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UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

THE NATURE AND EXTENT OF PALLIATIVE CARE IN THE NAIROBI HOSPICE

BY

ANNE MUKELI JUMAH

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Supervisor: Dr. J. Sekudu

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This dissertation is dedicated to my beloved late mother, **Pauline Mwisiwa Ngoto**, who never lived to share this great achievement with me.

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SUMMARY

THE NATURE AND EXTENT OF PALLIATIVE CARE IN THE NAIROBI HOSPICE

Department: Social Work and Criminology: University of Pretoria

Candidate: Anne Mukeli Jumah

Supervisor: Dr. J. Sekudu

Degree: MSW (Health Care)

The goal of this study was to explore the nature and extent of palliative care in the Nairobi Hospice, in Kenya. Owing to the limited information available on this subject, the study is based on a research question that seeks to deepen understanding of the experiences of palliative care services by patients facing life-threatening illnesses.

In answering the research question, the study employed a variety of methods. First, it used qualitative research approach in order to unearth personal experiences of the value of services received. Second, it employed applied research with the aim of using results to influence the formulation and improvement of palliative care programs in Nairobi. Further, the study employed the case study method as the research strategy.

Focus group interviews were utilised as the data collection technique. The researcher used an interview schedule and administered semi-structured questions on a group basis. Availability sampling method was used to draw a sample of 20 patients receiving palliative care at the Nairobi Hospice.

Confirmation from the study indicated that patients receive medical care, counselling, and spiritual care as well as day care services, usually provided

by the hospice staff. The study further confirmed the value of palliative care. Services provided offered a number of benefits for the patients for instance, enhanced hope, mobility, as well as improved state of health for these patients.

At the same time the study underscored the value of spiritual guidance. However this was provided as an additional service, being offered outside the hospice. Measures to integrate this service would improve the value of palliative care services in general. Further, it was noted that there was no particular time frame for receiving palliative care at the hospice since patients receive care at different intervals.

The study also disclosed that patients' illnesses impacted on their families negatively for example, a number of these patients were either abandoned or separated from their families, their families suffered financial strains while others were in denial and felt very desperate about the whole situation.

The study conclusively indicated that social workers can play a vital role in palliative care provision by either conducting regular home visits, educating and creating awareness as well as offering couselling services to both the patients and their families.

KEY CONCEPTS

ENGLISH	AFRIKAANS
AIDS	VIGS
Cancer	Kanker
Care givers	Versorger
Counselling	Berading
HIV	MIV
Health	Gesond
Hospice	Hospis
Palliative care	Palliatiefsorg
Social worker	Maatskaplikewerker
Terminal illness	Terminale siekte

CHAPTER 1

GENERAL INTRODUCTION

1.1 Introduction

According to the Palliative Care Advocacy Workshop (2003:21) over the last two decades, the developing world, and Africa in particular, has seen a massive rise in the number of people suffering from diseases that are not responsive to curative treatment. At the forefront of these vexing diseases are HIV/AIDS and cancer. From the first reported incidence of HIV/AIDS in Uganda in 1989, there was a meteoric rise in numbers of infection and deaths related to HIV/AIDS. By 2002, the World Health Organization estimates indicated that some 26.6 million people in Sub-Saharan Africa were living with HIV, with 3.2 million new infections and 2.3 million AIDS related deaths.

Today, some of the African countries, including South Africa and Botswana have some of the world highest infection rates of HIV/AIDS in the world. In Kenya, estimates indicate that up to 700 people die daily form HIV/AIDS related complications (Palliative Care Advocacy Workshop, 2003:21).

Additionally, WHO estimates from the Palliative Care Advocacy Workshop (2003:21) indicated that there were 0.5 million deaths per year from cancer in Africa and that by 2020, 70% of new cancer cases will be in the developing countries. The progression is also deemed that cancer rates in Africa are expected to grow by 400% over the next 50 years.

This rise in incidences of diseases has been paralleled by a great demand for palliative care. WHO (2004) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, being physical, psychosocial and spiritual. Thus the goal of palliative care is the achievement of the best possible quality of life for patients and their families through home-based care, nutritional support, counselling, pain and symptom control including availability of affordable morphine.

Muhombe (2004:8) states that the unit of care in palliative care is the patient and his/her family. Rather than focusing only on medical care, palliative care focuses on the things that may be important to a person as he/she nears the end of life. Attention to a person's emotional, social and spiritual needs can help to relieve much of the distress and loneliness of a person nearing death, therefore, the basic comfort of the sick person is of paramount importance. Ali (2005:1-2), further emphasises that palliative care encompasses diverse services like counselling, support for families and other individuals who care for patients with life threatening illnesses on an outpatient basis, in the hospice and in their home environment, with a combination of patient care, education and training of relatives, as well as community health care professionals. Most important is the provision of symptom control, psychological and bereavement support.

According to Njenga (2007) an official of the Nairobi Hospice, the hospice team offers a holistic approach when dealing with patients with life threatening illnesses, which in fact is in support of the hospice motto, “to put life into their days, not just days into their life”. Mwaura (2007) a social worker in Eastleigh Nairobi, concurs with Njenga (2007) by stating that the physical, emotional, social and spiritual pain influences the psychological well being of patients and their relatives, and therefore these people need on-going counselling support from multi-disciplinary teams.

On the other hand, Harding and Higginson (2004:17) assert that palliative care mainly originated from the western world but it is slowly moving into Africa where it has gained broad support as an important aspect in disease management. The above authors mention that the initiative by WHO has established the principle that states that, palliative care is in the framework of continuum of care from the time the incurable disease is diagnosed until the end of time.

Harding and Higginson (2005:1974) further state that international organizations particularly WHO has played a major role in encouraging African governments to develop effective palliative care strategies and institutions. For instance, the WHO foundation measures for cancer pain relief and the foundation of process measures has led to palliative care development across the region including Tanzania, Malawi, Uganda and South Africa. According to Harding and Higginson (2005:1974) similar priorities were identified by HIV end of life care providers in Africa. This include, advocacy for pain control and a good health through expansion of quality service coverage, technical assistance for monitoring and evaluation, collaboration, information sharing and resource security.

The researcher is of the view that some countries such as South Africa have moved further than their counterparts. Although there is still more to be improved, there is greater knowledge of and promotion of palliative care including development of instructions and structures. In contrast, in most African countries, like Kenya, there is dire need to promote palliative care and ensure that resources are allocated to provide a comprehensive service.

According to Stjernsward (2000:257-260) in the last 20 years, Sub-Saharan Africa has been overshadowed by the HIV/AIDS pandemic with limited access to anti-retroviral drugs (ARVs) or other pain and symptom controlling drugs, leading to many patients dying in pain, and isolation with uncontrolled symptoms. Most people present very late with HIV/AIDS which means that they need palliative care at the same time as or before going on ARVs. Palliative care, if made accessible, improves patients' quality of life and relieves pain and troubling symptoms.

Stjernsward (2000:260-264) further asserts that the WHO has recommended that palliative care be part of a national health strategy for all countries for without this, provision will never be universal. This is so because most countries in Sub-Saharan Africa have no national policy on palliative care in their government's health or national HIV/AIDS strategic plans. According to Stjernsward (2000:260-264) currently, the only country that has formally adopted the WHO's foundation measures for palliative care service is Uganda, a country whose success so far has been documented. Stjernsward (2000:260-64) further states that a few other countries including Kenya, South Africa, and Zimbabwe have some hospice services providing palliative care but the services remain outside the National Health Strategy.

The researcher's opinion is that since in many parts of Sub-Saharan Africa the availability of even simple pain relieving drugs and antibiotics is highly limited, Kenya included, where the researcher comes from, there is need for health systems to be strengthened and national health policies encouraged to provide for basic medication at the primary level of service delivery and relaxed importation laws for opiods. This means that in order to develop palliative care services that offer proper pain and symptom control, action and leadership at government level will be needed to ensure that essential basic drugs including morphine are widely available.

The East African Standard (2006:1) indicates that experts in palliative care were urging for the founding of a center at Kenyatta National Hospital, to take care of patients with life threatening illnesses. This is because patients with life limiting conditions no longer need curative treatment but rather need special care that relieves symptomatic pain. Palliative care however, has never been provided in Kenya's public hospitals, the service is only offered in hospices which are exclusive institutions for the terminally ill. East African Standard (2006:2) further states that, palliative caregivers feel that the hospices alone cannot cope with the rising demand for the services. The sceptics blame the situation on archaic legislation, patients' ignorance and poor and obsolete institutional structures in the health care sector.

A nursing officer who is also a counselor at the Nairobi Hospice has been quoted in the East African Standard (2006:2) saying that the hospice teams is only able to serve people whose homes are within an approximate radius of about 25 kilometre from the hospice. According to the fund development officer at the institution, many patients with life limiting illnesses end up in the hospice after spending all their life-time savings on the disease in vain, while others are abandoned by their relatives after becoming financial burdens. The fund development officer further mentions that, operations at the institution are mainly hampered by lack of funds.

According to the International Observatory on End of Life Care (2005:14) Kenya currently, has only six established hospices in the country located in Nairobi, Meru, Kisumu, Nyeri, Eldoret and Coast (Mombasa) respectively, and that a further service is developing in Nyahururu Hospital. On the other hand, there are palliative care teams in two mission hospitals. These are Chogoria and Maua Methodist Hospitals both situated in Meru district.

The International Observatory on End of Life Care (2005:14) further states that, palliative care coverage in Kenya is over stretched in terms of the distances these hospices have to cover to provide care to their esteemed patients. For instance, Nairobi Hospice covers a radius of about 25 kilometres and serves a population of approximately 3 million people. Meru Hospice covers a radius of about 20-50 kilometres and a population of 850,000 to 1.2 million. On the other hand, Eldoret Hospice covers a radius of about 150 kilometres, while Coast Hospice is responsible for palliative care patients in the whole province, which has an approximate of 3 million people. Lastly, Nyeri Hospice covers the whole of Nyeri, Kerugoya, Muranga', Laikipia and Nyahururu respectively. In order to meet these high demands, satellite hospices in these areas have been planned to take palliative care into these communities which has led to the establishment of a satellite hospice at Nyahururu hospital.

It is the observation of the researcher that palliative care in Kenya is inadequately met. So far there is only limited care offered by few hospices to a fast increasing population. This is so because each hospice covers a large population, which makes it very difficult to fully serve due to low human resource capacity, limited medicine, limited funds, transport availability and other logistics.

Bird (2005:1) argues that although one of the main aims of the hospices is to provide community and home-based care, not all people can be cared for at home, too often this assumption leads to home-based neglect due to the high cost per visit by health workers especially in the rural areas. Harding and Higginson (2004:37) concur with Bird (2005:1) by stating that an assessment of Kenyan community attitudes towards home-based care found great ambivalence, a lack of information and some rejection with a preference for institutionalised care, generally resulting into unwillingness for the community to provide care.

Bird (2005:1) further mentions that although it is suggested that home care is a corner stone of HIV and cancer care, sometimes coverage in Kenya is low and often patients' needs are higher than what home care can provide. Also health care workers travelling from home to home spend extended period of time, basic drugs are often not available and sometimes poverty is very overwhelming.

The researcher asserts that the above factors among others, are a great hindrance to the provision of adequate home and community-based care in Kenya as a whole, and this calls for a more structured institutional palliative care, to ensure that the patients receive a comprehensive service.

1.2 Problem formulation

A problem is defined as a difficult of which we are aware and about which something ought to be done (Grinnel, 1993:22; Grinnel and Williams, 1990:58). While Dreyer (1995:375) asserts that formulation of the problem is the starting point of a research project.

According to the International Observatory on End of Life Care (2005:1) the government of Kenya has no official palliative care policy although it is supportive of palliative care practice in the country. This author cites that despite the above, only recently did the ministry of health embark on drawing a five-year health sector strategic plan, and invited Nairobi Hospice to sit on that committee.

Although Kenya declared HIV/AIDS a natural disaster back in 1999 and developed a strategic plan to fight the epidemic, there was limited focus on palliative care. The National AIDS Control Council was formed to coordinate the implementation of the strategic plan which identifies four priority areas of intervention of focus, namely; prevention and advocacy, treatment, care and support, mitigation of socio-economic impact and research, monitoring and evaluation. According to the Palliative Care Advocacy Workshop (2003:17), in the strategic plan, palliative care is addressed under the second priority area, which is treatment, care and support. However although the strategic plan has a place for palliative care in the absence of a cure of AIDS, it is confronted by challenges. The biggest obstacle in the delivery of palliative care still remains the inadequacy of resources to meet the needs of huge numbers of the AIDS patients, while the second obstacle is the capacity to deliver palliative care.

Muhombe (2004:9) on the other hand asserts that coupled with this, the government has seen a high rise of the number of people with life threatening illnesses more specifically HIV/AIDS with an estimated number of 1.7 million infections and over 200,000 deaths by the end of 2003. HIV/AIDS prevalence currently stands at 10% and is responsible for about 700 deaths per day. This has resulted in an increase manifold of the number of patients in the main government hospitals with an occupation of about 1000 beds in the medical wards, 50% of these cases being tuberculosis (TB) related.

At the same time, the issue of cervical cancer cannot be overlooked since it is one of the leading causes of deaths among women in Kenya today. Muhombe (2004:9) further mentions that, WHO further estimates that there are about 30,000 new cases of cancer every year which therefore, makes HIV/AIDS and cancer the leading life threatening illnesses in Kenya. According to Muhombe (2004:9), this is so because about 80-90% of cancer patients are diagnosed late with about 70-80% becoming terminal cases which so far is a huge burden for the country and represents a great loss and impacts significantly on the health system, as well as family structures.

According to the researcher, despite these huge and increasing numbers, the capacity to deal with palliative care is very limited since there are only six established hospices in Kenya. These hospices are currently battling with high levels of caseload, and this is stretching the available resources very thin. For instance, according to a report by the International Observatory on End of Life Care (2005:2) Nairobi Hospice has an average caseload of 1,500 patients per month within the city environs, yet it has a capacity to deal with only 625 patients. The International Observatory on End of Life Care (2005:2) further stresses that referrals mainly come from Kenyatta National Hospital, private doctors, and hospitals in the Nairobi area and upcountry.

Furthermore, as indicated by The East African Standard (2006:1) statistics show that only about five out of twenty patients referred to the hospices end up reporting there while the rest are cared for at home, and in most cases die rejected after undergoing untold suffering.

The researcher thus states the problem to which this study relates to as:

Lack of information pertaining to the nature and extent of palliative care in Nairobi, resulting in inadequate palliative care services.

1.3 Goal and Objectives

1.3.1 Goal

According to Fouché and De Vos (2005:104) the term goal, purpose and aim are often used interchangeably as synonyms for one another. The above authors state that their meaning implies the broader, more abstract conception of the end toward which effort or ambition is directed, while objective denotes the more concrete, measurable and more speedily attainable conception of such an end toward which effort or ambition is directed.

As further mentioned by Fouché and De Vos (2005:104) the one (goal, purpose or aim) is the dream, the other (objective) is the steps one has to take, one by one, realistically at grass roots level, within a certain time span, in order to attain the dream.

Therefore, the goal of this study was to explore the nature and extent of palliative care in the Nairobi Hospice, in Kenya.

1.3.2 Objectives

This study focused on three major objectives as outlined below which led to the attainment of its goal:

To provide a broad theoretical background on palliative care,
To explore the nature and extent of palliative care in the Nairobi Hospice,
To provide conclusions and recommendation for improved palliative care services in the Nairobi Hospice.

1.4 Research Question

According to Morgan (1999:93) the objective of a research question may take the form of a general question to be answered or a specific hypothesis to be tested. Whether a general question or a specific hypothesis is to be used is determined by the existing knowledge base and previous research activity on the subject. The above author states that when more knowledge and research results are available, it is more likely that a specific hypothesis will be used while on the other hand where there is little knowledge and research results, general questions are used.

In this study, a research question was appropriate because there is very little information on this research subject. Therefore, the research question to this study was formulated as follows:

What is the nature and extent of palliative care in the Nairobi Hospice, Kenya?

1.5 Research Approach

As cited by Fouché and Delport (2005:73-74) at present there are two well-known and recognised approaches to research, namely, the qualitative and quantitative paradigms, which differ from each other. According to Fouché and Delport (2005:73-74) it is of importance that the prospective researcher should orient herself/himself to the differences between them and decide which one is the better choice for his/her project, or whether a combined quantitative/qualitative approach might be appropriate. Myers (1997:2) agrees with Fouché and Delport (2005:73-74) by arguing that research methods can be classified in various ways, however one of the most distinctions is between qualitative and quantitative research methods. According to Myers (1997:2) quantitative research methods were originally developed in the natural sciences to study natural phenomena, while on the other hand, qualitative research methods were developed in the social sciences to enable researchers to study social sciences and cultural phenomena.

Mouton (1993:155) on the other hand states that although the terms qualitative and quantitative are fairly commonly used, there is confusion about the exact meaning of these terms. According to Mouton (1993:155) quantitative approach may be described in general terms as that approach to research in social sciences that is more highly formalised and explicitly controlled, with a range that is more exactly defined, and which in terms of the methods used, is relatively close to the physical sciences. Mouton (1993:155) further states that, qualitative approaches are those approaches in which the procedures are not as strictly formalised, while the scope is more likely to be undefined, and a more philosophical mode of operation is adopted.

Qualitative approach was used in this study. By utilising a qualitative approach, an attempt was made to understand the experiences of patients receiving palliative care at the Nairobi Hospice with life threatening illnesses from their subjective perspective.

1.6 Type of Research

According to Neuman (1997:21) for over a century sociology has had two wings. Researchers in one adopt a more detached, scientific, and academic orientation, and those in the other are more activist, pragmatic, and reform oriented which in itself is not a rigid separation because researchers in the two co-operate and maintain friendly relations. Neuman (1997:21) argues that some focus on using research to advance knowledge, whereas others use it to solve specific problems. Those who seek an understanding of the fundamental nature of social reality are engaged in basic, also termed as academic research, or pure research. Applied researchers by contrast, primarily want to apply and tailor knowledge to address a specific issue. Neuman (1997:2) further states that this means they either want to answer a political question or solve a pressing social problem. On the other hand though, the knowledge produced through pure research is sought in order to add to the existing body of knowledge or research methods.

Kumar (2005:9) on the other hand cites that most of the research in social sciences is applied. In other words, the research techniques, procedures and methods that form the body of research methodology are applied to the collection of information about various aspects of a situation, issue, problem or phenomenon so that information gathered can be used in other ways such as for policy formulation, administration and the enhancement of understanding of a phenomenon.

In this study applied research was used because the study in question was conducted in the hope that the yielded results would have a significant potential value in the formulation or improvement of programs intended to improve palliative care in Nairobi.

1.7 Research design and Methodology

Fouché (2005:268) mentions that qualitative research designs differ depending on the purpose of the study, nature of the research designs and the skills and resources available to the researcher. According to Fouché (2005:268) qualitative research designs do not usually provide the researcher with a step by step plan to follow unlike in the quantitative designs which determine the researcher's choices and actions, rather qualitative researchers will simply create their own research project around the strategy selected.

1.7.1 Research Strategy

The research strategy that was used in this study was a case study. According to Creswell (1998:61) a case study can be regarded as an exploration or an in-depth analysis of a bounded system (bounded by time and/or place) or a single or multiple case, over a period of time. Yin (1994:13) on the other hand cites a case study is an empirical inquiry that investigates a contemporary phenomenon within its real life context, especially when the boundaries between phenomenon and context are not clearly evident. As further mentioned by Creswell (1998:61) the exploration and description of the case takes place through detailed, in-depth data collection methods, involving multiple sources of information that are rich in context. According to Creswell (1998:61) these can include interviews, documents, observation or archival records and as such, the researcher needs access to, and the confidence of participants.

Mark (1996:219) refers to three types of case studies, all with different purposes. The intrinsic case study is solely focused on the aim of gaining a better understanding of the individual case, the purpose being not to understand a broad social issue, but merely to describe the case being studied. On the other hand, the instrumental case study is used to elaborate on a theory or to gain a better understanding of a social issue and that the case study merely serves the purpose of facilitating the researcher's gaining knowledge about a social issue. Lastly, the collective case study furthers the understanding of the researcher about a social issue of the population being studied. According to Mark (1996:219) the interest in the individual case is secondary to the researcher's interest in a group of cases and this is so because cases are chosen so that comparisons can be made between cases and concepts so that theories can be extended and validated.

This study focused on the instrumental case study, which enabled the researcher to gain more knowledge and understanding of patients with life threatening illnesses through information that was collected from this particular group of people. This involved a thorough study through which the researcher precisely gained insight on issues that were involved in the study of this phenomenon.

1.7.2 Data collection techniques

This study utilised focus group interviews as described by Bless and Higson-Smith (2000:110) whereby their model of qualitative interviewing emphasises an in-depth conversation with a purpose. Kruger and Casey (2000:4) further ascertain that focus groups are group interviews and a means of better understanding on how people feel or think about an issue, product or service. According to Bless and Higson-Smith (2000:110) a focus group consists of four to eight respondents who are interviewed together and more importantly, that the participants should be carefully selected to explicitly stated criteria. Kruger and Casey (2000:4) concur with Bless and Higson-Smith (2000:110) by stating that participants are selected because they have certain characteristics in common that relate to the topic of the focus group. As further mentioned by Bless and Higson-Smith (2000:110), the focus group is conducted in an unstructured or semi-structured way for instance, the researcher or facilitator of the focus group draws up a list of broad questions, topics and themes which are used to develop a discussion among the focus group participants.

The group is focused in that it involves some kind of collective activity and that the researcher creates a tolerant environment in the focus group that encourages participants to share perceptions, points of views, experiences, wishes and concerns without pressurising participants to vote or reach consensus (Kruger and Casey, 2000:4).

According to Morgan and Kruger (1998:52-59) focus groups are useful since they create a process of sharing and comparing among the participants. The researcher creates them for a well-defined purpose and they produce large amounts of concentrated data in a short period of time. According to Morgan and Kruger (1998:52-59) what distinguishes focus groups from any other form of interview is the use of group discussion to generate the data.

Three focus group interviews comprising of seven, six and seven members respectively were conducted to collect data. Each session took approximately two hours to avoid boredom and exhaustion considering that the participants were patients. Time was also minimised through the sessions because the researcher was familiar with the language used by participants, which eliminated the need to engage an interpreter.

The researcher introduced herself together with the assistant then she allowed the participants to introduce themselves with whatever name(s) they wished to use which mainly put them at ease. After the introduction, the researcher explained the purpose of the focus group discussion, the kind of information needed, and how the information was to be used. Prior to this, she had sought for their informed consent to use a tape recorder. The role of the assistant was mainly to record all the proceedings of the interviews during the investigation.

1.7.3 Data Analysis

According to Neuman (1997:418) qualitative data is in the form of text, written words, phrases or symbols describing or representing people, actions, and events in social life. Neuman (1997:418) notes that qualitative researchers look for patterns or relationships but they begin analysis early in a research project, while they are still collecting data. Neuman (1997:418) further states that the results of early data analysis guide subsequent data collection and that this analysis is less a distinct final stage of research than a dimension of research that stretches across all stages.

With this therefore, the data was analysed using the approach of Rubin and Rubin (1995:226-227), of beginning data analysis while the interviews are still underway. This preliminary analysis enabled the researcher to redesign questions to mainly focus on the main themes as the interview went on. After completion of the interview, a more detailed and fine-grained analysis of what the respondents said began. In this formal analysis, additional themes and concepts were discovered which enabled the researcher to build towards an overall explanation.

To begin final analysis, categories were organised on the basis of themes and concepts or similar features from all the interviews, which eventually were linked to each other in terms of sequences. The goal was to integrate the themes and concept into theory that offers an accurate, detailed, yet subtle interpretation of the research arena.

1.8 Pilot Study

Pilot study plays an important role in ensuring that the actual study is successful.

The New Dictionary of Social Work (1995:45) defines pilot study as the process whereby the research design for a prospective survey is tested.

According to Strydom and Delport (2005:331) it is of paramount importance to conduct a pilot study whether it is a qualitative or a quantitative study that is being undertaken. Strydom and Delport (2005:331) note that in qualitative research the pilot study is usually informal, and a few respondents possessing the same characteristics as those of the main investigation can be involved in the study, merely to ascertain trends. Royse (1995:172) on the other hand states that the purpose of a pilot study is to determine whether the relevant data can be obtained from the respondents. As further mentioned by Monette, Sullivan and Dejong (1998:93) a pilot study also contributes to the establishment of questions with the respondents or with the community, as well as obtaining permission for the project.

Therefore, it can be noted that the pilot study is the process through which the researcher familiarises himself/herself with the envisaged project prior to the undertaking of the actual research. Thus this pilot study was undertaken to investigate the feasibility of the planned study, which entailed the following aspects:

1.8.1 Feasibility of the study

The researcher established contact and good working relationship with the staff of the Nairobi Hospice, which made the research process much easier. Although the hospice operates on outpatient basis respondents' availability was only on Thursdays during the day care session.

Permission to conduct the study at the Nairobi Hospice was obtained from the Chief Executive Officer (C.E.O) of the hospice, and it is attached as an appendix to this research report.

1.8.2 Pilot testing

Pilot testing involved four patients with life threatening illnesses who were receiving palliative care at the hospice, in a focus group context. This enabled the researcher to expose a few cases to exactly the same procedures in the final investigation with actual subjects. In so doing consideration was made to items that could cause confusion, boredom or annoyance and necessary modifications on preparation for the actual study were effected. The four patients involved in the pilot testing were not included in the sample.

1.9 Description of the universe, population, sample and sampling method

1.91 Universe

According to Saravanavel (1992:119) the terms population and universe are often used synonymously in social science research. The universe conceptually is the total number of units for which the population is an operational definition. In other words, the universe is what the sample is supposed to represent, and the population is what the sample actually represents after practical adjustments are made.

The universe in this study consisted of all the patients with life threatening illnesses in Kenya who received palliative care.

1.9.2 Population

As defined by Bless and Higson-Smith (1995:87) a population can sometimes be referred to as a “target group” which is the set of elements that the research focuses upon and to which the results obtained by testing the sample should be generalised. While Babbie (2005:196) on the other hand cites that the term population is used to mean the group or collection that a researcher is interested in general. Babbie (2005:196) further states that more formally a population is the theoretically specified aggregation of elements, and a study population is the aggregation of elements from which the sample is actually selected. As further mentioned by Bless and Higson-Smith (1995:87) it is absolutely essential to describe accurately the target group which can effectively be done by clearly defining the properties to be analysed, using an operational definition. Once this is done it should be possible to compile a list of all elements of this population, or at least, to determine whether or not an element belongs to the population under investigation. All the same Babbie (2005:196) argues that as a practical manner, researchers are seldom in a position to guarantee that every element meeting the theoretical definitions laid down actually has a chance of being selected in the sample.

The population of this study consisted of all the patients admitted at the Nairobi Hospice to receive palliative care, during the period June and August 2007.

1.9.3 Sample

According to Babbie (2005:195) although the term representative has no precise, scientific meaning, it carries a common sense meaning that makes it useful. A sample therefore, is a representative of the population from which it is selected if the aggregate characteristics of the sample closely approximate those same aggregate characteristics in the population. Babbie (2005:195) notes that a sample need not be representative in all aspects since representative is limited to those characteristics that are relevant to the substantive interests of the study though a researcher may not know in advance which characteristics are relevant.

Bless and Higson-Smith (1995:88) assert that a sample must have properties which make it representative of the whole. According to Bless and Higson-Smith (1995:88) one of the major issues in sampling is to determine samples that best represent a population so as to allow for an accurate generalisation of results, and such a group is called a representative sample. Bless and Higson-Smith (1995:88) further state that the first means of ensuring a representative sample is the use of a complete and correct sampling frame, which is the list of all units from which the sample is to be drawn to avoid a case of inadequacy in sampling frame which discards parts of the target population thus resulting into many poor research results.

The sample of this study consisted of three focus groups of seven, six, and seven members respectively.

1.9.4 Sampling Method

The sampling technique that was used in this study is availability sampling from the non-probability sampling method. Bless and Higson-Smith (2000:92) ascertain that non-probability sampling refers to the case where the probability of including each element of the population in the sample is unknown. Bless and Higson-Smith (2000:92) argue that this sampling method is the most rudimentary one consists of taking all cases on hand until the sample reaches the desired size and that the researcher chooses a convenient place where he/she is assured of finding many people.

This sampling technique was suitable for this study since the respondents were easily available due to the fact that the study took place within the hospice premises.

1.10 Ethical Issues

According to Strydom (2005:57) ethics is a set of moral principles which is suggested by an individual or group, is subsequently widely acceptable, and offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students.

The following ethical issues were followed in this study:

1.10.1 Avoidance of harm to participants

According to Babbie (2005:63) the social researcher should never injure the people being studied, regardless of whether they volunteer for the study. Perhaps the clearest instance of this norm in practice concerns the revealing of information that would embarrass subjects or endanger their home life, friendships, jobs and so forth. Babbie (2005:63) further cites that subjects can be harmed psychologically in the course of a social research study, thus the researcher must look for the subtlest danger and guard against them.

Neuman (2000:93) on the other hand argues that although the risk of physical harm is rare, researchers may place people in stressful, embarrassing, anxiety-producing or unpleasant situations.

Due to the sensitivity of the topic some participants experienced some emotional disturbance thus a debriefing session was provided immediately after the data collection. Similarly it was agreed that the hospice counsellor would provide long-term intervention where necessary.

1.10.2 Seeking informed consent

As mentioned by Kumar (2005:212) in every discipline it is considered unethical to collect information without the knowledge of participants and their expressed willingness and informed consent. Kumar (2005:212) states that informed consent implies that subjects are made adequately aware of the type of information the researcher wants from them, why the information is being sought, what purpose it will be put to, how they are expected to participate in the study, and how it will directly or indirectly affect them. According to Kumar (2005:212) it is important that the consent should also be voluntary and without pressure of any kind.

In this study all the participants were requested to sign consent forms which clearly stipulated every aspect of the study in terms of the procedures to be followed, the use of any electronic devices, the reason for conducting the study and their voluntary participation without any coercion.

1.10.3 Avoidance of deception to participants

According to Neuman (2005:95) social researchers sometimes deceive or lie to subjects in field and experiment research. Experimental researchers often deceive subjects to prevent them from learning the true hypothesis and reduce reactive effects. Neuman (2005:95) further states that deception occurs when the researcher intentionally misleads subjects by way of written or verbal instructions, the actions of other people, or certain aspects of the setting. As mentioned by Neuman (1997:449) deception is acceptable only if there is a specific methodological purpose for it. This author cites that a researcher who uses deception should obtain informed consent, never misrepresent risks, and always debrief subjects afterwards.

In this study all the participants were provided with the truth regarding the study as well as all the information pertaining to the procedure.

1.10.4 Maintaining anonymity and confidentiality

Babbie (2005:64) asserts that the clearest concern in the protection of the subjects' interests and well being is the protection of their identification. This is because a research project guarantees anonymity when the researcher and not just the people who read about the research cannot identify any subject afterwards.

As further mentioned by Babbie (2005:65) a research project guarantees confidentiality when the researcher can identify a given person's responses but essentially promises not to do so publicly.

The researcher ensured that all the information given by the respondents was not shared with other people other than for purposes of the research. Furthermore, the identifying particulars of participants are not used in the research report.

1.10.5 Actions and competence of researchers

Strydom (2005:63) asserts that researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the proposed investigation. According to Babbie (2001:475) the entire research project must run its course in an ethically correct manner because obligation rests on the researcher towards all colleagues in the scientific community to report correctly on the analysis of data and the results of the study.

The researcher was confidently competent and skilled to undertake this investigation especially in matters relating to cultural norms since she has a clear understanding of the cultural beliefs of the population under study. The researcher also completed her coursework on research methodology and its application, and the study was conducted under the guidance of a supervisor.

1.10.6 Co-operation with contributors

Strydom (2005:64) indicates colleagues are sometimes formally or informally involved in the research project. Often they only assist in selecting a relevant problem, drawing the most sampling frame, or even simply in deciding which research design would be most suitable. According to Strydom (2005:64) collaborators can be involved on full-scale basis, for instance when two or three researchers assume equal responsibility for the entire project. Strydom (2005:64) further mentions that whatever the extent of the involvement of each researcher, a formal contract between participants is preferable, merely because everyone then knows what everyone else’s role in the overall project comprises, this avoids any misunderstandings about participants’ involvement at any stage of the project.

This research employed the services of an assistant which was formalised through a contract to ensure avoidance of misunderstandings and to make sure that matters of privacy and confidentiality are taken seriously. The assistant involved in the study was designated the role of operating the tape recorder during the interview session. In so doing the project was conducted ethically.

1.10.7 Publication of the findings

According to Strydom (1994:18) the findings of the study must be introduced to the reading public in written form, otherwise even highly scientific investigation will mean very little and will not be viewed as research.

The participants were informed that the findings would be available for the reading public in the library of the University of Pretoria. A manuscript will also be prepared for possible publication in a professional journal, and participants were informed about this as well.

1.10.8 Debriefing of respondents

Judd, Smith and Kiddler (1991:517) ascertain that debriefing session during which subjects get the opportunity after the study to work through their experience and its aftermath, is one way in which the researcher can assist the subjects and minimise harm. Babbie (2001:475) argues that through debriefing, problems generated by the research experience can be corrected. Salkind (2000:38) cites that the easiest way to debrief participants is to discuss their feelings about the project immediately after the session or to send a newsletter telling them the basic intent or results of the study.

Debriefing sessions were conducted with all the respondents to minimise any harm that the study could have caused. This was done immediately after the data collection session to enable the participants to air their views regarding the project. For those who needed further intervention, the services of the counsellor at the hospice were utilised, as it has already been indicated earlier.

1.11 Definition of key concepts

The following terms are central to this study and were used within the frame of the following definitions:

1.11.1 Palliative care

The Social Work Dictionary (2003:311) defines palliative care as the provision for the common physical and emotional needs and comfort of a patient with a terminal illness after efforts to cure are no longer successful.

According to the *Longman Dictionary of Contemporary English* (1995:1021) palliative care refers to a medical treatment that will not cure a problem but will reduce the pain.

The term palliative care in the context of this study is used to describe the care that is intended to keep patients with life threatening illnesses as comfortable as possible or the provision of a holistic care approach to patients whose illness is not curable.

1.11.2 Hospice

According to the *New Dictionary of Social Work* (1995:31) hospice refers to a facility where terminally ill patients receive physical, psychological and spiritual care.

Random House Webster's Unabridged Dictionary (1998:924) defines a hospice as a health care facility for the terminally ill that emphasises pain control and emotional support for the patient and family, typically from taking extraordinary measures to prolong life.

The term hospice in this study implies a setting for people with life threatening illnesses in a non-hospital facility where a number of programs are offered for patients with life threatening illnesses.

1.11.3 Terminal illness

The Social Work Dictionary (2003:433) defines terminal illness as a disease that is expected to result in a person's death.

Chambers Encyclopedic English Dictionary (1994:1264) defines terminal illness as an illness that is fatal and causes death to a patient.

Terminal illness in this study refers to an incurable disease that is predicted to lead to death.

1.11.4 Cancer

According to *The Oxford Paperback Dictionary Thesaurus and Wordpower Guide* (2001:117) cancer is a disease caused by an uncontrolled division of abnormal cells in a part of the body, threatening the life of the patient.

Longman Dictionary of Contemporary English (1995:188) defines cancer as a very serious disease in which cells in one part of the body start to grow in a way that is not normal, often causing death.

The term cancer within this study context referred to a growth that is very difficult to contain and can easily spread to other parts of the body, and may lead to death.

1.11.5 AIDS

Webster's Comprehensive Dictionary (1998:30) defines AIDS as a disease that impairs the human immune system, caused by infection with transmitted immuno-deficiency virus transmitted through blood and bodily fluids characterised by development of recurrent or chronic opportunistic infections with an increased incidence of certain cancers.

According to the *Longman Dictionary of Contemporary English* (1995:30) AIDS is a very serious disease caused by a virus that stops your body from defending itself against infections.

This study refers to AIDS as the end stage of HIV infection, a stage where various diseases called opportunistic infections attack the weakened body.

1.11.6 HIV

Oxford Advanced Learner's Dictionary (2000:568) defines HIV as a virus, which is a simple living thing that causes infections or illnesses that, can cause AIDS (abbreviation for human immuno-deficiency virus).

According to *Chambers Encyclopaedic English Dictionary* (1994:595) HIV is an abbreviation for Human Immuno-deficiency virus, the virus responsible for the disease AIDS. It is known to be a retrovirus, and transmitted in blood, semen and vaginal fluid. Usually it destroys the immune system, in particular the T-helper cells (which manufacture antibodies) and macrophages (which engulf invading bacteria) leaving the body susceptible to potentially fatal infections such as pneumonia and kaposis sarcoma (an otherwise rare skin tumour).

The term HIV in this study refers to a virus that causes AIDS and attacks the immune system and weakens it whereby, the immune system becomes deficient leading to the infected person becoming easily susceptible to a variety of infections.

1.12 Problems encountered in the study

The problems experienced in this study are as stated below:

- There was scarcity of literature and existing research on the subject of palliative care in the Nairobi Hospice, especially with regard to the provision of adequate palliative care in the Nairobi area. In this case, studies from other African countries were utilised to provide more insight on the phenomenon for instance, Uganda, South Africa, Zimbabwe, Botswana as well as the developed countries like United States of America and England.

- Delays regarding the granting of permission to conduct the study in the Nairobi Hospice due to the fact that the senior medical officer in charge of the hospice, who the researcher had made contact and arrangements with on the above, had left the hospice for new employment elsewhere. This resulted into the researcher having to start all over again with the new management, a process that slowed the pace of the study. Thus while the University's Research Proposal and Ethics Committee gave a go ahead to the research in May 2007, the researcher had to wait until August of the same year to embark on the data collection exercise.

- The researcher also had difficulties getting the number of participants formerly anticipated. This was due to the fact that the only day that respondents were available was on Thursday's during the day care session despite the institution being operated on an outpatient basis.

1.13 Contents of the research report

The compiled report is organised in four chapters as follows:

Chapter 1: General Introduction.
Chapter 2: Literature review on palliative care as a phenomenon.
Chapter 3: Empirical findings.
Chapter 4: Conclusions and recommendations of the study.

CHAPTER 2

PALLIATIVE CARE

2.1 Introduction

According to Lucas (2006:1) more than 50 million people die throughout the world each year and that the majority of these deaths are in developing countries. HIV has increased the number of deaths, 3 million people dying in 2000, 2.4 million in Sub-Saharan Africa. Even where advanced therapies are available, length of life may be reduced for those with HIV. In addition, advanced HIV illness is associated with severe pain. Thus people living with HIV in developing countries can therefore expect a shorter life span and their death is likely to be unnecessarily painful and undignified.

According to Wikipedia (2007:1) palliative care maybe used generally to refer to any care that alleviates symptoms, even if there is hope of a cure by other means. In some cases, palliative treatments are used to alleviate the side effects of curative treatments, such as relieving the nausea associated with chemotherapy. The term palliative care is increasingly used with regard to diseases other than cancer, such as chronic, progressive pulmonary disorders, renal disease, chronic heart failure or progressive neurological conditions. In addition, the rapidly growing field of paediatric palliative care has clearly shown the need for services geared specifically for children with serious illnesses. According to Wikipedia (2007:1), though the concept of palliative care is not new, most physicians have traditionally concentrated on aggressively trying to cure patients since available treatments for alleviation of symptoms were viewed as hazardous and seen as inviting addiction and other unwanted side effects.

On the other hand, the American Academy of Family Physicians (2006:2) states that the key to effective palliative care is the provision of a safe way for the individuals to address their physical and psychological distress, that is to say their total suffering, a concept first thought up by Dame Cicely Saunders, and now widely used by other authors. Smith (2006:2) further cites that dealing with total suffering involves a broad range of concerns, starting with treating physical symptoms such as pain, nausea and loss of breath.

The following aspects are discussed in this chapter:

- Palliative care as a phenomenon
- Origins of palliative care
- Current palliative care practice
- Paediatric palliative care
- Models of care
- Role of social workers in palliative care.

2.2 Palliative Care as a Phenomenon

Several authors (Wikipedia, 2007:1; MedicineNet, 2007:1; American Academy of Family Physicians, 2006:1) agree that palliative care is any form of medical care or treatment that concentrates on reducing the severity of disease symptoms or slowing the disease's progress, rather than providing a cure.

According to Borgsteede (2006:63), in 1990, the World Health Organisation (WHO), defined palliative care as the active total care of people whose disease is not responsive to treatment. Control of pain, of other symptoms and of psychological, social, emotional and spiritual problems is paramount. Furthermore, WHO provided another definition in 2002 that views palliative care as a comprehensive approach that improves the quality of life of patients with life-threatening illnesses and their families. These improvements is ensured through the prevention and relieve of suffering by means of early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. Borgsteede (2006:63) asserts that according to both the 1990 and 2002 WHO's definitions, palliative care intends neither to hasten nor postpone death.

Foley (2005:43) argues that the current definition reflects an evolution in thinking about the role of palliative care in modern society. The definitions emphasize that palliative care should be provided throughout the continuum of patients' illness and that it should focus not only on treating suffering but on preventing suffering, in keeping with the role of palliative care as a public health approach to managing chronic diseases. On the other hand, Smith (2006:1); Abernethy and Currow (2006:84) agree that many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment. Smith (2006:1); Abernethy and Currow (2006:84) further mention that it is recognised that the principles of palliative care should be applied as early as possible in the course of any chronic disease.

According to the American Academy of Family Physicians (2006:1) both 1990 and 2002 definitions define the intentions or goals of palliative care, but are rather vague in describing the eligible population. MedicineNet (2007:2) further states that, while the goals are focusing on the symptoms and problems of the patients, the population in the WHO definitions is defined by the illness of the patient, for instance, disease not responsive to curative treatment (1990), or illness that is life threatening (2002). The American Academy of Family Physicians (2006:1) states that, as a consequence, palliative care populations have been defined by health policy makers or by researchers in many different ways, a major problem in the further development of palliative care being the lack of an accepted way of defining rural populations. MedicineNet (2007:2) however cites that, a clear population's criterion is essential to make possible the comparison of results across studies and countries.

It is further argued that the aim or goal of palliative care is the achievement and provision of the best possible quality of life for patients or people approaching the end of life and for their families (Lucas, 2006:1; Borgsteede, 2006:3; American Academy of Family Physicians, 2006:2).

The researcher is of the opinion that palliative care is a form of medicine provision that relieves pain without necessarily curing it. The researcher further asserts that this term has been defined by a number of authors who basically agree that palliative care focuses on pain and symptom management with an aim of providing the best possible quality of life for patients with life threatening illnesses as well as their families.

2.2.1 Origins of Palliative Care

Several authors (Hallenbeck, 2006:1; Gunten & Ferris, 2006:1) agree that the modern use of the term palliative care is usually attributed to Dr. Balfour Mount, one of the founders of the North American Hospice/Palliative Movement. Working in French-speaking Montreal, Mount felt the need to coin a new term for hospice, as the French equivalent referred to almshouse for the poor and the elderly. Being a synonym for hospice, he felt that it would be acceptable to both English-speaking and French-speaking Canadians. On the other hand, Smith (2006:1) states that the word hospice originated from Roman times, and throughout the early centuries the religious community ran establishments dedicated to the care of the sick and dying. These early hospices took a very holistic approach to care and focused on the specific needs of a dying individual. Following religious suppression, these places deteriorated and it was not until the late 19th century that the old idea of the hospice began to revive.

The experiences of Saunders as a nurse, social worker and physician convinced her that dying patients were often neglected and ignored, suffering unnecessarily for want of both basic symptom management and attention. Thus a new social institution was needed, and this institution became known as hospice (Hallenbeck, 2003:2; Bruce, 2006:2).

According to Portenoy and Glajachen (2006:1) in the United States, early hospice services were provided almost exclusively in patients' homes. The early United States hospice movement was created outside of the established health care system. In contrast with the United Kingdom, these teams were usually nurse and/or volunteer led. This prevailing pattern was systematised in the Medicare hospice benefit legislation passed in 1982 and implemented in 1983. Although there was an effort to mimic the British model of hospice with the founding of the Connecticut Hospice in conjunction with the Yale University 1974, this did not change predominant patterns.

According to Gunten and Ferris (2006:2), in the United Kingdom and Ireland, free standing inpatient units for the care of the dying developed first. These were developed for patients (predominantly with cancer) with difficult symptom and psychological problems that could not be met elsewhere in the health care system. Further, these patients were at a stage where treatments directed at the cancer were no longer efficacious. Patients admitted usually had a prognosis of weeks or months.

It is further argued by Portenoy and Glajchen (2006:2) that since patients wanted to be cared for and die at home, to augment the existing home care services hospices developed home care support teams to consult and assist the general practitioner and district nurse. At the same time also consultation through office-based and hospital-based consultation teams was needed to bring the expertise developed in the inpatient hospices to patients and families in other settings.

Hallenbeck (2003:2) concurs with Bruce (2006:2) by stating that traditions of kindness for the sick and dying patients are to be found in all societies from antiquity. Much of the theory and structure of modern hospice care in the United Kingdom can be credited to Dame Cicely Saunders, who observed the need for the spiritual and psychological care of dying patients whilst working as a hospital nurse.

According to the Foundation for Hospices in Sub-Saharan Africa (2007:1), the hospice and palliative care in Africa started in 1979 with the establishment of the first hospital program, Island Hospice, in Harare, Zimbabwe. This program and others that followed in South Africa, Kenya, and Uganda were modelled on the principles of hospice care from the United Kingdom but focused on the provision of home-based care for patients and not on specialised inpatient facilities.

The researcher is of the view that the origins of palliative care, as discussed above, has been approached from different angles by several sources. While some authors argue that its origins is attributed to Dr. Balfour Mount, one of the founders of the North American Hospice and Palliative Movement, the others state that the word hospice originates from the ancient Roman times. All the same though, the origin in both United States of America and elsewhere in Europe began a long time before its existence in Africa and especially in the Sub-Saharan Africa.

Therefore, it is apparent that the introduction of the hospice as a new social institution was sparked by the view that dying patients were usually neglected, ignored, and suffered without proper care. For this reason, they needed a way to alleviate their pain, control and manage it within an institution like the hospice, where they would receive palliation at the end of life.

2.2.2 Current Palliative Care Practice

Hallenbeck (2003:3) states that the 1990s witnessed remarkable changes in palliative care/hospice movement. While initially hospice was made available primarily to cancer patients, patients with other diseases have begun requesting such care. Pressure is growing to build upon lessons learnt in hospices and apply this knowledge to the care of other patients and in other venues. Clinicians are finally beginning to realise that their training has been grossly deficient in the skills and the art of palliative care perhaps most important, a significant portion of the public has been exposed to the hospice.

Several authors (Gunten & Ferris, 2006:3; and Portenoy & Glajchen, 2006:10) agree that palliative care consultation services started in the United States as a therapeutic approach with the same goals as hospice care but without the constraints. However, most palliative care services began inpatient consultation services in hospitals and in ambulatory clinics. According to

Gunten and Ferris (2006:3), these programs frequently linked with one or more hospice programs as a means to extend care to the home. The goal being to make insights and expertise originally developed within hospice programs more readily available to patients in other parts of the health care system.

According to Wikipedia (2007:2), in the United States, hospice and palliative care represent two different aspects of care with similar philosophy, but different payment systems and location of services. Palliative care services are most often provided in acute care hospitals organised around an interdisciplinary consultation service with or without an acute inpatient palliative care ward. Wikipedia (2007:2) further states that palliative care may also be provided in the dying person’s home as a bridge program between traditional US home care services and hospice care or provided in long-term care facilities. In contrast, over 80% of hospice care in the US is provided in a patient’s home, with the remainder provided to patients residing in long-term facilities or in free-standing hospice residential facilities.

Muhombe (2004:13) asserts that palliative care aims to maximise the quality of life and relieve the suffering of patients with life limiting incurable disease. It also focuses on the provision of care and support for their carers and families. The above author states that the breadth of support and intervention addresses the clinical needs of patients such as pain and symptoms as well as the psychological, social and spiritual needs of those affected during the disease trajectory.

It is further argued by Muhombe (2004:13) that this reflects the understanding that good management of physical and psychological pain can be required at many points when living with a life-limiting illness. For people in Sub-Saharan Africa with a life limiting illness, there is need for the introduction of a greater component of palliative care earlier in the disease course. This is due to the lack of access to anti-retroviral therapy for people with HIV disease, the late presentation, inadequate diagnostic facilities and assessment skills, poor chemotherapy and radiotherapy available for people with cancer.

Smith (2006:1) mentions that palliative care is a growing practice speciality, but also a general approach to patient care that should be integrated into daily clinical practice, it can be the main focus of care or can be given together with life-prolonging treatment. Ideally, palliative care begins when the condition is diagnosed and continues through cure or until death and family bereavement. Klinger and Connor (2005:386) concur with Smith (2006:1) by stating that, palliative care is given in multiple settings, including physicians' offices, hospitals, school clinics, nursing homes, emergency facilities and the home. This necessitates fundamental palliative care training for physicians across many treatment settings, access to formal palliative care teams and qualified specialists, and the establishment of referral patterns. Primary care physicians are expected to provide basic palliative care, such as pain assessment and management as part of their routine services. Klinger and Connor (2005:386) agree that in more complex situations, the patient or family may need the services of palliative care specialists.

On the other hand Kuziemsky, Yahne and Lau (2005:118) assert that traditionally, much of this end of life care has been provided by hospices or acute care centres. According to Moller (2005:19) although hospice is presumed gold standard of care for the dying, in practice it drifts towards middle class preconceptions and is limited in its value, both real and perceived, in serving those who are economically and racially vulnerable. That is why hospice should be evaluated with specific regard to its capacity to serve the urban poor.

Palliative care, whether for people with HIV or for others with chronic illness, is an essential part of any health care system. Thus the three foundation measures to scaling up the provision of such care as identified by World Health Organisation (WHO) are; development of a national policy, training for health workers, public education and pain control. This is so because ultimately what makes or breaks a palliative care program is its ability to generate and handle referrals. A program with a sophisticated approach to referrals will thrive, while a program without one may not survive (Meier, 2005:706; Lucas, 2006:3).

Harding and Higginson (2004:33) concur with Meier (2005:706) and Lucas, (2006:3) by asserting that referral systems can only be efficient when there is an appropriate and accessible care system with trained staff to whom referrals can be made. Coverage can only be achieved when issues of sustainability are addressed to guarantee continuity of that which is in place. Potential coverage is limited by the fact that many geographical areas where potential patients live are inaccessible for staff, therefore, many models of provision and integration are needed.

It is further cited that coverage may be best achieved through training across levels from public health institutions down to the village level, thereby rolling out the service into rural models. Although training is important, without health care sector and government support to make morphine available, trained staff is unable to achieve intended outcomes. The provision of palliative care training may be achieved during existing nursing and clinical courses, as this may avoid the feelings of overload at gaining skills and care paradigms (Harding & Higginson, 2004:34).

Meier and Beresford (2005:1092) further mention that the ultimate aim for a hospital palliative care consultation service is to put specially trained clinically skilled professionals at the bed side of seriously ill patients. This is crucial since they can help clarify, plan and problem solve the host of physical, psychological, spiritual, and practical concerns raised by the illness. Such face to face encounters by palliative care professionals are intended to reduce utilisation of health care resources and strengthen the hospital’s bottom line.

Several authors (Meier & Beresford, 2005:1092; Lucas, 2003:3; Moller, 2005:18) agree that a palliative care service needs a well designed administration infrastructure in order to facilitate these face to face clinical encounters effectively and efficiently. According to Meier and Beresford (2005:1092) the design for an infrastructure for palliative care may face challenges such as shoestring budgets, lack of support from the health systems, dearth of understanding palliative care, as well as lack of administration skills by physicians, nurses and other clinicians asked to establish these programs. Understandably, the focus of the team is primarily on patients' needs. However, Lucas (200:3) and Moller (2005:22) argue that if palliative care teams undervalue their contribution by failing to insist in advance on the level of infrastructure support required to run a quality clinical service, they threaten effectiveness of their work with patients as well as the long term survival of the service.

According to the Palliative Care Advocacy Workshop (2003:22) established palliative care services need not cost vast amounts of money. Decent palliative care for many, not just for few, is an attainable aim. But there are several conditions that must be met if services are to be effective, for instance:

- Principles of palliative care, including pain control, must be adopted as part of any country's national essential health care strategy.
- There needs to be a strong education and training programs for public health workers and health care staff in palliative care as well as for family carers.
- The public also needs to be made aware that treatment for pain exists. Rather than concentrating palliative care services in institutions like hospitals, there must be a broad approach to providing services that take account of a population's needs, especially in the rural areas.
- The most important obstacle that needs to be overcome in many Sub-Saharan African countries is the current attitude against the use of strong opiods, like morphine for the pain control, and the lack of other appropriate drugs to treat opportunistic infections.

Although palliative care originated in the 1960s, the combination of our ageing population and people with illness having longer survival times will require the delivery of increased palliative care services in the forthcoming decades.

Although increased financial resources will be needed to realise new visions for increasing palliative care delivery, governments are already under financial strain and the challenge is how to deliver more and better services with less resources (Kuziemsky *et.al.,* 2005:118).

The researcher is of the opinion that the hospice movement is drastically changing beyond providing palliative care to cancer patients only, to include patients with other life threatening illnesses as indicated. It is evident from the above information that palliative care services are provided both on inpatient and outpatient basis, with an aim of offering services that are readily available to all patients living with life threatening illnesses. These patients also need good management of both physical and psychological pain at one point or another during the course of their illnesses.

Palliative care whether for people with HIV or others with chronic illnesses is an essential part of any health care system. There has to also be efficient referral systems to ensure sufficient provision of palliative care. This is so because for any palliative care program to be efficient referral systems should be made possible with appropriate trained personnel, affordable costs and accessible services to all patients.

2.2.3 Paediatric Palliative Care

According to the American Academy of Paediatrics (2005:351) paediatric palliative care is important since it is a part of palliative care in general, thus there is a need to enhance a more and better understanding of this issue to the public. It is especially essential because it deals with infants and children living with life-threatening illnesses of terminal condition.

World Health Organisation (1998) defines paediatric palliative care as the active total care of the child’s body, mind and spirit, and also involves giving support to the family.

Palliative care includes the control of pain and other symptoms and addresses the psychological, social and spiritual problems of children (and their families) living with life threatening or terminal conditions. The goal of palliative care is the achievement of the best quality of life for patients and their families, consistent with their values, regardless of the location of the patient (Rowse, 2006:41; Bruce, 2006:164).

According to the American Academy of Paediatrics (2000:351), palliative care seeks to enhance and alleviate a child's physical, psychological, and social distress. This is so because effective palliative care requires a broad multi-disciplinary approach that includes the family and makes use of available community resources. Himelstein (2006:163) further supports this by stating that as no one person can provide all the necessary support for the child and family, palliative care is best provided using an integrated interdisciplinary approach. As stated by Himelstein (2006:163) the provision of palliative care for children involves a partnership between a large network of actors. These include the child, family, parents' employers, teachers, school staff, and health care professionals, including nurses, chaplains, bereavement counsellors, social workers, primary care physicians, sub-speciality physicians, and consultants, since their input is the cornerstone of palliative care for children.

Stein and Sherman (2005:1275) assert that, the American Academy of Paediatrics (AAP) issued a policy statement recommending the development and wide availability of palliative care and respite programs for children. It also recommended that health care professionals develop an integrated model of palliative care that continues throughout the course of the illness, regardless of the outcome. Stein and Sherman (2005:1275) further state that in addition, aspects of an integrated palliative care approach, including symptom management and counselling, may prove beneficial when provided early in the course of the child's illness.

Paediatric palliative care is not about dying, rather it is about helping children and families to participate to the fullest extent possible, while facing complex medical conditions. Thus family-centred paediatric palliative care is the art and science of improving the quality of life, attending to suffering, and assisting with medical decision making for a child with life threatening conditions (Himelstein, 2006:163; Stein & Sherman, 2005:1275; Harding & Higginson, 2004:23.)

Rowse (2006:41) asserts that as many children with chronic, life shortening illnesses are not living into adolescence and young adulthood, they require palliative care services as well to relieve their pain since it may have a major impact on their lives. Thus, the WHO protocol on pain management should not only be used for children with cancer only but should be incorporated into the care of all children with severe pain. Stein and Sherman (2005:1275) on the other hand cite that pain and suffering in dying children should be an integral part of care in neonatal and paediatric intensive care units as well.

According to the American Academy of Paediatrics (2000:353) the provision of palliative care for children includes sensitivity to and respect for the child and family's wishes. In consultation with the child's parent or guardian, the plan of care incorporates respect for the terminally ill child's preference concerning testing, monitoring, and treatment. Consistent with this principle of respect, information about palliative care should be readily available and parents may choose to initiate a referral to a paediatric palliative care program. The needs of families must be attended to both during the illness and after the child's death to improve their ability to survive the ordeal intact.

It is further argued by The American Academy of Paediatrics (2000:354) that, in addition to alleviating pain and other physical symptoms, physicians must provide access to therapies that are likely to improve the child's quality of life. Such therapies may include education, grief and family counselling, peer support for both the patient and siblings, and appropriate respite care. Respite care, the provision of care to an ill child (in his or her usual state of health) by qualified caregivers other than their family members allows the family time to rest and renew, whether for hours or days, on a schedule, or intermittently as needed. Families may benefit from provision of respite care throughout a child's illness, not only near the end.

Stein and Sherman (2005:1275) assert that appropriate paediatric respite care is often lacking, but it is considered by many families to be essential for their continued integrity and ability to care for the ill child, siblings, and themselves. Ideally, the patient’s paediatrician, family physician, and paediatric sub-specialist or surgeon should continue to care for the child, while making a timely referral to palliative and hospice care. According to Stein and Sherman (2005:1275) palliative care programs should assist the child’s usual caregivers in maintaining an ongoing role in the child’s care.

Several authors (Rowse, 2006:41; Himelstein, 2006:163; Stein & Sherman, 2005:1275;) agree that the future of paediatric palliative care will depend upon continued research, education and advocacy to improve care for the child with life-threatening condition. Although paediatric palliative care differs from that of adult patients, the philosophy and comfort for patients must remain a top priority for all health care providers. This is because whether it is paediatric palliative care or palliative care for adults, it all involves palliative care regardless of the age group.

The researcher deduces that paediatric palliative care has been defined as the active total care of the child’s body, mind and spirit which also involves giving support to the family. Its aim is to achieve the best quality of life for patients and their families.

Palliative care seeks to enhance and alleviate a child’s physical, psychological and social distress and usually is provided by an interdisciplinary team. In addition to alleviating pain and other physical symptoms, therapies should be made accessible to allow for improvement in the child’s quality of life throughout his/her illness, not only near the end of life. All the same paediatric respite is another important aspect in paediatric palliative care.

2.3 Models of Care

Defillippi, Cameroon and Merriman (2005:459) assert that for any palliative care project to run effectively it is imperative to consider the range of models as a basis for selecting the most appropriate one. This will lead to the improved quality of life for patients and their families within their communities.

According to the International Association of Hospice and Palliative Care (2007:16) there is no one right or wrong model for the provision of palliative care. Local needs and resources, in consultation with the local health care providers and authorities determine the best model. Each developing country should be encouraged and enabled to develop its own model of palliative care that is relevant. That means it should be appropriate to the needs of the local patients, supported by the available resources, taking advantage of the experience and expertise accumulated in developed countries, and not be expected to copy models more appropriate to affluent countries. Abernethy and Currow (2005:85) further state that models of palliative care delivery differ by country, state and service provider with varying levels of medical focus, community support, philanthropic support, and government interest primarily based on local historical models of development. All models are referral dependent and focus on better symptom management and optimising level of function as death approaches.

The International Association of Hospice and Palliative Care (2007) argues that for any palliative care project to be effective it is of paramount to consider the implementation of the most ideal models of care. This is because it is through this that the quality of life for patients with life threatening illnesses can be improved as well as that of their families and the community at large.

Each country should be encouraged to develop models of care that meet the needs of the local patients by putting into consideration the locally available resources, experiences and expertise as opposed to copying models more appropriate to the developed countries in the world. Although these models of care delivery differ by country or state they are all referral dependant and focus on symptom management and improving the quality of life of patients at the end of life.

2.3.1 Home-Based Care

According to Surgery Encyclopaedia (2007:1) home care is a form of health care service provided where a patient lives. Patients can receive home services whether they live in their own homes, with or without family members, or in an assisted living facility. The purpose of home care being to promote, maintain, or restore a patient's health and reduce the effects of disease.

According to Muhombe (2004:38) home-based care is by far the most common model of palliative care provision, a resource-led decision in response to high numbers of patients and modest resources, thereby maximising coverage and sustainability. Muhombe (2004:38) further cites that, home-based care offers flexibility and increased potential for culturally appropriate care, but is limited by the suitability and availability of a home and family care network, and by the geographic area that can be feasibly covered by palliative care providers. Kuziemsky *et al.* (2005:118) on the other hand ascertain that reports from governments at all levels are identifying increased home based care as a way of delivering needed palliative care services while allowing a patient to remain in the comfort of their own home.

There are several programs providing palliative care that serve as models for providing palliative care in Africa for example, Hospice Africa Uganda (HAU) has been described as a public health success which is also a resource and training centre for home-based care. HAU has successfully introduced oral morphine into the majority of government health units and trained clinicians on its use. Uganda is one of the few countries that included palliative care as an integral part of the country's health plan (Abernethy & Currow, 2006:85).

Lucas (2006:2) concurs with Abernethy and Currow (2006:85) by stating that in Africa, the Hospice movement has developed and expanded in a few countries, including South Africa, Uganda and Zimbabwe. The principles of the hospice movement, established initially in the United Kingdom, were developed in these projects to treat cancer patients, and are now working also with people with HIV under home based-care. Some of these, such as Hospice Uganda and Hospice South Africa (HASA) are able to provide training in palliative care to help increase the local capacity in implementing palliative care projects. According to Abernethy and Currow (2006:85) these hospices, in common with other smaller hospice projects are caring for people with HIV as well as those with cancer. This means understanding the issues peculiar to HIV, including stigma and discrimination and the importance of confidentiality, and the need to set up or link into other initiatives providing voluntary testing and counselling.

Lucas (2006:2) further states that other projects such as The Mildmay Centre for AIDS Palliative Care in Uganda, the Ministry of Health/NGO Home Care Program in Cambodia, and the Ndola Diocese Home Care Program in Zambia have been established in response to the HIV pandemic. Through these home-based care programs, optimum care has been made available to those who need it, and experiences from different angles have been shared as well. Furthermore, good referral systems in these projects have also been made essential to people living with HIV.

However Kuziemsky *et al.* (2005:18) differ with Lucas (2006:2) by citing that there are challenges to increased delivery of palliative care through home care. Because palliative care patients are no longer seeking curative treatment much of palliative care involves the relief of symptoms. Palliative patients frequently suffer from physical symptoms like pain, nausea and dyspenea (shortness of breath) as well as emotional symptoms for instance, anxiety and depression. Thus, in order to be a successful means of increasing palliative care delivery for home based care there is a need to enhance abilities to manage symptoms for patients at home.

Lucas (2006:1) further asserts that the HIV epidemic has led to increased efforts to provide care and support for people in their homes. While this has been a great step towards the care that people need, many home care projects are unable to provide the pain relief and treatment of symptoms that are needed to prolong life and ease dying and death. Huge investment is needed to ensure that when advanced treatment is no longer effective or when it is inaccessible for any reason, people can have access to symptomatic treatment and pain relief. The obstacles are political, financial and lack of understanding and training in the palliative care approach. As with other models of care, HIV brings its own particular challenges to the concept and implementation of palliative care.

The researcher concurs with the value of home based care as a model of care that allows for patients to receive services at their homes, the purpose being to provide for their needs in a familiar home environment.

2.3.2 Community Based-Care

According to Defilippi *et al.* (2005:459) Community based care is long term care provided to patients with life threatening illnesses within their communities rather than in hospitals or institutions.

It is further stated by Defilippi *et al.* (2006:459) that many support organizations have networks into the communities and involves caregivers at the village level. Using these community-based organisations (CBOs) is obviously a way to rapidly scale up care of the critically ill and those at end of life within the community. However, in taking on palliative care services, the CBOs must adapt their frequency of home visits. Also, palliative care must be available for any crisis and CBOs should have a separate palliative team to take referrals from the larger support team and provide more intensive care. These teams should at least have one palliative care nurse or clinical officer to take responsibilities, train and guide them.

According to Defilippi *et al.* (2006:460) the collaborative model of integrated community-based home care involves not a single organisation, but the collective efforts of many organisations working together, for instance a nongovernmental organisation, such a hospice, works closely with government hospitals and primary health care clinics. At the same time existing community and faith-based initiatives are drawn in and strengthened by means of active networking and the enhancement that flows from non-competitive mutual support. This system allows for trust to be built between the stakeholders and results in an effective referral system.

Abernethy and Currow (2006:86) state that it has become imperative for community-based home care programs to supplement hospital and clinical services. According to Abernethy and Currow (2006:86) it is of primary concern to ensure that community-based programs incorporate an effective clinical component that includes palliative care. In this situation, community caregivers should be issued with suitably equipped home care kits and be taught clinical skills that have traditionally been reserved for professional, who have become a scarce resource. The professionals in turn need to be empowered with supervisory, delegation, and management skills. Lucas (2006:2) concurs with Abernethy and Currow (2006:86) by asserting that palliative care programs should engage the services of volunteers to supplement the services of paid staff because in delivering care certain essential components should be put into consideration. This is so since the involvement and support of local communities in both planning and implementation of community- based programs is essential in terms of its acceptability and long-term sustainability. This includes pain and symptom control which is the most critical of all, as well as holistic care which addresses the financial, social, emotional and spiritual needs of the family.

Muhombe (2004:38) further ascertains that community-based projects offer feasibility, optimal coverage, and active referral networks. However, replication of successful demonstration projects would benefit from further process evaluation and description of resources and potential weaknesses, as well as further understanding of the clinical support and community capacity to care.

Several authors (Abernethy & Currow, 2006:86; Defilippi *et al*., 2006:460; Muhombe, 2004:38) agree that in so doing, community-based organisations will be able to help relieve the suffering of people living with HIV and AIDS as well as cancer, and their families who would otherwise have no access to services.

Community based care as a model provides services to patients within their communities, and has the potential of being very beneficial for the patients and their families as the service is within reach.

2.3.3 Day Care Units

Sometimes referred to as day care or day hospice palliative care units, day units usually form a part of a hospital or inpatient palliative care unit. Although oftenly a part of the continuum of services in developed countries, there is a role for community day care even in low-resourced countries. Here, the community comes together and prepares a day for the patients receiving palliative care to meet together in a centre, which maybe the community centre or a local church. Volunteers care for the patients, transport them to the centre, cater a meal and snacks, and offer diversional therapy and counselling. This gives the family carers some time off and enables the sharing community to attend to spiritual, cultural and social needs. Day care may not be a stand-alone service, but it can be part of a comprehensive set of services (Association for Hospice and Palliative Care, 2007:17).

Day units are usually get togethers that are organised by community members to enable patients receiving palliative care to meet together and share a meal and their experiences. Furthermore, day care is an interesting event for patients since it enables them to share their experiences and have time also to encourage each other during the course or their illness. In such a setting, every opportunity should be exploited to enhance the quality of life in a social context as far as palliative care patients are concerned.

2.3.4 Pain and Symptom Management

According to Hallenbeck (2003:2), a focus on illness can distract one from the process of living. When a patient is facing a chronic disease or progressive illness, there are many positive choices that can help him or her plan and achieve the best possible quality of life. The above author argues that the palliative medicine team works with the attending physicians to address symptom management, advance care planning; psychological support and spiritual care needs throughout the disease process. According to Hallenbeck (2003:2) palliative care is a specialised form of care that alleviates pain and other symptoms. The goal of palliative medicine is not to prolong life or hasten death, but rather, to keep the patient as comfortable as possible, while offering support to the patient and the family.

Several authors (Ripamonti & Bruera, 2006:1; Hallenbeck, 2003:1; Beck, 1996:16) agree that cancer-related pain afflicts approximately 9 million people worldwide annually. The incidence of pain at various stages of the disease is 51% and increases to 74% in the advanced and terminal stages. Among advanced cancer patients, pain is moderate to severe in 40%-50% and very severe or excruciating in 25%-30%. According to Ripamonti and Bruera (2006:1) in rating their pain, the majority of patients (69%) cite that which causes impairment of their ability to function is the worst pain. In most cases pain can be controlled through medications prescribed according to the WHO analgesic ladder, an approach using various levels of medication based on the severity of pain. This type of pain treatment using drugs is called pharmacological therapy, while therapies that do not rely primarily on medication to achieve effect are called non-pharmacological therapies.

Ripamonti and Bruera (2006:2) further state that pain is always subjective, it is what the patient says hurts, and that a patient's threshold of pain is an individual concept. Thus, successful pain control requires a multi-disciplinary approach to treatment that addresses all aspects of care and suffering. Ripamonti and Bruera (2006:2) emphasise that provision of adequate pain management requires, among other things, sensitivity training for caregivers.

This means all staff, including aides, social workers and chaplains, should be trained to help patients identify physical, emotional, social and spiritual roots of pain.

Kuziemsky *et al.* (2005:118) argue that part of the problem with managing symptoms at home is logistics, as palliative patients require on-going surveillance and responsiveness in order to effectively manage their symptoms. Management of symptoms such as pain is not a once off event but rather a continuing process where pain responses and needs develop over time. However, the ability to provide ongoing symptom management is necessary as it has been shown that daily pain ratings provide continuity in the pain management process, which allows proactive pain management. Therefore, there is necessity to develop ways of providing the means for ongoing daily pain assessment.

Defilippi *et al.* (2006:462) assert that in all African countries, doctors are scarce but are also the only prescribers of certain drugs, including morphine. For people in all communities to have access to effective pain management, nurses and clinical officers need to be trained and certified to prescribe morphine. This has been made possible in Zimbabwe as well as Uganda, where nurses and clinical officers with a nine-month course in palliative care can now prescribe morphine. However, the rate of practical training means the prescribing pool will increase very slowly.

According to Kinyanjui (2006:2) for the majority of the cancer patients, in Sub-Saharan Africa including Kenya, key barriers to adequate pain management are not the lack of technology but poverty and health systems inequality. Kinyanjui (2006:2) further argues that cancer pain management should not be seen as a technical issue, to be left to the specialists, an issue of benevolence to be dealt with by charitable institutions or a commodity to be sold by private hospitals. Rather it should be seen as a global public health problem. Otherwise efforts to address it will not make much impact in the world. Thus there is a need for international support in setting up comprehensive cancer management programs and resource poor countries of the developing world.

According to Lucas (2006:3), palliative care is not an alternative to other models of health care. It is not in competition with efforts to provide anti-retroviral and other advanced therapies. It is an essential part of a comprehensive health care system, which is missing in many developing countries, and must not be neglected in the efforts to improve greater accessibility to more technical drugs and therapies.

Pain and symptom management is essential in dealing with pain associated with life threatening illnesses. The goal of palliative medicine, therefore, is usually not to prolong life or hasten death, but rather to keep the patient comfortable and to offer support to both the patient and the family. Thus provision of adequate pain management and control requires an interdisciplinary approach to treatment, thus a need for on going provision of symptom management throughout the course of the illness.

The researcher is of the opinion that morphine should be made readily available and affordable to the patients to enable them receive the appropriate primary care drugs for relief of their symptoms with the minimum of delay.

2.4 The Role of Social Workers in Palliative Care

According to Bailey (2007:2) all social workers, regardless of practice settings, will inevitably work with clients facing acute or long-term situations involving life-limiting illness, dying, grief and bereavement. Using their expertise in working with populations from varying cultures, ages, socio-economic status, and non-traditional families, social workers help families across the life span in coping with such needs and intervene appropriately. Raymer ([sa]:1) further mentions that, the social work profession helps individuals, families and groups and/or communities enhance or restore their capacity for optimal psychological, emotional, spiritual, social and physical health. Bailey (2007:2) states that social workers are a core service in hospice and palliative care teams. Their professional values and skills are a perfect match with hospice and palliative care programs, which are designed to treat the whole person in an interdisciplinary manner to enhance quality of life during challenging times.

According to Christ and Blacker (2005:415), from the work of Dame Cicely Saunders to the social workers across the country today, social work has proud history in the field of end of life care. Social workers are fundamentally trained to practice from a person-in situation perspective. This theoretical view is invaluable to the health care team, especially where patients and families confront life-threatening deteriorating illness, trauma, and death.

Several authors (Bailey, 2007:2; Christ & Blacker, 2005:415; Raymer, ([Sa]:2) agree that social work’s unique perspective is shaped by its practice divergent setting across the life span. This includes its expertise in grief and psychosocial aspects of well being, its knowledge of communication and system of care, and its major commitment to promote humane, culturally competent members of society. According to Christ and Blacker (2005:415) social work practice settings addressing palliative and end of life care include a wide range of spaces. These include health and mental health agencies, hospitals, hospices, home care, nursing homes, day care and senior centres, schools, courts, child welfare and family service agencies, correctional systems, agencies serving immigrants and refugees, substance abuse programs, and employee assistance programs. Thus social work is a broadly based profession that can meet the needs of individuals and families.

Bailey (2007:4) further asserts that, social workers have unique, in-depth knowledge of, and expertise in, working with a range of circumstances and groups. These include ethnic, cultural, and economic diversity, family and support networks, multidimensional symptom management, bereavement, trauma and disaster relief, interdisciplinary practice, interventions across the life cycle, and system interventions that address the fragmentation, gaps, and insufficiency in health care. According to Bailey (2007:4) these are critical areas for implementing change in palliative care and end of life care. Stein and Sherman (2005:1275) argue that social workers also have expertise in generating information, and effecting the required changes. They can analyse, influence and implement policy change and development at local, state and federal levels that can be used to make important improvements in the care of patients living with life-limiting illness and the dying. According to Stein and Sherman (2005:1275), social research in the care of the dying is also developing and addressing many previously overlooked areas of end of life care, such as issues concerning ethnic, cultural and economic diversity, and interventions in community contexts.

Luff and Blanch (1998:1316) also mention that social workers possess knowledge about navigating the medical and social systems that frequently present barriers to clients. Luff and Blanch (1998:1316) further ascertain that social workers have expertise in communication. Within families and between clients, families and health care or interdisciplinary teams, thus drawing on knowledge of family systems and interpersonal dynamics, the social worker is able to examine the family's experience in a unique way, to conduct a biopsychosocial, spiritual factors into their deliberations, planning, and interactions.

Raymer ([sa]:1) cites that assessment is the foundation of practice since social workers plan interventions with their clients based on assessments and must be prepared to constantly re-assess and revise treatment plans in response to newly identified need and altered goals of care. Raymer ([sa]:1) further states that comprehensive and culturally competent social work assessment in the context of palliative and end of life care includes considering relevant biopsychosocial factors and the needs of the individual client and the family. Clausen and Kendall (2005:275) concur with Raymer ([sa]:1) by asserting that social workers incorporate assessments in developing and implementing intervention plans that enhance the clients' abilities and decision in palliative care and end of life care by using various perspectives and skills in delivering interventions and developing treatment plans. According to Clausen and Kendall (2005:275) social workers are able to adapt techniques to work effectively with individuals from different age groups, ethinicities, cultures, religions, socio-economic, educational background, lifestyle, and differing states of mental health and disability, and in diverse non-medical care settings.

On the other hand Murray and Worth (2007:278) argue that social workers in palliative and end of life care demonstrate attitude, compassion and sensitivity to clients, respecting clients’ rights to self-determination and dignity. They are also aware of their own beliefs, feelings, and how their personal self may influence their practice. Thus social workers demonstrate empathy and sensitivity in responding to the pain, suffering, and distress of others.

Murray and Worth (2007:280) ascertain that social workers are a part of interdisciplinary effort for the comprehensive delivery of palliative and end of life services. They strive to collaborate with team members and advocate for clients’ needs with objectivity and respect to reinforce relationships with providers who have cared for the patient along the continuum of the disease. Therefore, interdisciplinary teamwork is an essential component in palliative care and end of life care whereby social workers are integral members of a health care team. Bailey (2007:8) argues that teamwork requires collaboration and an ability to empower and advocate when necessary. Therefore, the psychosocial expertise of the social worker assists the interdisciplinary team to enhance understanding, interventions, decisions, formulate treatment plans, and in addition the social worker identifies resources, provides counselling, support services, and practical interventions.

Clausen and Kendall (2005:283) state that social workers continue to grow in their knowledge of theories and practice in palliative care and end of life care to effectively work with individuals and families due to their professional development in their professional education. Since palliative and end of life care is a rapidly expanding and changing field which crosses all practice settings, in addition to clinical competence, social workers enhance their skills and understanding by keeping abreast of research, so that their practice reflects the most current knowledge. Stein and Sherman (2007:1271) concur with Clausen and Kendall (2005:283) by mentioning that social workers offer their expertise to individuals, groups and organisations as well as offering training and monitoring opportunities to beginning social workers or those transitioning into palliative and end of life care. According to Stein and Sherman (2007:1271), social workers also work in conjunction with schools of social work to advocate for programs in palliative and end of life care, as well as enhance and encourage interest in this specialisation. At the same time, social workers contribute to research initiatives not only to demonstrate the efficacy of social work, but also to advance the recognition among colleagues in other professions of the essential need to address psychological needs of individuals and their families.

Social workers are well placed to intervene holistically as far as the needs of patients and their families are concerned; based on their training which entails an understanding of both social and cultural backgrounds among others. Social workers can also easily assess pain and at the same time provide education, counselling and other intervention related to pain management. Some very useful and appropriate intervention techniques employed by social workers when dealing with palliative care patients include maximising feelings of control and enhancing coping skills and functional abilities among others.

2.5 Summary

This chapter gives a broad overview of palliative care both internationally and within the Sub-Saharan Africa. The chapter also provides a detailed description of palliative care as a phenomenon. An attempt has also been made to outline the origins of palliative care, the current palliative care practice as well as the most essential models of care. Furthermore, paediatric palliative care has been elaborately provided and lastly, the role of social workers has been discussed in terms of how they augment palliative care.

CHAPTER 3

EMPIRICAL FINDINGS

3.1 Introduction

This chapter focuses on the following aspects: Research methodology, which will be briefly discussed since more elaborate details are provided in chapter one of this research report. Research findings will also be discussed by interpretation of themes extracted from the discussion with three focus groups. These themes were guided by the research question and, verbatim quotes are used from the participants' responses as captured in the transcribed interviews to provide and enhance a richer and broader picture of the whole situation.

3.2 Research Methodology

The researcher used qualitative approach in order to gain first hand understanding of the phenomenon under investigation as cited by Fouché and Delport (2005:73-74), that at present there are two well known and recognised approaches to research, namely, the qualitative and quantitative paradigms, which differ from each other. According to Myers (1997:2) qualitative research methods were developed in social sciences to enable researchers to study social sciences and cultural phenomena. Mouton (1993:155) on the other hand states that qualitative approaches are approaches in which the procedures are not as strictly formalised, the scope is undefined and that a more philosophical mode of operation is adopted. According to Clemens (2007:1) qualitative research involves an in-depth understanding of human beings and the reasons that govern human behaviour. Clemens (2007:1) further asserts that, qualitative research relies on reasons behind various aspects of behaviour and investigates the way and how of decision making as compared to what, where and when of quantitative research.

Applied research was used in this study. According to Neuman (1997:21) sociology has had two wings, whereby researchers in one adopt a more detailed, scientific and academic orientation, and those in the other are more activist, pragmatic, and reform oriented. Neuman (1997:21) further states that applied researchers apply and tailor knowledge to address a specific issue like either to answer a political question or solve a pressing social problem. Kumar (2005:9) concurs with Neuman (1997:21) by asserting that most of the research in social sciences is applied.

The research strategy that was used is a case study since it seeks to gain more knowledge and understanding as well as interpret the meanings given by subjects as far as their normal daily lives are concerned. Yin (1994:13) mentions that a case study is an empirical inquiry that investigates a contemporary phenomenon within its real life contexts, especially when the boundaries between phenomenon and context are not clearly evident.

3.2.1 Instrument of data collection

The focus group discussions as used in this study is discussed as follows:

- **Focus groups**

Data was gathered by means of focus group interviews during the period August to September 2007. Three focus groups were utilised comprising of 7, 6 and 7 members respectively. A sample consisting of 20 patients receiving palliative care at the Nairobi hospice was drawn. The following criteria was used to select the participants:

- **Patient** – to be regarded as a patient, the person must be suffering from a life threatening illness, receiving palliative care in the Nairobi hospice during the period July – September 2007.

- **Gender** – Both females and males were included in the study.

- **Age** – Patients included in the study were above 18 years of age.

- **Procedure**

The researcher introduced herself together with her assistant. Then she allowed the participants to introduce themselves by whatever names they wished to use, which mainly put them at ease. After the introductions, the researcher explained the nature and purpose of the research to the participants. At this juncture the participants were given consent forms to sign prior to the commencement of data collection. The participants had an option to choose between two languages both of which the researcher was conversant with during the interview, namely English and/or Kiswahili. They opted for Kiswahili mainly because it is the national language in Kenya and the one mostly spoken by a majority of them. They felt that it would be much easier and comfortable for them to express their feelings in that language. According to them, Kiswahili was the common language amongst them. The researcher then introduced the topic and asked the guiding questions when appropriate.

The three focus group discussions were audio taped and field notes were made during and after the interviews. Impressions were written down as soon as the interviews were finished. Each focus group discussion lasted about two hours. At the end of each session, the researcher summarised salient points that arose during the discussion and invited further comments and discussions around these points. An assurance was made to the participants regarding their confidentiality and anonymity. The researcher informed them that the information would be stored for at least 10 years in a safe place, as a requirement from the University of Pretoria.

- **Data analysis**

The recorded data was transcribed verbatim. The initial impressions were written down as soon as the interviews were completed to make sure that there was enough back up in case of mechanical difficulties with the tape recorder. The data was then analysed thematically. Subsequently, data was then compared and similar incidents were grouped together. This process of grouping concepts at a higher more abstract level was referred to as categorising. Categories were then organised on the basis of themes and concepts from all the interviews and then linked together in terms of sequences. The objective was to identify the core category and logically relate other main categories to the core.

3.3 Discussion of research findings

Below are the main categories under which the results are discussed:

- The type of services they receive from the hospice.
- The benefits of these services.
- Any other services they receive outside the hospice.
- The time frame for receiving palliative care at the hospice.
- Extent to which their illness has affected their families.
- How they knew about the hospice.
- The role social workers can play in palliative care.

3.3.1 The type of services they receive from the hospice

The following sub-categories emerged from the above mentioned theme:

- Medical care
- Counselling
- Day care services
- Spiritual care

- **Medical Care**

The participants commented that they receive medical care which is usually offered by doctors and nurses for treatment of any other illness that may arise, and management of distressing symptoms for instance, excruciating pain commonly seen in terminal cancer. The medication is usually available and less expensive as stated by one participant…” *I am given medication even when I don’t have the exact amount needed to pay for the drugs’’.*

Another participant mentioned that “ *I get medication and the cost of them are less expensive as compared to other medical institutions”.*

Another particular participant concurred with the above one by mentioning that “ *I get medical care that is extensive and the cost is at least affordable which is a great thing that has happened to me. This is because before my referral at the hospice, it was extremely difficult for me to get any proper medical attention”.*

While another participant stated that “*I get medical care, which is very encouraging”.*

The above mentioned opinions support the hospices’ mission: to be a leading and sustainable national institution providing and promoting quality and cost effective palliative care for patients with life threatening illnesses. By receiving different services at the hospice, these patients with life threatening illness are able to receive appropriate palliative care. This is confirmed by (Lucas, 2006:1; Borgsteede, 2006:3; American Academy of Hospices and Palliative Medicine, 2006:1) when they state that the aim or goal of palliative care is the achievement and provision of the best quality of life for patients or people approaching the end of life, as well as their families.

Doctors and nurses at the hospice usually provide medical care for treatment of any other illness that may arise, and also they manage any distressing symptoms such as excruciating pain commonly seen in patients with life threatening illnesses. So far medical care has proven to be effective to all patients receiving this service. Since palliative care is accepted as an integral part of disease management providing pain and symptom control to patients with life threatening illness, so far it is easily accessible and affordable to patients receiving palliation in this institution.

- **Counselling**

Counselling is one of the services provided by the hospice staff members who are experts in this field. They provide counselling to patients and their families to empower them to face the situations positively and to prepare for the inevitable last moment. One participant confirmed the above statement by stating that…''*I get counselling services and I am also cared for very well by the hospice staff without any prejudice whatsoever as opposed to other public institutions where care is often absent".*

Another participant responded by saying, *"through counselling services I am currently receiving here at the hospice, I have realised that my distress has reduced drastically unlike before".*

A further response from a participant who seemed relaxed stated that "*I get counselling at the hospice, which is showing beneficial effects as far as my anxiety and stress levels are concerned. These days I am able to cope and handle any stressful situation better as compared to how I used to react before I started my counselling sessions".*

Another participant agreed that counselling is crucial to her life by mentioning that *"counselling has really helped me deal with my fears especially concerning my feelings towards my illness and now I am able to identify positive ways of coping with such fears".*

According to Muhombe (2004:22) when considering psychological needs, which are even less clear than clinical needs in Sub-Saharan Africa, counselling should be contextualised in training. Muhombe (2004:22) further affirms that however, basic lay education and training should not be overlooked since this can create a situation whereby lay carers of relatives with life threatening illness can lack knowledge particularly in relation to symptom control.

Psychological interventions at the hospice have played an important role in patients lives at what is often a particularly stressful time. The interventions, which include, among others, counselling are inexpensive in contrast to invasive medical procedures. It is evident that any form of psychological support such as group or individual therapy is very essential to all patients with life threatening illnesses.

The researcher deduces that such interventions can be provided by the social workers since they have the expertise and skills to do so. Through such counselling services, patients and their families are able to cope better with the situation at hand as well as deal with their psychological, physical, emotional, social and spiritual pain that influences their well being.

- **Day Care Services**

A majority of the participants felt that through their attendance at the weekly get-together day care that occurs every Thursday at the hospice, they were able to gain opportunities to enhance their quality of life in a social context.

"*I come on Thursday to the hospice for day care where I am offered food and drinks together with other patients in similar situations.* This participant further stated that *"sharing a meal as a group gives me the opportunity to share experiences with other patients".*

Another participant responded by saying…"*I have time to share a lot with other patients which gives me encouragement to know that there are other people going through the same situation and condition as mine… in so doing we are able to support one another as a group."*

Another participant mentioned that *"by attending the day care every Thursday, I am able to meet with other patients in similar circumstances which has initiated the spirit of sharing and caring amongst us as patients".* This particular participant further said that "*by attending the day care my patience has been restored because I used to be generally very impatient before".*

Sometimes referred to as day hospice palliative care units, day units form a part of a hospital or in- patient palliative care unit. The community comes together and prepares a day when patients receiving palliative care can meet together at a centre where meals and snacks are catered for, and therapy and counselling provided (International Association of Hospice and Palliative Care, 2007:17).

Day care at the hospice continues to be an interesting event for patients every Thursday where they are treated to refreshments, snacks and lunch. Through such a forum patients are able to share their feelings, experiences and opinions as well as encourage one another. Similarly, psychological interventions by the social workers can also play a vital role during day care services. This would be basically to enable patients have the best quality of life as they approach their end of life.

- **Spiritual Care**

It was evident that all the participants took solace in religion and spiritual belief as elaborated herein by the participants.

One participant mentioned that…"*through prayers I am able to communicate to my God, which gives me encouragement to revive my strength and confidence…*however, this participant lamented by stating that *" all the same sometimes I wonder why this had to happen to me and not someone else".*

Another participant stated that…"*I always find it very comforting and reassuring when in prayers because I know God has a purpose for me in life and he alone knows why I am in this kind of a situation".*

Another response was "*since my diagnosis, prayers have made it easy for me to make peace with my creator and come to terms with my illness.* This participant further added that *"this has enabled me embrace my situation without any complaints or questions".*

A participant who seemed distraught stated that “*through prayers I am able to deal with all the difficulties I am encountering in the course of my illness and thank God for all the strength he has restored upon me at this time.* This participant concluded by saying this: *“what I know is that God has a reason for what is happening to me”.*

Muhombe (2004:55) cites that it is important to be respectful of and responsive to the spiritual and religious beliefs of a patient and his/her family, no matter what religion they practice. As confirmed by Muhombe (2004:55) a person with life threatening illness can be helped to find spiritual peace, comfort and accept the inevitable death. This can be done through prayer groups, church elders or any other person who may be able to offer support.

Although a majority of patients with life threatening illnesses find solace in spiritual beliefs which is comforting, sometimes it can be the source of questions and doubts. A patient may have thoughts and questions about his/her life and what will happen after he/she dies. He/she may believe that it is important to make peace with his/her God or do things to keep his/her soul or spirit safe after he/she dies.

3.3.2 The benefits of these services

The following sub-categories emerged from the above theme:

- Hope
- Mobility
- Improved state of health

- **Hope**

The participants concurred with each other by citing that there are several benefits attributed to the services they receive at the hospice. They mainly agreed that they have been able to cope with their illness well and managed to embrace it without questioning. This is attributed to the fact that some of their fellow patients have been receiving palliative care for a longer period of time. Below is a demonstration of the above situation:

One particular participant said, "*It gives me a lot of hope to go on and cope with my illness."*

Another participant agreed with the above statement by citing that *"my hope has been restored since I started receiving services at the hospice and this has enabled me to cope well with my illness".*

Another response was that, "*I realise that there are other people who share the same problems with me or even worse and this gives me hope and motivation to carry on without any form of resentment".*

A further response from a different participant indicated that *" I have realised that I am not the only one dealing with a serious condition and this gives me a lot of hope and faith to embrace life in general".*

One particular participant who seemed very hopeful said, *"it gives me hope especially knowing that some patients have been receiving palliative care services much longer than me. This has given me a lot of strength and encouragement to go on with my daily activities without harbouring any hard feelings".*

It is essential for any patient with life threatening illness to have hope no matter how hard the situation might seem. As stated by the participants, patients have been able to restore their hope and shun away the feelings of hopelessness and loneliness. This means that there is a dire need for family members and friends to continue encouraging and supporting these patients to be hopeful and optimistic as they approach their end of life.

- **Mobility**

An important issue that cropped up during the discussion was that of an improved mobility of participants, made possible by an easy access to medication. One of the participant stated that "*before I joined the hospice, I never managed to get here by myself without help, however since I started receiving medication here, I am able to move freely and get here by myself when need be."*

A participant who concurred with the above one mentioned that…*"before joining the hospice it was extremely impossible for me to walk properly, but since I started coming to the hospice I am glad to say that I am able to walk on my own without major difficulties".* This participant further said, *"this means I am not dependent on my family and friends anymore".*

Another response from a different participant stated that *"when I initially started coming to the hospice, I depended on my family's help to get me here, but since I started receiving treatment I can confidently bring myself to the hospice without having to rely on my family members for help".*

Mobility especially amongst women suffering from cervical cancer can be a major drawback. This is confirmed by the research findings of Muhombe (2004:36) who asserts that many women with advanced cervical cancer may experience severe swelling in one or both legs. Usually, this is accompanied by swollen glands that cause blockage in the flow of fluid from the limb(s), at which point no treatment is successful. This therefore, explains the mobility issue above as elaborated by the participants.

It seems that the issue about mobility was a major concern for a majority of the patients prior to their joining the hospice. However, it is evident that there was an improvement after they started receiving palliative care services at the hospice. This was achieved through the medical care they received at the hospice. The responses further give evidence to the fact that medical care enabled these patients to gain the use of their limbs especially when they needed medical attention. This so far has enabled these patients to have control of their lives as opposed to being dependent on other people.

- **Improved health**

The participants agreed that their experiences with the hospice has changed a lot and has had a great impact on their lives, in particular since drugs that cater for their various sources of pain are available. These drugs enable them to endure their pain as well as increase their appetite because many a times' loss of appetite is a major concern to them. One particular participant stated that: "*it has been a blessing since joining the hospice, this is because previously I never had adequate medication to carry on with my life. However, I am happy to say that I have been receiving adequate medication, as well as undivided attention and care provided by the fantastic hospice staff, and this has really improved my health".*

Another participant responded by noting that *"my health has really improved, basically due to the services I receive at the hospice more particularly, the appropriate medication usually provided by the hospice staff".*

Another participant stated that *"I have noticed a very positive change as far as my health is concerned. Prior to joining the hospice, I was not getting adequate medication which affected my general state of health, but I am glad to say that lately my health is gradually improving which has really boosted my confidence and my self esteem".*

Palliative care services should strive towards improving the health of all patients with life threatening illnesses. This means that adequate medication is paramount as well as a balanced diet. According to these patients, the medication they receive has enabled them to deal with their pain and their appetite has increased than before.

3.3.3 Any other services being offered outside the hospice

The only sub-category that emerged from the above theme is:

- **Spiritual guidance**

It seems that apart from the services received at the hospice, these participants only receive spiritual guidance outside the hospice, usually provided by their respective local pastors and spiritual counsellors. One participant indicated that "*the only other service I am currently receiving outside the hospice is spiritual guidance from my local church pastor since this is the best the church can offer me, even though I would have appreciated some material assistance as well which is lacking in my church".*

Another participant substantiated the above theme by stating that *"I am receiving spiritual counselling together with my family to enable me cope with my illness".*

A participant who looked a bit tired mentioned that *"I usually get spiritual guidance once a week from one of our church elders who guides me through an intense prayer session so as to strengthen my faith in God".*

A participant who complimented the above one stated that *" I am delighted that at least I can get spiritual guidance from my local church usually provided by the parish priest whenever I am in need of spiritual nourishment. This has really helped me together with my family members to embrace the will of God"*

Another participant who never believed in the existence of God before his diagnosis stated that *"before my diagnosis I never really used to go to church but after becoming aware of my illness, I turned to one of the pastors in a* *nearby church for spiritual guidance and nurturing. Through this I am able to understand and cope with my illness without being angry at God".*

According to Muhombe (2004:55) a patient may believe that it is important to make peace with his/her God or do things to keep his/her soul or spirit safe after he/she dies. He/she may know someone in his/her community whose spiritual advice of wisdom could help him/her find peace. Although some patients may not want to speak with a spiritual or religious person, they may want to discuss spiritual issues with someone they respect all together.

Spiritual guidance for patients and their family is crucial whether provided by a pastor, priest, church elder, or a counsellor, although none of the interviewees sought guidance outside religious leadership. The aim is to help the concerned patients and their families to embrace their illness and to trust in God. By so doing, they are able to deal with and confront their illness in a spiritual manner.

3.3.4 The time frame for receiving palliative care at the hospice

There is no particular time frame for receiving palliative care at the hospice. It seems that participants have generally been receiving care here at different intervals. Some have been here for years, others for just a few months, while others have been receiving services for only a number of days. Thus, there is no fixed time frame for palliative care provision at the hospice. This statement is supported by the fact that amongst the 20 participants interviewed, 2 of them have been receiving palliative care for the longest time, which is between 7-9 years respectively. Further, 10 participants have been receiving palliative care between 1-8 months, while 8 of the participants have been receiving palliative care between 1-3 days only.

One of the participants who has been receiving palliative care services for a longer period stated that *" I have been receiving services here at the hospice for the last seven years and so far, I am very happy and content with the help* *provided by the hospice staff. I can confirm that my life has really improved since I joined the hospice".*

Another participant who has been here for a longer time agreed with the above participant by mentioning that *"the last nine years of my receiving palliative care services here at the hospice have been good and I have gradually improved since then. The staff members have been very caring and loving regardless of my time here and this has really boosted my morale and motivated me a lot".*

Being the first time of receiving palliative care services at the hospice one of the participants stated that *"although this is my first day here at the hospice, I am very happy and hopeful that I will continue to get the care and attention that I need in the course of my illness".*

Another participant mentioned that *"this being my third day of receiving palliative care services at the hospice has been of great encouragement especially since I have met patients who have been here longer than me and they all seem happy and content. This gives me an assurance that I will also receive good care and that my life will eventually improve with time".*

Although the time frame for receiving palliative care at the hospice differs from one patient to another, usually the services provided are the same. The respondents seemed content so far with the services offered to them by the hospice staff despite the time span.

However, what can't be ruled out is the fact that, patients who had received palliative care services for a longer period of time seemed much better than their counterparts who had received services for a shorter time. This was evidenced by their improved state of health, confidence and their self-esteem. Therefore, it can be pointed out that since palliative care has been made easily accessible and affordable to patients at the hospice, it has proved that these services are beneficial to those able to access them consistently.

3.3.5 Extent to which their illness has affected their families

Sub-categories that emerged from the above theme are as follows:

- Abandonment
- Financial strain
- Denial

- **Abandonment**

It is evident that these patients' illness has affected their families in one way or another as one of them mentioned that "*I was abandoned by my family and unfortunately my husband is deceased, thus I get no form of assistance from any of my family members". Further this participant stated that "I have to fend for myself since on one seems to care about me despite my serious illness. This has made life very difficult rendering me to live in a very vulnerable poor condition."* This participant was very emotional at this point that the researcher allowed her enough time to deal with her emotions.

Another participant lamented that "*my life has been very miserable since I got sick, for instance, my husband disappeared and left me without neither any finances nor any one to take care of me".*

A participant who seemed very disturbed commented that *"my husband abandoned me due to my illness and prior to this he oftenly used to reject me and this made my illness worse. Occasionally this would make me feel really guilty about the whole issue".*

Another participant stated that *"I was abandoned by my children when my illness became worse because they said I am a burden to them. Now I have to rely on my neighbours for help which is becoming very difficult and miserable for me, I am not sure for how long I can handle this situation I am really worried".*

The above sentiments portray that in the event of one family member becoming very ill he/she will have to depend a lot more on his/her family and friends for care and support. In this regard therefore, relationships within families will have to change, and people will need to take on new responsibilities. Coupled with all this, family stress is inevitable at this juncture.

The issue regarding abandonment especially of women being abandoned by their husbands in times of serious illness seems to be a common phenomenon. As stated by Lucas (2006:4) in some cases, a sick woman’s husband may spend less and less time at home as her illness gets worse. Lucas (2006:4) further confirms that due to her illness, he may also abandon her when he learns that she is dying. This is because he may not want to take care of her. Sometimes he may also feel so upset that it is too painful to stay and watch her get sicker and weaker. Whatever the reason, it will be important to comfort the woman and provide her with emotional, social, and spiritual support.

It is a common phenomenon for patients to be abandoned by their family members due to their illness as stated by the participants. Abandonment by either spouses or other family members is evident and it seems to affect the relationship between several family members. The services rendered by the hospice become very important for these patients to assist them to cope with their lives.

- **Financial strain**

This particular theme caught the researcher’s attention since the majority of the participants stated that financial strain is one of the major drawbacks as far as their illness is concerned. This is because a majority of them are vulnerable unemployed women or otherwise abandoned by their husbands, while others are casual workers with no permanent employment whatsoever. Others operate very small-scale businesses to sustain their livelihood.

Coupled with this, they reside in informal settlements within the city centre under very harsh and severe conditions.

One participant mentioned that “*my family has been financially strained due to my illness since I am unemployed which means that they have to take care of all the expenses that my illness has incurred”.*

A participant who seemed very angry commented that *“my family right now feels that I am contributing to our financial crisis since I am using up the family’s resources to cater for my medical expenses”.*

Another distraught participant stated that *“I have no financial assistance at the moment because since becoming sick, I* can’t *go on with my small scale business of selling second hand clothes”.*

Another participant who seemed very disturbed mentioned that “*my illness has really affected my family since I am the only bread winner and everyone depends on me for financial support…my family is in dire need of my help yet I* can’t *offer it to them at the moment due to my serious illness…my illness has forced my wife to come and take care of me here in the city while she should be up-country”.*

It is evident that individuals who usually provide for their families also need their families help in times of sickness. This is confirmed by Bruce (2006:5) who states that a sick person may need help to find ways to get food, pay for housing, pay for medications or medical care. As further mentioned by Bruce (2006:5) it is helpful for friends, family and others in community to support the sick person and raise the necessary funds.

It is not unusual for financial strain to occur in times of difficulties especially where an illness is concerned. Financial difficulties seemed to be a major drawback as expressed by the participants. According to these participants, financial strain occurred due to a majority of them being unemployed which made them to entirely depend on their families for support. For those otherwise in employment usually as casual workers, their absence from work due to their illness affected them too financially, as they do not get a full payment.

- **Denial**

One participant who is a farmer was concerned that her family is in denial since she was diagnosed with cancer, but her relieve is that her family has been there for her despite their overwhelming denial about her sickness. She stated that…”*my family is in denial since my diagnosis was made but I am grateful to them for taking good care of me and giving me all the love I need during this difficult time … I only wish they could accept what has happened to me because it is the will of God”.*

A participant who seemed concerned about her husband’s denial lamented by saying that *“my husband is in denial about my illness since my diagnosis was made and as much as I tell him to accept it he keeps on saying that he knows my illness will eventually be cured”.*

Another participant who seemed a bit worried stated that *“I am a single mother of two children, unfortunately my children are in total denial when it comes to my illness. Sometimes they even seem to blame it on my doctors by saying that maybe the diagnosis was not correct. My only consolation is that they really take good care of me despite their overwhelming denial”.*

Since denial is usually one of the first reactions to finding out about a life threatening illness, it is important to remember that it acts as a buffer against the shock of the diagnosis and the inevitable death of a loved one. Therefore, for the sake of the family members who are in denial it is always good for health care service providers to remember not to be judgmental of their behaviours, but instead to be good listeners and available when there is a need to talk.

3.3.6 How they knew about the hospice

Under the above theme only one major sub-category emerged from it, which is referral.

- **Referral**

All the participants knew about the hospice through referrals, done by their respective doctors in either the public or private hospitals within the Nairobi area and its outskirts. A majority of these referrals being from Kenyatta National Hospital in whose ground the Nairobi Hospice is located, while others knew about it through their local community churches or friends who had been clients of the hospice previously.

One participant stated that *" I knew about the hospice after being referred here by my doctor".*

Another participant stated that "*I was referred at the hospice from Kenyatta National Hospital by my doctor after completing my therapy…infact I had never heard about it before my referral".*

Another participant mentioned that *"I came to know about the hospice through our local community church".*

Further another participant said this "*I knew about the hospice through a friend of mine with whom I was admitted in the hospital and had previously received services at the hospice".*

Harding and Higginson (2004:10) mention that efficient referral systems must be established to connect those in need of palliative care services. These services may be professional or lay and can operate between various settings for instance, hospital, specialist consultancy, generic or specialist co-management or community volunteer. As confirmed by Harding and Higginson (2004:10) palliative care does not need to be provided in all care settings, but if effective referral systems are in place generalised providers can ensure these patients receive palliation when required. As further ascertained by Harding and Higginson (2004:10) referral systems can only be efficient when there is an appropriate and accessible care system with trained staff to whom referrals can be made.

The provision of palliative care services at the Nairobi Hospice is on referral basis as stated by the participants. So far this system is proving to be effective since the hospice staff are well trained to provide services to all the patients who need palliation at the end of life.

3.3.7 The role they think Social Workers can play in palliative care

The following sub-categories emerged from the above mentioned theme:

- Home visits
- Education
- Counselling

One particular group of participants indicated that they had no suggestion about the role social workers can play in palliative care since they had no idea of the existence of any social workers in their respective communities. So, they claimed, they were not able to comment or express their views on this matter.

- **Home visits**

Since home visits are an integral part of palliative care, the participants felt that through home visits, it would also be easier for follow-up to be done as regards their treatment.

One participant said, "*social workers and the other team members, should ensure that regular home visits are made to us patients in our respective* *homes as a way of ensuring that we are in tune with what the hospice staff expects of us and this should be done at the grass root level".*

A participant who seemed a bit anxious stated that *"social workers together with the other members of the multidisciplinary team should make attempts to visit us at our homes. In so doing it makes it possible for the team members to understand the nature of the difficulties we are faced with in the course of our illness".*

Another participant commented that *"I think through home visits, social workers can be able to help patients like us. Home visits guarantee us the assurance that there are people who really care and want to assist us in this difficult situation".*

Since home visits are done in the reflective light of the patient's personal, family and community systems, social workers should embrace this idea because home visits are not done to find patients out but rather to find how to help them better. Therefore, social workers should see this as an opportunity to perform duties that are often overlooked by other team members. This will also enable social workers to have a better understanding of the social environment of the patients hence enhance the process of developing relevant interventions, that are responsive to the real needs.

- **Education**

It seems that there is dire need to ensure that on-going education is undertaken by social workers to create awareness as well as integrate knowledge among the communities about life threatening illnesses like cancer.

One particular participant who was rather perturbed by the absence of social workers in her community said this "*there is a need for social workers to provide on-going education and create awareness on issues relating to life threatening illnesses like cancer. This is so because in many communities* *cancer patients like us are often overlooked whereas a lot of emphasis is given to patients suffering from HIV/AIDS and TB".*

A participant who seemed concerned stated that " *I think through education, awareness will be created pertaining to our illness, which is important to avoid a lot of ignorance and lack of information on this matter".*

Another participant stated that *"through education patients like we together with our families can be able to understand our condition and look for ways of coping with it".*

Reinforcing the value of education, another participant noted that *"through education also we can be able to deal with our anxiety and diminish the fears of uncertainty, as well as normalise our experiences".*

Education is an effective tool in helping patients with life threatening illnesses and their families understand the disease process. This includes understanding issues related to pain, symptoms, and the various treatment options. Social workers should ensure that there is on going education available to the public to create awareness and equip people with the correct information pertaining to cancer. At the same time awareness should also be created about the other life threatening illnesses as well.

- **Counselling**

All groups of participants unanimously agreed that counselling is an integral part of palliative care and should be a priority given to all patients with life threatening illnesses.

One participant said " *social workers should also offer counselling services to us patients as well as organising support groups within our communities so that we are able to have amble time to share our experiences with other patients in similar conditions.* This particular participant further stated that *“through such forums, I am certain that I will be encouraged to embrace my illness and cope with it better ”.*

A participant who seemed exhausted commented that *“through counselling social workers can help to ease the suffering of patients with life threatening illnesses like us”.*

Another participant said *“I think by offering individual counselling, social workers can educate us about the nature and course of our disease process in terms of the pain we experience, anxiety, dependency and any other effects”.*

One particular participant pointed out that *“it is important for social workers to engage in direct counselling with us patients as well as our families, so as to help us deal with our feelings and experiences during this difficult period. I believe in so doing we can be able to cope well with our illness”.*

Counselling in palliative care empowers patients and their families to face difficult situations positively and prepare for the inevitable last moment. This is confirmed by Bird (2005:4) who sees counselling as aimed at alleviating the physical and mental suffering of patients with life-threatening illness, and enable them make the most of the time they have left, so that they have the best possible quality of life, until the last moment.

Patients with life threatening illnesses need on going psychological support to manage the physical, social and emotional aspects of pain in their lives. Social workers can provide this kind of support through individual, group or family counselling. By listening, communicating empathy and offering hope to such patients, social workers can manage even the most disheartened patients.

3.4 Summary

This chapter focused on the research methodology, which consisted of the research approach, the type of research, research strategy, instrument of data collection in the form of focus groups. This was then followed by the criteria for participation as well as the procedure followed during the data collection period. Further, verbatim presentation using the case study method was provided thematically from the transcribed interviews obtained from the three focus groups. Lastly, discussions of the research findings were provided to emphasise the nature and extent of palliative care in the Nairobi hospice.

CHAPTER 4

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

In this chapter, a summary of the entire study is outlined. The nature and extent of palliative care in the Nairobi Hospice and palliative care as a phenomenon are recounted; conclusions drawn from both the literature study and the empirical data highlighted; and recommendations derived from the study presented.

4.2 Chapter 1

4.2.1 Summary

The following aspects were discussed in chapter 1:
A general introduction to the study, theoretical background for the study, problem formulation, goal and objectives of the study, the research methodology, ethical issues, definition of key concepts, problems encountered in the study and contents of the research report.

In chapter 1 the goal and objectives were formulated as follows:

Goal of the Study: **To explore the nature and extent of palliative care in the Nairobi hospice.**

The goal of this study was achieved in that cognition of the insights, views and opinions of patients receiving palliative care services were attained. This included the different types of services rendered as well as the coverage of service delivery, which was done in reference to the literature study. Further, the benefits of the services rendered at the Nairobi hospice was analysed as indicated in chapter 3 of this report.

Objective 1: To provide a theoretical background on palliative care.

Chapter 2 accomplished the objective of describing palliative care as a phenomenon through a detailed in depth literature study. The concepts realized under this included the origins of palliative care, current palliative care practice, paediatric palliative care, models of care and the role of social workers in palliative care delivery.

Objective 2: To explore the nature and extent of palliative care in the Nairobi hospice.

The objective of exploring the nature and extent of palliative care in the Nairobi hospice was accomplished in Chapter 3. An understanding was gained as far as the benefits and difficulties that patients with life threatening illnesses undergo.

Objective 3: To provide recommendations for improved palliative care in Nairobi hospice.

The objective of providing improved palliative care in the Nairobi hospice was accomplished and detailed in chapter 4. From the study, gaps in inadequate palliative care delivery provision were identified and recommendations provided for the way forward as far as the government, and the multidisciplinary teams in health institutions could do to address this situation.

Also, crucial contributions as regards provision of adequate palliative care in Nairobi Hospice in terms of information that can be used as a basis for future research were recommended as well.

4.3 Chapter 2

4.3.1 Palliative Care

Chapter 2 focused on the following aspects:
Palliative care as a phenomenon, origins of palliative care, current palliative care practice, paediatric palliative care, models of care and the role of social workers in palliative care.

4.4 Chapter 3

4.4.1 Research findings

The data covered in this section includes the nature of services rendered as well as the quality of service provision at the Nairobi Hospice. In this section also, the benefits of palliative care services rendered to patients were outlined. An attempt was also made to determine whether there were any other additional services the participants received outside the hospice. Furthermore, this section also determined whether there was any particular time frame for receiving services. An establishment was also made regarding the impact caused by the participants' illness as well as their experiences as far as their families were concerned. Lastly also covered under this section were the different roles social workers can engage in as regards palliative care provision.

4.5 Conclusions

Conclusions drawn from both the literature study and the empirical study findings are as follows:

- The aim of palliative care is the achievement and provision of the best possible quality of life for patients approaching the end of life as well as for their families.

- Origins of palliative care are attributed to Dr. Balfour Mount as well as the Roman times. However, its origin in both the United States of America and other parts of the world began a long time before its existence in Africa.
- Currently, palliative care practice is provided both on in-patient and out - patient bases, with the aim of offering services that are readily available for all patients with life threatening illnesses.
- Paediatric palliative care is integral to general palliative care, and involves the active total care of the child's body, mind and spirit. Its aim is the achievement of the best quality of life for patients and their families.
- Models of care are important as far as palliative care is concerned since they lead to the improvement of quality of life for patients, their families and the community at large.
- The role of social workers in palliative care is paramount since social workers look at the needs of patients and their families holistically.
- Palliative care is inadequately met in Kenya with overstretched coverage resulting in patients not receiving sufficient services.
- There is a dire need to increase the number of hospices so as to ease congestion and workload in the few available ones.
- It is evident from the study that palliative care needs to be integrated into existing policies or otherwise an official palliative care policy is developed through the Ministry of Health.
- Kenyan institutional framework including laws should be reviewed to make it easier for patients with life threatening illnesses to access palliative care in general including pain relieving medication such as morphine.
- There is also a need to address the issue of intensifying palliative care training for specialised nurses, clinical officers and social workers among others to increase personnel in all the hospices country wide.
- Palliative care should be included in health curricular since so far, Nairobi hospice is the only major institution providing palliative training in Kenya.
- The study revealed that, palliative care provision is on out-patient basis since in -patient palliative care is usually unthinkable due to lack of capacity and cost, and sometimes its perceived as being socially unacceptable.

- From the findings it is evident that patients receiving palliative care do so at different intervals since there is not particular time frame for receiving services at the hospice.
- The study indicated that for the majority of the patients, their illness had impacted negatively on their families.
- From the findings it is evident that all the participants at the hospice were on referral basis only.
- Palliative care needs a holistic approach to address the needs of the patients. This can be achieved with the involvement of all the multidisciplinary team members.
- The study findings show that there are several services rendered at the Nairobi Hospice which according to the participants are of great benefit.
- The participants' lives were miserable before they started receiving palliative care services. However, their lives and health improved drastically while receiving the services rendered at the hospice.
- Patients require on going counselling and psychological support to deal with the challenges that face them at the end of life.

4.6 Recommendations

- Palliative care as an integral part of disease management should be made easily accessible and affordable to every patient in need.
- The importance of palliative care is recognised, since it provides pain and symptom control to patients with life threatening illnesses, and offers psychological support to patients and their families from diagnosis till the end of life.
- There is need to create public awareness about palliative care as far as the needs of patients with life threatening illnesses, their families and friends are concerned.
- Since patients with life threatening illnesses are on the increase, there should be on going education at grass root levels to integrate knowledge on this phenomenon.

- A holistic approach is needed to address the needs of the patients as well as the difficulties they face at the end of life.
- Social workers should form a part of the multidisciplinary team that provides services in all health facilities.
- There is a dire need to increase the number of social workers in all health facilities especially in the hospices and hospitals, to ensure effective needs assessment for the patients, their families and their entire communities.
- Social workers should become assertive and play their role as team members. This would enable them to gain recognition for their expertise and skills in service delivery.
- There is a need to educate the public on the role of social workers regarding life-threatening illnesses.

4.6.1 Recommendations for future research

This research study mainly focused on the nature and extent of palliative care at the Nairobi hospice, the centre of attention being the patients. Therefore, the hypothesis and assumptions for further future research includes the following:

- If national policies and strategies were established, adequate palliative care structures could be ensured.
- If there is effective capacity building initiatives, appropriate palliative care delivery could be enhanced.
- If palliative care services were made easily accessible and affordable to all who need it, patients with life threatening illnesses would have good quality of life.
- If palliative care is inadequately met, patients with life threatening illnesses may end up dying miserably and in a lot of pain.
- A further future research focusing on a comparative study encompassing all the existing hospices, to determine the effectiveness of institutional palliative care in Kenya, as well as the role of the multidisciplinary team in service provision should be undertaken.

4.6.2 Concluding remarks

The Nairobi hospice was established in 1990, in the Kenyatta National Hospital complex, being a non-profit registered organization that cares for and supports patients with life threatening illnesses, with full participation of families. It is an outpatient facility, the first of its kind in East Africa.

Palliative care is in line with the overall aspirations of the strategic plan developed by the government of Kenya in 1999 to fight the HIV/AIDS epidemic, which saw the formation of the National AIDS Control Council to co-ordinate the implementations of this strategic plan. This has seen the spearheading of capacity building initiatives to enhance the delivery of palliative care to patients and their families wherever they may be.

However, although palliative care is addressed under the second priority area in the strategic plan which is treatment, care and support many patients with life threatening illnesses still cannot access this kind of service. This led to the motivation to recognise the nature and extent of palliative care at the Nairobi hospice, so as to ensure effective and reliable service provision as far as palliative care is concerned.

It seems though palliative care provision is inadequately met, due to the lack of proper information on palliative care and the enlarging demand, against limited capacity. Thus national policies and strategies need to be established in Kenya to ensure adequate palliative care structures. Although a small number of centres like Nairobi hospice offer high quality care, they are not integrated into wider health care and at the same time appear to be unevaluated.

If palliative care provision is to succeed the number of issues affirmed in this inquiry as previously addressed in the limited literature on palliative care need to be addressed. Particularly, the creating of multidisciplinary capacities that focus on all aspects/needs of patients from medical, to psychological, social, spiritual guidance among others.

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