

# CHAPTER 1

## INTRODUCTION

### 1.0 Overview

This chapter focuses on the background to the study, the problem statement, the purpose of the study, objectives, research questions, significance of the study, limitations, as well as operational definitions of terms.

### 1.1 Background to the Study

For the past 2000 years, the Catholic Church has been a consistent and persistent patron of medicine. The Church has been very closely associated with most of what has been accomplished in the field of medicine. Throughout the history of Christianity, the Church has been in intimate relation with the healing of humankind, both body and soul, and it has always been associated with the development of the science of healing as well as the exercise of charity. Throughout the world, the Catholic Church has been involved in the running of hospitals, clinics and hospices. In Zambia, the Church has been involved in taking care of the sick through their hospitals. With the coming of AIDS, the Church has been involved in the mitigation of the pandemic through running hospices and Home-Based-Care, where terminally ill patients are looked after until they die. This healing mission of the Church has its roots in the healing ministry of Jesus Christ who is the head of the Church. McManus (1984: 9) asserts:

'Jesus still speaks, acts, and heals through his Body, the Church; he speaks and acts and heals in a special and especially efficacious way through the sacraments of the Church. The sacraments are the church's hands, the hands of Christ's body, the hands of Jesus reaching out to touch us and heal us.

The healing power of the Catholic Church is holistic and can be expressed in two dimensions. The first dimension is that of healing by divine grace through the holy sacraments of the Church. This type of healing is spiritual in nature and is closely associated with the functions of clergymen who are the official dispensers of Church sacraments. The second dimension is that of healing through the powers of nature.

This type of healing is physical and is closely associated with science and is dispensed in hospitals, clinics and hospices scattered all over the world. The two dimensions provide for holistic care. This study looked at this holistic care for terminally ill patients (AIDS patients) by the Catholic Church in three hospices of Lusaka, namely; Our Lady, Mother of Mercy and Mother Theresa. In order to understand the holistic care offered in hospices in context, it is important first to look at the devastating impact of HIV and AIDS on society.

HIV and AIDS are now recognized to be a major global health problem. It needs concerted efforts of all stakeholders, such as world governments, international organisations, religious groups and many others, in order to conquer the pandemic. The World Health Organization (WHO) has been mobilizing resources throughout the world to combat the spread of HIV (Chitando, 2008: 23). According to Kirkpatrick (1993), the WHO expects a quarter of the population in certain African countries to be destroyed by the virus, especially countries in the sub-Sahara Africa, which have the highest prevalence of HIV.

According to UNAIDS (2008) report, HIV infection is spreading at an alarming rate. For example, during 2008, an estimated 2.7 million new infections occurred, 'more than five every minute, or one every twelve seconds' (Kelly, 2010). According to UNGASS (2001:17), 'prevention of HIV infection must be the mainstay of the national, regional and international response to the epidemic.' More infections mean more patients of HIV/AIDS related diseases and more deaths. AIDS is a slow and painful killer; it does not kill within hours or days or weeks. A patient can be sick for over six months before dying. During this period, the patient needs to be nursed with a lot of love and care. Governments have tried in their own way to provide this care in their hospitals but the burden has been too heavy to bear.

In fulfilling its mission of healing and caring for the sick, the Catholic Church has offered itself to give compassion to the sick as it helps governments in looking after the sick. The Catholic Church has been one of the major stakeholders in the fight against HIV and AIDS. According to Kelly (2006:35), the Catholic Church has been 'recognized as being the world's largest provider of AIDS care, accounting for more than 25 per cent of the global support and care for those infected or affected.' The

problem of HIV and AIDS has been compounded by the fact that there is no cure for AIDS. The Church being on the compassionate side and mandated to care for all God's people has made efforts to combat the spread of the disease and even far beyond in caring for those affected and infected by HIV and AIDS. As asked by Ruzindaza (2001: 7), 'shall we live long enough to see AIDS treated as any other disease?' The Catholic Church has refused to treat AIDS as any other disease, but as a disease that calls for an urgent solution.

According to Kelly (2010), the Catholic Church has responded to HIV and AIDS epidemic in five principal areas: prevention; care and treatment; mitigation of the impacts of HIV or AIDS on those infected or affected; spiritual accompaniment; and advocacy for the disadvantaged and for improvements in the provision of treatment, health, education and social services. This research focuses on the areas of care and treatment through the physical care and treatment for the terminally ill by provision of antiretroviral drugs in hospices, mitigation of the impacts of HIV and AIDS on the infected and affected through the services of Home-Based-Care, and in the area of spiritual accompaniment, especially through spiritual counseling, dispensation of Church sacraments and preaching of the word of God to the victims. These three areas comprise the holistic care provided by the Church to the terminally ill.

## **1.2. Statement of the Problem**

Care of the sick has been part of the Catholic Church's mission for a long time. This has been seen in the building of many hospitals wherever the church has been established. With the coming of AIDS, the Catholic Church again has taken a leading role in seeing to it that both the infected and affected are taken care of spiritually, emotionally and physically through home based care services and hospices. Hospices are a new phenomenon in Zambia. They are said to be offering holistic care to the terminally ill and their families. From the time of their inception, hospices have not been studied from an academic point of view. The researcher therefore intends to investigate the effectiveness of this holistic care offered in the hospices in Lusaka District, Zambia. It is important to find out how this holistic care is being executed to the AIDS patients by the nurses, caregivers, family members and hospice administrators.

### **1.3. Purpose of Study**

The purpose of the study was to investigate the assumption that Catholic-run hospices provided holistic care to HIV and AIDS patients and their families.

### **1.4. Significance of the Study**

The findings of this study may benefit anthropologists, students of religious studies, educationalists, Non-Governmental Organisations (NGOs), the Ministry of Health, churches and policy makers to appreciate what is being done by the Catholic Church in caring for HIV and AIDS patients, families and the community at large. It may also contribute to the knowledge on the care being offered by the hospices. It may help the students of religious studies not only to research on HIV and AIDS in relation to religion and healing but also to find interventions which will provide solutions to the problem at hand.

### **1.5. Research Objectives**

- (a) To establish the nature of care offered in our lady's, mother of mercy and mother Teresa hospices.
- (b) To establish the services rendered to the patients and their families as part of the holistic care.
- (c) To ascertain the benefits if any of the holistic care being provided.
- (d) To find out the challenges if any being faced by hospices in the provision and accessing of care to patients and families.

### **1.6. Research Questions**

- (a) What is the nature of care offered at Our Lady's, Mother Theresa and Mother of Mercy hospices?
- (b) What kinds of services are being rendered to patients and their families?
- (c) What are the benefits, if any, of the holistic care being provided?
- (d) What challenges, if any, are being faced by hospices, patients and families in the provision and accessing of holistic care?

### **1.7. Limitations of the Study**

Since the topic was new and quite sensitive, there was fear that the respondents would not give detailed information about the care that they were offered and received from

the hospices. Documented information about hospices was also another worry of the researcher as the topic was a new one. These concerns were put to rest when most of the respondents displayed some degree of frankness and also documented information was accessed at the same hospices.

### **1.8. Delimitations of the study**

It would have been desirable for the study to cover hospices run by other denominations but due to a large number of hospices run by the Catholic Church, the researcher decided to settle on the latter.

### **1.9. Definition of Terms**

#### **Chaplain**

Refers to a religious person in-charge of a group of people.

#### **Epidemic**

Refers to a disease outbreak confined to a small area, town or country.

#### **Holistic**

Refers to the patient viewed as a person with physical, psychological, social, spiritual and cultural gifts and needs, which are special to that person.

#### **Hospice**

Refers to a place where the chronically ill and dying are taken care of.

#### **Opportunistic infection**

Any infection that is caused by a micro-organism commonly found in the environment but that causes disease only in persons with low immunity. These infections are frequently the immediate cause of death in AIDS patients.

#### **Palliative**

Refers to a medical specialty focused on pain, stress and other debilitating symptoms of serious illness without removing its cause.

**Pandemic**

This refers to world outbreak of a disease.

**Physiotherapy**

Refers to the treatment of injuries and physical disabilities by a trained person under the supervision of a specialist in physical medicine.

**Retrovirus**

A virus containing RNA as the genetic material that causes cancer in animals.

**1.10. Summary**

The study explores the contribution of the Catholic run hospices in caring for HIV and AIDS patients and their families. The study has specifically focused on three hospices in Lusaka district. It is believed that the Church has taken part in the efforts aimed at trying to curb the scourge of AIDS and also to provide care to the victims through home-based care. Stopping the spread has proved difficult but the care of the sick has been managed successfully through hospices and home based care programmes. The Church has gone further in building hospices where these patients can access medication and receive good nutrition to enable them face death with dignity. The information that has been collected will help show the role of hospices in caring and treatment of HIV and AIDS patients.

In short, Chapter one has focused on the background of the study, research questions, objectives and the importance of the study. The researcher also explained the operational terms used in the study as well as what prompted the study. In Chapter two, the researcher will discuss the literature related to the study.

## CHAPTER 2

### LITERATURE REVIEW

#### **2.0. Overview**

The issues discussed in this chapter include the background of HIV and AIDS in Zambia and government's as well as the Catholic Church's response to HIV and AIDS. The chapter also discusses the historical background of the hospice movement in the world and in Zambia, the operations of the hospices visited, the care given to patients and how the patients eventually come to terms with the disease.

#### **2.1. Background of HIV and AIDS in Zambia**

The HIV and AIDS scourge has been in existence for many years now, to be specific, since the 1980s in Zambia. Worldwide, it is very difficult to come up with the exact time when the disease started. Iliffe (2006:3) postulates that the symptoms of the disease were first observed on a fifteen-year old sexually active American youth who died in 1969. He died with multiple symptoms including an aggressive form of *Kaposi's Sarcoma*, a tumor common in advanced AIDS patients. His stored blood tested positive to HIV by Western Blot. More stored specimens of patients who displayed unusual symptoms in the 1980s tested positive to HIV. Like many other countries in Africa and elsewhere, the HIV and AIDS pandemic has had a devastating effect on the lives of many people in Zambia, cutting across the cultural, economic and social strata.

Globally, HIV infection continues to spread at an alarming rate. According to Kelly (2010), during 2008, an estimated 2.7 million new HIV infections occurred worldwide. In Zambia, an estimated 82, 700 adults together with 9, 000 children became newly infected with HIV in the year 2009. In every region of the world, the number of those who become infected annually exceeds the number of those who die of AIDS. The latest estimates for 2008 are that 2.7 million individuals became newly infected and the disease claimed two million lives. The decrease in the number of deaths from AIDS has been due to the increased availability of antiretroviral drugs (ARVs). The number of HIV infections is also steadily increasing due to the ARV drugs, which enable infected people to live longer and continue to spread the virus.

Although HIV and AIDS were first recognized among gays in the United States of America in the early 1980s, it is the African continent that has been hardest hit by the pandemic. Chitando (2008: 72) states that, 'in fact, HIV and AIDS' devastating effects on the African continent, particularly sub-Saharan Africa, continue unabated.' UNAIDS (2006) reports that in 2006, 24.7 million people were living with HIV in sub-Saharan Africa. It further states that 2.8 million new HIV infections were reported and 2.1 million people died from AIDS in 2006.

Among the Central-Southern African countries, Zambia's statistics indicate that the prevalence of AIDS is fast growing and is posing a great challenge to the economy and in the provision of social welfare. The spread of the disease has reached an advanced stage. This situation may be attributed to a number of factors such as cultural practices (polygamy, etc.), poverty, ignorance (lack of information on how to prevent the HIV infection), and many others. It is not only adults who are infected and dying from the pandemic, but children too. Many children who are born from sick mothers are at risk of contracting the virus at birth or during lactation period. There are also those children who contract the virus by being sexually abused by irresponsible adults. It is estimated that over one million people are living with the disease in Zambia.

The prevalence of HIV has been on the increase and the virus has the unique slow characteristic of claiming lives, making the disease be on the increase and aggravate further the incidence of poverty. The trend is, when people become infected with the disease, their life style becomes disturbed because in the first place the disease has no cure and secondly, it weakens the body so that productive work, which may bring food on the table is brought to a halt. The patients spend much of their meager resources on medication and this disturbs the economic zone of the family (Shikaputo, 2007).

With the coming of HIV and AIDS, every sector of society has been affected. This includes individuals, families and the church. Dube (2005:16-17) postulates that 'when AIDS comes to church, it affects the entire body or community of faith, its self understanding and mission'. The effects of HIV and AIDS are being felt by the education, health, agriculture, social and economic sectors. The pandemic has a major



impact on poverty and has negatively affected development through a range of direct and indirect means. Therefore, it can be contested that a country that has the highest number of people suffering from AIDS is a poor country.

There is a vicious circle of poverty and AIDS that tends to be mutually reinforcing. While poverty does not cause AIDS, it facilitates the transmission of the virus and makes the treatment impossible to afford, thus accelerating death from AIDS related illnesses, thereby, multiplying the social impact of the pandemic. Therefore, it can be said that AIDS accelerates poverty and poverty accelerates AIDS. Thus, AIDS has brought about untold suffering and death on the continent (Chitando, 2008). According to Smith and McDonagh (2003), the number of people living in poverty has already increased by five per cent as a result of the epidemic, hence, jeopardising the efforts to reach the United Nations Millennium Summit Goal by the year 2015.

## **2.2. The Response of the Government of Zambia**

The Zambia AIDSLAW Research and Advocacy Network (July-December 2005:4) shows that 'with a national adult prevalence rate of about seventeen per cent, HIV and AIDS is one of Zambia's most critical developmental and humanitarian challenges. Life expectancy has decreased from sixty years to thirty-seven years, largely as a result of HIV and AIDS'. This has prompted the government to come up with measures on how it can best solve the problem. For instance, in 2004, President Mwanawasa declared HIV and AIDS a national emergency and promised to provide antiretroviral drugs to 10, 000 people by the end of the year. Having exceeded this target in 2004, he set yet another of 100, 000 for the year 2005. Thus, 13 August 2005 marked the beginning of free supply of ARVs in all government clinics and hospitals countrywide.

On 30 December 2010, President Rupiah Banda reported that about 36, 000 people were on ART countrywide. Out of this number, 23, 000 were children. The percentage of people on ART is estimated at eighty-nine per cent now. That is just on treatment but the caring part has been left out. The challenge of HIV and AIDS to the government of Zambia is that it has added on to the already overburdened responsibility of poverty and disease eradication in the country. Hospitals are now filled to capacity due to patients suffering from AIDS related diseases. Medical

personnel are limited and hospitals and clinics are not enough to absorb the terminally ill patients. This is one of the reasons why the Catholic Church, and other faith groups, have come in to lessen the government's burden of looking after the terminally ill.

### **2.3. The Response of the Catholic Church to the Pandemic**

The prevalence of HIV has posed a challenge to the Church, which is to objectively look at the whole God-given gift of life and how people with HIV and AIDS are to be treated. The basic vocational responsibility for Christians is to be lovers of all God's people. Irrespective of what their ailment is, all people are to be embraced with friendship. Christians are to be as compassionate as the Father is compassionate (Matthew 5: 48). Kirkpatrick (1988: 97) points out that one cannot be compassionate unless they know the state of the heart of the person suffering. As ministering carers, Christians need to encourage the development of a 'Charter for Care' (similar to the one passed at the 1986 General Convention of the Episcopal Church, USA) whose vision is:

- To offer compassionate care towards all who are living with the HIV infection, including their partners, families and friends.
- To repudiate constantly any condemnation, rejection or judgment against those who are living with the viral infection.
- To stress the crucial need for education and to be in the forefront of this first line of defense against infection.
- To be with, to pray with, to remember liturgically and to serve sacramentally the sick, the dying, the bereaved and all who care with and for them.

The church is expected to be a 'people's ministry' to all the children of God, especially to the marginalized, the sick, the suffering (infected) and those who suffer with them (affected).

The Catholic Church, in line with its mission of healing and its social teaching, as enshrined in its Vatican II documents; *Sacrosanctum Concillium* of 4 December 1963 extended her help towards the caring of the sick. Fr. Komakoma (2003: 20) states that

‘there should be proper treatment of AIDS victims; there should be care for them preferably in their families where the local community can be involved.’ This reaffirmed the concept of extended family that was present in traditional African/Zambian societies, and the values of communal responsibility of looking after the sick and weak members in the community. In another pastoral letter, entitled ‘*Choose to Live*’, the Zambia Episcopal Conference (2003:214) postulates that the fact that not all families may be able to provide for their sick members, especially in the later stages of the disease, means that the introduction of institutional care, which is similar to a home would be imminent. These institutions are known as hospices. Hospices are a new concept in Zambia; they are run by the Catholic Church but accommodate anyone who has AIDS or cancer. Hospice care caters for the infected and the affected to help alleviate their sufferings as well as to give shelter and comfort to those who are facing rejection in their own families.

Hospice care was introduced in Zambia in 1992 by the Sisters of St. Charles Borromeo, with the first hospice known as ‘Mother of Mercy’ in Chilanga township Lusaka. After realising that there were more people who needed hospice care, more hospices were opened throughout Zambia. In Lusaka alone, there are three such institutions under the Catholic Church, that is, Our Lady’s hospice in Kalingalinga, Mother Theresa’s hospice in Mtendere and Mother of Mercy hospice in Chilanga township. The Catholic Church is playing an important role in trying to provide care alongside treatment that is provided by the government. Since the cure for HIV/AIDS is far from being found, measures to prevent, care and console those who are infected and affected should be introduced by both the government and the Church whose duty it is to care for the sick.

The Catholic Church was the first to introduce hospice care in Zambia in a bid to help in the fight not only against HIV and AIDS but also against stigma and loneliness, which patients and their families faced. Although this phenomenon of hospices is new in Zambia as it only came into existence in 1992, worldwide, it is quite old. It was offered first to the injured and provided shelter to those attacked by bandits in the medieval period. Later in the twentieth century, hospices were built for cancer patients and those who had terminal diseases. Hospices provide comfort and support to the dying and their families. Aside from running home-based care services to the

terminally ill, where patients were given medical treatment and food as well as nursing care, the Church also decided to introduce hospice care. Hospice care provides twenty-four hour and seven-days-a-week care and medication to patients and families to alleviate the sufferings being endured by family members.

In its care for the terminally ill, the Church is more concerned about the dignity of human beings. Apparently, the greatest impact of the pandemic is on the dignity of the human person (Shikaputo, 2007). Therefore, according to Cosstick (1987: 44), the type of treatment the Church offers should centre on the spiritual and mental well-being of the sufferer. AIDS patients should be helped to appreciate the meaning of death according to their religious beliefs. In the absence of medical cure, the spiritual potential of the patient must be stimulated by faith in Jesus Christ so as to fight the effects of the virus. Our society should be able to help AIDS patients on their deathbeds so that they may have a realistic encounter with their personal death. As the government, through the Ministry of Health, continues to provide antiretroviral drugs to sustain the patients, the Church should also do its part. The Church should fully attend to other needs of the patients and their families, such as compassion and encouragement especially to those who go into the terminal stage of the disease.

#### **2.4. Hospice Movement**

Having looked at the response by the Catholic Church towards the pandemic, especially its decision to introduce hospices, this section looks at the historical development of the hospice movement. This will help in the analysis of what the Church is currently doing in the three hospices under study.

The term 'hospice' comes from the Latin word '*hospis*' meaning host and guest. The concept of hospices, therefore, started as guest houses where travellers found safety, rest and refuge from bandits in Biblical times. In the 4<sup>th</sup> century in Rome, the concept of hospice as a place to care for the sick and dying came into being under the direction of Fabiola, a member of the Roman Patrician class who was well known in her day as a generous provider of care and comfort to the sick and dying. In 1842, the term hospice was used for the first time to identify a place to care for the chronically ill and dying in France where Mme. Jean Gamier is credited with establishing an institution dedicated to the care of the dying (Doyle, and McDonald, 1998). Later in

the 19<sup>th</sup> century, the Irish Sisters of Charity, a religious order of the Catholic Church in Ireland and England, established hospices for the dying (<http://www.medscape.com>, accessed on 23<sup>rd</sup> March, 2010).

The first ever widely known modern hospice was established in 1967. Doka and Davidson (2001:19) state that the modern application of the word began with Dame Cicely Saunders in her establishment of St. Christopher in the United Kingdom in London. She is actually known as the founder of the modern hospice movement. She was a prominent Anglican nurse, physician and writer. She helped the dying and terminally ill end their lives in the most comfortable way possible. She emphasised the importance of palliative care even in modern medicine with the motto 'you matter because you are YOU. You matter up to the last moment of your life and we will do all that we can to help you LIVE until you die' (ibid). In the commitment to address the needs and wishes of a person who is dying, 'hospice' has an implicit belief in his/her worth. Regardless of progressive physical decline and the inability to be productive, 'hospice' sees an individual as having a significant value.

## **2.5. Hospice Care**

Hospice and hospice care refer to a philosophy of care rather than a specific building or service. It may encompass a programme of care and an array of skills deliverable in a wide range of settings. Therefore, in a bid to help alleviate the pain and sufferings of the AIDS patients and their family members, the Catholic Church adopted this philosophy to help combat stigma and loneliness which the patients and families faced. The goal of any hospice or supportive care programme is to keep the patient as comfortable as possible by relieving pain and other discomforting symptoms. Care in the hospice should be able to help the patient and family accept that death can occur at any time (Kubler-Ross, 1970). Hospice care helps the patients go through the five stages of suffering, which are; denial, rage and anger, bargaining, depression, acceptance and waiting ... managing deaths approaching (Kirkpatrick, 1988: 59, 60).

The hospice also offers support to both the patient and family by helping them understand and manage what is happening. Chemack (1997) states that hospices and supportive care view 'family' in the broadest sense, including spouses, lovers, partners, children and any loved ones who form the patients' basis for social and

emotional support. The hospice provides pastoral care. Patients living with HIV, their partners, relatives or friends need pastoral care to help them cope with their own strong feelings of anger, sorrow, failure or guilt, which are buried very deeply in their subconscious (Kirkpatrick, 1988).

According to the research carried out in London by Doyle and MacDonald (1998:193), it was discovered that the AIDS patients receive less care and attention. Basic interventions to maintain comfort were not often provided and hygiene, thirst and nutritional needs were often not attended to. Contact between nurses and the dying patients was minimal. Distancing and isolation of patients by most medical and nursing staff were evident. This isolation increased as death approached and there was poor communication leading to inadequate support for relatives.

The above research findings are also evident in most of the Zambian hospitals. Sometimes, AIDS patients are even stigmatized by being put in their own wards with less health conditions and care. This stigmatisation and loneliness was the more reason why the Catholic Church had to come up with hospices, which would offer a conducive environment for both patients and their families. The patients need a home-like environment for them to recover or die a dignified death and this is what hospices provide. Hospices are not just managed by nurses and doctors; there is a team of experts carrying out palliative care to both patients and their families. The team consists of doctors, nurses, chaplains, nutritionists, physiotherapists and pharmacists among others.

## **2.6. The Concept of Holistic Approach**

The unique feature of Catholic hospices is the holistic care given to the patients. Holistic means that the patient is viewed as a person with physical, psychological, social, spiritual and cultural gifts and needs, which are special to that person. Therefore, in order to provide full care for a patient, all these areas of human endeavour must be attended to. Holistic approach addresses all parts of the individual, not just the physical aspect of a person where manifested illnesses are most apparent. Doyle (2006:33) states that 'holistic' also means the team takes a holistic approach using the different talents in a team to assist in various aspects of the illness. Pastoral

and palliative care through drugs, food and nutrition are very important aspects of holistic care as seen in the following sub-sections.

### **2.6.1. Pastoral Care**

As already alluded to above, hospice care is often offered by a team of experts. These experts include a priest, religious sisters or religious groups who have given themselves to give meaning to the lives of dying souls. Pastoral care is very important for people living with the HIV virus because of various reasons; some feel that they got the disease because they have been promiscuous (Sims and Moss, 1954:136) and God is punishing them. They feel they deserve what they have, while others blame themselves for infecting their unborn children believing that God would never forgive them. Such kinds of people need spiritual counselling from a priest, pastor or nun, to convince them that God can forgive them. At the hospice, the chaplain's duty is to talk to these people and reassure them that AIDS is not a punishment from God but just a disease. In such situations, team work of doctors, nurses and spiritual carers may result in resolution of fears and relief of problems or symptoms, leading to death marked by peace of mind instead of conflict.

As followers of Christ who said: 'I came that they may have life, and have it abundantly', (Dube, 2005:72). Christians are expected to give help to people with AIDS by taking care of their material needs and providing companionship for them. This involves helping them to face death without fear (Cosstick 1987: 80). Many people both at home and in hospitals face death alone with no one by their side partly because of stigmatization. In hospitals AIDS patients are often left alone with less care and attention from both nurses and doctors. This could be because of lack of personnel or just negligence. Sick people need other people they can trust to talk about their illnesses, but they just find themselves staring at the walls which symbolize no hope of life. Kubler-Ross (1972) postulates that many of these patients need to break this monotony by having someone (chaplain or nurse) by the bed side to share their grief and pain with. According to Kubler-Ross (*ibid.*), one patient in hospital asked to talk to someone she really had trust in; she even exclaimed that 'if only I can speak to him, I would die smiling.' This shows how meaningful relations established with patients can bring hope and happiness to them. Kubler-Ross (*ibid.*) still postulates that some of these AIDS patients, whether in hospital or at home,

desperately need human care from their families, doctors and nurses during their agonizing hours. But at times, it appears doctors and nurses are too busy with other patients while family members are also busy looking for food and money. Therefore, the part of companionship is left out. This is the part that should be filled in by chaplains and other religious people to bring back hope, love and happiness in these patients.

In hospices, the pastoral care or the spiritual part is given by a priest or religious sisters and brothers. Other people who offer solace to patients are counsellors as they do post-test counselling. Post-test counselling plays an important role in the recovery and acceptance of one's ailment. Patients find it easier and lighter to share their fears and anxieties with priests, especially when the disease reaches an advanced stage. Soulen (1978) states that patients can become childish and would want to have someone around them to talk to and listen to their fears, pain and isolation. It is, therefore, the duty of the pastoral care team to offer companionship to these helpless souls so that as they pass on, they die with joy and dignity. Kirkpatrick (1988:42) would consider them to be dying into the completeness of life. The priest or chaplain has a duty to lead the patient into taking a journey into 'healing unto death'. Patients making this journey need constant assurance that they will be as free as possible of pain, dying with dignity, surrounded by the most significant people in their life, and that they will find some answer to the question, 'what happens to me when I die?' (Kirkpatrick, 1988:60).

The chaplain has the duty of creating awareness in the patients that no one is excluded from the love of God. The other important thing that patients with AIDS need is the affirmative act of authentication to themselves that they are of value even when they are dying. Caring for the dying is a very demanding and emotionally exhausting experience for we neither want to consider death for ourselves nor do we want to be with persons who are dying. The first matter of importance in working with the dying then is to accept the reality of death. Those who give hospice care, therefore, should be ready to accept death first and then, they will be able to help those dying from AIDS. To a large extent, the hospice care-givers do meet patients who are actually in denial but most importantly they should help them come to terms with the disease rather than force patients to accept death. In Zambia, the majority of patients receive



hospice care in their homes due to limited space in established institutions. It is important to let the family take note of the patient's moods. Hospice offers hope to patients and helps them to attain a sense of well being, which enables them to shift that focus of care to the quality of life (Linn & Linn, 1978). Another important aspect of the holistic care approach is the palliative care as seen in the following sub-section.

### **2.6.2. The Palliative Care Approach**

One of the unique features of hospice care is the emphasis on the palliative care approach. Palliative care is the medical specialty focused on relief of the pain, stress and other debilitating symptoms of serious illness without removing its cause (<http://www.who.int/cancer/palliative/definition/en/> accessed on 23<sup>rd</sup> March, 2010). Many modern medicines, even the antiretroviral drugs, just palliate (ease) the pain but do not cure the illness. Palliative care is not dependent on prognosis and can be delivered at the same time as treatment that is meant to cure somebody. The goal is to relieve suffering and provide the best possible quality of life for patients and their families. Watson *et. al.*, (2006) state that palliative care that is used in the hospices is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the presentation and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.

At the moment, the most effective palliative care is the antiretroviral therapy. The ARVs aim to suppress the viral activity, hence preventing the development of the illness by maintaining the integrity of the body's immune system. According to Smith and McDonagh (2003), huge advances in drug technology saw the introduction of Highly Active Anti Retroviral Therapies (HAART) or a combination therapy in mid to late 1990's. But these drugs were not easy to access due to the high price at which they were sold. Poor people could not manage buying them and as a result, many deaths occurred. These drugs are able to reduce the viral load to undetectable levels and have had a dramatic effect on both the quality and life expectancy of those who are infected.

Through CHAZ, hospices help patients to access these drugs which have since 2003 been offered free to patients in Zambia. Many patients, who, prior to commencing

HAART, were bedridden and confronting imminent death, have, in a few short months, been subsequently restored to good health and have been able to resume active working and social lives (*ibid*). Therefore, in these instances, living with HIV has changed from living with an impending life-threatening infection to living with a chronic yet manageable condition.

However, it should be noted that HAART is not a cure and a number of people do not respond to this treatment. Those taking these drugs have to observe a strict treatment regime which can be very disruptive. The regime involves a daily intake and taken at the same time each day for life. The hospice management through the healing ministry sees to it that patients on HAART adhere to their medication without disruptions. Clinical studies as purported by Smith and McDonagh (2003) have shown that unless the treatment is taken as prescribed, resistance to the drug can develop. Resistance to the drugs can also be passed on to both uninfected and infected sexual partners.

Palliative care is not a one-size-fits-all approach. Patients have a range of diseases and respond differently to treatment options. For instance, some patients on antiretroviral therapy react differently to treatment. A key benefit of palliative care is that it customises treatment to meet the individual needs of each patient. It relieves symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty with sleeping. It helps patients gain strength and carry on with daily life. It improves their ability to tolerate medical treatments. Furthermore, it helps them better understand their choices for care (Doyle, 2006: 34). Overall, palliative care offers patients the best possible quality of life during their illness.

Apart from palliative care through drugs, hospices have also developed a palliative care programme through food and nutrition. Food is the most important drug in the fight against HIV and AIDS. Reports from poor countries indicate that the reality for many people living with HIV is that they are malnourished (Smith and McDonagh, 2003). Simon Chanda Fikansa, the then Deputy Director of the Ndola Home-Based Care programme, when interviewed in 1999 on Channel 4TV in the United Kingdom, about the lack of essential drugs for the treatment of people with HIV, responded that in fact what people needed mostly was food because they were hungry. He asked:

‘What is the point of giving people sophisticated drugs when they will die from hunger?’ (*ibid*).

This is true of those patients taking tuberculosis (TB) drugs; these drugs improve the patient’s appetite but if there is no food to satisfy the hunger, then the patients stop taking the drugs because the distress caused by hunger is worse than the illness itself. James Morris, then United Nations Special Envoy for Southern Africa, commented: ‘The first thing poor families affected by AIDS ask for is not cash or drugs; it is food and, therefore, food has to be one of the weapons in the arsenal against this disease.’(*ibid*). That is the main reason why the Catholic Church, through its healing ministry and taking a holistic approach to the fight against AIDS, has decided to provide food and drugs to the sick through the hospice institutions and the home based care programmes.

Palliative care benefits both patients and their families and that is the reason why it has been adopted in hospice care. Palliative care is given by a team of experts: nurses and trained care-givers, relatives to the patient and local volunteers who have been given special nursing training to provide simple basic nursing skills (Merriman 2006:34). Along with symptom management, communication and support for the family are the main goals. The team helps patients and families make medical decisions and choose treatments that are in line with their goals.

However, palliative care is not the same as hospice care. Palliative care may be provided at any time during a person’s illness, even from the time of diagnosis. For instance, those people who choose to go for an early HIV test may choose to seek palliative care just when the symptoms start to occur. In addition, palliative care may be given at the same time as curative treatment. Nevertheless, hospice care always provides palliative care. Hospice care is focused on terminally ill patients who no longer seek treatment to cure them and who are expected to live for about six months or less. This was the case with cancer patients, who were taken to hospices after the doctors had confirmed that they had few months to live. But this has not been the case with the AIDS patients, for they are given care which may assist them to regain their strength and become helpful to their families and community at large.

Sims and Moss (1995:5) postulate that hospices offer twenty-four hours multi-professional care, that is, time for patients and their families, time to care, time to listen or just time to be there. The AIDS patients and their families need all the attention that they can get to feel they are human and that they are being cared for and loved. According to Watson *et. al.*, (2006:35), palliative care should be an integral part of the comprehensive care and support for people living with HIV and AIDS as well as cancer patients. It should be provided as a continuum of care from the time of diagnosis of any of these incurable diseases until the end of life. Palliative care, including symptom management should be applied as early as possible in the case of HIV and AIDS. It should be noted that the terminal stages of the disease for those living with HIV can be extremely distressing for those who are sick, their families and the care-givers. The nature of the disease often means that the person is living with numerous illnesses and conditions. As well as being very emaciated and weak, the patient can also have difficulties in breathing, suffer chronic diarrhoea and be in continuous pain. Effective and compassionate care is essential. Although there are many examples of exemplary palliative care projects and numerous quality home based care programmes across the world, it is still the case that too many people die without adequate symptom control and relief. Smith and McDonagh (2003) associate this partly to a lack of education about palliative care principles and skills but it is all too often a result of the lack of availability of essential medicines. The dying patients are supposed to be given the kind of treatment and care responses, which seek to lessen the impact of the secondary effects of HIV infection. That is, treating conditions and illnesses that result from HIV infection.

The combination of both pastoral and palliative care adopted by hospices offers this holistic care. As hospices are a new phenomenon in Zambia, very few people know about them or have access to hospice care. In these hospices, the Catholic Church over the years has highly recommended the 'ABC approach', that is, **A**bstain from sex (whether until a permanent commitment is made, by way of delaying the age of first sexual encounter or as a conscious choice by discordant couples); **B**e faithful and mutually so to your one sexual partner; Use a **C**ondom (Smith and McDonagh, 2003). Condoms can only be used as the last option and use of condoms should not be encouraged as it only leads to more promiscuity. Recently, Pope Benedict XVI (BBC News, 20 November 2010) recommended that condoms could be used in certain

instances to prevent the spread of AIDS (thus to save lives) in the fight against AIDS. The government encourages the use of condoms and behavioural change.

### **2.7. Funding and Running of Hospices**

Funding for hospices and palliative services vary. In the United Kingdom, all palliative care is offered free to patients and their families. It is offered either through National Health Service or through charities working in partnership with the social health services (<http://www.who.int/cancer/palliative/definition/en/> accessed on 23rd March 2010). In Zambia, hospice care is also offered freely to all patients and their family members. They only get assistance through charitable organizations, usually by asking for assistance from abroad.

The Churches Health Association of Zambia (CHAZ) also helps in providing finance and medication to hospices across the country, although not enough to run the institutions. Palliative Care Association of Zambia (PCAZ) also contributes some finances and training though limited.

Hospices in Zambia are run by religious sisters and were established by them. The sisters and priests are not working alone but are helped by volunteers, nurses, doctors and churches. It should be noted that the church first started with the Home-Based Care Programme in the quest of helping AIDS patients. This programme worked for some time and even hospitals referred terminal cases to home-based care. This was supported by the Church in one of the pastoral letters by the bishops of Zambia (Komakoma, 1988:20) which ‘urge the proper treatment of AIDS victims; there should be care for them preferably in their families where the local community can be involved.’ They should not be isolated but given medical, moral and spiritual support. It reaffirmed the concept of extended family that was present in traditional African/Zambian societies and values of communal responsibility for looking after the sick and weak ones in the community. Then the church realized that in some cases, this would not be possible due to poverty levels and urbanization. Consequently, in another pastoral letter called ‘Choose to Live,’ the bishops (ibid: 214) state that, ‘in fact, not all families may be able to provide for their sick members, especially in the later stages of the disease. We foresee the need to open hospices to receive AIDS victims, not to isolate them but to give them better medical, moral and spiritual

support.’ These should be small-scale and decentralized so that relatives and the local community may be involved and should be manned to a large extent by volunteers.

In Home-Based Care run by Sisters of Mercy of St. Charles Borromeo, nutrition and pain, weakness and confusion were found to be difficult problems to manage in the community. A call for special places where these patients could be cared for was proposed, hence the birth of hospices. Hospices focused on training nurses and carers, who were given special training on how to care for patients with such acute problems, (Doyle and MacDonald, 1998:188). Hence, the first hospice was opened in 1992 to work side by side with home based care while using the church building to care for the critically ill patients. In 1997, they started using the hospice facilities at their own building. Thus, the first hospice to be opened was Mother of Mercy Hospice in Chilanga. More hospices were opened in Lusaka and other parts of the country. In Lusaka, where research was carried out, there are five hospices: Mother of Mercy in Chilanga, Our Lady’s in Kalingalinga, Mother Teresa in Mtendere, a non-Catholic one in Kamwala and Flying Angels in N’gombe which offer services to these densely populated communities.

### **2.7.1. The Mother of Mercy Hospice**

As already alluded to above the hospices started as an extension of the home-based care services in Chilanga area in 1992, and finally opened as a hospice in 1997 by the Sisters of Mercy of St. Charles Borromeo. The hospice is run and managed by the same sisters with the help of two medical doctors, four nurses, one clinical officer and several care givers. The number of full time staff was twenty-five at the time of the research.

The hospice provides palliative care services to its patients and family members. In March 2005, the hospice formed the Mother of Mercy Hospice Trust in order to assist with the operations of the hospice and to raise its profile for the purpose of raising the much needed funds. In January 2006, the hospice was granted charitable status by Zambia Revenue Authority (ZRA), which is a great help towards fund-raising with corporate donors in particular.

In 2008, the hospice opened an ARV distribution centre. The centre is a joint initiative between CHAZ (Churches Health Association of Zambia) and the hospice together with the Japanese Government whose 'Grass Roots' community care programme provided the funds to construct the building as well as supplying some equipment.

The hospice also houses a community school which offers free primary level education to orphans who have lost their parents to HIV and AIDS and other vulnerable children in the community. These children receive nutritional supplements from the World Food Programme. They also receive school requisites and clothes among others when such donations are available. The school currently has an enrolment of over 350 orphans and vulnerable children.

The hospice offers free, voluntary counselling and testing services to people. Those that are found to be HIV positive are referred to the Antiretroviral Therapy clinic and the Hospice Clinical officer for further care and medical management of the HIV condition. The hospice offers its services to both adults and children.

### **2.7.2. Our Lady's Hospice**

The hospice was opened in 2003 by the Catholic nuns of Franciscan Missionaries of the Divine Motherhood (FMDM) with the help of Fr. Ernest Wildi. The hospice is situated in Kalingalinga compound. It offers its services to all those who have AIDS and admits adults only.

The hospice also provides palliative care to patients and their family members. The hospice offers Voluntary Counseling and Testing services to people. They have clinic days when both adults and children come to get medication and check-up. Medication includes antiretroviral therapy tablets to help prolong people's lives as well as tuberculosis tablets.

Our Lady's hospice is bigger than Chilanga's Mother of Mercy. It has a bed space of thirty with five houses. It has sixty-five members of staff. It has a bigger area than the other two visited and has a vegetable garden to sustain it. It has a training conference room, kitchen and a big orchard where they get fruits for their patients. The hospice has a high cost house which is mostly self-contained. Hospices play a special role

with care givers during the end of life period, providing compassionate service at many levels, medical, emotional and spiritual. Thus, the hospice is said to offer holistic care to its patients and families. Doka and Davidson (2001:v) affirms that hospice care if well managed really offers holistic care to the infected and affected members by looking at all sides of human needs.

### **Summary**

The insights into the care gained from the literature provide a profile of how the holistic care is supposed to be offered in hospices. The above literature revealed that hospice care as a philosophy is of great help to the sick and their families. It has also revealed that pastoral care plays a major role in caring for the patients' spiritual needs as well as psychological needs.

The services offered through palliative care programmes help the AIDS patients and their families cope with the sufferings that they go through. Palliative care programme involves giving a good nutrition to the patients and medication. This helps the relatives focus on offering their sick relatives love that they need instead of going round looking for food. The literature has also revealed that, if hospice care is well executed, it can help patients live long and become useful in the society. It also reveals that the staffs offering hospice and palliative care need to be trained in palliative care for good results.

The research methodology for this study will be discussed in chapter three.



## CHAPTER 3

### METHODOLOGY

#### **3.0. Overview**

In this chapter, the researcher describes the research design and methods that were used in the study. It endeavors to highlight the research paradigm applied in the study, the research design, population, study location, sample size, sampling procedure, research instruments, credibility and trustworthiness, transferability, dependability and ethical issues. It also shows how data, which was guided by the research questions given in chapter one was collected and analysed.

#### **3.1. Research Design**

The desire for an in-depth understanding prompted the researcher to adopt an exploratory case study design. Yin (1989:23) defines a case study as ‘an empirical inquiry that investigates a contemporary phenomenon within its real life context, when the boundaries between phenomenon and context are not clearly evident and in which multiple sources of evidence are used.’ Similarly, Sternhouse (1985:645) defines a case study method as involving ‘collection and recording of data about a case or cases and the preparation of a report or presentation of the case.’ It can also be said to be an ‘approach to research which utilizes ethnographic research methods to obtain and portray a ‘rich’ descriptive account of meaning and experiences of people in an identified social setting (Chiyongo 2010:95). That entity being studied is studied intensively, meaning that there is an in-depth account of that entity. The researcher used the case study because of its ability of presenting real life situations of the case in question and providing a holistic account of phenomenon and insights that assist the reader to visualise the experiences of people in the phenomenon (Merriman, 1998; Cohen *et.al.*, 2007).

However, it is necessary to acknowledge that case studies have been criticised for their inability to generalise findings. Nevertheless, some scholars (Bryman, 2004 and Yin, 1989) have argued that findings obtained in the study of one institution or place can be transferable to other institutions or places with similar situations as has been described. Moreover, the generalisation is made to the theoretical propositions, not the population. This means that generalisation is not ascribed to the frequencies of

sample, but rather, to what has emerged as a grounded theory after analysis has been made (Yin, 1989). It is in this line that the researcher applied the case study design in this research.

In this respect, the researcher chose to look at three hospices, which were studied as one case. As the case study usually happens in natural settings and carries a feature of holistic view, the researcher sought to find out about this new phenomenon of hospice care provision by the Catholic Church in Zambia. The research used both primary and secondary sources of data to come up with good results and recommendations regarding the care being offered in hospices. The primary sources came from interviews and observations, while secondary information was taken from the internet, books and pamphlets.

### **3.2. Qualitative Approach**

A qualitative approach was employed in order to satisfactorily answer the research questions posed in this study. In this study the qualitative method used consisted of three kinds of data collection: (1) in-depth, open-ended interviews, (2) direct observation, and (3) written documents.

According to Leedy and Ormrod (2005), to answer research questions, we cannot skim across the surface. We must dig deep to get a complete understanding of the phenomenon we are studying. In qualitative research, we do indeed dig deep: we collect numerous forms of data and examine them from various angles to construct a rich and meaningful picture of a complex, multifaceted situation.

The qualitative approach was chosen to enable the researcher recognize many aspects related to the new concept of hospice. It enabled the participants to discuss freely and give valuable information. In this research, a few documents available were examined in addition to interviews and observations.

Since this research was mainly concerned with care and treatment the hospices provide to patients, the researcher was interested in knowing how these hospices provided holistic care to their patients. At the time of this research, there were claims that hospices provided holistic care to patients and their family members. Therefore, a

qualitative paradigm was used to verify the claim as the researcher had intentions of building a complex and holistic picture. Analyse words, report detailed views of information, and conduct the study in a natural setting, which was a hospice. According to Chiyongo (2010:94) qualitative methods have a tendency to be linked to the subjective nature of social realism which enables researchers to study cases in detail.

### **3.3. Study Location**

This involves the site where the research was carried out. Kombo and Tromp (2006: 75) state that the site influences the usefulness of the information produced. In this case, the site that was chosen was Lusaka urban, Zambia. It was chosen because it has the largest number of hospices which were within reach for the researcher. Another reason is that in Zambia, hospices were first introduced in Lusaka and so have been in existence for a longer time there than elsewhere.

### **3.4. Target Population**

A population is a group of individuals, objects or items from which samples are taken for measurement (Kombo and Tromp, 2006:76). Bless and Achola (1988:59) also agree that a population is the entire set of objects and events or groups of people which is the object of research and about which the researcher wants to determine some characteristics. The participants of the study were drawn from the three hospices and comprised administrators, chaplains, nurses, care-givers and family members or bedsiders. These were the people considered to have experience on hospices and could give valuable information.

According to Barbie and Mouton (2001: 173), a population is defined as ‘the theoretically specified aggregation of study elements.’ Parahoo (1997:218) also describes a study population as ‘the total number of units from which data can potentially be collected.’ The units may be individuals, organisations, events or artifacts.

### **3.5. Sample Size**

A sample is a group of subjects or situations selected from a larger population, (White 2005:252). This is affirmed by Bless and Achola (1988: 60) who defined a sample as

the sub-set of the whole population which is actually investigated by a researcher and whose characteristics will be generalized to the entire population. Research conclusions and generalizations are only as good as the sample they are based on. The way in which a researcher selects subjects for a study will determine how one is able to generalize the results of the study.

The sample size consisted of chaplains, administrators, nurses, care-givers and bedsiders or family members found in the three hospices. The total number of the sample was 60. However, the researcher only managed to interview 45 participants.

### **3.6. Sampling Procedure**

Sampling is the procedure a researcher uses to gather people, places or things to study. It is a process of selecting a number of individuals or objects from a population such that the selected group contains elements representative of the characteristics found in the entire group (Kombo and Tromp, 2006). A sample is a finite part of a statistical population whose properties are studied to gain information about the whole. It is a set of respondents selected from a larger population. The researcher employed purposive sampling design in this study in order to come up with the most required information. Usually, purposive sampling involves choosing participants considered to be knowledgeable and informed about the topic of the study (McMillan and Schumacher, 2006). Therefore, all respondents in this study were picked purposively. In this case, purposive sampling was used because the selected participants were in a position to discuss issues concerning the care in hospices. The researcher purposively targeted a group of people believed to be reliable for the study. Leedy and Ormrod (2005) argue that purposive sampling technique ensures that participants with the needed information about the topic are selected. The researcher noted that in purposive sampling, rich information rather than the number of participants was important.

### **3.7. Research Instruments**

Kombo and Tromp (2006:99) describe data collection as the gathering of information in order to serve or prove some facts. In data collection, the researcher must have a clear understanding of what they hope to obtain and how it is to be obtained. Data collection is vital in everyday living. For instance, the government of any given nation

would need to know the population of the country in order to effectively plan. In data collection, the researcher must have a clear vision of the instruments to be used, the respondents and the selected area. Some instruments like questionnaires to illiterate people may prove to be ineffective. Therefore, it is important that the researcher chooses appropriate instruments in collecting valuable information.

In a qualitative research, many instruments can be used. In this particular research, the researcher used interviews, observations and document reviews as data collection methods. In the quest of acquiring in-depth information, the researcher used these three methods. The researcher also ventured into participant observation in order to collect first hand information and gain more insight. Observation and interviews are the most common data collection methods in qualitative studies.

### **3.8. Interviews**

According to White (2005:143), an interview ‘provides access to what is inside a person’s head, makes it possible to measure what a person knows (knowledge or information), what a person likes or dislikes (values and preferences) and what a person thinks (attitudes and beliefs).’ Interviews may be structured or unstructured. The researcher used the unstructured interview guide to enable extraction of more information. This strategy was preferred because it enables probing and illuminating what has been said by the respondent by asking for further clarifications there and then. The order in which the questions were asked depended on the order of the conversation. During the interviews, the researcher used both the English and Chinyanja languages to extract information from participants.

Unstructured interviews allow the researcher to be flexible and free to move around. In short, they are an open-situation and suitable for conducting qualitative studies. According to Sidhu (2003: 148), unstructured interviews are flexible, have few restrictions and are based on the participants’ answers. Notes were taken by the interviewer during the interviews. Unfortunately, due to lack of equipment and some ethical considerations at play, these sessions were not tape-recorded. However, this did not affect verification of data collected in the sense that the researcher carefully noted every word said by respondents in her notebook.

### **3.9. Participant Observation**

Participant observation is a strategy where the researcher actually lives and works among the people being observed or studied. The researcher used this in order to verify the information that participants gave during the interviews. According to LeCompte and Preissle (1993: 195), ‘participant observers live as much as possible with the individuals they are investigating, trying to blend in and take part in their daily activities. The participant observer watches what people do, listens to what they say, and interacts with the participants.’ White (2005: 158) postulates that the purpose of observational data is to describe:

- a) The setting that was observed;
- b) The activities of the participants that took place in that setting; and
- c) The people who participated in those activities and their contributions.

In this study, participant observation was applied as a data collection instrument because the researcher was interested in seeing the care that was being offered to the HIV and AIDS patients. Care was taken to ensure that the researcher did not dwell on personal interpretations but rather make comparisons of the observations with those of the participants. The researcher did participant observation by actually doing work at the hospice in the wards such as spreading beds, helping patients with bed pans, counselling those who were actually having problems in coming to terms with the disease, and most of all, by being present to those patients who sought her presence. The researcher also attended weekly meetings where reviews of the previous week’s work were discussed.

### **3.10. Document Analysis**

Document reviews were also used to support the interview method and observations which were the main data collection strategies. Among the documents reviewed were pamphlets and some statements on notice boards (see Appendix). It was important to analyse the contents of those documents so as to verify the information obtained using other methods of data collection. According to Gay (1996:244), the use of other data collection strategies (triangulation) act as a safeguard to detect serious observer effect too.

### **3.11. Data Analysis**

In qualitative approach, data analysis proceeds in tandem with data collection (Yin, 1994). According to Kombo and Tromp (2006), data analysis refers to examining what has been collected in a survey and making deductions and inferences. It involves scrutinizing the acquired information and drawing conclusions. In qualitative study, the raw data consists of words and sometimes visual materials such as photographs. Furthermore, the data includes primary field notes often supplemented by documents and interview transcripts. This has been approved by Rudestam & Newton (1992: 31), who pointed out that ‘qualitative implies that data are in the form of words as opposed to numbers.’ According to White (2008), data analysis is the climax of the research and it involves selecting, categorizing, comparing, synthesizing and interpreting information collected to provide explanations of the single phenomenon of interest.

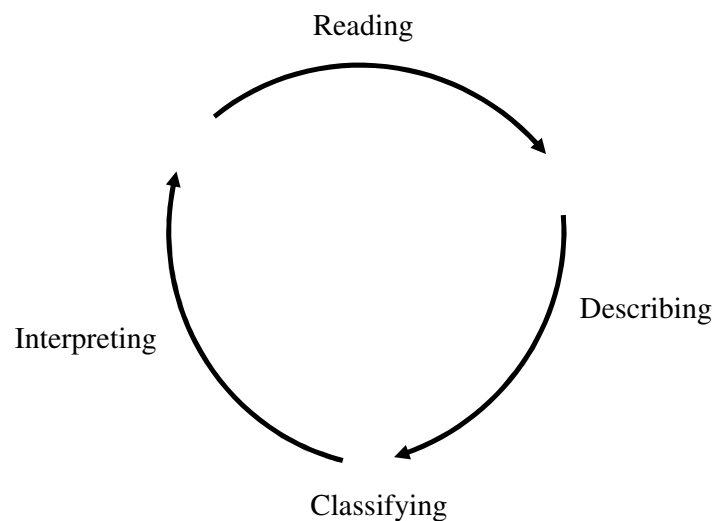
In this study, the researcher collected documents related to care given in hospices so as to be able to relate the findings with what is contained in the documents. According to Gay (1996: 243), ‘observation is often supplemented by the collection of relevant documents (minutes of meetings and memoranda) and in-depth, unstructured interviews.’ In view of the above statement, the researcher collected more facts on the care of the sick through content analysis reviewing documents and attending meetings that were held every week at the hospice where research was being undertaken. The meetings involved review of the previous week’s work. The matron was always alert to criticise when some care-giver members did not perform according to the set standards of the hospice. She also gave praise to those who did well and encouraged them to continue taking care of the patients. The duty rota for the week was also read out during such meetings.

Data was analyzed in tandem with data collection. This is in line with White (2005: 186), who says that analysis of qualitative data takes place simultaneously with data collection, the first step being that of managing the data so that they can be studied. Furthermore, he states that the cyclical process of data analysis, as shown in the diagram below, focuses on:

- a) Becoming familiar with the data and identifying main themes in them (reading);

- b) Examining the data in-depth so as to provide detailed descriptions of the settings, participants and activities (describing);
- c) Categorizing and coding pieces of data and physically grouping them into themes (classifying); and
- d) Interpreting and synthesizing the organised data into general conclusions (interpreting).

*Steps in analysing qualitative data*



*Figure 3.1: Source: (White, 2005:186)*

Data which was generated in this study from the interviews, observations and document analysis was categorised and arranged according to key concepts which corresponded with research questions, and was presented in a narrative manner. The process of data analysis was done manually. It involved comparing what was said and what was observed with the support of what had been gathered from reading literature related to the topic.

### **3.12. Credibility and Trustworthiness of Research Findings**

Credibility is elucidated as a process of establishing how believable or true the findings are from the participants' perspective (Trochim, 2001). While credibility and trustworthiness are considered important elements of research, how practical such steps are, has been questioned. It has been argued that even when a researcher gives a



participant his/her findings to validate, at the end of the day the presentations of the findings will depend on the researcher's impression and predilection (Bryman, 2004). Aside from what has been said, credibility and trustworthiness in this study were provided by continuously comparing what was said with what was observed. The use of multiple data collection procedures also contributed to the credibility of the findings.

### **3.13. Transferability**

By transferability is meant the degree to which results of the research can be generalised or transferred to another similar context or setting (Bryman, 2004; Trochim, 2001). As already pointed out above, case studies have been criticised for their inability to generalise the research findings due to the uniqueness of the social world of study and small size of the sample. It should, however, be argued that transferability of research outcome is possible by comparing the findings with other hospices in the country. In this study, transferability may be made possible by the detailed description of field experiences covering the research methods and all that occurred in the field during and after research.

### **3.14. Dependability**

Dependability involves repeating the research with the same participants, same context but at different times in order to replicate the findings. Like in transferability, dependability is difficult to achieve in a case study due to small size of the sample and uniqueness of the phenomenon studied. Most importantly, the change of time has repercussions on the findings as it may alter the perceptions participants have had on the phenomenon.

However, along with the broad spectrum of data collection techniques, the insider perspective enabled the researcher to assess contextual factors that influenced the respondents and account for variations in their responses. This helped the researcher to make a good judgement of what she had been told and observed. Therefore, dependability in this study could be made possible by scrutinising verbatim interview transcripts and use of actual words uttered by the respondent. Pertinent to the issue is the detailed explanation of the whole process of data collection that the researcher has given and the use of multiple techniques to collect data.

### **3.15. Ethical Issues**

In order to collect the much needed information, it is usually important to put into consideration the participants. An introductory letter was sought from the assistant Dean, Post Graduate Studies at the University of Zambia, School of Education. In a special case, as requested by hospice administration, another letter was obtained from the Department of Religious Studies. To conduct the study, the researcher sought and obtained permission from the hospice administration, chaplain and nurses from the three hospices visited. That was in agreement with Kombo and Tromp (2006: 98) who emphasize the fact that a researcher requires a research permit before embarking on the study. Ethical considerations in this area included the patients' right to privacy and the need for confidentiality. Being a trained psychosocial counsellor, the researcher took advantage of keeping confidentiality and was able to be allowed to have an interview with the patient's relatives and in some cases the patients themselves. The patients were interviewed to obtain valuable information about how they were cared for.

### **Summary**

The just ended chapter has highlighted a number of procedures, which the researcher followed in conducting this study. An indication is given about the research paradigm used, the design, the methods of data collection and how data was collected and analysed. The data collection methods comprised in-depth interviews, participant observations and the collection and analysis of relevant documents. The analysis of data was done simultaneously with data collection. The researcher has also explained issues of ethical considerations. It was done in order to verify that the study was conducted with due ethical considerations.

Chapter 4 will deal with the research findings.

## **CHAPTER 4**

### **PRESENTATION OF THE FINDINGS**

#### **4.0. Overview**

This chapter presents results of the interviews carried out in hospices around Lusaka, namely, Our Lady's, Mother of Mercy and Mother Teresa's orphanage and hospices. The results are presented under sub-headings derived from research questions and from interview guides. These include: holistic care being offered in hospices, the practical part of holistic care, whether it is important to have a chaplain at a hospice, what help the family is getting and the challenges being faced by hospices, patients and family members in the provision and accessing of holistic care. To achieve the objectives, the discussion has mainly focused on interview guides and research questions.

#### **4.1. Respondent's Profile**

The respondents the researcher interviewed comprised two priests from Our Lady's Hospice where one of them is the Chaplain, three administrators or Sisters in-charge of the three hospices, five nurses and the rest being family members and care-givers in groups. All these respondents were from the hospices the researcher visited. The researcher has mentioned the names of the chaplains, administrators, nurses and some caregivers but has left out the names of the patients and family members for anonymity's sake.

#### **4.2. The Nature of the Care Offered at Hospices to Patients and Families**

The hospice administrators from the three hospices reported that hospices offered palliative care to their patients. They provided palliative care through intense care of the seriously ill, thus managing pain by giving strong pain killers to those experiencing pain. Palliative care involves taking care of the patient through pain control, pastoral counselling, provision of antiretroviral therapy and giving a good nutritional diet to the patients. The matron, Miss Shamoya from our lady's hospice revealed that in controlling pain as a key component of palliative care the patient is the most important member of the team as he or she is the one who knows the severity of the pain. They also provided antiretroviral therapy through the holistic care model,

a model which involves giving counselling services to family members and patients too. They further mentioned that hospices offer inter-disciplinary care to the terminally ill patients and their families by the management of pain and symptoms. *'We offer palliative care to our patients and try to give them a dignified death'*, as revealed by Sr. Kay from our Lady's. This service is usually provided by the nurses. They also have nutritionists who supplement nutrition and vitamins to the patients. In case of bereavement, a team of experts with the Chaplain in the forefront offers counselling services to the bereaved family.

Chaplains and religious sisters also provide psychological and spiritual support both to the patients and family members. Apart from Our Lady's, the other two hospices have special units for those orphaned as a result of AIDS. For instance, the sister-in-charge from Mother of Mercy Hospice, sister Jeremia revealed that a school has been built for orphans at Mother of Mercy Hospice in Chilanga while in Mtendere, Mother Teresa even provides shelter to those orphaned starting from a day old to about sixteen years of age as revealed by Sr. Lynette. The training in the care of the sick is being provided by care-givers to the family members. Counsellors also give training on HIV and AIDS prevention. The presence of a matron at Kalingalinga's Our Lady's hospice makes it possible to provide training to the care givers.

#### **4.3. The Services Rendered to the Patients and their Families**

On the services rendered to patients and their families the chaplain's importance has also been pointed out as he plays an important role in the recovery or giving a dignified death. Most of the patients and family members reported that the hospices were offering many services that were missing in hospitals and clinics. The patients mentioned that the hospice offered a clean environment which included clean linen. One patient mentioned that she was able to recover because the bed sheets and blankets she was covered in were clean. *'I feel very well now, better than when I was at the University Teaching Hospital (UTH) where the linen was not up to this standard they have here. I also don't feel bad when I go to the toilet because they are always kept clean just like at home,'* said one male patient from Mother of Mercy.

During interviews, it was learnt that hospices also feed their patients very well with a balanced diet. The patients were also given a choice to choose the kind of food they

wanted to eat on a particular day and at what time. It was also revealed that, although the menu was being followed, there was some flexibility to suit with the nutritionist's advice on what the patient should eat. This provided some kind of respect to the patient's rights to good palliative food care as stipulated in the rights of patients. A nutritionist by the name of Concilia from Our Lady's made the following comment:

The food that the patients demand for at home is usually difficult to obtain but here we are able to have them fed because of the availability of the food. We try to give them what they ask for but we also bear in mind a balanced diet. Mostly they ask for fruits, soft food like custard porridge and soft drinks which are difficult to provide at home. We feed them five times per day with the main meals being breakfast, lunch and supper.

The care-givers indicated that the patients are usually fed five times a day. The nutritionist told the researcher that the patients are fed on a balanced diet to enable them gain weight and recover quickly. Even those who are very sick are usually fed on light meals like fruit juice and some custard porridge to enable them die with dignity. There were three big gardens and orchards for vegetables and fruits to enable patients have a balanced diet. Sr. Lynnette mentioned that fruits are given to patients at 11:00 hours and 17:00 hours.

Another service that the hospices offered was medication. The interviewees, especially bedsiders from Our Lady's expressed happiness towards the medical services that they received from the hospices. It was learned that the patients received all the drugs that they required without being given prescriptions to go and buy from chemists. The hospices had everything in stock, starting from simple panadol to strong pain killers like morphine to handle severe pain. There were only rare cases when relatives would be told to buy medicines from chemists and that usually happened if the patient could not wait for that drug to be purchased. Most of the patients and family members told the researcher that they would prefer to be admitted to a hospice than to a hospital because everything was being provided in the hospices. The researcher also found out that patients were being treated with dignity and extra care. For example, those who needed antiretroviral treatment were instructed carefully on how the drugs were to be taken and care-givers would come to remind the

bedsiders to administer medication. A bedsider from Mother of Mercy hospice said this concerning administration of medication: *'when we came in, my patient was not able to swallow a pill, so the care-giver taught me to crush and give my patient at stipulated times until my patient now is able to swallow on her own.'* Mine is still not able to feed himself and I can't feed him either but a caregiver has been assigned to give the service by the matron. She comes in at specific times to give him light food" said a bedsider from high cost at our Lady's.

Those recovered patients found at Mother Teresa said that they were being assisted by the sisters in terms of giving them work around the hospice to enable them make a living. *We go home during Christmas and Easter with food for our children and we eat from here.* In terms of spiritual counselling and other services, the interviews revealed that the patients and families received these from the priests, counsellors and the sisters around. One family member from Mother of Mercy had this to say concerning spiritual counselling and other services rendered by hospices:

Other services that we receive from the hospices are spiritual counselling and physiotherapy. In terms of spiritual counselling, the priest comes in to talk to us about the love God has for us.' In our case, when we came in, my focus was only to receive medication, but I realized that my patient needed spiritual counselling which I could not provide. The priest came in and talked to my patient about the love of God and his forgiveness. I saw a smile for the first time on my patient's face since she got ill and to me that was care at its highest peak.

The priests themselves revealed that both patients and family members needed spiritual counseling to help them cope with the disease. The Chaplain, Father Wildi from Our Lady's Hospice further stated that some patients, who are Catholics, are usually given the sacraments right there in the wards. Mass is usually conducted twice in a week to pray for the patients and their family members as well as for those who assist with donations to keep the hospices running. Some patients talked to said that they were very happy that they had a chance to listen to the word of God even on their death beds.

Other services provided to the patients included physiotherapy. The physiotherapists interviewed said that patients loved to be massaged as that proved that they were accepted and not discriminated or regarded as untouchables. Care-givers did the massaging as well during bed baths to those who had no one to bath them. Joshua, the physiotherapists also said that exercises helped with mobility and also in relaxation of muscles.

#### **4.3.1 The Importance of a Chaplain at a Hospice**

*'Well since the disease affects the dignity of a human being and the disease is not out there but within, the chaplain is the rightful person to help both the patient and family to face the disease,'* said the father Wildi from Our Lady's Hospice. At the other hospices, the chaplains came three to four times in a week to offer sacraments of the sick, Baptism and the Eucharist to the patients and families. While at Our Lady's the two priests, Fathers Wildi and Walter work every day with the patients. The researcher asked the chaplain Father Wildi, in what way he felt that prayers assisted patients and their families to face death. He explained that he believed in the power of prayer, especially if a patient or family asks for it. *Usually there is joy on the faces of those that are dying as they lie on their beds which is an indication that the patient had accepted the situation.* He said what was important was to help the patient and family to come to terms with death. He went on to say that, it was not good to follow written prayers but to say a spontaneous prayer from the heart according to the context especially when dealing with very ill patients. When asked: Since the hospice does not offer its care to Catholics only, how do you deal with non-Catholics? The Chaplain explained that he had not faced any indifference from the non-Catholics. Both Catholics and non-Catholics accept the help of the Catholic priests. He went on to say that all that the patients needed most was a listening ear and someone who did not stigmatise them but accepted them as they are. Father Walter explained to the researcher who had asked him about the kind of patients that he had come across so far, very sick, slightly sick or dying, he revealed that he had dealt with all the three conditions.

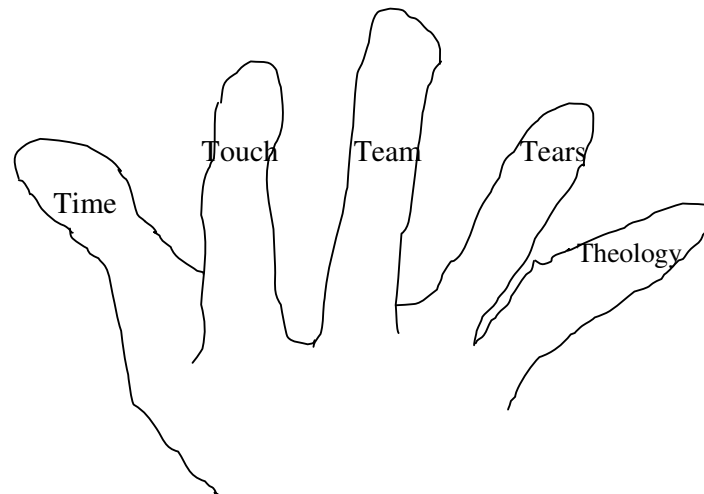
#### **4.4. Care of Patients**

The researcher asked as to who assisted with the care of patients. From the three hospices visited by the researcher, the response to this question was the same. The

family members and administrators' answers were that they were assisted by a team of skilled personnel which included nurses, doctors, sisters, care-givers and the chaplain. Some family members talked to said that the care-givers do a lot of work in terms of the help they give by cleaning the surrounding and teaching the bedsiders how to look after their sick and actually helping by bathing the patients. In view of the above statement one religious sister from the Little Servants of Mary Immaculate (LSMI) found nursing her mother at our lady's had this to say concerning the benefits of holistic care; *"we brought our mother here because we could not give her the nursing care that was agent. She could not swallow food because of stroke and she was discharged from UTH. But when we brought her here she was straight away commenced on a drip she is now recovering her strength and speech, able to respond when one asks her a question. So I feel holistic care being offered here has more benefits to the patients.* The chaplain is also an important person in delivering holistic care to the sick. One chaplain, Father Wildi emphasized team work while administering to the sick by drawing the symbol of a hand where each finger represented a particular **T**, making them the five **Ts** of pastoral care as indicated in figure 4.1 below. The five **Ts** stand for; *team, tears, theology, touch, and time.* There is need to interact with each other when working as a team to save lives or help people accept death.

The diagram below shows the five Ts

*The working culture of a hospice.*



*Figure 4.1: Source: Fr. Ernest Wildi (from Our Lady's Hospice)*



The chaplain explained what each word meant in the care of the sick. The first one was 'team' which meant that the care of the sick has to be done as a team, and then the individuals in a team have to have 'time' to minister to the sick so that they can feel loved and cared for. 'Touch' as the team spends some time with the patients, there is need to hold the patients' hands so that they feel they are not alone or isolated in their pain. 'Tears' in the care of the terminally ill, sometimes when a patient least expected to die, passes away, the care giver would be touched and mourn with the family. Father Wildi from Our Lady's hospice had this to say concerning emotional breakdown: *I actually cried when I learnt that the patient I had been visiting and talking to had actually passed on just after I had left the hospice. I went back to the hospice and mourned with the family.* 'Theology' as used in this context mainly concerns explaining the word of God to the patients and making them realize the love that God has for them. Father Walter a priest at our Lady's revealed that: mass is usually celebrated for the patients and with them, he also revealed that regardless of which denomination the patient belonged to, they always embraced the word of God from a priest as it was part of holistic care provided.

Although nurses were few, they played a very important role in the delivery of quality services to the terminally ill patients. They put up drips and did some counselling sessions to the patients and their families. Some family members interviewed said that the nurses in hospices have a different attitude from the hospital nurses. Those from the hospices had time to chat with patients which helped with acceptance of the illness. According the findings, the benefits of holistic care being provided in hospices are that the patients are brought back to a good health and integrated in their families. For those who are so weak, they are enabled to die a dignified death. The research revealed that more nurses were needed to cope with the growing number of patients.

#### **4.4.1 Help that the Terminally Ill Need**

When HIV has advanced into AIDS, patients are prone to so many ailments, which are known as opportunistic infections that make them experience a lot of pain. As a result, there is need to exercise a lot of patience and tolerance with them. The two virtues need to be exercised because most of the patients have not yet come to terms with the disease. They tend to blame their partners for infecting them and their children. One priest, father Walter remarked: "Those patients who feel that their

partners are to blame are usually advised to focus on their present situation, the healing process and God's forgiveness. We also advise their relatives to tolerate their patients' behaviour and give them the love that they need." Naomi a care giver from our Lady's also narrated how she helped an aggressive patient come to terms with the disease.

I was told by my friends that there was a patient who kept to himself and would respond angrily when talked to. I went in the ward where he was and called him by his name; he immediately pulled off the blanket from his head and answered. I greeted him and asked him what he wanted to eat. He responded quite well because I had gone closer to him to hold his hand. When the food was ready, I took it to him and fed him since he was unable to feed himself. When I was leaving he called me and requested that I bring him a fritter the following day, which I did. From then on, we became friends.

That kind of encounter clearly shows that patients need to be touched reassured that others do care for them. One family member from Mother Theresa revealed that most patients need to be told that the disease is not a punishment from God and so they have to accept their situation. As she sat next to her daughter's bed, she narrated how much help she had received from the sisters around. *"When we came in we talked very little with my daughter who only told me that she was being punished by god with the disease. But the sisters came and talked to her about God's love for us and I saw some change in the attitude."* The chaplain also reported that the patients are usually told that God does not send punishment to his children and so just like Christ suffered and accepted what he went through, they also should accept their situation. Father Wildi revealed that the patients needed companionship which they rarely get at home because their relatives are usually busy looking for food. One interviewee from Mother of Mercy made the following remark concerning companionship at home:

In my case it's difficult to sit and chat with the patient because of other household chores that have to be done especially seeing to it that there's food for the patient. Sometimes I don't know when the patient needs me and what things I can say to make the patient happy. But here, we don't need to worry about food and medication because these are provided and we have been counselled on how to handle the

patients. Our duty is just to sit and chat with them. Here also, spiritual needs are satisfied by the chaplain and many religious people who come to visit them.

However, there were some care-givers who seemed not to be dedicated to their work and made patients complain. As to how long the patients were kept in the hospice, there was a consensus that the patients were usually nursed until they had fully recovered. Others stay only for a short time because they go to the hospice already in a bad condition and so they die. These were responses from the chaplain, administrators and sisters in charge. For those who die, the hospice management would respect the deceased's wish and families are assisted to bury their dead. Others recover and are given work to assist around the hospice. For instance, the researcher found recovered patients at Mother Teresa assisting their friends by spreading beds and preparing meals. Does hospice care continue after being discharged? 'Yes, hospice care usually continues even after the patient has been discharged. One patient from Our Lady's interviewed at the OPD had this to say; "*we are usually advised to come back for medication and checkup; sometimes nurses and caregivers follow us in our homes to see how we are progressing*".

#### **4.5. Challenges Encountered in the Provision and Accessing of Holistic Care**

The administrators explained that the main challenge relates to finance. As a result, the two hospices, Kalingalinga and Chilanga, do charge their patients as they are admitted while Mother Theresa's hospice does not charge any fee. '*We started by not receiving any money from patients but we faced some difficulties financially, so we resorted to charging K25, 000 as admission fee. But if the patient does not have that money, we still admit them,*' said the administrator Sister Jeremia from Chilanga. The Sister-in-charge, Sister Kay from Our Lady's said that they levy the patients K50, 000 as admission fee and K100, 000 paid monthly as maintenance. However, no patient has ever been discharged because they were not able to pay their monthly fee. The hospice also offers extra comfort for those who need to be in their own rooms but at an extra fee of K100, 000 per week at Our Lady's Hospice. Concerning the daily running of the hospices, '*we depend solely on donations from charitable organisations and churches*', said the Sister Lynnette from Mother Teresa hospice, which makes the management of the hospice difficulty. Generally, there was a

concern from the patients, especially those who were referred by hospitals and clinics that although holistic care was being offered, charges were too high. Some even said that they did not know if they would manage to pay the bills upon discharge. As a result only a few patients were happy to be referred to hospice care. One bedside from Our Lady's hospice interviewed had this to say concerning non-payment of hospice charges:

We are usually not bothered by the sister-in charge about payments. We just pay when we bring in our patient and then as we stay on, we pay if we have the money. If we don't have, they don't even bother us or threaten us with discharge. It's just our conscience which bothers us and so we try to find money to pay so as to help with food.

The sisters-in-charge sisters Kay and Jeremia also revealed that they never discharged any patient for non-payment of hospice fees. One patient from our Lady's hospice wanted to be discharged because he thought he would not manage to pay the fees but was advised by the administrator to stay on until he had recovered and not to worry himself with the bill because that was not important at the time of pain.

The other challenge was expressed by care givers from our Lady's hospice, who said that they were not happy with the salaries they were receiving. According to the cost of living the salary was too small to cater for basic needs especially rentals. So they were of the view that their salaries be increased from what they were getting.

Another challenge was lack of staff. The nurses that attend to the patients are few compared to the number of patients that they nurse. A nurse by the name of Mercy from Mother of Mercy revealed that there was too much work because of shortage of staff. They even use retired nurses or those who have resigned from Ministry of health or part time nurses from clinics. Sister Kay said lack of staff makes palliative care a bit difficult.

#### **4.6. Lessons Learnt from the Patients**

The chaplain, nurses and care-givers expressed the view that they had learnt something from nursing AIDS patients. For instance, the chaplains revealed that most

of the patients were very hopeful that they would recover and reunite with their families. So they waited for their recovery with a lot of patience and plans. Most of the patients are usually emotionally disturbed and so the chaplain, nurses and care-givers have to be close at hand to answer to their needs. The care-givers expressed the point that from what they have observed, every person needed to be recognised and wanted to keep a care-giver close to them for a longer period of time, chatting to the extent that when they indicate that they would want to take leave, the patients would ask them if they would come back the following day. Some family members even wanted the number of hospices to be increased due to the demand. The care-givers also revealed that there was joy in nursing the AIDS and terminally ill patients, especially as they watched them recover steadily. They also learnt that keeping confidentiality brought the patients closer to them. The chaplain revealed that some patients were able to smile even in the midst of pain, which was a clear sign that they were slowly overcoming pain.

#### **4.7. RESEARCHER'S OBSERVATIONS CONCERNING CARE BEING OFFERED**

The following were observations made at different hospices.

##### **4.7.1. OUR LADY'S HOSPICE**

The hospice is found in Kalingalinga compound east of Lusaka. The compound is densely populated.

###### **4.7.1.1 *Out Patients Department (OPD)***

At the out patient department, the researcher observed that many people were coming in for review and were being attended to with a lot of care by both nurses and care-givers. The doctors were seen to be taking time, talking and investigating how individual patients were fairing. The patients and family members talked to seemed to express satisfaction with the treatment and rapport that prevailed between patient and nurses and care-givers. The surrounding was sparkling clean with all emergence equipment in place.

#### **4.7.1.2. Pharmacy**

The researcher observed that the pharmacy was well-stocked with all kinds of medicines or drugs that the patients needed. The pharmacists worked with such efficiency that the patients were served quickly and there were no long queues. For the few times that the researcher sat on the bench observing, no patient was turned away or told to go and buy medication from somewhere else. All the patients were given their prescribed drugs in the hospice pharmacy.

#### **4.7.1.3. The Houses**

The main house called St. Francis was well managed by the matron who seemed to be very dedicated to the work of saving souls. She was being assisted by care-givers but she did most of the professional work herself, giving injections and putting up drips. The care-givers were seen to be chatting with and helping patients especially those who had no bedsiders or family members. Most of the bedsiders in all the wards were women and a handful of men. There were a few empty beds which were being filled in by new admissions.

At other houses, the nurses who were on duty together with care-givers attended to the patients with dedication. Those who needed special diets were given their special meals. Family members were shown how to bed bath their very sick relatives. Those who were not able to feed their patients were being helped by care-givers. All the care-givers were women, including the two counsellors that the observer found at the out patients' department. The nurses were also women.

There were five houses and each house was being looked after by three care-givers who clean the houses and spend time chatting with patients and family members. The hospice has its own sewing room where all the uniforms for nurses, matron and care-givers are sewn. One care-giver who is specialized in sewing does the work diligently. Laundry is also done by the care-givers. Care-givers make the beds for patients and see to it that no patient develops bedsores by attending to those that regularly need attention.

Every morning at 07:30hrs, the care-givers reported to the matron for sharing of responsibilities. The researcher attended the meetings on Mondays at 07:00hrs where assigning of the week's duties was done.

#### **4.7.1.4. *Physiotherapy Department***

It is an important department in the caring process for the terminally ill. The department is fully equipped and a few patients were seen to be exercising as some of them had strokes due to the disease. A physiotherapist attended to them. Each morning, there were patients taken by care-givers for massage therapy to loosen the muscles and to bring bones back into shape.

The role of a physiotherapist is aimed at maximizing the patient's diminishing resources. A paralysed person will need massage and other exercises to prevent painful constructs and improve circulation. Massage can be very relaxing for aching muscles as well as providing opportunity for talking.

#### **4.7.1.5. *Chaplain and Administrator***

There were two priests who attended to spiritual needs of the patients and sometimes material needs. For instance, the chaplain was observed talking to the patients, who seemed to have a lot of interest in the message of the priest which he showed by nodding the head and smiling occasionally. Another priest was seen giving water and food he brought to a patient.

The administrator, a sister was observed attending to other issues pertaining to the running of the hospice. She was seen attending to visitors who had come to the hospice, probably donors. Occasionally, the sister in-charge was observed going round the houses visiting patients and talking to family members.

Generally, considering the amount of work that was seen around the hospice, there is need for more donors to come in and help alleviate the sufferings of the AIDS patients and also assist the hospice in managing finances. Nevertheless, Our Lady's hospice was doing fine in caring for AIDS patients, the terminally ill and their families. However some family members felt like not staying long in the hospice because they could not afford monthly payments being asked from them. But they were stopped

from being worried by the chaplain who told them to concentrate on the healing of their relatives.

#### **4.7.1.6. *Patient's Rights in Palliative Care***

As AIDS and cancer is a multi-system disease, its presentation in terminal care is varied and often complex. The patients in the advanced stages of the disease may be ulcerated from the mouth to the anus with difficulty in eating and swallowing. They may be emaciated, having torrential diarrhea of several litres a day and vomiting. They will be weak and tired and may look prematurely old, displaying skin lesions over many parts of the body. Despite all these ailments, they still are human beings who are entitled to their rights (See Appendix I).

#### **4.7.2. MOTHER OF MERCY'S HOSPICE**

The hospice is situated in the southern part of Lusaka, in Chilanga township.

##### **4.7.2.1 *The Out Patient Department (OPD)***

The OPD consists of offices for the doctor, counselors and finance. The researcher observed that there were many patients at the out patients' department in the morning when counselling and testing was done. Acute cases were immediately admitted to the wards. Although, according to the researcher's observation, there were few beds for admissions in both male and female wards, all the same care and treatment was still being extended to those who were referred to the clinics or hospital.

##### **4.7.2.2 *The Wards***

The surrounding was clean and patient's toilets were exceptionally clean. The researcher observed that there were few care-givers cleaning and that there were fewer care-givers at Mother of Mercy than at Our Lady's. Moreover, the hospice looks smaller than Our Lady's and Mother Teresa's. Patients were given individual attention and they seemed to be happy. Nurses went round talking to patients and bedsiders. There was good rapport between family members and nurses including the Sister-in-charge which was shown in the way she was talking to patients. The family members also seemed to portray some amount of freedom.



#### ***4.7.2.3 Physiotherapy***

It was observed that at the time of observations, the physiotherapy department was not in full use but the machinery was there. It was under renovation. The department's equipment was suitable for treatment of physically disabled patients. Massage therapists were ready to work with the patients at any time. Generally, the care being given to the patients and relatives is holistic for it covers all areas. It is true that the hospices were looking at the dignity of the human person and the value of life. At the hospice, patients and their families are taken care of by the hospice management.

#### **4.7.3. MOTHER TERESA'S HOSPICE**

The place is a combination of orphanage and hospice for the terminally ill. The hospice has more beds for the terminally ill than the other two hospices. According to the researcher's observation, patients enjoy staying in the hospice for a long time even after recovery. The reasons being that the care the hospice gives is very good. The patients even recover quickly because they have a good diet and good counsellors.

##### ***4.7.3.1 Pharmacy***

At Mother Teresa's hospice depends on the nearest clinic for medication. Even then, the patients do not lack or miss their treatment. The sisters collect all medicines. The hospice also does not have testing instruments; patients are sent to clinics for testing but come to the hospice for treatment.

##### ***4.7.3.2 The Wards***

The hospice has three wards; children, female and male wards. The researcher observed that the children had more than one compartment it had many sections that were divided according to ages of children. Those children who were not well were kept in their own house until recovery. The female ward was a large room with 50 beds and at the time of research there were only four patients who seemed to be seriously ill and they were being looked after by their relatives, one on each bed space. Sister Lynnette explained that they allowed only one person to avoid overcrowding. Those patients who had recovered were still being accommodated at the hospice and in the same ward where the others were. The male ward had 50 beds and many of the beds were occupied with seriously ill patients. The wards generally looked clean with sisters constantly checking up and giving nursing care. Of the three

hospices, Mother Teresa had the biggest number of bed spaces. The care givers greeted the researcher with a song on her first visit and that was not observed from the other hospices. The women really looked happy from the way they were singing and going around their duties.

#### ***4.7.3.1 Self-Sustainability***

The hospice has a big garden and an orchard where all the vegetables and fruits come from. They also have a chicken run to provide its patients with proteins. In the event that a patient dies, a decent funeral is provided by the cooperative effort of the hospice management and the deceased's family members.

One day, the researcher found the hospice deserted as the care-givers and sisters had gone for the burial of one patient.

#### **Summary**

The just ended chapter focused on the findings of the study and the researcher's findings. The researcher has discussed the findings from the interviews with administrators, chaplains, nurses, care givers and family members. The researcher has also included the observations made at the hospices.

The findings revealed that there was indeed holistic care provision at the hospices. Besides treatment, the hospices do provide palliative care to their patients in order to help them recover and for the dying to die a dignified death. Team work assists in ensuring that holistic care is provided to both the infected and affected. The findings also revealed that the chaplain plays an important role in bringing peace and tranquility to the patients and their families. He helps them go through the stages of suffering with hope and trust in God and eventually they come to face death with dignity. The team take the words of Saunders into practice; 'you matter till the end.' Therefore, every patient is given due respect and helped to pull through sickness to the last minute.

However, there were some challenges being encountered in managing the hospices. These were financial constraints being encountered by all the three hospices. This was revealed by all the administrators who said that some of the donors had pulled out and this was creating a problem with management. The research revealed that the only

sources of income were charitable organisations, CHAZ, PCAZ and donations from the parishes around and very little coming from the patients' fees. The research also revealed that there was shortage of staff. The hospices have few nurses mainly because they were not affiliated to the MOH.

## CHAPTER 5

### DISCUSSION OF THE FINDINGS

#### **5.0. Overview**

This study sought to bring out the contributions of the Catholic Church in caring for HIV and AIDS patients through hospices. The Catholic Church has been working side by side with governments' world over in alleviating the sufferings of AIDS victims. The study has sought in particular to show and bring out the holistic care that hospices claim to provide. This chapter, therefore, discusses the themes that emerged from the findings of the study as presented and discussed in Chapter 4.

#### **5.1. The Role and Importance of a Chaplain**

The chaplain is an important member of the team offering palliative care. The sick are usually devastated by the disease and easily give up life. When they are diagnosed with HIV, they feel their life has come to an end as was revealed by most of the family members. This is where the chaplain comes in to console and empathise with them. Most of them revealed that their patients talked less to them before they got to the hospice but after a few visits from the chaplain, they were able to at least brighten up after a few jokes from the chaplain.

The priests in the Catholic Church have a duty to bring to the people the sacraments. The patients regardless of their religious affiliations find it easy to accept the word of God from the priest. The findings indicated that the chaplain tries to give company to all patients. Patients find it easier and lighter to share their fears and anxieties with a person like the chaplain so that as they advance in their illness they come to accept the disease and finally die with honour. Soulen (1978) states that sometimes patients can become childish and would want to have someone around them, to talk to them and listen to their problems of pain and isolation. The Chaplain offers solutions to such kind of patients and is also in the right position to offer such kind of services.

All the three hospices acknowledged the importance of a Chaplain; reasons being that Chaplains are trained to handle confidential issues and bring to life the drooping spirit. They said that a priest usually sees with a spiritual eye and does not discriminate against any AIDS patient. The other hospices that do not have Chaplains

should emulate Our Lady's hospice. The Chaplain brings to light, as it were, the truth about God, and HIV and AIDS not as a punishment. He tells the patients and their families that AIDS has never and will never be punishment from God because even innocent people suffer from the same disease. A Chaplain helps to transform sheer human tragedy into the possibility of new life and love (Smith and McDonagh 2003:45). Indeed, a Chaplain plays an important role in the provision of holistic care in the hospices.

## **5.2. Importance of Hospice Care**

The research found out that in the face of the impenetrable problem of an evil such as the current pandemic where intellectual effort falters, it is more enriching and enlightening to look to other alternatives of solving the problem. Just as Jesus ministered to the sick and bereaved, the hospice team has offered to help alleviate the sufferings of both the infected and affected in designated areas known as hospices. The findings further revealed that people feel more at home in hospices than in hospitals. The twenty-four hour care being received brings more comfort and meaning to the infected and affected individuals. The terminal stages for those living with HIV can be extremely distressing for those who are sick, their families and the carers. As such, they need a place which can bring to them comfort and people who are ready to share with them love and compassion. Thus, the hospice staff as substantiated by research findings provided to those afflicted, effective and compassionate palliative care. For example, the patients are not kept waiting in long queues but are usually received by care-givers on arrival and ushered to the Doctor's office for examinations without delays. The findings revealed that most of the HIV patients experience excruciating pain as they pass from one symptom to another. The nurses and care-givers found in the three hospices have been well trained in palliative care principles and skills to manage the pain that patients go through. Those patients who are undergoing too much pain are usually given the most effective pain killers to ease their pain.

Hospices provide holistic care as revealed by all the three hospice management staff interviewed as well as observations done by the researcher. As a philosophy, hospices intend to address and meet the needs for the seriously ill and dying (Becker, 2009). In other words, one would say that the hospice provides holistic life. The hospice offers

hope to patients to enable them attain a sense of well being which enables patients shift that focus of care to quality of life (Linn,1978). Thus every social aspect, health and economic aspect is dealt with by hospice management.

The social and spiritual aspects are ably provided by care-givers, nurses and the Chaplain who spend time chatting with the patients. Churches are also encouraged to offer their social and spiritual support. The health aspect which includes pain management, symptom management and counselling for testing are being well-managed by doctors and nurses. A clean environment is being provided by the care-givers and other general workers together with the hospice administrators. Drugs to suppress the viral activity known as Anti-Retroviral (ARVs) are being provided on time without lapses being observed from those admitted. The matron at one of the hospices revealed that there were some patients who still develop resistance to drugs due to lapses but those were not among those admitted but those who were discharged. In such cases, she told the researcher that follow-ups are usually done to keep the patients on drugs.

Despite the hospices operating very well, they have limited staff and space to accommodate all patients that go to seek treatment there.

### **5.3. Staffing**

The hospices have very few nurses according to what was found out. For example, at our Lady's hospice, there were four nurses against thirty terminally ill patients who needed special attention. It was the same with Mother of Mercy which had four nurses, one clinical officer and two doctors. At mother Teresa, the sisters do the nursing part while out-patients volunteer to do care giving. As a result, some of the trained care-givers do nursing work. However, despite the shortfall of trained nurses, the hospices still manage to give the needed care to the sick. More assistance is being provided by the nuns. Besides this, more nurses are needed especially to do follow-ups on discharged patients and also those who receive hospice care from their homes.

### **5.4. Space**

The two hospices namely, Our Lady's and Mother of Mercy that the researcher visited revealed that due to good services offered to the infected and the affected, there was

need for more hospices to be built in strategic areas. Out of the three hospices visited, the only hospice with a large number of bed spaces was Mother Theresa, which had fifty bed spaces for females and another fifty for males. Children also have a large number of beds. The other two hospices, Our Lady's and Mother of Mercy, need more bed spaces. However, the hospice management does not turn away those that need care even if the bed spaces at the hospice are full. Instead, they provide first aid and send them to hospitals and in some cases, if the symptoms can be managed at home, there is a provision for home-hospice care. The findings showed that nurses played an important role when patients needed drips especially for those who usually have diarrhoea as this forms the basis for admission into the hospice in such cases. Therefore, most interviewees requested for more hospices to be built in strategic areas or positions where there are higher rates of people living with AIDS. Others even requested that bigger hospitals such as the University Teaching Hospital (UTH) are supposed to have a hospice beside it so that the hospice management would use the available bed spaces at the institution and provide similar care.

### **5.5. Palliative Care**

The hospice uses palliative care philosophy to meet problems for the terminally ill and dying. It incorporates pain and symptom relief, allowing the patient to die with dignity. This type of caring has been appreciated by both patients and the families as it lessens the pain patients go through and prolongs the life of the sick. For example, both patients and families cooperated fully with the medical staff in ensuring that the ARVs are taken on time.

### **5.6. Financial Challenges**

Hospices literally depend on donors and charitable organisations. Under this heading, there are two aspects to be discussed; financing of hospices and patients' contributions.

#### **5.6.1. Funding of Hospices**

The findings revealed that the hospices are funded by donors from overseas charitable organisations. Local churches, such as parishes within Lusaka and the United Church of Zambia, also contribute to hospices up-keep in material form. Local organisations like the Lions Club, Zambeef and Shoprite Checkers also do give in some donations

in form of food stuffs. They usually bring food stuffs and detergent pastes to clean linen. Others even go to hospices to clean the wards and pray with the patients. Other donations from overseas come from individual donors. For instance, Donch (1990:102) donated the revenue from her book sales to the Kasisi Orphanage in support of orphans whose parents have died from AIDS and also for building a hospice for AIDS victims in Chilanga, Zambia. Donch (1990) was motivated to donate due to the personal experience she had while nursing her late brother suffering from the pandemic. Mother Teresa's hospice literally depends on donations in terms of medication and up-keep.

Those from overseas just send money to help in building structures and buy some equipment to use at the hospices. For instance, at Our Lady's hospice, a kitchen building was funded by an overseas organisation. At the time of research, the building had not yet been completed. The hospice also is self-reliant in terms of food; they have a chicken-run, piggery, vegetable garden and an orchard of fruits to maintain patients' diet. It is the same with Our Lady's where they have a large garden and an orchard.

Therefore, there is need to bring on board other stakeholders such as the government, non-governmental organisations, charitable organisations such as the Lions Clubs, and other faith-based groups, to come and help not only financially but also in terms of other forms of donation and manpower. Many financially sound business houses should also participate in donating to the hospices as the hospices provide care to everyone regardless of religion or status. Therefore, the Catholic Church has really been part of the solution to the suffering masses.

#### ***5.6.2. Hospice Charges on Patients***

This research revealed that patients who are admitted to the two hospices, Mother of Mercy and Our Lady's pay admission fees of K25, 000 and K50, 000 respectively. In addition, Our Lady's hospice charges a monthly fee of K100, 000. Furthermore, Our Lady's hospice also has a high cost house in which patients are required to pay K100, 000 weekly.



Some patients and family members expressed displeasure about the issue of payment, while others interviewed were in favour of the idea considering the care tendered to the patients. The staff interviewed revealed that the money being charged especially at Mother of Mercy was not enough to cater for all the needs the patients required especially in terms of food.

It is imperative to note that hospices in Zambia are not the only ones charging patients, as some hospices elsewhere such as those in Uganda do charge 5 000 Shillings to their patients as admission fee (Merriman, 2006). These charges are done only to complement the little that comes from the donors to maintain a good diet as food plays an important role in the recovery of patients. The hospice management, however, does not turn away patients who fail to pay their admission or weekly charges. Research indicated that they were treated the same way as those who met the financial charges.

### **5.7. Nutrition**

According to Smith and McDonagh (2003:85), the reality for many people living with HIV in some of the world's poorest countries, Zambia in particular, is that they are malnourished. The interviews revealed that those who were on drugs, especially Tuberculosis drugs, needed a lot of nutritional food. People who are sick need food as it is part of the healing process. When patients are at home, being nursed by their relatives, they are sometimes not fed well because of lack of money. Whereas, in the hospice, they are usually provided with a good diet and they eat what they ask for. Donch (1990:55) echoed that the time she was nursing her brother in the hospice, she had an opportunity to choose the food that her brother would eat. The research in all the three hospices indicated that most patients were given the chance to choose their menu for the day and the time that meal would be provided. Those patients who could neither feed themselves nor be fed by their relatives were fed by the care-givers. In those three hospices that the researcher visited, it was revealed that patients were fed five times a day. One would say food is the most important drug in the fight against HIV and AIDS.

The hospices in their quest to give holistic care to their patients have realized that food is an integral part of the healing process. As such, they provide a good

nutritional menu, one that is lacking in most patients' families. Smith and McDonagh (2003: 86) postulates that 'the first thing that poor families affected by AIDS ask for is not drugs or cash, it is food, and food has to be one of the weapons in the arsenal against this disease'. Poor nutrition accelerates the death of those infected with AIDS. The hospices even have nutritionists to advice on the diet of patients. It should further be noted that the food available in the hospice is strictly for patients and not family members except in special cases.

From the above stated reasons on nutrition of patients in hospices, most patients even recover fast because of good feeding habits and being given a well-balanced menu.

CHAZ does provide the hospice with the much needed drugs and the hospices also get their ARVs from hospitals. From the findings, it was clear that, although these patients get their fill, they worry about their children at home. Most of them are bread winners and so while they are admitted in the hospices, their families are starving. Some of them have presented their concerns to either administrators or the chaplain who sometimes would assist them when they have bigger supplies.

Finally, the most frightening thing is that AIDS is continually sweeping away the youths who are the producers and developers of the countries' economies. As at now ART is well-financed by UNAIDS -Joint United Nations Programme on HIV/AIDS (Kelly, 2010: 46). The costs and sustainability of ART services has given rise to justice and equity questions about maintaining treatment for those already on ART. For instance, how much is it likely to cost to get everybody who is eligible onto ART and where will the resources come from to implement the WHO recommendation that people with HIV should start sooner on ART? And what assurance is there that the treatment will remain available for the lifetime of a patient? These are some of the ethical issues which threaten the operations of hospices in their provision of palliative care to patients.

Furthermore, the administrators of the hospices the researcher visited indicated that there was still a lot to be done concerning the care and running of the hospices. Each day that breaks for them is spent writing request letters to charitable organisations for any form of assistance to help in the smooth running of the hospices. Practically, they

stated that hospices are doing a good job in trying to give meaning to life. They actually stated that hospices are providing and have been providing a solution to the AIDS pandemic. They are the only refuge so far since the cure has not yet been found.

### **Summary**

The chapter focused on holistic care, the importance of a chaplain in executing holistic care and the challenges that the hospice managements go through as they give palliative care. The hospices are offering palliative care as a way of coping with the untold sufferings AIDS patients are going through as well as their families. In order to provide relief from pain and rejection as well as a good diet for patients, the hospice requires trained personnel in counselling and caring of patients. It was also revealed that those who are on antiretroviral drugs need a good diet like one that the hospices provide. However there are challenges that the hospices encounter as they provide holistic care; lack of funds, low salaries paid to workers, lack of nursing staff and inadequate bed space for more patients.

The next chapter concludes the research discussions as well as giving recommendations.

## CHAPTER 6

### CONCLUSION AND RECOMMENDATIONS

#### **6.1. Conclusion**

The researcher came up with a few conclusions based on the issues raised in the study. Following the objectives closely the concerns raised were as stated below:

First of all the research sought to establish the nature of care offered in hospices. It was revealed that palliative care was being offered in hospices through intense care of the seriously ill, thus managing pain by giving strong pain killers to those experiencing excruciating pain. Hospices with their palliative care approach tend to ease the pain the patients are going through as well as prolonging life through the holistic care model by giving antiretroviral treatment. The family members were counselled on how to assist their sick members. Pain management also involved spiritual counselling to both patients and families. What is really important is to help the patients come to terms with the disease and also accept the approaching death.

Secondly the research sought to establish the services that hospices render to their patients and their families. A clean environment, good nutrition, counseling, provision of an environment which is stigma free and good medication were being provided to the patients and their families. Physiotherapy was being given also to patients to straighten the muscles. All these services were provided by a team of experts who sought to bring to practice the words of dame Cicely Saunders who said a patient mattered till the end of life and so they were to be taken care of.

Thirdly, the benefits of holistic care were that some patients were still able to regain their strength and be reunited with their families as a result of holistic care. Those patients who came to hospices so weak were accorded a dignified death and family members helped to bury their dead and cope with the grief. However, there were challenges that stood in the way of provision of holistic care such as financial challenges, lack of space, insufficient nurses and low salaries for workers. Some patients also felt that the charges being asked were too high and caused some discomfort among the patients. The researcher felt that if these challenges were given due attention, a hospice would be a pleasant place for AIDS patients.

In view of the above objectives, the research revealed that in executing holistic care to the terminally ill, there was need for team work by the chaplain, doctors, nurses, administrators and care-givers. Each member of this team has got an important role to play in the provision of holistic care. In the light of no cure or vaccine yet found, the hospice with holistic care remains the ideal solution to this devastating disease. The team, according to the findings, offers to the terminally ill medical, spiritual and emotional support. The team has been well-trained to handle AIDS patients and bereaved families. Holistic care practically requires the team of experts to offer the patients the five Ts as on page 55 which are: *team work* – working together; *time* – create time to spend with the patients instead of them just staring at the walls of the hospices; *touch* - another aspect that the patients require as they lie down in pain, words do not help but coming closer to hold their hands so that they would also feel loved and cared for; *tears* - carers emotionally breakdown when someone they least expect to die actually dies, they tend to mourn with the family. The other aspect is *theology*; the chaplain offers the word of God for them to understand the ‘big’ heart that God has for all mankind. God is the creator and father of all creation and all the creation is good (Genesis 1). Most importantly, God created man and woman in his own image and likeness. This makes a human being to be the highest creature above all others and is the creature most loved by God. The role of a chaplain is to make the sick understand that despite being sick, God still loves them even more than those who are in good health. The other aspect of theology the chaplain should bring out is that death is not an end of life but rather the beginning of new life in union with God.

Therefore, a chaplain should prepare patients to encounter death peacefully, making them understand that God also heals through death. As the team works towards maintaining the dignity of the afflicted, they sometimes empathise with the bereaved families for their loss and express this with tears. They mourn together the person who dies despite the many efforts they make in order to save his or her life.

The research also revealed that the teams of experts learn a lot from patients and their family members as they give them care. They learn the virtues of patience, joy even in pain and total surrender to the will of God. The research revealed that most of the patients die happily and others express a lot of confidence that they would get well and go back to their families. Indeed, many have become well and have decided to dedicate their lives helping out at the same hospices.

However, there are always challenges that accompany every institution as they execute their duties. The following were the challenges that hospices faced as they did their noble duties:

- Funds for the smooth running of the hospices. Very few people locally offered their support to the hospices. As a result, hospices were forced to charge a small fee to patients.
- In some cases, the little funding had affected manpower. The findings revealed that there are very few nurses doing professional work.
- Due to good and effective services that hospice management offer to the people, there is a cry for more bed spaces in named the hospices.

Finally as the fight against HIV and AIDS continues, it has come to light that the pandemic holds people captive and dependent on therapies. As the medical world seeks to find or break the stranglehold of this captivity, one of the most effective solutions as discovered by the church lies in receiving palliative care from the hospices strategically placed in the country. At the moment, the antiretroviral therapy preserves the lives of the AIDS patients but at the cost of a lifetime of total dependence on a strict regime of drugs.

The hospices offer solace and comfort for those who have been abandoned or rejected by society. The hospice prepares the dying to die in dignity and peace knowing someone cares. The hospice also offers medical care for patients relieving the families and communities from over-burdening themselves once a patient cannot be managed at home.

## **6.2. Recommendations**

In view of the findings and conclusions of the study the researcher made the following recommendations:

*i. To the institutions offering holistic care:*

As much as the institutions receive little help from the government, there is need to review the fees being charged on the patients.

There is need for the hospices to affiliate themselves with the government so that they can receive some funds to help in the running of hospices including paying the workers.

*ii. To other churches:*

The hospices are facing a challenge of inadequate bed spaces; there is need for other churches which are not yet involved in caring for the sick to get involved as AIDS continues to affect many people.

*iii. To the Government especially the Ministry of Health:*

There is need to supplement services being offered by the Catholic Church in caring for the sick. This could be done by providing the nurses and doctors to work in these hospices.

*iv. To the Public:*

There should be more community involvement in activities going on at the hospices and visitations of the sick. Through such acts of love, patients will feel loved and accepted unlike situations where patients feel rejected and stigmatized.

*v. Recommendations for further researcher:*

- Scholars of Religious studies should take a leading role through research, in finding ways and means of reconciling religion with the reality of HIV and AIDS
- The use of a large sample of a qualitative and quantitative nature to investigate patients' adherence to Anti-retroviral drugs.

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## **APPENDICES**

### **Appendix 1**

#### **Physical Rights of Patients**

- They have the right to receive total pain management.
- They have the right to weight gain.
- They have the right to mobility.
- They have the right to maintain personal safety.
- They have the right, if it is essential that the partner or family members is encouraged to continue to be a key member of the caring team if they and the patient wish it and provided they do not need respite themselves.
- Right of information relating to opinions available in the hospice. This places considerable responsibility on care givers.
- Right to have highly skilled medical care
- Right to good nutrition.
- Right to complain when necessary.
- Right to better treatment.
- Right to confidentiality.
- Right to have good rest and sleep.
- Right to adequate hydration.
- Right to shelter.
- Right to safe environment.
- Right to adequate respiration.

#### **Emotional Rights of Patients**

- Right of the patient to maintain hope to survive.
- Right to be respected according to their wish
- Freedom from right of isolation, rejection, guilt, fear and misery with pain.
- Right to be encouraged and motivated when need arises.
- Right to be reassured that they are not alone.

### **Spiritual Rights of Patients**

- Patients have a right to worship according to their faith and this should be facilitated whenever possible.
- Right to receive sacrament if the patient is baptized in the Catholic faith in the hospice.
- Right to have pastoral care.
- Right not to be pressured regarding their spiritual needs.
- Right to their religious beliefs or the fact that they have no religious beliefs must be respected.

### **Finance Rights of Patients**

- Right to have employment when capable.

### **Social Rights of Patients**

- Right to be cared for in the community.

*Source: Pratt, R (1995) (from HIV and AIDS: A Strategy for Nursing Care). Pg 233*

*Mallett, J & Dougherty, L (2000) (from Manual of Clinical Nursing Procedure, eds.)*

## Appendix 2

# NOTES FROM THE NOTICE BOARDS

## Palliative Guidelines “7 Cs”

The Gold Standard Framework aim to improve and support patients nearing end of life

1. Communication
2. Co-ordination
3. Control of Symptoms
4. Continuity
5. Continued Learning
6. Carer Support
7. Care of the Dying

## Palliative Guidelines

Code of Professional Conduct

- Respect the patient or client as an individual
- Obtain consent before you give treatment or care and explain the procedure
- Protect confidential information
- Co-operative with others in the team
- Maintain your professional knowledge and competence
- Be trustworthy
- Act to identify and minimize risk to patients and clients

### Appendix 3

## DAILY MENU

	<b>Breakfast</b>	<b>Lunch</b>	<b>Supper</b>
<b>Monday</b>	Rice and Milk or Cornflakes Tea and Bread, Eggs or Custard	Nshima / Potatoes, Beef and Vegetables	Rice / Nshima plus Chicken and Vegetables
<b>Tuesday</b>	Rice and Milk or Cornflakes Tea and Bread, Eggs or Custard	Nshima / Rice and Beans, Chicken and Vegetables	Nshima / Potatoes plus Fresh Fish and Vegetables
<b>Wednesday</b>	Rice and Milk or Cornflakes Tea and Bread, Eggs or Custard	Nshima / Rice and Chicken plus Vegetables	Nshima / Potatoes plus Mince and Vegetables or Boiled Eggs
<b>Thursday</b>	Rice and Milk or Cornflakes Tea and Bread, Eggs or Custard	Nshima and Fresh plus Vegetables	Nshima / Rice plus Beef Stew and Vegetables
<b>Friday</b>	Rice and Milk or Cornflakes Tea and Bread, Eggs or Custard	Nshima / Rice plus Beans / Mince and Vegetables	Rice / Nshima plus Chicken and Vegetables
<b>Saturday</b>	Rice and Milk or Cornflakes Tea and Bread, Eggs or Custard	Nshima / Potatoes plus Beef Stew and Vegetables	Rice / Nshima plus Fresh Fish and Vegetables
<b>Sunday</b>	Rice and Milk or Cornflakes Tea and Bread, Eggs or Custard	Nshima / Rice plus Chicken, Stew and Vegetables	Rice / Potatoes plus Fried Chicken and Vegetables

### Nasal Gastric Feed

Soup  
Custard plus Milk  
Mealie-meal porridge  
Egg Flips

## Appendix 4

### Interview guide for chaplain

1. How long have you been a chaplain at this institution?
2. What kind of care do you offer at this hospice?
3. How many patients do you talk to every day on average?
4. What has been your inspiration in this job?
5. How often do you come to the hospice?
6. What have you learnt from the patients about the care you provide?
7. How do you assist the families for these patients?
8. What kind of care do you offer as a chaplain?
9. What kind of patients have you dealt with?

Very sick

Slightly sick

Dying

## **Appendix 5**

### **Interview guide administrators**

1. How many patients can the hospice accommodate?
2. What is your role as administrator of this hospice?
3. What kind of care do you offer to both the sick and families?
4. How long do you keep the patients in the hospice?
5. How do you get your patients, are they referred to hospice by the hospitals? Do they come on their own or through home based care?
6. Who assists you in the caring of the patients?
7. For how long have you been in existence in Zambia?
8. Do you just assist patients or their families as well?
9. Have you ever had complaints from patients concerning the care that is offered?
10. What are the conditions of being admitted into the hospice?
11. Does hospice care continue even when the patients are discharged?



**Appendix 6**  
**Interview guide for nurses**

1. How long have you been working in this hospice?
2. Do you like working with the terminally ill?
3. What kind of help do the terminally ill need?
4. Do you think the patients here receive better care than those in hospitals?
5. Do you chat with patients?
6. How often do you do that?
7. Do you find it difficult to chat with patients?
8. What have you learnt from the patients about the care you provide?
9. Do you as well interact with their family members?
10. If so what kind of worries do they express about their sick members?
11. Are you happy working with the staff/administration here?

## **Appendix 7**

### **Interview guide for family/relatives to the patients**

1. When did you bring your relative to the hospice?
2. How have you found hospice care?
3. Why would you say the kind of care offered by the hospice is good for your sick relative?
4. Are you free to discuss issues concerning the welfare of your patients with the administrator, chaplain and nurses?
5. What relief has the hospice provided to you as a family?
6. Do you recommend establishing more hospices?