not know the name and location of any hospice in Lusaka District, 14 (28%) stated Our Lady's Hospice in Kalingalinga community, 8 (16%) stated Jon Hospice in Kamwala, while 6 (12%) stated Mother of Mercy Hospice in Chilanga (*Table 4*). Most of the respondents do not know because apart from the concept being new as stated earlier on, there is inadequate or no publicity at all on the availability and importance of hospice to the general public. This calls for massive sensitisation of the general public on the importance and benefits of a hospice services. Our Lady's Hospice was the most popular hospice in Lusaka District probably because it is centrally located in the community as opposed to Mother of Mercy Hospice in Chilanga. Mayo (2007) observed that 90% of American hospice care is provided at home in the community, they are available wherever people actually live.

Upon considering various aspects of hospice knowledge to determine the overall knowledge level of the respondents, an impression was created that the majority of the respondents had low knowledge of hospice service. Majority 33 (66%) of the respondents had low knowledge of hospice services, 13 (26%) had moderate knowledge of hospice, while 4 (8%) had high knowledge of hospice service (*Figure 7*). This knowledge level among the respondents is worrisome. There is need to redesign the sensitisation programmes so that even people in areas where they lack such services, could have the right information about a hospice and eventually advocate for such services. Once information about hospice is adequately disseminated there would be an improvement in knowledge levels and utilisation of the services.

Sex of an individual is likely to have an influence on ones knowledge of some health care services. Females are likely to have more information on health care services than males.

This is because when a member of the family is sick, usually female relatives take the responsibilities of ensuring that they are taken to the hospital and in that way they learn a lot about the services that are available. With regard to the respondents' knowledge in relation to sex, out of the 16 (32%) male respondents, majority 13 (81.3%) of them had low knowledge of hospice, while out of the 34 female respondents, more than half 20 (58.8%) had low knowledge of hospice (*Table 16*). This statement is in the same direction to the findings in a study conducted by Campbell (2006) although statistics were much higher in Australia than our setup. He established that majority 89% of the female respondents in Australia had knowledge of palliative and hospice service while the males had 76%.

With regard to the respondents' knowledge in relation to education attainment, out of the 7 (14%) respondents with no education attainment, majority 6 (85.7%) of them had low knowledge, while out of the 19 (38%) respondents who had attained primary education, most 13 (68.4%) of them had low knowledge (*Table 17*). These findings suggest that education play a pivotal role in understanding of health care services. The figures may appear quite high in those who had attained primary as well as secondary education. This may be attributed to lack of information to the respondents.

Most hospice services in Lusaka District are managed by Faith Based Organisations. These organisations have a duty to inform their followers about the programmes they offer apart from nourishing them spiritually. With regard to the respondents' knowledge in relation to denomination, out of the 9 (18%) respondents who were Catholics, slightly more than half 5 (55%) of them had moderate knowledge, while out of the 28 (56%) respondents from Pentecostal Churches majority 18 (64.3%) had low knowledge of hospice (*Table 21*). This is probably because the Catholic Church runs this programme and has an extensive Home Based Care programme with most of its members involved in charity work. However, there is need for the Faith Based Organisation like the Catholic Church to provide adequate information to its members. In a normal situation most Catholics respondents were supposed to have high knowledge of hospice because of the status quo.

Hospice services could be beneficial to patients with life threatening chronic and terminal conditions; however, in this study majority of the respondents seem not to have knowledge

about hospice and palliative services. These services could help patients and their relatives cope with stress of being sick and looking after the sick. There is need to give more information to people so that they may have knowledge of such important services. Jan stjernsward (2003) wrote and I quote *“nothing would have a greater impact on the care of patient with advanced incurable diseases than instilling the knowledge we have now to improve their quality of life”*.

5.3.2 ATTITUDE

An attitude is an internal state that influences or moderates the choices of personal action made by the individual (Gagne, 1985:63). Attitudes are learnt as individuals develop during child and adult life. However, in this regard we are going to restrict our selves to the attitudes that individuals may have towards hospice services. In order to determine attitudes of respondents towards hospice services, they were asked questions on how they feel about the service in question and if they were likely to utilise it.

An individual is likely to utilise a service if his/her attitude towards that service is positive. Respondents were asked on whether they would take their relatives to a hospice. Slightly above half 27 (54%) of the respondents were unwilling to take patients to a hospice, while 23 (46%) of the respondents were willing (*Table 5*). This could be generally attributed to non availability of information on hospice services as well lack of knowledge among the respondents.

Table 6 shows that out of the 27 (54%) respondents who stated unwillingness to take patients to a hospice, majority 22 (81.5%) of them reported lack of knowledge as a reason for their unwillingness to take patients to a hospice, 2 (7.4%) stated that hospice service were for HIV/AIDS patients and another 2 (7.4%) stated TB. This study apart from revealing lack of knowledge as one of the factors influencing willingness to use hospice services also revealed an element of stigma. This mind set could be changed by improving on information dissemination both in the communities and in hospitals.

People fail to utilise a service and develop a negative attitude towards such a service if stigma is attached, and they feel ashamed to access and utilise the service. Majority 49 (98%) of the respondents stated that they would not feel ashamed to take their ill relatives

to a hospice (*Table 7*). These findings suggest that hospice services were accepted and majority had a positive attitude towards the service.

Sharing of information about hospice by people who have utilised the services before could be one of the best and most effective way of disseminating information to the general public. Majority 39 (78%) of the respondents stated that they would share their experience at hospice with others (*Table 9*). On the other hand, *figure 9* shows that out of the 11 who stated that they would not share their experience at hospice with others, majority 9 (81.8%) stated lack of knowledge as a reason, while 1 (9.1%) stated that they would be ashamed to share their experience with others. In the same manner, most 30 (60%) of the respondents stated that they would advise others to seek hospice service (*Table 10*). These findings indicate that people are likely to share the information on hospice services, if they are well informed and benefited from the service themselves as they may be able to recommend the service to others. In order to support this assertion, out of the 20 (40%) who stated unwillingness to give advice to anyone to seek hospice service, majority 18 (90%) of them mentioned lack of information (*Table 11*).

It is very imperative to establish if clients could accept any advice to seek hospice services. Majority 36 (72%) of the respondents stated they would like to be referred to a hospice by a Doctor, while 14 (28%) stated that they would not like to be referred to a hospice by a Doctor (*Figure 11*). Furthermore, *figure 12* shows that out of the 14 (28%) who stated that they would not like to be referred to a hospice by a doctor, majority 10 (71.4%) of them stated lack of information while 3 (21.4%) stated that they would not just like the idea.

After considering and analysing various aspects that may encompass an attitude in general, it has been revealed that the majority 40 (80%) of the respondents in Lusaka District had positive attitude towards hospice service (*Figure 13*). This is similar to the findings in a study by Garran (2006) who established that over 88% of Australians had positive attitude towards hospice and palliative care. In general there was a positive attitude towards hospice services and this signifies the acceptability of hospice services.

With regard to the respondents' attitude towards hospice service in relation to respondents' sex, most 11 (68.7%) of the male respondents had positive attitude towards hospice services, while majority 24 (84.3%) of the female respondents had positive attitude

towards hospice services (*Table 27*). This suggests that females generally are more likely to have a positive attitude towards health services than males. By giving them necessary support and information they could utilise the service to the fullest and be key in influencing their male counterparts.

With regard to the respondents' attitude in relation to utilisation, out of the 44 (88%) respondents who had not utilised hospice service, majority 35 (79.5%) of them had positive attitude towards hospice services, while out of the 6 (12%) respondents who had utilised hospice service, all 6 (100%) of them had positive attitude (*Table 34*). This implies that attitude towards a service may influence its utilisation; however, there are other factors such as accessibility that may come about due to distance and location of a service. These may also influence hospice services utilisation, apart from lack of information that has been discussed in most cases.

Knowledge of an individual on a particular health care may influence his/her attitude towards that service. With regard to the respondents' knowledge in relation to attitude, most 25 (61.1%) of the respondents who had positive attitude had low knowledge of hospice, while majority 8 (88.9%) of the respondents with negative attitude had low knowledge (*Table 25*). This indicates that knowledge has an influence on the peoples' attitude towards a service.

This study concludes that over 80% of the respondents had positive attitude towards hospice service. Service providers should take advantage of the positive attitude of individuals and ensure that they provide necessary information to the general public on the benefits of hospice services to the patients and their families.

5.3.3 UTILISATION

Utilisation of hospice service in this case is making use of the available hospice services. If care for patients with chronic and terminal illnesses is to be improved, when a diagnosis is made of such, the reasons for utilising hospice and end-of-life or hospice services must be clearly explained by the service providers and referring health institutions to enhance or impart knowledge on clients.

In order to establish the current situation in as far as hospice utilisation is concerned, it is imperative to find out the utilisation pattern among the respondents. Majority 44 (88%) of the respondents stated that they had not utilised a hospice service, while 6 (12%) of them stated that they had utilised a hospice service before (*Table 12*). This is contrary to what Tang (2003) found in Connecticut when he studied on the determinants of hospice home care use among the terminally ill cancer patients. It was found that utilisation rate was 50.4%. There is low utilisation in Lusaka District because of factors like people not having the right information on hospice services, and others like distance and location which may affect accessibility.

Generally people do not shun health care services without valid reasons, in order to explore the reasons for not utilising a hospice by the majority, slightly more than half 24 (55%) of the respondents stated lack of knowledge as a reason for not utilising the service, while 5 (11%) stated that it was for patients with HIV/AIDS/TB, 8 (18%) reported that it is because, it was their first admission to hospital, while 7 (16%) stated that they could manage at home (*Table 13*). Similarly in a study by Christakis and Escarce (1996), it was established that the reasons for underutilisation of palliative and hospice services by the minority African-American was lack of knowledge about the benefits associated with end-of-life health care needs.

Among the respondents who reported having utilised hospice and to what extent have they utilised the services? Most 2 (34%) of the respondents stated that they utilise hospice service twice a year (*Figure 14*). This may be viewed as underutilisation of hospice service, because under normal circumstance they are supposed to be seen twice a month by the hospice care team or more depending on the condition of the patient (Wright, 2003).

Some people have utilised hospice services for various reasons, how did they benefit and what could be their opinions on the services they received? Majority 5 (83%) of the respondents stated that the services offered at a hospice were good, 1 (17%) reported that the services were just like those offered in the hospital (*Table 14*). Similar results were obtained by Rickerson (2005) on timing of hospice referrals and families' perception of services offered at a hospice, which indicated that they received greater benefits. On the other hand, this assertion that hospice service is same as hospital care, could be true to somebody who does not understand what goes on in a hospice.

In trying to explore and exhaust other factors that may influence hospice utilisation in addition to the already known factors like lack of knowledge. *Figure 15* shows that more than half 28 (56%) of the respondents stated lack of knowledge, and 12 (24%) did not state any factors, 5 (10%) stated distance and lack of transport, 3 (6%) stated stigma, while 2 (4%) stated discouragement from church leaders. The respondents who did not give any reasons most probably do not have any information on hospice. Church leaders have a role to guide their members genuinely; they should not discourage their flock. Moreover, according to UNAIDS (2000) palliative care is a collaborative service where medical services are integrated with spiritual and psycho social support.

With regard to the respondents' hospice utilisation in relation to residential area, the study shows that out of the 34 (68%) respondents from the high density area, majority 30 (88.2%) of them had not utilised hospice service, while out of the 10 (20%) respondents from the medium density area, 8 (80%) of them had not utilised the services (*Table 36*). This could be attributed to stigma attached to hospice service utilisation in various communities, which comes about as a result of lack of knowledge of hospice and palliative care.

With regard to the respondents' hospice utilisation in relation to religious denomination, majority 26 (92.9%) of the Pentecostal respondents had not utilised hospice service, while most 6 (66.7%) of the Catholic respondents had not utilised the service (*Table 37*). Referring back to *figure 15* on the factors that influence hospice service utilisation, Church leaders especially non Catholics could play an influential role on whether their flock could seek hospice service or not. The findings also revealed that there are few Catholics although more than non Catholics who utilised hospice services, probably because they do not understand the benefit of the services.

With regard to the respondents' hospice utilisation in relation to attitude, majority 35 (85.4%) of the respondents with positive attitude had not utilised hospice services, while all 9 (100%) of the respondents with negative attitude had not utilised hospice services (*Table 38*). People generally have positive attitude towards hospice services, however what is lacking is adequate information and non availability of hospice services in most areas.

With regard to the respondents' knowledge in relation to utilisation, half 3 (50%) of the respondents who had utilised hospice service before had low knowledge and another half 3 (50%) of them had moderate knowledge, while majority 30 (68.2%) of the respondents who had not utilised hospice service before had low knowledge of hospice (*Table 26*). This suggests that apart from low knowledge there are other factors that may influence hospice service utilisation such as inability to buy a medical scheme from Government health institutions, lack of money to buy drugs and in most cases hospice service team provide food to their disadvantaged patients who are not admitted and could not afford a decent meal per day.

Hospice service utilisation could improve if people learn about the benefits of the services and if other factors like distance to the facility could be looked in to. The true picture of hospice utilisation could be determined if hospice services are found throughout Lusaka District.

5.4 IMPLICATIONS TO HEALTH CARE SYSTEM

The health care system has an important and leading role of disseminating information and educating its citizenry on the health services that are offered in the country if they are to be accessed. Besides, In 1991 the Government of Zambia embarked on reforms to achieve *"quality of access to cost-effective quality health care close to the family as close as possible"* [Ministry of Health (MoH) National Health Policies and Strategies, 1992]. Hospice services have some implications in the health care delivery especially the areas stated below.

5.4.1 Nursing Practice and Education

- Hospice service increases the scope of Nursing Practice. Since palliation in hospice service involves pain management, spiritual care, counselling of both patients and families, this speciality demands adequate training and specialisation in this field. It also provides an opportunity for nurses to improve in decision making skills, clinical assessment and prescription of palliative care.
- In terms of Nursing Education, this demands for regular curriculum reviews to incorporate current trends in nursing in relation to hospice and palliative care. Curriculum review is a costly exercise, implying that statutory board of nursing

like the General Nursing Council of Zambia need to identify collaborating partners to provide logistic and technical support in that areas of regular curriculum review and development.

5.4.2 To the Government.

- Budgetary allocation to the Ministries such as Health, Social Services as well as Local Government increases to meet the increasing demand on training of health personnel.
- Infrastructure development such as Training Schools for palliative care providers, upgrading hospitals and health centres within the country. Infrastructure development in the area of shanty compounds upgrading and road development in order to make them very accessible.
- Meeting the costs of training or developing human resource out side the country, currently the only country that is able to provide training in palliation in the region is Uganda.
- Since hospice services may also be offered in the community there is need to improve social amenities, water supply and sanitary conditions in communities.

5.4.3 To the Communities

- The Communities are partners in the care of the terminally ill patients and they are supposed to be involved in decision making. Communities should be empowered with basic skills to handle some of these cases in the community. Enough funds are needed to meet the cost of training.

5.5 CONCLUSION

The study was carried out to assess the knowledge, attitude and utilisation of hospice by families with chronically and terminally ill patients in Lusaka District. Its purpose was to highlight the prevailing situation and some of the factors that affect the utilisation of hospice services. This could help in coming up with solutions to help the service providers enhance information dissemination and the quality of the services that are provided. Hospice service is a multidisciplinary, comprehensive way of offering palliative care to the chronically and terminally ill patients and their families. The study revealed that majority of the respondents had low knowledge of hospice service. In terms of attitude, majority of the respondents had positive attitude towards hospice service, and generally the utilisation

level was very low. The results also revealed that there is need to intensify information dissemination mechanisms, if people are to be knowledgeable about hospice and be able to make informed choices in as far as hospice utilisation is concerned. The null hypotheses which were (1) There is no relationship between knowledge level of hospice and palliative care services and utilisation. (2) Negative attitude towards hospice care is not associated with low utilisation among family members. These null hypotheses have been rejected and proved the research hypotheses, the findings suggests that (1) There is a relationship between knowledge level of hospice and palliative care services and utilisation. (2) Negative attitude towards hospice care is associated with low utilisation of the service among family members. However, this hospice service have some implication on the delivery of health services such as increasing the scope of nursing practice which calls for speciality training in this area of nursing profession. It also calls for an increase in budgetary allocation to meet training needs and infrastructure development.

5.6 RECOMMENDATIONS

In view of the findings in the study, the following are the recommendations:

5.6.1 To the Ministry of Health

- Formulation of the National Policy on Palliative and Hospice care: The Ministry of Health should speed up the process for formulation of a National Policy on Palliation, as this would provide standards and guideline for quality provision of hospice and palliative care services to the citizens of Zambia.
- Promote and give guidelines on the availability of palliative care drugs and their administration especially the analgesia/narcotics like morphine.
- Human Resource Development: The Ministry of Health should ensure that there are staff that are trained in palliative care. Currently, in Zambia there is only one clinical officer who has been trained in palliative care. The Ministry should ensure that Nurses and Doctors are also trained in this field.
- Infrastructure Development: The Ministry should consider coming up with Government owned hospice care services if the citizens could have access to hospice services at any level of the health care service provision.
- The Government through the Ministry of Health should adequately help fund the FBOs and NGOs who are currently offering this service to the public as it is a costly venture. If these organisations are adequately funded by the Government

they would not only sustain their operations but may also consider expanding the services to areas where they are not available. There is need for the government to consider such organisations as partners in development.

- The Ministry of Health should consider doing this research on a larger scale in order to generalise the findings.
- Research to determine staff knowledge, attitude and practice in hospice and palliative care in Government health institutions should be considered as well.

5.6.2 To the Hospice Movement both FBOs and NGOs

- The Faith Based Organisations (FBOs) and Non Governmental Organisation (NGOs) should continue offering palliative and hospice care services to the general public, and consider expanding the mobile hospice service for wider coverage.
- Should revise or come up with extensive information dissemination programme about hospice. This would help the general public to understand the benefits of hospice services. There is need to enhance the intersectoral collaboration with the Ministry of Information and Broadcasting and other private Medias in information dissemination.
- They should work hand in hand with the Palliative Care Association of Zambia to come up with the '*palliative care day*' to be commemorated every year. This should be used to promote charity works and sensitising the general public about hospice services.

5.6.3 To the District Management Health Team.

- The District Health Management Team should incorporate or include palliative and hospice care services in its health Information Education Communication Programme, or incorporate it in the programmes for management of HIV/AIDS and other chronic conditions, and work towards improving the referral system.

5.6.4 To the University Teaching Hospital.

- They should consider intensifying palliative care service, if possible come up with a ward offering specialised palliative and hospice care service. They should also intensify their Information Education Communication programme on palliative and

hospice services. Recommending a client for palliation by Doctors should not be seen as a personal failure, we all have limits no matter how good we could be in one area.

- Management of the Hospital should consider establishing a Department of palliative care which would work in collaboration with other departments like Medicine, Surgery Nursing, Physiotherapy, Pharmacy, Social works; Spiritual leaders etc. apart from working in collaboration it should be a multidisciplinary.
- Should develop palliative care guidelines and clear guideline on hospice referrals.

5.6.5 To the Church Mother Bodies; Zambia Episcopal Conference, Christian Council of Zambia, Evangelical Fellowship of Zambia.

- The churches should come up with a deliberate policy, so that once a while they could explain the benefits of palliative and hospice service to its flock, as most of them appear to lack the desired knowledge of the health services offered by the church.
- Should consider coming up with networks in charity work that should be interdenominational, so that all Christians could put up resources together and work for the common goal in the service of a human being. This should be organised in such a way like they do on Palm Sundays where all the Christians regardless of their denomination come together to pray.

5.6.6 To the Palliative Care Association of Zambia.

- They should intensify their sensitisation programmes on palliation and hospice services.
- They should endeavour to recruit people from all disciplines such as Doctors, Nurses, Physiotherapists etc.
- They should not just concentrate their services in Lusaka only.

6.0 DISSEMINATION AND UTILISATION OF FINDINGS

Dissemination of findings entails the measures that would be undertaken to communicate the findings from the study to others (Polit and Hungler, 2001).

The findings of the study will be communicated to the Lusaka District Health Management Team (LDHMT) and the University Teaching Hospital Management, Church mother bodies, Jon Hospice, Mother of Mercy and Our Lady's Hospices for implementation. Further, copies of written reports will be distributed to the Department of Post Basic Nursing, University of Zambia Medical Library, and Palliative Care Association of Zambia and Ministry of Health to use as reference material by students and health care professionals. Presenting of the study findings will be done during the Research Day which will be organized by the research coordinator in the school. The researcher would take advantage of management meetings at U.T.H., Chawama and Kalingalinga Health Institutions to organise a day for communicating the information to the respondents.

7.0 LIMITATIONS ENCOUNTERED DURING THE STUDY

- The limitation of the study was that the sample size of 50 respondents was too small to generalise the findings onto the general population. This was due to the short period in which the study had to be conducted.
- The time for carrying out the study was limited and made it impossible for the researcher to conduct focus group discussions

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Please assist
Patrick with his research
Se. Kang D'Arcy



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P.O. Box 50110
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11th May, 2007

The Director
Our Lady of Mercy Hospice
LUSAKA

Dear Sir/Vac'am,

RE: REQUEST FOR PERMISSION TO COLLECT DATA

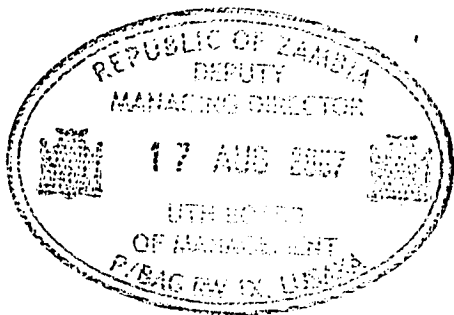
The bearer of this letter Malisawa Patrick is a 4th year student at the Department of Post Basic Nursing, School of Medicine at the University of Zambia.

In partial fulfillment of the Bachelor of Science in Nursing Degree the student is required to conduct a research study. His research topic is on "The knowledge and attitudes of family members of chronically/terminally ill patients towards hospice care." The purpose of writing this letter is to request for permission to collect information on the mentioned topic.

Your favorable response and assistance will be highly appreciated.

Yours faithfully,

P. M. Ndele (Mrs.)
ACTING HEAD, DEPARTMENT OF POST BASIC NURSING

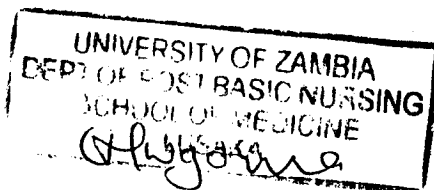


The University of Zambia
School of Medicine
Department of Post Basic Nursing
P. O. Box 50110
LUSAKA

17th August, 2007

The Managing Director
University Teaching Hospital
LUSAKA

UFS: The Head of Department
Post Basic Nursing
LUSAKA



Dear Sir/Madam,

Re: PERMISSION TO CONDUCT A RESEARCH STUDY AT THE UNIVERSITY TEACHING HOSPITAL.

I am a fourth year student at the University of Zambia School of Medicine, Department of Post Basic Nursing, pursuing a Bachelor of Science degree in Nursing programme.

In partial fulfillment of this programme, I am required to conduct a research study. My topic is 'knowledge, attitudes and utilisation of hospice services by families with chronically and terminally ill patients in Lusaka District'.

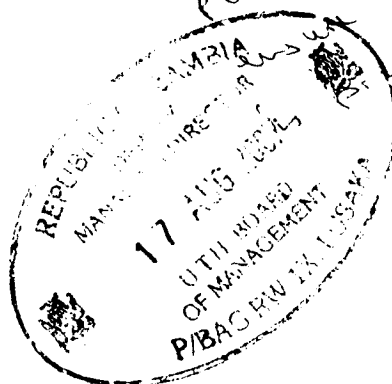
Therefore, I write to request for permission to carry out the pilot and actual research studies, by collecting data from Family members at the bedside of the patients in your organisation during the of August - September, 2007.

Your favourable response sir will be highly appreciated.

Yours faithfully,

Patrick Malisawa.

4th YEAR B.Sc. NURSING STUDENT
c.c. Director of Nursing U.T.H.



Pub Relations Mg
Please facilitate this.
Patient Confidential
V...

2P/8215
Agreed as
long as Cochrane
S

TO : Heads of Departments/ Nursing Officers

FROM : Public Relations Manager

DATE : 20th August 2007

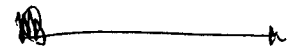
SUBJECT : PERMISSION TO CONDUCT A RESEARCH STUDY AT UTH

Permission has been granted to Mr. Patrick Malisawa, a fourth year B. Sc. Nursing student to collect data from family members at the bedsides of patients at UTH for his research.

In doing so however, patients' confidentiality should be observed at all times and he is therefore not allowed to have any access to patients' medical files.

Any assistance you may render to him will greatly be appreciated.

Thank you

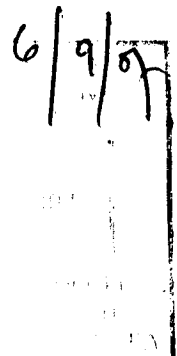


Pauline Mbangweta

20 AUG 2007

Cc Managing Director
Cc Deputy Managing Director
Cc Director of Nursing



6/9/07


P.O. Box 50827
Lusaka
Tel: +260-1-235554
Fax: +260-1-236429



Republic of Zambia

MINISTRY OF HEALTH

LUSAKA DISTRICT HEALTH MANAGEMENT TEAM



Date 15 August, 2007

The In-Charge
Citawana Health Centre
P.O. Box 50827
LUSAKA

Dear Sir/Madam,

RE: RESEARCH PROJECT- MR. PATRICK MARISAWA

Be informed that permission has been granted for the above named student to be attached to your health centre for a research project.

However this should be done with minimal disruption to the day to day activities at the Health centre and at no cost to Lusaka District Health Management Team.

Your usual cooperation will be appreciated.

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

CC Khangamwa H/C

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